

Debunking Delusions

DEBUNKING DELUSIONS

The TAC Campaign against
Aids Denialism

Nathan Geffen



In memory of Ronald Louw and Maurice Geffen

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I am solely responsible for this book's views and errors.

Abbreviations

Aids	Acquired Immune Deficiency Syndrome
ALP	Aids Law Project
ANC	African National Congress
ARV	antiretroviral
Asasa	Advertising Standards Authority of South Africa
BMS	Bristol-Myers Squibb
CDC	Centers for Disease Control
Cosatu	Congress of South African Trade Unions
DA	Democratic Alliance
LEU	Law Enforcement Unit
FDA	Food and Drug Administration
Haart	Highly Active Antiretroviral Treatment
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICC	International Criminal Court
MCC	Medicines Control Council
MEC	Member of Executive Council
MRC	Medical Research Council
MSF	Médecins Sans Frontières
Napwa	National Association of People with Aids
NCI	National Cancer Institute
Nedlac	National Economic and Development Council

NICUS	Nutrition Information Centre at the University of Stellenbosch
NIH	National Institutes of Health
PCP	pneumocystis pneumonia
PMA	Pharmaceutical Manufacturers' Association
PMTCT	prevention of mother-to-child transmission of HIV
SACP	South African Communist Party
Sama	South African Medical Association
Sanco	South African National Civic Organisation
TAC	Treatment Action Campaign
TB	tuberculosis
THO	Traditional Healers' Organisation
TRC	Truth and Reconciliation Commission
UCT	University of Cape Town

1

Introduction

‘quack: a pretender to medical skill : an ignorant or dishonest practitioner’

– *Journal of the American Medical Association*

The President, his minister and the Aids epidemic

Over two and half million people have died of Aids in South Africa, most of them during the time that Thabo Mbeki served as President. Life expectancy dropped from 62 years in 1990 to 51 in 2005. Without HIV, it would most likely have increased to close to 70. Hundreds of thousands of Aids deaths and HIV infections could have been avoided had the state’s response to the epidemic been informed by science and the right to access healthcare services enshrined in the South African Constitution.¹

Throughout their terms in office Mbeki and his Health Minister, Manto Tshabalala-Msimang, obstructed policies to provide life-saving medicines to people with HIV or at risk of contracting it. They promoted confusion and doubt about the prevention and treatment of HIV. And they protected and promoted people who marketed untested remedies.

This is the story of the struggle of the Treatment Action Campaign (TAC) to stop Mbeki, Tshabalala-Msimang and the state from supporting charlatans selling Aids cures and from promoting what was in effect Aids anti-science. I have been involved in the organisation’s campaign to change the state’s response to the HIV epidemic since 2000. A large part of our work has been to expose state-supported quackery and to explain which

medicines are actually effective for managing HIV. This book is a product of that effort.

Quackery is the promotion of remedies that either do not work or have not been tested. It occurs in every society. What made South Africa different was that quackery received the support of the President and many of his powerful supporters. This caused confusion and hampered the work of scientists, doctors and nurses. It crippled the Medicines Control Council (MCC), the institution responsible for regulating medicines. Mbeki also used his control of the ruling African National Congress (ANC) to generate widespread political support for quackery and unscientific beliefs about Aids. The deadly delusions of the President and his Minister of Health infected a country and paralysed its response to the worst health epidemic of our time. The consequences were tragic.

Mbeki is an Aids denier, someone who promotes one or more of three views: that HIV does not cause Aids, that there is not a large Aids epidemic in sub-Saharan Africa and that antiretrovirals (ARVs) cause more harm than good. While some Aids deniers promote only one of these fallacies, Mbeki promoted all three at one time or another.

He was not always a denier, at least not so far as the public record shows. In October 1998 he spoke on behalf of President Mandela and declared a Partnership Against HIV/Aids.

HIV/Aids is among us. It is real. It is spreading. We can only win against HIV/Aids if we join hands to save our nation. For too long we have closed our eyes as a nation, hoping the truth was not so real. For many years, we have allowed the H-I-Virus to spread, and at a rate in our country which is one of the fastest in the world. Every single day a further 1,500 people in South Africa get infected. To date, more than three million people have been infected.²

There is no indication in this speech of the disastrous positions and decisions he was to take over the next few years. But there were already signs from his other actions that his response to the epidemic would be unreasonable.

In 1996, the culmination of a series of medical breakthroughs turned HIV from a fatal infection into a chronic manageable disease treatable with ARVs, but it would be another eight years before these medicines became widely available in South Africa. In the same year the Department of Health sponsored a play called *Sarafina II*. It was supposed to promote Aids awareness and prevention, but its message was equivocal and dubious. It cost several million rands of improperly allocated European Union funds. The media and activists harshly criticised the Minister of Health, then Nkosazana Dlamini-Zuma, for this blunder. She made matters worse by responding defensively. But in the greater scheme of things, the *Sarafina II* scandal was a relatively minor affair.³

James Myburgh, who runs a news and political analysis website, has carefully documented the much more serious Virodene affair. It began in 1997, when a group of University of Pretoria researchers, who claimed to have developed a treatment for Aids, were allowed to present their findings to Cabinet without having published a single paper in a medical journal showing its safety or efficacy. At the presentation, two HIV-positive patients testified about the wonders of the drug. The Cabinet applauded them. At a press conference afterwards Mbeki said, ‘The Aids victims described what had happened to them as a result of the treatment. They were in the Cabinet room, walking about, perfectly all right. It was a worthy thing to see because the general assumption is that if you get to a particular point with Aids it really is a matter of time before you die.’⁴

Clinical trials are the scientific gold standard for determining if medicines are effective. The MCC has the legal responsibility for deciding if a clinical trial of a medicine on humans can proceed. It had not given the Virodene researchers authorisation to test their drug and so, quite correctly, it halted further testing of the medicine on humans. A fallout followed between Mbeki and the chair of the MCC, Professor Peter Folb, who was consequently dismissed from his position. This marked the beginning of the erosion of the MCC’s independence. The Virodene scandal dragged on for years. There is a strong suggestion that either the state or the ruling ANC sponsored a clinical trial of the drug on Tanzanian

soldiers. Journalist Fiona Forde reported that about R40 million was paid to the Virodene researchers in 2001 and 2002 from the President's office. It was, according to Forde's source, always paid in \$100 bills stashed in briefcases. Tshabalala–Msimang visited the Tanzanian trial site, 'to evaluate the usefulness of Virodene,' as she explained. That trial's results have, so far as I can determine, never been published in a peer-reviewed scientific journal, yet the Virodene website has a glossy pamphlet claiming that the trial found the drug safe and effective without adequately explaining how this conclusion was reached.⁵

Virodene is a toxic industrial solvent. The Tanzanian trial patients taking Virodene showed no improvement in a key measure of the efficacy of an Aids drug, the amount of virus in their bloodstreams. There is no prospect of its being a treatment for Aids. It was the first of many quack remedies that would receive the support of Mbeki's government.⁶

The evidence is immense that HIV causes Aids, that the benefits of ARVs for people with Aids far outweigh their risks and that there is a large HIV epidemic in sub-Saharan Africa. Aids denialism is factually wrong. The arguments used to support it are pseudo-scientific; they have the superficial appearance of being scientific, but they do not stand up to scrutiny.

Aids denialism is inextricably linked to quackery. Quacks selling remedies for Aids are often denialists because they discourage their patients from taking ARVs. Many of the prominent denialists have also promoted quack treatments for Aids. On the other hand, some sellers of untested treatments market their wares as adjuncts to ARV treatment. They do not discourage their patients from using ARVs with their products. Their medicines are promoted as complementary rather than alternative.

Studies of HIV-positive patients in the United States and Australia show that many, probably more than half, use complementary medicines with their ARVs. Whether a medicine is complementary or alternative depends on its marketing and whether or not the person taking it uses it with or as an alternative to scientifically tested and approved medicines. Perhaps there is a psychological benefit for some people who use untested medicines: this

is certainly suggested by the Australian survey and others. Arguably, selling complementary medicines is still ethically dubious because the people selling them make unproven claims. The line between complementary and alternative medicines is also often blurred. Nevertheless, in this book the quack remedies I deal with are or were sold unequivocally as alternatives to scientifically tested medicines.⁷

Quackery is not uniform. This book tells the stories of Tine van der Maas and Matthias Rath. Compared with Rath, Van der Maas is a small operator who I suspect is driven primarily by genuine belief rather than money. Rath's quackery, on the other hand, is on an industrial scale. Then there is the complex subject of traditional medicine. Not all traditional healers are quacks, at least when it comes to people with Aids. Many fulfil a critical psychological support role for patients and refer them to the public health system for medicines. Among those that are unequivocally quacks, there are small-scale, very poor ones operating from corrugated-iron shacks and struggling to make ends meet and there are others like Zebulon Gwala, who runs a large business selling his product called Ubhejane.

Quackery is a form of deceit. It is a way of interacting with the world based on dubious testimonies (rather than medical trials), false information and false assumptions. Usually it merely causes people to part with small amounts of money, but when it comes to the treatment of potentially fatal illnesses like Aids, tuberculosis (TB) and cancer, quackery can be deadly. It is driven not only by money but also by an ideological antagonism to science, a hostility shared by both quacks and their patients.

With the proliferation of new medicines in the last few decades, many of them both effective and potentially dangerous, governments across the world have increased the regulation of healthcare provision to protect patients from harm, including the harm of quacks. Most of us understand little about how to treat our illnesses. We also do not know how to repair our cars when they break down. This is why we are so often ripped off by car mechanics. But fixing our health properly is somewhat more important than fixing our cars. We depend on health providers to make us better and often have, at best, a slight understanding of how our doctor,

nurse or traditional or alternative healer does this. Unless we are health professionals, we simply do not have the time to learn what we need to know to maximise the chances of treating our illnesses successfully. Even health professionals do not usually treat themselves, and with the growing specialisation of medicine, there is hardly a doctor in the world who would have the knowledge to be able to treat all the illnesses with which she or he could be afflicted.

Regulatory frameworks for healthcare have been created to protect patients because of the lopsided distribution of knowledge between them and their health providers. A key principle of this regulation is that the best available scientifically obtained evidence should determine which medicines are safe and effective for treating illnesses. There is a term that describes this: the scientific governance of medicine. It may not sound like a particularly exciting concept or one worth defending in a book, but many people, including friends and colleagues of mine, would most likely be alive today if Thabo Mbeki had respected the scientific governance of medicine. While Mbeki's involvement in this country's notorious arms deal and his handling of Zimbabwe have rightly been condemned, it is through his interference with the scientific governance of medicine that his worst errors were committed which will ultimately leave his legacy shattered.

Here a quack, there a quack, everywhere a quack-quack

As I strolled down St George's Mall, the main pedestrian walkway in Cape Town, I was handed a pamphlet that advertised a 'unique natural complementary medicine' to 'inactivate and remove' HIV 'from the body.' I had collected many similar pamphlets before. One advertised that a 'Lady Doctor' Fazira and Alibawa had a 'a very strong treatment for Aids'. Another, from a Dr Araphat, claimed more or less the same. But this one had such an alluring name that I had to find out more. It was called Ozone Rectal Therapy. So I could not resist an invitation to accompany a television crew to their interview with the seller of this unique remedy. The crew had been commissioned by a media organisation called Health-e to do an exposé of Aids quackery. I have been interested, actually obsessed, for

nearly a decade in debunking quack remedies for Aids as part of my work with the TAC.

We were greeted by a Mr Vlok, a white-haired, bespectacled gentleman in a grey suit. His company is called NCM-O₃, which stands for 'Natural Complementary Medicine with Ozone'. His dingy office walls were covered with pamphlets promoting ozone as a treatment for Aids. How is ozone administered? Well, the name of the product says it all, by suppository up the rectum. It is best done at night according to Vlok.⁸

He explained to us, somewhat incoherently and in a hushed tone, how Mark Shuttleworth – one of South Africa's richest people and the first African in space – conducted an experiment in space which achieved the great breakthrough in ozone treatment. Shuttleworth, no doubt, would be most intrigued to learn that he has been part of such an auspicious medical discovery. Vlok also drew a fantastical picture of how ozone kills HIV. He explained to us that, unlike ARVs, ozone gets into the body's HIV infected cells. The interviewer, Anna-Maria Lombard, asked him how ozone, which according to Vlok kills not only HIV but cancerous cells and many other viruses and germs, knew how to differentiate between healthy cells, viruses and germs. 'The infected cells have a marker on them,' he answered, as if it was obvious. Like a bullseye, I imagined. Vlok said that he tests for HIV on his premises (which, incidentally, is in breach of the National Health Act). He even showed us the test he uses. When people test positive, he reassures them that it is okay and that they won't die.

His whole three-month package cost R2,000 to R4,000. He told us this was much cheaper than ARVs. But actually this is nearly double the price of ARVs in the private sector for three months' supply. And ARVs have actually been shown to work.

Vlok kept on stressing how he had worked in a hospital. Eventually Lombard asked what he did there. He answered sheepishly in Afrikaans, 'I was a clerk.'

I did some research on the Internet into ozone therapy. A whole gamut of people offer it as a treatment for many diseases, including Aids. Vlok is not the first person to come up with this idea. Even his method of administering

it is not unique. Ozone has in fact been tested as a treatment for Aids. I was surprised by this. In most of my encounters with quacks, they have sold products which have never been tested in properly controlled clinical trials. Perhaps this gives them sufficient leeway to market their products using anecdotes or their own badly conducted and often illegal clinical trials which they have dressed up in scientific jargon.

In the early 1990s, long before HIV had become the chronic manageable disease that it is today and when the search for treatments was desperate, a Canadian research team injected ozone into patients with HIV. They did this for eight weeks and then observed them for a month. The ozone-treated patients did no better on any relevant measurement than a group that did not receive the treatment. This means that ozone is unlikely to work against HIV. Admittedly, the Canadians used injections, not enemas, but I cannot see how the latter are likely to be an improvement.⁹

Sometimes quack advertising is more subtle than Vlok's and Aids is mentioned euphemistically or in a way that only the advertisers' target market will understand. I have a pamphlet that I obtained in Cape Town's largest township, Khayelitsha, home to the city's highest concentration of people with HIV. This one says it treats *umbulalazme*, the Xhosa word for Aids. Right outside Khayelitsha's main shopping centre is a billboard with a large photo of the beautiful actress Joyce Skefu from the popular soapie *Generations*. She's holding a bottle of Aloe4U, extra strength, which claims to boost the immune system naturally.

Not far from the City Hall in the centre of Cape Town there's Diskom, a departmental chain store aimed at low-income shoppers. I went shopping there with the Health-e crew and bought Ingwe Booster, Impilo Gold, Impilo Sutherlandia, Impilo African Potato extract, Spiraforce's Alo Vera and quite a few others. I could have bought many more, but after years of receiving an NGO salary, R250 was my limit. They all claimed to boost your immune system, which in South Africa is often a coded way of saying they treat Aids. These products were not hiding in an obscure dusty corner of the shop. The immune-boosting section is large, conspicuous and near the cash tills. Diskom is not the only shop selling these remedies. You can

also find similar products with similar claims in other large chains. E-tv ran the Health-e documentary on the popular muck-raking programme *3rd Degree*. At the end of the show, the presenter, Debora Patta, said that Diskom had agreed to remove these products. I went back to Diskom a few weeks later and then a few months later. Exactly the same remedies were on sale on exactly the same shelves.

Far more cavalier with the products they sell than any of these chains is your local chemist. We would like to see pharmacies as reliable purveyors of proven medicines. They are not. My local chemist has a big window advertisement selling Secomet, which allegedly treats a whole range of symptoms remarkably similar to those of Aids. In fact the manufacturer has made claims on its website that Secomet treats Aids. The company worked with Girish Kotwal, who used to be a professor at the University of Cape Town (UCT), to promote the product. Kotwal conducted dodgy experiments on university property with Secomet, which caused a small scandal. So the university reached a polite arrangement with him and he departed. In my capacity as TAC's policy director I lodged a complaint against Secomet with the Department of Health's Law Enforcement Unit (LEU) in November 2006. Nothing consequential came of it during the time that Tshabalala-Msimang served as Health Minister. Over two years later, and only after Barbara Hogan became Health Minister, one of the LEU's inspectors tried to stop Secomet, but the unit was hopelessly underfunded and understaffed and the Director of Public Prosecutions declined to take action against the company.

The reach of quackery goes beyond marketing to predominantly working-class people; it also goes beyond race. Middle-class South Africa, white and black, indulges in quackery on a large scale. The ubiquity of quackery in South Africa is, as I explain in this book, a direct consequence of bad state policies and support for it by the country's leaders. Unfortunately quackery is not just an absurd collection of giggles and gags. The Health-e investigation uncovered the fact that most of the scams – the ones with the exotic names, that is – are connected. The pamphlets are recycled with slightly different text and the names of the 'doctors' are changed. This is

why you can read in one pamphlet that Professor Shafiq and Maama Zayna have a ‘new steaming method (Biocell Herb Method)’ and on another that Dr Mama Fatumo and Kibo have a ‘new steaming method (Biocell Herb Method)’. Many operate in the same buildings, and they simply get up and leave if they suspect the police are on to them. Health-e interviewed a man called Kingsley (presumably a pseudonym) who claimed he had been to one of these healers to rid his house of evil spirits and parted with hundreds of thousands of rands. So he laid a charge of fraud. I cannot help wondering if he is very gullible or a teller of tall tales.

And here is a decidedly unfunny story. Andile Madondile went to see traditional healers in the Free State and Cape Town. But his illness just got worse. His body was wasted and covered with blisters. So Andile tied a noose in a rope. He hung the rope from the roof of his shack. He placed a chair under the rope. He stood on the chair, put the noose of the rope around his neck, removed its slack, kicked the chair away, dropped and dangled.

Andile was born in Baragwanath Hospital in Soweto, Johannesburg. It is one of the world’s largest hospitals. It admits 150,000 patients and treats 500,000 outpatients a year. When Andile was born, on Christmas Day 1978 according to his mother, none of Baragwanath’s patients had HIV; today it treats more people with HIV than any other health facility on the planet.¹⁰ Twenty-six years later, Andile tried to kill himself because he had Aids.

As he swung from the rope, dizzy and gasping for breath, his three-year-old daughter, Elihle, walked into the room and screamed.

* * *

It is not good enough in a book such as this to say that ARVs are effective and other medicines for treating HIV are not. It is also important to explain why this is so, to describe the science of HIV and the medicines used to treat it. The stories I tell here would be incomplete without some scientific explanations as well. At the root of the struggle between the TAC and Mbeki was the contest between science and anti-science. Moreover, Aids

has killed and is killing many of our friends and colleagues. Maybe you, too, have HIV, have been confused by the debates of the last decade and want to understand things more clearly. While some of the science of HIV is complex, there is a level of understanding that most people can acquire without too much effort. I have tried to find a balance between explaining concepts simply but not so simply that all meaning is lost.

I hope this book conveys the atmosphere and human consequences of what has been a horrific period of South African history. But the full picture is not just one of horror. Also woven into this book is Andile Madondile’s story. While parts of it are tragic and disturbing, his is ultimately a story of hope and the restoration of dignity.

2

What we know about Aids

‘I have often been asked what it was like to be one of the early Aids investigators. To me, it all began as a medical mystery. As time went on, however, I gradually began to see that what we were studying was much bigger than I had first imagined. Once it was clear that the disease was sexually transmitted, we knew that the disease would not be limited to [men who have sex with men]. And once we knew that the agent was in the blood supply, we knew many more people were at risk. The medical mystery would soon become the global pandemic.’

– Harold Jaffe¹

An epidemic emerges

The cause of Aids has been discovered, been named, become a deadly global epidemic and become treatable, all in less than three decades. In a generation it has evolved into a dreaded scourge and then into a chronic manageable disease. Its spread and growth were made possible by an increasingly globalised world, in which communication, travel and migration have woven the world’s people together. Yet, in contrast to the many plagues of human history, the same factors responsible for its spread have helped raise and spend, often wisely, sometimes not, the billions of dollars that have made HIV infection treatable.

UNAids estimated that 30 to 36 million people were living with HIV in 2007, two million of them children. Well over three million people are

on ARV treatment, and yet another ten million people need it now. Their fates are being decided by a combination of politics and global economic inequality epitomised by the inadequate health systems of the poor countries of the world. Over 25 million people have died of Aids since the start of the epidemic. With the possible exception of the Spanish influenza pandemic, this is the shortest period of time in which so many have died of a single infectious agent in history.

These statistics need to be treated with a great deal of caution. Nevertheless, uncertainty about the precise number of infections and deaths due to Aids should not be mistaken for ignorance. We know that tens of millions of people are infected with HIV, that sub-Saharan Africa bears the brunt of the epidemic and that South Africa has an enormous problem. Perhaps there are not five million people with HIV in South Africa; maybe there are four million, or even seven million. But it makes no difference to this point: that millions of people in South Africa are infected and most of them will die of Aids unless they access ARVs in time. There is ample evidence from waiting lists and death statistics that the number of people receiving ARVs is far short of the number who need it, even if we do not know the exact amounts for either.

This chapter explains the basics of HIV science. Understanding this is essential to understanding why Aids denialism and the quackery surrounding it are factually and morally wrong.

The origin of Aids

Research in the last few years has made it possible to describe approximately when and where the first HIV infections occurred and the route the virus took on its way to becoming an epidemic. First, it is important to understand that there are several varieties of HIV, with a common ancestry: HIV-1 and HIV-2. HIV-1 is the type you almost always read about, while HIV-2 is less easily transmitted and is only occasionally found outside West Africa. HIV-1 is divided into several groups, of which Group M is the one responsible for the worldwide epidemic. The remainder of this book deals with HIV-1 Group M.

Nearly identical viruses to HIV-1 and HIV-2 have been found in captured chimpanzees and sooty mangabey monkeys respectively, both sub-Saharan African animals. This gave scientists clues to the virus's origins. But the vital evidence on the origins of Aids was found in poop. In 2006 a team of researchers from the US, UK and Cameroon, led by Brandon Keele and Beatrice Hahn, discovered a virus almost identical to HIV in the faeces of wild chimpanzees living in southern Cameroon. They compared HIV-1 Group M with it, using genetic sequencing technology, and found that the human virus had most likely evolved from particular chimpanzee communities, probably in the early part of the 20th century as a result of hunting and butchering.²

You might think that for a virus to cross from primate to man is unlikely, but recent research that looked at hunters in Cameroon shows that it is not. This demonstrated that viruses similar to HIV continue to cross over to humans frequently. So it is not so surprising then that there are at least two HIV epidemics, one of which is global in scale. The recent swine and avian flu outbreaks also show that for a virus to cross from animal to human is not unusual.³

Frozen blood and tissue samples from decades ago have helped uncover the pattern of HIV's global journey. An adult man who lived in the Belgian Congo (now DRC) in 1959 is currently the oldest known HIV-1 infection. Nothing is known of who he was or what became of him. We know he had HIV because a blood sample of his was stored and then tested in the late 1990s.⁴

A body fluid sample taken from a similarly anonymous Congolese woman in 1960 was recently discovered to have HIV. Genetically her virus is sufficiently different from the first known infection to lead researchers to conclude that HIV was quite diverse in the Congo by 1960. This suggests that the virus had already begun spreading through the population by then, 'long before the recognised Aids pandemic', as Michael Worobey and his team explain in their fascinating research.⁵

By isolating HIV from the blood of infected people across the world and then comparing how their strains of HIV differ genetically, scientists

have shown that the virus spread from Africa to Haiti in about 1966 and then shortly thereafter to the US. Yet in South Africa, HIV tests of stored blood samples from 1970 to 1974 of over 2,000 miners from Mozambique, Malawi, South Africa, Lesotho, Botswana, Angola and Swaziland showed no conclusive evidence of the virus. So HIV was probably not widely present in southern Africa until at least the mid-1970s, possibly even later. We can therefore be quite sure that HIV is a new epidemic of the last three decades in this part of the world. Southern Africa now has the bulk of the world's HIV-positive population, even though the virus only reached this part of the globe recently.⁶

The origins of Aids and the first cases were only discovered in the last three decades. On 12 December 1977, the first serious clue of this new disease presented itself. A Danish doctor, Margrethe Rask, who had worked in a hospital in Zaire (now DRC), died at the age of 47. An autopsy revealed that the cause was pneumocystis carinii pneumonia (PCP), a rare disease at the time, but one that soon became known as one of the biggest causes of death in people with HIV.⁷

From the last quarter of 1980 to May 1981, doctors and scientists in New York, Los Angeles, San Francisco and Atlanta started to notice strange medical phenomena: young gay men were falling ill with very rare diseases. The news of this was broken in the June 1981 issue of the Centers for Disease Control's weekly *Morbidity and Mortality Report*.⁸ This went on to describe the disease progression of each patient, two of whom had already died. It was the first scientific report of the epidemic. Reports of people dying with similar symptoms started coming out of the UK and France. The disease received the name Acquired Immune Deficiency Syndrome, or Aids, in August 1982. In 1983 a report in *The Lancet*, a leading medical journal published in the UK, described the cases of five men from Zaire and Chad with Aids who had been living in Belgium. At the same time Ugandan doctors started noticing similarities between their patients and the cases being reported from Europe and North America. They called it Slim disease. In 1985 a Ugandan medical report showed that Slim and Aids were likely identical; the symptoms were similar and the only thing that

could explain the transmission of the disease was sex.⁹

This, then, is what the evidence shows about the start of Aids. There are many gaps and some of the facts might be reassessed as new information arises. Debates over the origins and spread of the epidemic are often acrimonious. In his popular book *And the Band Played On*, the late Randy Shilts held a Canadian air steward, Gaetan Dugas, better known as Patient Zero, responsible for the spread of HIV in North America. Shilts described Dugas as a man with a voracious uncontrolled sexual appetite who failed to cooperate with health authorities. Subsequent research has shown that this accusation was unfair. Similarly, the journalist Edward Hooper has proposed the implausible theory that a World Health Organisation (WHO) polio vaccination programme was responsible for the spread of HIV.

The stigma of HIV encourages a search for blame. Deflecting blame for one's disease onto scientists, drug companies, the American government or the WHO is appealing. At its extreme, it seems to me to be often the driving force behind Aids denialism. On the other hand, blaming the disease on gay men or Africans is equally unfair, increasing stigma and promoting the search for conspiracies where none exist.¹⁰

Aids comes to South Africa

“‘Gay Plague’: More victims?’ This was the headline of a story in South Africa's bestselling weekly newspaper, the *Sunday Times*, on 9 January 1983.

The early epidemic was concentrated among white gay men; there are very few accounts about the disease's early progression amongst black people. Apartheid's oppressive environment meant that few people were willing to fight an epidemic that mainly affected marginalised people, and so there are not many written accounts from that time.¹¹

In early 1982, a 42-year-old South African Airways air steward, Ralph Kretzen, whose flight routes included the US, complained to his doctor that he had influenza and was losing weight. By July his condition had worsened. He was coughing and had a fever and diarrhoea. Tests showed that he had symptoms of illness caused by cytomegalovirus (CMV)

infection. His white blood cell count was abnormal. Although there was no HIV test in those days, these were signs that he had the same disease that had broken out in the US and Europe. He improved – ‘dramatically’, according to his case report – after being given various medications. But five days later he was readmitted to hospital, struggling to breathe. He died on 26 August. An autopsy showed that he had PCP. On 1 January 1983 another air steward, Charles Steyn, died of Aids in Pretoria. The *South African Medical Journal (SAMJ)* published the Kretzen and Steyn case reports in July 1983. They were the first two recorded Aids deaths of South Africans. Both were white and gay.¹²

Their stories were known a while before the *SAMJ* article. The front page of the *Cape Argus* three days after Steyn died read, “‘Homosexual’ disease kills SAA stewards’. The report continued, ‘Described by *Time Magazine* as a “mysterious and deadly epidemic”, it was at first thought that Aids was confined to male homosexuals. But developments in the United States over the past three weeks have revealed that Aids has spread to heterosexual drug-abusers, Haitians, haemophiliacs and children.’ On 9 January 1983 the *Sunday Times* ran its gay plague story.¹³

Aids quackery in South Africa started very soon afterwards. On 13 January the *Argus* ran a story headed, ‘Aids can be cured, claim homeopaths.’ ‘Acquired Immune Deficiency Syndrome and homosexuality can be cured through homeopathy, several homeopaths claim.’ The article quotes the spokesman for the South African Homeopathic Society explaining that homosexuality is a psychological problem and therefore treatable. Aids could be treated because homeopathic remedies could build up the body's immune systems. ‘It isn't an easy treatment and would take quite a long time, but there are medicines in our profession that would work.’ He admitted never having seen an Aids patient.¹⁴

Throughout the eighties, Aids continued to kill people, though at a slow rate. By 14 December 1988, only 166 Aids cases had been reported in South Africa, most of them white men. While a handful of people contracted HIV through blood transfusions, the vast majority, 125, did so through homosexual sex; 24 were heterosexual transmissions. Only three were

children. The total number of recorded HIV infections (including people who had not advanced to Aids) was 1,857, of whom more than half were white and almost all were men. (These figures excluded the mining industry for which I do not have data.) There were undoubtedly many more people who were undiagnosed. Because they enjoyed better health services, whites were probably over-represented in the data. Nevertheless, the epidemic was still small and would remain so for a while. The demographics of the epidemic would also soon change dramatically.¹⁵

In 1990, the first antenatal survey was conducted. The Department of Health anonymously tested thousands of pregnant women attending public health clinics. Less than one in 100 women tested positive in the first study. By 2005 the ratio was more than 30 in 100. A large household survey, also conducted in 2005, showed that over 10% of people over the age of two were infected, mostly women. There are now at least 60,000 infants infected annually, mostly during labour and from breastmilk. How Aids in South Africa turned from a seemingly manageable outbreak in the 1980s and early 1990s to the world's largest epidemic in less than a decade is the subject of much unresolved discussion.¹⁶

Incompetence in responding to the epidemic certainly did not start with Thabo Mbeki. The apartheid government was for the most part uninterested in Aids and it was private individuals, mainly in the gay community, who ran awareness programmes in the early years of the epidemic. Considering that homosexuality was illegal at the time, this was not easy. The state response was minimal, particularly in black areas. Sometimes it was destructive. In October 1987, a government regulation banned the employment of HIV-positive foreign workers. It also gave immigration authorities the power to test, detain and deport non-South Africans with HIV. In 1992, a condom awareness campaign developed by the Medical Research Council (MRC) was opposed by the Cape Town City Council, which stopped billboards from being placed at a prominent intersection of the city. A condom awareness advert at the city's Metro train station also caused a furor. At one point the SABC, the public broadcaster, decided to screen condom advertisements, but only after 9 pm out of regard

for public sensibilities. John Scott, a popular Cape Town satirist, cleverly quipped that this 'will persuade many viewers to stay up later than usual, so that they can be disgusted'.¹⁷

This all preceded the era of Aids denialism. More accurately it took place during an era of a different type of government denial, the ostrich-in-the-sand approach. ARVs were unaffordable during this period and in any case were not particularly effective until 1996. Even from 1994 to 1999 under the first democratic government headed by Nelson Mandela, Aids remained low on the radar, something for which Mandela has since expressed regret. Journalist Donald McNeil provides a possible explanation for this. 'In 1991, when [Mandela] endorsed safe sex to some Mpumalanga parents, he said, "I could see they thought I was saying something revolting. After, they came to me and said, "How can you talk about this? You want to encourage prostitution among our children?"' So he quit.'¹⁸

South Africa has never had an effective government HIV prevention information campaign. A useful strategy document developed by the National Aids Coordinating Committee of South Africa was endorsed by the Cabinet in 1994, but it was not adequately implemented. An insipid, only slightly improved, attitude to HIV awareness continues to this day. Useful information about how to avoid contracting HIV was particularly subdued in the era of Aids denialism. Safer sex was promoted publicly, but also obscurely. This was epitomised by very strange billboard messages placed by a government-funded NGO featuring expensively dressed adolescents making meaningless statements like 'Do you love yourself enough?' Condom advertisements, while not invisible, were shown occasionally on television and seemed like a novelty when one saw them, usually after 9 pm.

Finding the cause

After the Centers for Disease Control published its article showing that people were becoming ill from a strange new disease, it set up a small but skilled task force to try to find out what was going on. Harold Jaffe, who was part of this team, has explained the mystery they were confronted with.

Why were men who had sex with men getting opportunistic infections? Was a virus or bacterium involved? If so was it perhaps transmitted through sex? Or was it related to recreational drug use?

As more Aids cases emerged in gay men, recipients of blood transfusions, intravenous drug-users, heterosexual Haitians as well as in five infants, Jaffe's team determined through interviews and tracing contacts of sick people that an infectious agent was very likely involved and that it was transmitted in blood or blood products. They also determined that this agent could be carried by and transmitted from people who had no symptoms of Aids. The incubation period of the disease was potentially long. These were vital clues for laboratories looking for the cause.¹⁹

Every human is made up of trillions of cells. Each cell contains 46 chromosomes. Each chromosome contains DNA, the chemical instructions for making proteins and reproducing the cell. If you look at a piece of DNA, it is composed of two long facing strands of chemicals that spiral around each other. Sections of these encode genes. Each gene is a set of chemical instructions that usually tell the cell how to make one protein. You can think of a protein as a little machine that fulfils a specialised bodily function. One type of protein is an enzyme. These are proteins that speed up chemical processes. The process involved in making a protein from a gene is complex. One of the steps along the way is to construct single strands of chemical instructions from the gene. These single strands are called RNA. So essentially in the process of making proteins, DNA is converted to RNA. At least that's the way it works for humans.

Viruses lack the chemicals to reproduce themselves. They need to use the reproductive machinery of a cell, such as a human one. Many viruses that infect humans, such as herpes and smallpox, are made up of DNA. Others, including influenza and polio, are made up of RNA instead of DNA. There is a subset of RNA viruses called retroviruses. These work by converting their viral RNA into viral DNA, which is then inserted into its host's DNA. There is a viral enzyme that makes this happen. Because it converts RNA into DNA, the opposite direction of the process in humans and most other creatures, it is called reverse transcriptase. It was discovered in the 1970s.

Françoise Barré-Sinoussi, Luc Montagnier and their team at the Viral Oncology Unit at the Pasteur Institute in Paris realised that the swollen lymph nodes of people with Aids most likely contained the infectious agent suspected by Jaffe's team as the cause of Aids. The lymph nodes contain large numbers of white blood cells including CD4 ones and patients were losing CD4 cells, so possibly the virus or bacterium was attacking these. They grew – or cultured, as scientists say – white blood cells. While culturing these cells from people with Aids symptoms, the Pasteur Institute team discovered reverse transcriptase at work, which suggested to them that Aids was caused by a retrovirus. This was striking because retroviruses in humans were unusual.²⁰

The reverse transcriptase activity would stop unless new healthy cells were added to the culture. This suggested that the virus was infecting cells, using them to reproduce but killing them in the process. When a virus invades the body, the immune system generates antibodies to destroy them. Barré-Sinoussi and Montagnier detected antibodies that were specific to a new retrovirus. They showed that healthy blood could be infected by this new virus and named it Lymphadenopathy Associated Virus or simply LAV. On 20 May 1983 they published in the leading journal *Science* their finding that they had isolated a retrovirus from a patient with Aids symptoms, but added, 'the role of this virus in the etiology of Aids remains to be determined'.²¹

The French team also isolated retroviruses from haemophiliac siblings, one of whom already had Aids symptoms. They named this Immunodeficiency Associated Virus (IDAV), just in case it was different from LAV. They studied a range of people and found the same type of retroviruses in those with Aids symptoms or at risk of developing Aids. They could not detect it in people with other diseases or with no known risk factors for Aids.²²

Meanwhile similar work was being conducted by Robert Gallo and his team at the National Institutes of Health (NIH) in the US and Jay Levy at the University of California–San Francisco School of Medicine. In May 1984 Gallo's team published four papers in *Science* which showed clearly that Aids

was caused by a newly discovered retrovirus. Gallo's group also developed a reliable method to detect the antibodies: this was the first HIV test.

The three groups soon realised they were all working on the same virus. In 1985 it was named Human Immunodeficiency Virus, or HIV. For their work Barré-Sinoussi and Montagnier received the 2008 Nobel Prize for Medicine. Unfortunately credit for the discovery of the virus became mired in controversy. Some Aids denialists are obsessed with this to this day, even though it has no bearing on the science of HIV.

Retroviruses, unlike most other viruses, infect you for life. Your immune system usually cannot clear them from your body. The reason is that they insert themselves into the DNA of some of your cells. Whenever infected cells create proteins, they also create new copies of the virus. When these cells reproduce, the viral DNA is copied along with the human DNA into the replicated cells.²³

Over the years, a massive body of evidence has accumulated confirming that HIV causes Aids. Here's a very small selection of this evidence:

- Three laboratory workers, with no other risk factors, developed Aids after being infected with HIV in laboratory accidents.
- A dentist transmitted HIV to his patients and they developed Aids. Genetic analysis showed that the virus his patients had very probably came from him.
- Health workers who have injured themselves with needles contaminated with HIV, but with no other known risk factors, have developed Aids.
- Many haemophiliacs who received blood transfusions contaminated with HIV developed Aids. Those that have not received contaminated transfusions did not, unless they had other risk factors.
- Epidemiological studies in the US, Europe, Uganda and South Africa have shown that people who are HIV-positive are much more likely to get Aids-related illnesses and die younger than people in whom the virus cannot be detected.
- HIV is photographed regularly using electron microscopes. Its genes have been sequenced. Scientists have developed a detailed, albeit incomplete,

explanation, confirmed by experiments, of how it invades the body, attacks CD4 cells and progressively destroys the immune system. HIV is isolated daily in laboratories across the world.

- Tests can measure the amount of HIV in a drop of blood taken from a person. There is a strong correlation between the amount of HIV and the person's health. Also, when people are on ARVs, the amount of HIV drops to barely detectable levels. If the amount of HIV increases again, this is a sign that treatment has stopped working.

It is fair to say that there is no other infectious disease whose cause has been confirmed as thoroughly as HIV.

Scientists have looked for other causes without success. A favourite one advocated by Aids denialists, particularly Professor Peter Duesberg of the University of California at Berkeley, is that recreational drug use in gay communities caused Aids. But studies have been done in gay communities to check this and found too many people who do not use recreational drugs that have developed Aids. By contrast, too many people who do use these drugs do not develop Aids unless they are HIV-positive.

Over a hundred years ago Robert Koch described four postulates that must be met to enable one to say with great confidence that a particular kind of germ is the cause of a disease in an animal. They have been slightly modified over time and some scientists have proposed alternative, perhaps better, conditions. But Koch's postulates are still accepted as the ultimate proof of cause. Slightly modified, here they are:

1. The disease should only occur in animals infected with the germ. Not every infected animal needs to get the disease, though.
2. It must be possible to take the germ from the diseased animal (or isolate the germ as scientists say) and grow it in a laboratory. In other words, it should be possible to culture it.
3. It must be possible for a previously uninfected animal to become sick if it is infected with germs grown in culture.
4. It must be possible to again isolate the germ from an animal infected via postulate 3.

For many infectious diseases, including Aids in its early period, scientists agree on the cause long before all the postulates are met. But HIV has indeed met this high burden of proof. Postulates 3 and 4 have been fulfilled in the tragic accidents in which HIV laboratory workers got infected.

The first postulate is the most important. It means that the germ must be highly correlated with the disease. If it is not, then it cannot be the cause. Yet medical data are full of exceptions in every field. This is because the tools used to measure what is going on in the human body are prone to error. There is always noise in the data, anomalies that cannot be explained and plain old human errors. No medical test is always accurate. Occasionally misdiagnoses are made. (Think of the pregnancy test.) So on extremely rare occasions, people have developed Aids despite testing negative for HIV. Nevertheless with time, the accuracy of the standard HIV testing algorithms has approached, albeit not quite reached, 100%. There are two well-understood exceptions to this: babies younger than 18 months born to HIV-positive mothers and people still in the several-week window period just after infection. The former, because they have their mother's antibodies temporarily, often test HIV-positive when they are not infected and the latter often test HIV-negative because they have not produced sufficient antibodies to show up on the test.

The progress of the virus can be fairly summarily described. HIV progressively depletes the immune system of CD4 T-cells. These are the white blood cells that help coordinate the body's response to infections. They are also therefore known as T Helper Cells. The consequence of their depletion is that people with HIV gradually become more susceptible to a range of infectious diseases. Diseases that attack people with compromised immune systems are called opportunistic infections. People in the early stages of HIV infection might have no symptoms or experience only a higher-than-normal number of minor illnesses. But with time, they are much more likely to get TB, the disease that kills most people with HIV in southern Africa. They are also more likely to get what are otherwise very rare opportunistic infections: PCP, Kaposi's sarcoma, cryptococcal meningitis, toxoplasmosis and many more unpleasant and often deadly

diseases. It is sufficient for an Aids diagnosis for a person with HIV to have any of these. In other words, Aids is simply a stage of HIV infection, the last one. Often when people have Aids, they become ill with multiple opportunistic infections, suffer constantly from diarrhoea and lose far too much weight.²⁴

Without treatment, it takes most people about two to ten years from infection to the onset of Aids. From then it takes about two to three years to die. But there is large individual variability. A UK study showed that about a quarter of people went on to treatment less than two years after being infected. These are known as fast progressors. On the other hand, some very few but lucky people do not show symptoms of Aids even two decades after infection, despite receiving no treatment. They are known as slow progressors, non-progressors or – a term that only medical scientists could have thought of – elite controllers. One's genes appear to be the most important factor affecting the rate of progression, not how well one eats, how much one exercises, to whom one prays or what herbal concoction one takes.²⁵

During the asymptomatic phase of HIV infection, the immune system and the virus are locked in struggle. Millions of viruses are produced daily and destroy millions of CD4 cells. The body counters by producing millions of CD4 cells and destroying millions of viruses. Eventually, for reasons scientists are still grappling with, HIV wins the battle in at least 95% of people, and Aids develops. The battle between HIV and CD4 cells is complicated. HIV infects a minority of CD4 cells, only 1 in 100 to about 1 in 1,000. But those infected cells send signals to uninfected cells to die prematurely. When we are infected with viruses like influenza or one of the common cold ones, the immune system successfully clears the infection from the body. HIV is not cleared and so the immune system constantly detects that it is infected. Therefore it repeatedly produces CD4 cells to fight the infection, but these simply become new targets for HIV to attack. In effect, the immune system behaves like a dog chasing its tail, as a friend of mine put it. Scientists call this immune hyperactivation and it causes a range of health problems. ARV treatment massively reduces the number

of viruses in the body and ends this vicious cycle, allowing the immune system to relax.

Poverty and Aids

A common Aids denialist argument is that Aids in Africa is a new name to cover a range of old diseases caused by living in poverty. Mbeki appeared to agree with this view. Here is an extract of an interview he gave to *Time* Magazine, one of many occasions in which he alluded to it.

Clearly there is such a thing as acquired immune deficiency. The question you have to ask is, what produces this deficiency? ... Now, if you go through the literature, ordinary standard literature available in medical schools, there will be a whole variety of things [that] can cause the immune system to collapse ... Endemic poverty, the impact of nutrition, contaminated water, all of these things, will result in immune deficiency.

Then *Time* asked him, 'Are you prepared to acknowledge that there is a link between HIV and Aids?' He answered:

No, I am saying that you cannot attribute immune deficiency solely and exclusively to a virus. There may very well be a virus. But TB, for example, destroys the immune system and at a certain point if you have TB you will test HIV-positive because the immune system is fighting the TB which is destroying it. Then you will go further to say TB is an opportunistic disease of Aids whereas in fact TB is the thing that destroyed the immune system in the first place. But if you come to the conclusion that the only thing that destroys immune systems is HIV then your only response is to give them ARV drugs. There's no point in attending to this TB business because that's just an opportunistic disease. If the scientists ... say this virus is part of the variety of things from which people acquire immune deficiency, I have no problem with that.²⁶

This answer exemplifies Mbeki's statements on Aids from 2000

onwards: confused and equivocal. He reduces the importance of the virus as a cause of Aids and elevates other causes, in this case the effects of poverty: contaminated water, poor nutrition and TB, which is a disease much more likely to occur in poor people. As his words show, this was his justification for withholding ARVs from the public health system. Mbeki's comments were not merely a misrepresentation of truth. He fudged the cause of Aids by denigrating the role of ARVs and appealing to genuine concerns about the role of poverty. The nonsense of his response in *Time* is made worse by his misunderstanding of how TB is treated. It, too, is treated with drugs, different ones from ARVs. Mbeki's description of the causal relationship between HIV and TB is particularly confused.

Andile Madondile took me to his tiny shack in Khayelitsha which he shares with his wife and two children. There is barely any privacy. Dirt roads crisscross almost randomly between houses. When it rains heavily, those roads become rivulets. But on the day we were there, the sun was baking his shack. There are no shady trees; there is hardly any vegetation at all. Just ugly dilapidated shacks cobbled together from wood and corrugated iron, one after another, packed together nearly on top of each other. And this is not the worst part of the area. There is even more dense 'housing' just down the road from Andile which he says has a lot of people with TB. There is no tap in Andile's shack. The one a few metres from it was vandalised by *tsotsis* and Andile's ward councillor has not done anything to repair it despite promising to do so. So the nearest tap is about 100 metres from his shack. The nearest toilet is even further. His shack, the tap and toilet make a triangle of inconvenient town-planning with devastating public health consequences.

How is poverty related to Aids? For one thing, as Andile's circumstances show, it makes day-to-day living with the virus and opportunistic infections difficult. Diarrhoea is a part of life in the advanced stages of HIV. For many people it occurs often enough at all stages of HIV infection. There is also compelling evidence that poverty increases the risk of HIV infection. Until there's evidence to the contrary, it seems prudent to assume that food insecurity puts people at higher risk of contracting HIV. Aids affects far

more poor than middle-class people. And malnutrition worsens the decline of the immune system after HIV infection.²⁷

But there have been too many well-off people who have died of Aids for poverty to be its cause. Many scientific studies have debunked this notion, but one in particular is worth describing. Nelson Sewankambo and his team of scientists at Makerere University in Kampala have done a series of important epidemiological studies in the Rakai district of Uganda. Over a period of more than three years they followed nearly 20,000 adults under the age of 60. This was long before ARVs became generally available in Uganda. Slightly more than 16% of their cohort was HIV-positive. People with the virus were more than seven times likelier to die during the study period. Babies of HIV-positive mothers were more than twice as likely to die. Younger adults were more at risk of dying from HIV-related illnesses than older ones. None of this is surprising, except for this: HIV deaths were higher among better-educated adults and civil servants, a finding that demolishes the notion that poverty is the cause of Aids.²⁸ And contrary to Mbeki's theory, studies from Thailand, Côte d'Ivoire, Uganda and Tanzania show that, if anything, Aids exacerbates poverty.²⁹

TAC has since its inception in 1998 produced T-shirts which say 'HIV-positive' in bold letters on them. They are worn by HIV-positive and HIV-negative people. The purpose is to show solidarity with infected people, encourage openness and destigmatise the disease. Each edition of the T-shirt has a different message on the back. TAC's response to Mbeki's suggestion that poverty caused Aids was to produce an edition of the T-shirt with the slogan 'Aids causes poverty'. As with Mbeki's view, it was an oversimplification, but it was designed to make an important political point. Most poverty existed before Aids, but the evidence shows that the HIV epidemic has made many people poorer and even thrown well-off people into poverty.

There is one particularly crucial way in which poverty exacerbates Aids that Mbeki almost entirely ignored except, so far as I can find, for one fleeting reference in a speech that otherwise expressed his deep scepticism about HIV as the cause of Aids as well as the benefits of ARVs. Poor people

do not have access to the health services of the well-off. Besides having poorer health facilities, they cannot afford to buy expensive medicines. Until ARVs and other medicines for opportunistic infections were widely available in the public health system – and even since – the poor died of Aids in large numbers in South Africa precisely because it was much more difficult for them than for well-off people with medical insurance to get ARVs.

Finding the first treatment

The search for a cure or treatment for HIV began in earnest once it was shown to cause Aids. Samuel Broder, the clinical director of a special Aids task force established at the US National Cancer Institute (NCI), requested pharmaceutical companies to send drugs which might be effective against HIV to his institute for testing. Drug companies store thousands of compounds in the hope that they might one day be beneficial and potential money-spinners.³⁰

Broder's lab ended up testing over 180 compounds. The most promising was azidothymidine, popularly known today by its abbreviation AZT and also by the more pronounceable name zidovudine. It killed the virus in laboratory tests. In 1985, a small trial was carried out on 35 patients with HIV to work out what the dosage for AZT should be. The trial also concluded that it was safe enough for testing to be taken further.

The process of testing a drug is complex, expensive and time-consuming. The thalidomide scandal of the 1960s, in which thousands of deformed babies were born to women who took the drug, precipitated stringent standards for the testing and approval of new medicines. Typically a new drug must be designed, then tested in a laboratory, then tested on animals, then tested on a small number of healthy volunteers to establish dosage and safety (a step skipped in the case of AZT but incorporated in the next step), then tested on a small number of ill people to determine what dosage, if any, is effective against the relevant disease. Finally, a large study comparing the drug with the best available standard of care must be carried out. If there is nothing available to treat a disease, as with Aids in 1987, then the drug must

be compared to a placebo that is inert but looks and tastes like the drug. This is the decisive step, often called a phase III clinical trial, although in the case of AZT it was the second phase of the human clinical trials. The group taking the real drug is called the intervention or test arm. The group taking the placebo is called the control arm.³¹

Phase III trials need to be randomised, which means that anyone selected to participate in the trial must have an equal chance of being allocated the placebo or the real thing. This is critical. If, for example, the placebo arm had only women and the test drug arm only men, one could miss problems with the drug that are specific to women. Randomisation helps distribute evenly over the two arms of the trial all the factors that could confound the results, so that neither arm is likely to be biased. Analyses of trials show that those that are not properly randomised tend to produce results heavily biased in favour of the test drug.³²

Ideally, trials should also be blinded, meaning that the patients do not know which arm of the trial they are on until it is finished. Even better, trials should be double-blinded, meaning the doctors or nurses treating the patients do not know which arm they are on either. Trials that are not double-blinded tend to produce results biased in favour of the test drug. Not all trials can be blinded, however, sometimes for ethical reasons and sometimes for practical reasons. For example, three randomised controlled trials have looked at the effect of circumcision on HIV transmission. They could not be blinded because it would be somewhat challenging to administer a placebo circumcision.

If a drug outperforms the placebo better than can be explained by chance, then the trial has what is called a statistically significant result. It means, all other things being satisfactory, that one can assume the drug is effective. Unfortunately, even if a trial delivers a statistically significant result, this does not mean one can be absolutely sure the drug is effective, but it is likely. Sometimes, unluckily, a clinical trial produces the wrong result and scientists might not realise it for decades or for ever. There are no absolute guarantees in medicine. However, the better the drug performs compared with the placebo, the more confident we can be. Moreover, if

multiple clinical trials confirm each other's results, we can be even more confident. As we shall see, with ARVs we can be extremely confident.

Safety must also be considered. No drug is entirely safe, because to be effective it has to have some effect on the complex chemistry inside the human body. If a product claims that it has no side-effects – a commonly made claim for quack remedies – it either is false or probably has only a placebo effect. Homeopathic remedies are an example of the latter. When you read a claim that says 'No side-effects', replace this in your head with 'Very likely to be complete bullshit'.

The trial researchers and regulatory authorities, such as the FDA or the South African MCC, decide on all the available evidence if the benefits of the drug outweigh its safety concerns. If so, and if the drug can be manufactured according to strict quality-control standards, it is registered for the treatment of the ailment it was tested on. After a drug is registered, reports of serious or previously unknown side-effects have to be tracked. The registration can be reviewed if a previously undetected problem occurs. Registration is important to drug companies – at least it should be. In South Africa it is illegal for someone selling a medicine to claim that it treats a viral disease, such as Aids, unless it is registered for the treatment of that disease. In chapter 8 I explain why this law is often ignored.

The registration procedure is there to ensure that the medicines people take are acceptably safe, effective and of good quality. It is a reasonably good system that works well much of the time. But despite the numerous checks and balances, things can go wrong, sometimes because of greed and corruption. Tragically, despite the lessons of thalidomide, there continue to be scandals such as that surrounding the painkiller Vioxx, which is thought to have caused nearly 30,000 heart attacks or sudden cardiac deaths in the US alone. It is incidents like this, which are too common unfortunately, that erode public confidence in the pharmaceutical industry and fuel conspiracy theories that lead to Aids denialism.³³

The blinded placebo-controlled trial for AZT, known as BW002, commenced in 1986. All 282 HIV-positive patients were ill, either with Aids or nearly there. The study was terminated early because, within six months,

19 patients out of 137 on placebo died versus only 1 out of 145 taking AZT. The odds of this result having been obtained by luck are less than one in a thousand: AZT is effective. AZT was therefore registered by the Food and Drug Administration (FDA) on 20 March 1987. It took less than three years from the NCI experiments on AZT to registration, extraordinarily quick by drug development standards. This was a consequence of pressure from Aids activists and a realisation by scientists and the FDA that finding treatments for Aids was an emergency.³⁴

The AZT trial was a critical moment in the history not only of Aids but also of Aids denialism. Although it was a breakthrough for people with HIV, the combination of several problems soon undermined public confidence in the drug.

The drug was simply overhyped by its manufacturers and doctors. AZT was not a cure for Aids – and was never marketed as one – but even its efficacy as a chronically taken treatment proved to be double-edged. The trial lasted less than six months. Only 27 subjects were on it for more than four months. Had it continued a bit longer, one problem with the drug would have become apparent: HIV develops resistance to AZT quickly, within months in most patients. The benefit the drug conferred was transient. Even in the trial this had started to become apparent, but it did not last long enough to reveal how serious the problem was.

Resistance is a serious problem. The reason it occurs so readily when patients only take one ARV is that HIV often makes mistakes when reproducing itself. These mistakes are called mutations. Most of the time mutations are actually a problem for the virus, not the infected human. But occasionally some mutations help the virus by making a drug like AZT ineffective against it. Copies of the virus with this resistant mutation have a huge survival advantage over other viruses that are being wiped out by AZT. Soon the resistant viruses become dominant and AZT no longer works. While resistance occurs with all viral and bacterial infections, HIV's replication is speedy and particularly error-prone. This results in resistant strains developing quickly when patients take only one ARV or with suboptimal treatment.

To make matters worse, AZT in those days was prescribed in extremely high doses. Patients were given 1.5 grams of the drug daily. Today the adult dosage is just over a third of that. The drug elicited serious side-effects, which for people with advanced HIV and poor immune systems were sometimes deadly. The perception developed among people with HIV that they faced the possibility of certain death by Aids or likely death by AZT. Moreover, AZT was often prescribed to people with HIV long before they had symptoms of Aids. The problem with this is that resistance would evolve and the drug would then be useless by the time Aids developed. In fact, a clinical trial called Concorde demonstrated that it made more sense to defer treatment with AZT until Aids.³⁵

And then there was the price. It cost \$7,000 to \$10,000 per patient per year. Burroughs Wellcome had patented the drug, effectively giving it a monopoly on its production and sale. American activists protested against the company and Congressional hearings were held over the extortionate prices being charged to people facing death.

All these problems with AZT fuelled public scepticism of Aids researchers and, even more so, scepticism of pharmaceutical companies, primarily in the US and other countries where AZT was available. Much of this scepticism, especially of the drug industry, was healthy and justified, but extreme versions manifested as Aids denialism and the claim that AZT, not Aids, was killing people. Duesberg was at the forefront of this claim. He had made important discoveries on cancer in the 1970s. In March 1987, a few weeks before AZT was registered by the FDA, he published a long article in the journal *Cancer Research* contending that HIV was not the cause of Aids. He began writing prolifically on the subject, becoming the scientific face of the Aids denialist movement. Soon he began to allege that AZT was one of the causes of Aids.³⁶

A common denialist argument is to attack the findings of the BW002 trial. As a recent example, an article was published in the March 2006 issue of *Harper's*, a highbrow American magazine, by Celia Farber, an Aids denialist and Duesberg disciple. In it she said: 'Members of the control group began to acquire AZT independently or from other study participants, and

eventually the study was aborted and everyone was put on the drug.’ This implies that the study was ‘aborted’ because it became unblinded. But that is not why the study was stopped. The FDA explained that the study was stopped in September 1986 ‘after preliminary data strongly suggested that AZT prolonged short-term survival in Aids patients who received it’. In other words, it was stopped because people on placebo were dying and those on AZT were staying alive, and therefore it was unethical to continue giving people a placebo when a life-saving drug was known to be available.³⁷

AZT has been compared against a placebo in 15 clinical trials for people at various stages of HIV infection. Not a single trial has shown that it is worse than the placebo and several show that it is much better.³⁸ Also, many observational studies of AZT in practice have been carried out. They too found that people who had access to AZT had fewer opportunistic infections and increased life expectancy. Duesberg’s claim that AZT causes Aids is unsupported by evidence.³⁹

Duesberg’s arguments have been rejected by his scientific peers. His steadfast refusal to change his dogmatic views has resulted in his scientific star waning. While once he was considered an outstanding scientist, he has for nearly two decades been regarded as an intransigent cuckoo who courts controversy instead of making scientifically tenable arguments. Mbeki used Duesberg’s scientific authority to promote Aids denialism, a role Duesberg happily fulfilled. Consequently, he shares at least some responsibility for the misery caused by his dogma. Thus, though Aids denialism would find its most powerful adherent at the helm of South Africa, its roots were American.

HIV becomes a chronic manageable disease

After AZT was registered, it took a few years before new drugs were added to the ARV arsenal. Didanosine was registered in 1991, zalcitabine in 1992. Clinical trials showed that patients who used one of these drugs together with AZT were less likely to get sick or die. Then two more drugs followed, stavudine in 1994 and lamivudine a year later. Except for zalcitabine, whose side-effects are worse than the others, all of these remain in use today. One

of the sites for the phase III trial of lamivudine was in South Africa and was run by local clinicians.⁴⁰ I make this point as a counter to the nationalistic view, promoted implicitly by Mbeki, that ARVs are a Western import and that Africa must find its own solutions to Aids. Science has become a global enterprise and Africa certainly contributes, albeit not nearly enough. Lamivudine (known to many people by the trademark 3TC) is still one of the most commonly prescribed ARVs because it seldom causes serious side-effects.

From 1991 until 1995 standard ARV treatment involved taking two drugs. But the effects of treatment were still time-limited, although less so than with one drug. While the life expectancy of people with HIV with access to treatment had been extended, it was still a fatal disease and the drugs merely delayed the inevitable. Then came a major breakthrough. A drug in a new class of ARVs was registered by the FDA in December 1995. It was called saquinavir. Its development is described by Merrill Goozner in *The 800 Million Dollar Pill: The Truth behind the Cost of New Drugs*. Read it to find good reasons for being sceptical of the pharmaceutical industry.⁴¹

Up to that point all ARVs worked by hampering reverse transcriptase, the enzyme that converts the virus’s RNA into viral DNA. AZT and the drugs in its class bind to the end of the viral DNA as it is being generated by reverse transcriptase. This stops the viral DNA from being completed and it becomes useless, like a half-written computer programme. But if the viral DNA is successfully created, it is inserted into the human cell’s DNA. Now the human cell’s DNA contains the code for making HIV. Therefore when the cell makes proteins, it also inadvertently makes the component parts for new viruses. These parts are assembled by another viral enzyme called protease. This is essentially HIV’s equivalent to a robot in a car manufacturing plant. Saquinavir is called a protease inhibitor because it stops protease from assembling the viral parts.⁴²

In 1996 several more protease inhibitors were registered as well as a third class of ARVs. By 1997 the death rate from Aids in the US had dropped by nearly half. Yet it would be another seven years before it became government policy in South Africa to provide ARVs.

Clinical trials as well as research from ARVs used in practice show that using three drugs, preferably from two different classes, substantially increases the time until resistance develops. With one drug, a virus only has to mutate to be resistant to that drug. If a person takes three ARVs, a virus will require more mutations to be resistant to all of them. Also, by using more ARVs the amount of virus in the blood is reduced to very low levels. Few new viruses are produced and so this lessens the chance of resistant mutations developing. If people on ARVs take their drugs daily at about the same time, the probability of a mutated virus emerging in their bloodstream is small. It is therefore possible to take the same regimen for years.

Today there are over 25 different ARVs available. More are being developed. While the early ARVs were renowned for their dreadful side-effects – partly because of the dosages prescribed – the side-effects of the new regimens are much more manageable and for many people are not a problem at all. Patients who become resistant to one regimen should be able to move on to a second line of treatment, and even third and fourth salvage regimens if need be. However, each successive regimen change usually makes treatment increasingly difficult and expensive.

An enormous number of studies have looked at the effectiveness of ARV treatment. A meta-analysis conducted by Rachel Jordan and her team at the University of Birmingham found that in clinical trials, taking two drugs versus just one resulted in a 40% less chance of disease progression or death. Taking three drugs reduced the risk by a further 40%. Taken together, ARV clinical trials show that taking triple-drug treatment reduces the risk of disease progression or death by about 75%. In practice, the results are often better because only the best regimens found by clinical trials need be used. On the other hand, second-rate regimens are also often used because they are cheaper.⁴³

Taking three, sometimes four, ARV drugs a day is now the standard of care for people with HIV whose immune systems have declined to the point where they have Aids or nearly have Aids. It is called Highly Active Antiretroviral Treatment, or Haart. Haart is not a cure for Aids; there is

none yet. Currently, it has to be taken for life.

Aids denialists argue that Haart has not been proved to work in a randomised controlled clinical trial and therefore has not met medicine's golden standard. This is not true. The trials of three drugs against two analysed in Jordan's meta-analysis, for example, disprove this. You might ask why Haart has not been tested against only a placebo. In other words, why are some patients taking three ARVs not compared to a similar group of patients taking only placebos? This would generally be unethical. People who participate in clinical trials are entitled to the current standard of care. When scientists in the mid-1990s thought that three drugs might do better than two, it was already known that two drugs were better than one or none. This is an important point, not only for ARVs. If you have a medicine that you think can treat HIV, you can only get approval to run a clinical trial testing that medicine if you ensure that all patients participating in the trial get the accepted medical standard of care.

Nevertheless, as it happens, an ethical trial was recently conducted that did in fact compare Haart to nothing (not placebo), although this was not its primary intention. In the early 2000s there was much talk amongst scientists and patient groups about the possibility of what is called structured treatment interruptions. Because taking Haart daily for life is a schlep and is also associated with side-effects, scientists and patients wondered if it was possible for patients to take a temporary break from Haart when their immune systems recovered. Besides improving adherence, they reasoned, this would also save on the cost of drugs. So the NIH funded the largest ARV study planned, with over 5,000 patients. It was known as SMART and it tested whether structured treatment interruptions could be used without being detrimental to health. There was great excitement about SMART. My colleagues and I were really hoping it would show that interruptions were not harmful. One South African mining company which started covering the cost of treatment for its workers saw treatment interruptions as a potentially huge cost-saver.

Unfortunately SMART showed that structured treatment interruptions, at least as they were used in the trial protocol, could not work. People on

the interruption arm were more than twice as likely to get sick or die. This was not what was hoped for or expected. But think about what this means: patients on Haart all the time did better than patients on Haart some of the time. If Haart was poisonous, patients taking it more often should do worse. The SMART trial showed precisely the opposite. It debunks the notion that the toxicity of Haart outweighs its benefits. Three other treatment interruption studies in adults have reached similar conclusions to SMART.⁴⁴

Hundreds of studies collectively involving tens of thousands of adults and children on Haart from Africa, Europe, the Middle East, South America, Haiti and the US have been published. They have found that the benefits of ARV treatment are enormous, extending life expectancy, reducing opportunistic infections and allowing people who previously faced a near-certain early death to resume their lives with the reasonable expectation of dying in old age, probably of something unrelated to HIV.⁴⁵

Blinded placebo-controlled trials have also shown that ARVs reduce the risk of pregnant women passing the virus on to their babies. The science of this has advanced swiftly over the past decade. A protocol that reduces mother-to-child transmission to less than 2% has been developed. Without any health intervention, the combined risk of transmission due to pregnancy, labour and breastfeeding is in the region of 30% to 40%.⁴⁶

While for practical and ethical reasons it is not possible to do clinical trials showing that ARVs are effective in reducing the risk of an HIV-negative rape survivor contracting the virus, an accumulation of data from health facilities comparing women who received ARVs within 72 hours after rape with women who did not shows that very likely they do work for this purpose. ARVs also most likely reduce the risk of hospital workers contracting HIV after they have been injured with contaminated hypodermic needles. And relatively new evidence shows that HIV-positive people on ARVs are less likely to pass the virus on to their sexual partners.⁴⁷

All ARVs achieve the same goal: the number of viruses diminishes to very low levels, allowing the body to replenish its CD4 cells. Consequently the risk of getting an opportunistic infection becomes much smaller. ARVs

work incredibly well, often bringing people on the verge of death back to life. They work irrespective of whether a person is male or female, black or white, gay or straight, child or adult, health fanatic or intravenous heroin user. They work for fast progressors too. But ARVs do have two serious problems: side-effects and resistance.

ARVs are obviously not the panacea for the Aids pandemic. Many other health interventions are essential, such as condom distribution, mass public information campaigns, campaigns that promote HIV testing, offering heterosexual men in high-prevalence epidemics circumcision, and sex education in schools, to name a few. Improving the living conditions of poor people could also help lower the HIV transmission rate.

I have dwelt in detail on how we know that ARVs are safe and effective because the success of these medicines elicits the crux of what is wrong with Aids denialism and Aids quackery. The evidence is immense that by and large people who test HIV-positive and then either develop Aids-related illnesses or have low CD4 counts do extremely well on Haart, much better than those who do not take them. Yet Aids denialists have disputed and continue to dispute this. Aids quacks dispute it implicitly by offering unproven alternatives to ARVs. It is therefore on this aspect of the debate, the benefits of ARVs versus alternative remedies, that the central battle for life and death was fought during the era of Aids denialism.

Side-effects

In March 2002 the President's office released this statement: '[Mbeki] said he was aware that there was some controversy in the country about the issue of ARV drugs. He had no desire to enter this debate. This was because he did not believe that drugs were central to the fight against Aids. Even in the US, various complications relating to these drugs had not been resolved.'⁴⁸

Thabo Mbeki does not like AZT. On 28 October 1999 he addressed the National Council of Provinces about South Africa's high incidence of rape. There was already evidence, albeit limited, at the time that AZT could reduce the risk to a person who had been raped of contracting HIV. Some had begun calling for the drug to be made available to rape survivors. The

TAC had also called for AZT to be made available to pregnant women. Mbeki vetoed the idea:

Concerned to respond appropriately to this threat, many in our country have called on the Government to make the drug AZT available in our public health system.

Two matters in this regard have been brought to our attention. One of these is that there are legal cases pending in this country, the United Kingdom and the United States against AZT on the basis that this drug is harmful to health.

There also exists a large volume of scientific literature alleging that, among other things, the toxicity of this drug is such that it is in fact a danger to health.⁴⁹

As far as I can tell, the legal cases he referred to had been initiated by Aids denialists and they were dismissed. Two weeks later, the Minister of Health announced that she had asked the MCC to review the safety of AZT before it could be used to prevent mother-to-child transmission. In February 2000 she rejected their findings, which had endorsed AZT. The arrogance of this was breathtaking. At the time the MCC's impartiality and expertise were still respected. The institution's ability to determine the safety and efficacy of AZT outstripped any other source the Minister of Health might have consulted.⁵⁰

Mbeki wrote a letter to world leaders who were giving him a hard time about his Aids policies, including Kofi Annan and Bill Clinton:

Demands are being made within the country for the public health system to provide ARV drugs for various indications, including mother-to-child transmission.

We are discussing this matter, among others with our statutory licensing authority for medicines and drugs, the MCC.

Toward the end of last year, speaking in our national parliament, I said that I had asked our Minister of Health to look into various controversies

taking place among scientists on HIV/Aids and the toxicity of a particular ARV drug.⁵¹

Here is an exchange between Mbeki and a caller in a BBC radio interview on 6 June 2000:

Mark Rolfe, Scotland: Why do you deny pregnant women the use of AZT during pregnancy and labour when there is solid evidence it reduces the transmission of HIV from mother to child?

President Mbeki: This is part of the discussion that is now taking place. The latest circular from the World Health Organisation was specifically on AZT. It says when you dispense AZT, it must be done under close medical supervision, bearing in mind the contra-indications and potential toxicities. The idea you can just give out this ARV without the proper health infrastructure – because in many instances you've got to check this patient every day – you cannot do it in a rural district hospital. This infrastructure does not exist. One of the issues that the scientists are looking at is – where you have to dispense these ARVs to large numbers of people in a poor country, with a weak health delivery system? What the WHO is warning about – is that if you don't do it properly, you might kill the pregnant mothers because of the toxicity in the drugs.⁵²

The side-effects of ARVs have become the stuff of legend in South Africa. One of the most frequent and hardest tasks that TAC members face is to convince people sick with Aids that they need to start Haart. Doctors frequently complain that their patients leave Haart until too late, when they have become very ill, because they are scared of the side-effects. I have even seen this apprehension of side-effects in colleagues and friends who have reached the point where they need to start treatment. They know the benefits of Haart, they teach about HIV, yet even they are nervous. Fear of the side-effects of Haart is, I suspect, one reason why people are dying of Aids now in South Africa without ever getting treated, even though the medicines might be available in a clinic nearby. The myth created by Aids

denialists, that it is ARVs and not HIV that kill, permeates our society. It is a dangerous and deadly illusion.

The patient information sheets that come in ARV pill boxes list dozens of side-effects. Aids denialists love quoting them. Many side-effects are indeed dangerous. The most commonly reported serious ones are lactic acidosis, peripheral neuropathy (this feels like numbness or bad pins and needles in fingers, toes, hands or feet), rashes, anaemia, lipodystrophy (the redistribution of fat to different parts of the body), and lipoatrophy (loss of body fat from the face, legs and arms). Of these, peripheral neuropathy, lipodystrophy and lipoatrophy are not deadly, but they are serious and can make treatment intolerable.

The deadliest and scariest side-effect is lactic acidosis. This is a build-up of lactic acid in the blood and tissues. The symptoms are tiredness, pains in the abdomen, weight loss, an enlarged liver and lots of vomiting. Unfortunately, these are the same symptoms for many other diseases and it usually requires a test to confirm the diagnosis. I knew two TAC members who died of this side-effect, partly because they lived miles from their hospitals and did not have access to decent transportation to get them help in time. It comes on quite suddenly and a person can reach the point of no return quickly. But it can be picked up in time if clinics can test lactic acid levels. This is not expensive and it is done in resource-poor settings like Khayelitsha. If it is not picked up in time, the person will have to be hospitalised and there's a high risk of death. It is caused primarily by an ARV called d4T. This is a cheap drug that is used as part of the standard of care in the South African public health system. For years, activists have been trying to get the government to phase it out and replace it with a better drug, yet Tshabalala-Msimang, who claimed to be terribly concerned about ARV side-effects, alternately ignored and resisted these calls.

What is the risk of getting a serious side-effect if you are on Haart? It differs widely from place to place because of the different stages at which patients are getting treated, quality of care and other local factors. We have seen that the risk of dying from not going on Haart is very much higher. A 2003 analysis of US patients showed that about 30% of patients

who had been on treatment for three years had had a serious side-effect. A small fraction died from these, but without Haart nearly 100% would have died.

Dealing with side-effects is usually straightforward: you change your drugs. There are quite a lot of ARVs, so patients usually have options. The copious reports on Haart coming out of the South African public health system show that our health professionals, be they nurses or doctors, generally handle side-effects remarkably well, whether in the centre of Johannesburg or the remote rural village of Lusikisiki, where thousands of people are on Haart and doing well. Arguably the most critical factor is that patients should be treated in clinics that are an affordable and convenient travelling distance from where they live, but even if this is not possible, the benefits of Haart still far outweigh the risks.

Side-effects in children whose mothers took ARVs while pregnant

At the South African Aids Conference in 2009 a pamphlet produced by Aids denialist Anthony Brink was distributed by an elderly man to the delegates as they entered the conference hall. 'Why do Zackie Achmat, Nathan Geffen and Mark Heywood want pregnant African women and their babies to be given AZT?' The pamphlet reproduced quotations from about 15 medical studies, most of them of good quality. The quotations read alone would lead you to believe that ARVs for pregnant women are extremely dangerous for their unborn children.

Brink's pamphlet is misleading because the three people referred to in its title advocate AZT and other ARVs only for HIV-positive pregnant women and we do so irrespective of whether they are African or not. Moreover, none of us are scientists, but what we advocate is firmly supported by scientific institutions across the planet, as well as many HIV-positive women in TAC who have healthy babies today thanks to ARVs.

Far more misleading is the selectivity of Brink's quotes. Nearly every study from which he quotes actually supports the provision of ARVs to pregnant women. It is true that babies born to HIV-positive women who took ARVs while pregnant can experience side-effects. But the question to

ask is whether the baby is likely to have been better off if the mother had not taken ARVs.

The Cochrane Collaboration is an independent organisation that evaluates the evidence for different medical interventions. It is respected for its independence and for the high quality of its reviews. In fact it is fair to say that it is the most respected evaluator of medical evidence there is. Using the best experts in a particular field, Cochrane reviews make recommendations after examining all the available relevant high-quality evidence.

In 2007, the Cochrane Collaboration reviewed ARVs for the prevention of mother-to-child transmission (PMTCT). Its conclusion was unequivocal. It 'found that short courses of certain ARV drugs are effective in reducing mother-to-child transmission of HIV, and are not associated with any safety concerns in the short term'.⁵³

What about long-term side-effects? This is a bit trickier. There are long-term concerns. The most serious of these is that there is evidence that ARVs damage the foetus's mitochondria. Exactly what the consequences of this are we do not yet know. Some researchers suspect it might put these babies at higher risk of cancer. But given that this intervention only started in the 1990s, it is too early to tell. More long-term data on children whose mothers took ARVs while they were pregnant are still needed. Nevertheless, the largest and best-conducted follow-ups so far reveal that very few children have suffered serious side-effects attributable to the drugs.⁵⁴

Consider that nearly half of all babies born with HIV die by the time they are three years old unless they get Haart. Consider also that even in an excellent health system in which HIV-positive children receive Haart from the day they are diagnosed, at least 4% will die at a young age. Finally, consider that so far very few serious side-effects have been seen in children born of mothers who took ARVs when they were pregnant, despite 15 years of AZT use and over 10 years of Haart use. Taken together, these points make the case for PMTCT very compelling. Then there is also the crucial point that many pregnant HIV-positive women need Haart for their own health.

That is why Zackie Achmat, Mark Heywood and Nathan Geffen, as well as nearly every HIV activist and scientist in the world, want HIV-positive pregnant women to get ARVs.

Micronutrients and Aids

The last topic we need to consider in this chapter on the science of Aids is the value of micronutrients for those with Aids. Multivitamin or micronutrient supplements have been touted by many, including Matthias Rath, whom I shall deal with at length in later chapters, as a preferred treatment instead of ARVs and we need to consider briefly the scientific evidence for their claims.

Micronutrient supplements are a huge multibillion-dollar industry. Exaggerated claims and aggressive advertising characterise the marketing of these products. Often they are marketed as a natural, non-pharmaceutical solution to healthcare, but they have to be artificially manufactured, just like any other pharmaceutical product. Moreover, despite the anti-drug company approach of advertising for these products, some of the big drug companies, such as GlaxoSmithKline and Pfizer, are also major sellers of multivitamin pills, with substantial markets in developing countries like India. Micronutrients are cheap and easy to manufacture and very easy to sell at a high price, hence the size of the industry.

So what is the evidence for Rath's claim that micronutrients reverse the course of Aids? To answer this, it will help to take a brief look at the evidence when HIV is not considered. Numerous clinical trials have been and continue to be conducted on micronutrients, far too many in fact. This plethora of trials is driven less by health needs and more by the potential for large profits. The outcomes of these trials are a complex mesh of contradictory results. Unsurprisingly, trials conducted by the micronutrient industry or by researchers with close links to it tend to find positive results. Large, well-conducted trials on the other hand tend to find minimal or no benefits from micronutrient supplements and sometimes even find that they are harmful.⁵⁵

The Cochrane Collaboration has also reviewed micronutrient

supplements for people with HIV. The trials in adults give inconsistent results. Some showed no benefit from vitamin supplements; others show small benefits on progression to Aids and mortality. Two small trials of vitamin A in children with HIV showed reduced mortality, improved growth and reduced diarrhoea.⁵⁶

One of the studies considered was carried out by Harvard researchers in Tanzania. It is the best of the vitamin trials that found positive results. At the time of the trial, Haart was not available in Tanzania and the researchers wanted to see if vitamins could delay the onset of Aids in a poor country. It was never their intention to promote vitamins as an alternative to Haart and the modest results of the trial, albeit positive for vitamins, show unequivocally that they cannot be used as an alternative. The trial researchers' conclusion was straightforward and honest; 'Multivitamin supplements delay the progression of HIV disease and provide an effective, low-cost means of *delaying* the initiation of [Haart] in HIV-infected women' [my emphasis].⁵⁷ The lead author of this study, Wafaie Fawzi, has also stated, 'It is important to underscore that multivitamin supplements should not be considered as an alternative to [Haart] in developing countries but as a complementary intervention that is part of a comprehensive care package.'⁵⁸

Although Rath has consistently overstated the findings of this study in his advertisements, the Cochrane reviewers took a cautious approach when examining this and other controlled trials. 'There is no conclusive evidence at present to show that micronutrient supplementation effectively reduces morbidity and mortality among HIV-infected adults. There is evidence of benefit of vitamin A supplementation in children. The long-term clinical benefits, adverse effects, and optimal formulation of micronutrient supplements require further investigation.'

I went to my local pharmacy and found that a month's worth of a leading multivitamin brand was just under R100 (many times what they cost to manufacture). They will not fill you up or alleviate your hunger in any way. They come with no carbohydrates, fats or proteins. You will therefore not get any energy from them. If you are a healthy person, HIV-negative or -positive, you are better off spending the money on a selection of foods,

for example liver, eggs, oranges and milk (if you are a vegetarian there are many other options). These will give you the micronutrients you need and a lot of macronutrients to boot.

As one of the authors of the Cochrane review has wisely said: 'The most that micronutrient supplementation can have been demonstrated to achieve in people with HIV is to assist recovery from malnutrition, delay the onset of Aids, or improve the response to ARV treatment. However, further research is needed to determine conclusively whether or not they achieve this.'

* * *

This book is not the appropriate place to traverse every detail of HIV science or address every false argument given by Aids denialists. But I hope this chapter has given you an understanding of why Aids denialism is wrong. I have referred to many excellent scientific papers. If you want to know more, they are a good place to start. The aidstruth.org website also debunks most of the common myths spread by denialists and the explanations are usually easy to follow.

A brief history of the TAC

‘The NEC used the opportunity to clarify the position of the ANC on HIV/Aids. It re-affirmed that the ANC’s approach to [the] epidemic is informed by the *assumption* that HIV causes Aids ...’

– *ANC Today*¹

Essop Pahad, the former Minister in the Presidency, has been Thabo Mbeki’s right-hand man for decades. After they had both lost power, Pahad started a new magazine called *The Thinker*. In the first issue, he interviewed Mbeki and, in a parody of the McCarthy-style inquisition, asked him, ‘Are you or have you ever been an HIV-denialist?’ Mbeki’s answer is obfusatory waffle, but implicit in it is the answer yes, he is and was a denialist. He claimed that the ‘issues we raised’ about the cause of Aids ‘never impacted on the implementation of the government programme which, then as now, was based in part on the thesis that HIV causes Aids’. But this is false. From 2000 until 2004, when ARV treatment finally became generally available in the public health system, the state’s response to Aids was dominated by Aids denialism, only gradually eroding in subsequent years. It was as a result of TAC’s efforts that state-supported Aids denialism was ultimately defeated.²

When the TAC was formed on 10 December 1998, the founding members did not envisage that the South African government would become their main adversary. Nelson Mandela was still President and

Mbeki appeared to be an able Deputy President. TAC started as a campaign within the National Association of People with Aids (Napwa). It launched itself as a small protest outside St George’s Cathedral when fewer than ten people fasted for most of the day. This small group demanded that the state develop a ‘comprehensive and affordable treatment plan for all people living with HIV/Aids’. They also called for the Minister of Health, Nkosazana Dlamini-Zuma, and the Minister of Finance, Trevor Manuel, to put aside resources to provide AZT to HIV-positive pregnant women. The drug had by then been shown to reduce the risk of a woman passing the virus to her unborn children. Yet despite being addressed to the state, the first ever TAC statement emphasised that the key problem lay with the high prices that pharmaceutical companies were charging for their drugs.³

In June 1999 Mbeki became President. Dlamini-Zuma became the Minister of Foreign Affairs and Manto Tshabalala-Msimang was promoted from Deputy Minister of Justice to Health Minister.

The TAC soon split from Napwa because of many disagreements, a key one being the view of TAC leaders that no money should be taken from pharmaceutical companies. Napwa then changed its leadership and descended into ineptitude and corruption. Tshabalala-Msimang would eventually use Napwa’s leaders, Nkululeko Nxesi and Thanduxolo Doro, as a tool against the TAC. Napwa would oppose ARV treatment and advocate nutrition as an alternative. It would also join Matthias Rath in his campaign against the TAC.⁴

For most of its first two years, TAC’s energy was directed primarily against the pharmaceutical industry. About 40 drug companies, led by the Pharmaceutical Manufacturers’ Association (PMA) and with the backing of the American government, had teamed up to take the South African government to court to stop changes to the Medicines Act from coming into force, the net effect of which would be to reduce drug prices. Much of our campaigning was in support of this new legislation and to shame the drug companies into dropping their action.

One of our first campaigns was to get the drug company Pfizer to reduce the price of its patented medicine fluconazole. This drug is used

to treat two potentially fatal opportunistic infections, systemic thrush and cryptococcal meningitis. Pfizer was charging an exorbitant price for the drug. One of our members, Christopher Moraka, who was suffering from thrush, testified to the Parliamentary Portfolio Committee on Health about the need to compel Pfizer to drop the price or allow other companies to sell generic versions so that the price could be brought down by competition. Shortly after that, Moraka died.

One evening, about five of us met at Deena Bosch's house and planned the importation of a cheap WHO-approved generic brand of fluconazole, called Biozole, from Thailand in violation of Pfizer's patent. I researched Biozole to make sure it was a quality product medically equivalent to Pfizer's drug. Zackie Achmat and Jack Lewis then travelled to Thailand, bought the drugs and returned to South Africa with 3,000 capsules in Achmat's baggage. That they got through customs with ease should raise eyebrows.

A day after returning, Achmat announced what we had done at a press conference, causing a media furore which highlighted the exorbitant cost of the drug. The official opposition Democratic Alliance (DA) condemned our action. The Law Enforcement Unit (LEU) of the Department of Health raided Achmat's house and confiscated the pills. He was almost prosecuted for breaching medicine importation laws. But public opinion and the media appeared to side with us. No wonder: for the price of those 3,000 capsules of generic fluconazole, we would have been able to buy only about 60 capsules of Pfizer's brand. So no charges were pressed and instead the MCC used a special legal power to give the late Dr Steve Andrews, who was assisting us, permission to continue importing Biozole. This enabled us to purchase more than 100,000 capsules over the next few years, which we distributed free to doctors and clinics across the country, saving or improving thousands of lives. We named this defiance campaign against Pfizer's patent after Christopher Moraka. Pfizer wisely never litigated against us for breaching their patent, but they did agree to enter a partnership with the state and distribute their fluconazole free to public health facilities both in South Africa and other sub-Saharan African countries. This was not quite what we demanded. We were concerned about

the problems that might arise from the strict distribution conditions of the donation, but it was nevertheless a victory. Later we would use similar tactics to import cheaper generic ARVs from Brazil, a campaign in which Médecins Sans Frontières (MSF) and the Congress of South African Trade Unions (Cosatu) assisted us.⁵

Over the course of TAC's existence, we have had many successes against the pharmaceutical industry. After we took GlaxoSmithKline and Boehringer Ingelheim to the Competition Commission, they ultimately agreed to allow generic manufacturers to compete against them and produce the patented antiretrovirals AZT, lamivudine and nevirapine, not only for South Africa, but for much of the continent. Pressure on Bristol-Myers Squibb (BMS) resulted in the company reducing the prices of its antiretrovirals didanosine and stavudine. We also lodged a complaint against Merck's local subsidiary, MSD, with the Competition Commission. This was enough to get them to agree to our major demands that resulted in generic competition and subsequently lower prices for an ARV called efavirenz.⁶

When Judge Edwin Cameron started ARV treatment in 1997, his monthly regimen cost R3,419. The result of these campaigns was that by 2008 the entire ARV regimen for one patient was available in the private sector for just under R240 per month. The state purchased an equivalent regimen for the public health system for half that sum. In other words, the price of ARV treatment for a new patient became less than a tenth of the 1998 price even before correcting for inflation. Much of this has been possible because of the excellent legal work of the Aids Law Project (ALP), especially its lawyers at the time, Jonathan Berger, Fatima Hassan and Adila Hassim.⁷

At that time we did not think that the state would become a major adversary. Yes, we expected the usual bureaucratic resistance that often greets demands for state resources, but we thought we could overcome these relatively easily – at least I did. Over time it became clearer that the path was not going to be straightforward. First there had been the Virodene incident. Then Dlamini-Zuma backtracked on a commitment to make

AZT available for pregnant women. Mbeki also began making statements questioning the cause of Aids and stressing the toxicity of AZT.⁸

The protest outside St George's Cathedral was a modest start. TAC's leadership was an informal collection of friends most of whom had campaigned together against apartheid. The organisation's first chairperson was Mazibuko Jara. Siphso Mthathi, a former teacher, and Mandla Majola, a community activist in the Cape Town township of Gugulethu, soon joined as well. They worked to establish volunteer-run branches in Cape Town's poorest townships to educate people about Aids and alert the rest of the organisation to problems at their local clinics and hospitals. Mthathi, Majola, Hermann Reuter and Colwyn Poole, a young medical student, worked especially hard at this and sowed the seeds for the organisation's future strength in Khayelitsha. Jack Lewis ran a small non-profit film production company, Community Health Media Trust (CHMT), which documented TAC's work from the beginning. CHMT's footage helped to establish TAC's initial footprint in the media.⁹

Reuter, a doctor, also joined MSF, which under the leadership of the Belgian doctor Eric Goemaere started the first project to provide ARVs to pregnant HIV-positive women. This helped cement an alliance that would be critical to our successes over the years. Organising took place in Johannesburg as well, under the leadership of Mark Heywood (who also ran the ALP), Sharon Ekambaram and Pholokgolo Ramothwala. At about the time I joined in January 2000, work had just begun in Durban too. My first roles were to sort out the organisation's information technology needs and serve as its treasurer. The reality of a small fledgling organisation is that all its volunteers chip in with a bit of everything.

Except for Reuter, we knew very little about the science of HIV, so we set to work. We studied and ran reading groups. Activists in Europe and the US had been through a similar experience in the 1980s and 1990s. Facing their and their friends' mortality from HIV infection, they became experts on HIV. Their assistance was vital. An American organisation called the Treatment Action Group ran a detailed training course on HIV science for TAC's volunteers. Local clinicians and nurses also taught us a lot.

We soon developed members with a useful working knowledge of ARVs, mother-to-child transmission, opportunistic infections, medicine patents, how drugs are developed and much else relevant to our struggle for access to treatment. There was a sense of desperation behind our eagerness to learn: nearly every week a member of TAC or someone close to one of our members died. We needed to be well informed not just for our intellectual stimulation, but because the lives of our members were at risk.

In early 2000 Mbeki formed a Presidential Aids Advisory Panel. The panel had two formal meetings at which there was a roughly even division between HIV scientists and Aids denialists. Peter Duesberg, David Rasnick and Sam Mhlongo were part of the panel. If Mbeki had constituted the panel fairly, so that Aids denialists were represented proportionate to their influence on the science of Aids, there would not have been any on the panel. There are many differences of opinion, even controversies, among scientists in the Aids world. A conference to examine some of these questions, such as when to start treatment, which are the best feeding methods for children born to HIV-positive women or what is the best ARV regimen, might have been useful. But the cause of the disease is now and was then uncontroversial in scientific circles. Nevertheless, the purpose of the meeting was clear: to create the impression, albeit false, that there was a difference of opinion among scientists about the cause of Aids.

The President's spokesperson, Parks Mankahlana, told the *Village Voice* that Mbeki was 'not an advocate' for the denialists. Yet he also explained that Mbeki had ordered Tshabalala-Msimang to assemble a panel to look into 'everything about Aids', including the merits of drugs like AZT, whether HIV caused Aids and whether it even existed. He expressed the sceptical agenda underlying the formation of the panel when he wrote, 'We humans know very little about HIV/Aids ... The international panel must strive to give us answers to all the unknowns. They must attempt to unravel the "mysteries" of HIV/Aids, including and more especially what the profit-takers cannot tell us.' Shortly thereafter Mankahlana told Jon Cohen of *Science*, one of the world's leading scientific journals, that the government was concerned about providing AZT to pregnant women to prevent HIV

transmission because ‘That mother is going to die, and that HIV-negative child will be an orphan. That child must be brought up. Who’s going to bring the child up? It’s the state, the state. That’s resources, you see?’ This equivocation and inconsistency exemplified Mbeki’s and his apologists’ response to the epidemic. Mankahlana died a few months later, very likely of Aids.¹⁰

Mbeki’s remarks at the first meeting of the advisory panel are illuminating. He quoted a poem by the Irish poet Patrick Pearce called ‘The Fool’, Pearce’s ironic designation of himself for questioning conventional wisdom. Mbeki sarcastically described his encounters with Aids denialist beliefs. ‘I am somewhat embarrassed to say that I discovered that there had been a controversy around these matters for quite some time. I honestly didn’t know. I was a bit comforted later when I checked with a number of our ministers and found that they were as ignorant as I, so I wasn’t quite alone.’

The bureaucratic language of the final report reflected the panel’s inability to reach consensus on any substantive issue. It concluded, ‘The nature and format of the deliberations of the panel could not allow the in-depth scientific argumentation that is necessary to resolve many of the differences over scientific issues of a fundamental nature. An inevitable consequence of this reality was different sets of recommendations made from the varying perspectives of what is perceived to be the “real” cause of Aids.’¹¹

On 9 July 2000, TAC, together with the American organisation HealthGAP, led a march of 5,000 people to the International Aids Conference in Durban. It was our biggest event yet and signalled that we had become an organisation to be reckoned with. We had invested huge energy into turning out people to support the march. Every day for nearly a month before the march, a group of us drove from township to township in Durban. We spoke to people about Aids explaining that it could be treated but the medicine prices were too high. We distributed tens of thousands of pamphlets and plastered the city with posters. Our newly formed Durban office held meeting upon meeting with other organisations to get them to

support the march. It paid off. The march made it on to BBC and CNN. Winnie Madikizela-Mandela, Nelson Mandela’s ex-wife and one of the country’s most popular (albeit deeply flawed) politicians, made a powerful speech. She started it with ‘Viva Thabo Mbeki’. For a moment the TAC organisers panicked. But then she said, ‘HIV causes Aids.’ She received huge applause for that. It was spoilt later that day when Mbeki made a speech at the conference’s opening ceremony that obfuscated the cause of Aids. Nevertheless, the march and a well-attended community meeting MSF hosted with TAC just before the conference helped change the Aids debate worldwide. Until then, there had been much prevarication by the WHO and other institutions about whether Haart should be a priority for poor countries.

For the conference, 5,000 scientists throughout the world had signed the Durban Declaration, which stated that the evidence that Aids is caused by HIV is ‘clear-cut, exhaustive and unambiguous, meeting the highest standards of science’. According to a news report, Parks Mankahlana dismissed it. ‘If the drafters of the declaration expect to give it to the President, or the government, it will find its comfortable place among the dustbins of the office.’¹²

While we organised the march, one of the people who worked closely with me on it, Sbu Mkhize, was admitted to the King Edward Hospital with cryptococcal meningitis, an Aids illness with a high fatality rate. Neither my colleagues nor I knew that he had HIV until then. When I visited him in hospital, I was astounded by the number of young people sharing the ward with him, who all appeared very ill. Dirty floors and walls with paint peeling off them made the place particularly unpleasant. Mkhize recovered temporarily, but he needed ARV treatment. He died a few weeks later. This was my first personal experience of the consequences when people with Aids do not obtain ARVs.

In March 2001, TAC called for worldwide protests against the drug companies ahead of the court case against the Pharmaceutical Manufacturers’ Association. We also joined the case as an *amicus curiae* (friend of the court), because as an organisation representing people with

HIV who needed affordable medicine we had an interest in its outcome. Our intervention was intended to help the government win, and so our lawyers worked with theirs. It worked. In April, faced with a barrage of criticism and protests worldwide, as well as a large demonstration outside court organised by TAC and Cosatu, the drug companies dropped their case. It was a huge victory for the South African government, largely engineered by TAC, and a dreadful embarrassment for the drug industry.

But the day of victory also brought the end of our relationship with Tshabalala-Msimang, who gave a press conference at which she did not have the courtesy to thank TAC by name. More importantly, she equivocated on the rollout of ARVs, citing price, safety, side-effects and resistance as barriers. The director-general of health at the time claimed the infrastructure was not in place to monitor the administration of the drugs. Though there had been growing tensions between the minister and TAC before then, the relationship was perhaps still salvageable. After this, and a further private meeting with TAC in which the minister delivered a rude tirade against Achmat and Heywood, the relationship broke down irrevocably.¹³

Mbeki's denialism was often expressed more explicitly behind closed doors, encouraging those faithful to him to carry his message forward. ANC MP Andrew Feinstein recorded Mbeki's exact words in a closed-door party caucus meeting. 'If we say HIV = Aids then [we] must say = drugs. Pharmaceutical companies want to sell drugs which they can't do unless HIV causes Aids.' He also said, 'The Treatment Action Campaign is leading the statements and vitriol against one. They are funded by the pharmaceutical companies in the US.' (Like the Queen, Mbeki frequently talks about himself in the third person.) Feinstein was horrified and leaked his notes to the *Mail & Guardian*. The allegation that TAC was funded by drug companies would be repeated frequently by ANC politicians and Aids denialists. It would ultimately take a court case against Matthias Rath many years later to dispel this false allegation.¹⁴

In October 2001, Mbeki took a veiled public swipe at TAC in a statement that yet again implied he did not believe HIV caused Aids. In a speech delivered at Fort Hare University he said, 'And thus does it happen

that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease.'¹⁵

That year, together with the Children's Rights Centre, directed by Cati Vawda, and a group of paediatricians, represented by Dr Haroon Saloojee, we took the Minister of Health to court to compel her to allow facilities in the public health system to provide nevirapine or other suitable ARVs to pregnant women with HIV. Before going to court we spent much time discussing whether we should make nevirapine or AZT the drug at the centre of the case. Our campaign poster had read 'President Mbeki, AZT/nevirapine for pregnant women', indicating our equivocation about which regimen would be better.

The nevirapine regimen consisted of a single dose to mother and child when the mother went into labour. In a trial it had reduced the risk of transmission by almost half (almost the same as the alternative short-course AZT regimen) and it was also much simpler to administer and cheaper than AZT. On the other hand women who took it were likely to develop resistance to the drug, making it unclear whether it would work for them if they needed it for their own treatment in the future. Also, because the AZT regimen would have to be taken for several weeks, the occasional missed dose or late start would not be as serious as missing the all-or-nothing single dose of nevirapine, something that could easily happen in poorly organised and under-resourced public health facilities. After pressure from the TAC, the state had committed itself to making nevirapine available at 18 pilot sites around the country. However, the minister was delaying the rollout to many of these sites and steadfastly refused to go beyond them. The decision of the state to use nevirapine at these sites eventually led to us deciding that nevirapine should be the drug we focused on in court and in the campaign. It was a decision for which overseas HIV information organisations criticised us, arguing that the nevirapine resistance issue would come back to haunt us.

We won the case in the Pretoria High Court, but the state appealed. So we applied for an interim execution order which would compel the minister to abide by the court order while it was under appeal. The state opposed our application, but we won that too. The case went to the Constitutional Court and on 5 July 2002 it handed down a unanimous verdict in our favour.¹⁶ The court found that South Africa's Constitution 'required the government to devise and implement within its available resources a comprehensive and co-ordinated programme to realise progressively the rights of pregnant women and their newborn children to have access to health services to combat mother-to-child transmission of HIV'. It ordered the state to 'remove the restrictions that prevent nevirapine from being made available for the purpose of reducing the risk of mother-to-child transmission of HIV at public hospitals and clinics that are not research and training sites'.¹⁷

Importantly, the court also said that nothing in its judgment prevented the state from adapting the programme if other better methods became available. Better methods already existed and more came along after the judgment. They also became affordable. It also kept the door open for AZT to be introduced. Tshabalala-Msimang later told the lie that the judgment only allowed her to use nevirapine, so that she could delay the implementation of one of these better methods.¹⁸

The case was marked by the bitterest acrimony. TAC organised many demonstrations against the Department of Health. As with the PMA case, we were again supported by Cosatu, the ANC's main alliance partner. This helped establish our credibility amongst ANC supporters beyond our relatively small membership and was crucial to isolating Mbeki and Tshabalala-Msimang. Opinion pieces in the media, with very few exceptions, also supported TAC. The minister and her department responded with defensiveness, obstinacy and the closing of ranks. Government officials were, to put it euphemistically, economical with the truth in their court affidavits.

Also questionable was the Medicines Control Council's conduct. Its chairperson, Peter Eagles, appealed to African nationalist sentiment when

he said on SAfm, a leading news radio station, that nevirapine had not been tested in Africa. It had. In any case, it is unclear how this would have been relevant to its efficacy and safety. I went on the same show immediately after he had spoken and angrily corrected him, pointing out that it had been tested in Uganda. Achmat had recommended before I went on air not to use the word 'lie', so instead I accused Eagles of misrepresenting the truth. The MCC, on the most dubious pretences, mucked about with the registration status of nevirapine before, during and after the court case, causing confusion, shaking public confidence in the drug and generating extra work for us as we scrambled to deal with the invariable media fallout.¹⁹

In March 2002, after the High Court case, but before the appeal had been heard, a document titled *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics: HIV/Aids and the Struggle for the Humanisation of the African* was circulated to ANC branches. As James Myburgh explains, it was 'distributed at a key ANC National Executive Committee [NEC] held on 15 to 17 of March. The meeting effectively came out in support of Mbeki's opposition to the provision of ARVs – even if it did not completely side with his ideological justifications. The NEC affirmed government policy on nevirapine, and stated that ARVs "could not be provided in public health institutions" for either the victims of sexual assault or needle-stick injuries.'

The document is a long tirade against what it calls the 'thesis of HIV/Aids'. It is mostly a cut-and-paste job of arguments from denialist websites laced with appeals to a crude form of African nationalism and racial paranoia, like this: 'The HIV/Aids thesis as it has affected and affects Africans and black people in general, is also informed by deeply entrenched and centuries-old white racist beliefs and concepts about Africans and black people. At the same time as this thesis is based on these racist beliefs and concepts, it makes a powerful contribution to the further entrenchment and popularisation of racism.' And this: '[This document] rejects the assertion that, as Africans, we are prone to rape and abuse of women and that we uphold a value system that belongs to the world of wild animals, and that this accounts for the alleged "high incidence" of "HIV infection" in our country.'

The Castro Hlongwane of the title was a black youth who had been turned away from a caravan park because the owner believed that he had Aids and would rape other campers. The grotesque racism of the park owner in this not untypical incident in South Africa was therefore used to fuel distrust of HIV science as a pharmaceutical company conspiracy supported by racists in Western countries and in South Africa.

Authorship of the document was claimed by Peter Mokaba, Mbeki's close aide, an ANC NEC member and a former president of the ANC Youth League. He was an outspoken Aids denialist. Almost certainly, Mbeki edited a large part of it, at the least. Its racial nationalism is reminiscent of his Fort Hare speech I quoted from above and it has the hallmarks of his writing style. Also, the *Mail & Guardian* and DA found that the Microsoft Word document in which it was written indicated it had been on Mbeki's computer. The journalist Glynnis Underhill interviewed Mokaba about the book. She wrote, 'Mokaba confirmed he had sent out a questionnaire to ANC members asking for input and the result was "a collective", he said, which manifested in *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics: HIV/Aids and the Struggle for the Humanisation of the African*.'²⁰

Mokaba died in June 2002. The cause of his death has not been disclosed, but as Nicoli Natrass says in *Mortal Combat*, 'he clearly died of something that rendered him unable to work for four years and that left him in such a weak state that near the end his voice was barely audible'. Mokaba very likely died of Aids.²¹

The importance of the distribution of the *Castro Hlongwane* document is paramount. It is an example, perhaps the salient one, of how Mbeki mobilised ANC branches to support his views on Aids. The document appeals to important truths. Racism against Africans in South Africa and elsewhere has been rife and the profit motive of multinational companies, including pharmaceutical ones, often leads to unethical behaviour and inappropriate use of their considerable power. Mbeki, Mokaba and their supporters used these genuine concerns to gather support for Aids denialism. The document also tapped into the belief that Africa should

become less dependent on the West by developing solutions appropriate to the continent. But this laudable goal can quickly turn into dogma. In today's world, few technological innovations emanate solely from one region. They are the product of work across the globe, including Africa, even though Africa's potential to contribute more does need to be realised.

Even after we won the case, it was not plain sailing for PMTCT. Mpumalanga province under the Health MEC Sibongile Manana failed to start implementation. She had previously been responsible for the dismissal of two doctors, one for allowing an organisation called Grip to supply ARVs to rape survivors in a public hospital and the other for writing an affidavit supporting Grip in a related court case. Legal proceedings, some of them handled by the ALP, ultimately vindicated both doctors, but only years after they were fired.

We prepared a contempt of court action against Manana. This was sufficient to push her into initiating the programme – we never actually had to go to court. Today the PMTCT programme is still poorly implemented. There are hardly any recent data on its availability or efficacy in the South African public health system. Nevertheless, it has very likely prevented many children from becoming infected and saved many lives. It also laid the groundwork for an even more important health intervention: making ARV treatment available to all people with Aids.²²

With the impetus of the PMTCT victory, we needed to push for ARV treatment to be introduced into the public health system. Very few of the country's HIV-positive people could afford treatment then (or can now) and their only realistic means of obtaining treatment was through public clinics and hospitals.

There was some hope that the government would finally take a more rational position on Aids. A Cabinet statement had acknowledged 'that [ARVs] can improve the conditions of people with HIV'. It committed the government to PMTCT and to providing ARVs to rape survivors to reduce the risk of their contracting HIV. There were also promising developments at the National Economic and Development Council (Nedlac), a forum in which business, labour, civil society and the government try to reach

consensus on social and economic policy. Through much behind-the-scenes effort, Heywood managed to get the discussion of a treatment plan going at Nedlac. Cosatu's support was essential for this. For months Heywood met with and cajoled the Nedlac government and business representatives, with assistance from Ebrahim Patel, then general secretary of the Cosatu-aligned Southern African Clothing and Textile Workers' Union.

A few days before World Aids Day in 2002, it appeared to be a done deal. All parties had agreed on the substance of a framework for a treatment plan. A few details remained unresolved, but they could wait. Heywood told the *Sunday Independent* that there was an agreement and the paper ran it as a front-page headline on 1 December. The government representatives immediately denied the report, saying there was no deal. The business representative at Nedlac went along with the state. It was a devastating blow for us, especially Heywood, who had invested considerable effort in the process. But most of all it was a deadly blow for thousands of people who would have to wait much longer before the state changed its policy on ARV treatment.²³

Our campaign was, however, helped incalculably by Nelson Mandela, who visited TAC members at Achmat's house. He stood with Achmat at a press conference and asked him to take ARVs at a time when Achmat refused on principle to do so. Then in December, as the Nedlac process collapsed and just before the ANC's national conference in Stellenbosch, Mandela attended the MSF pilot ARV programme in Khayelitsha. He wore TAC's trademark HIV-positive T-shirt. The symbolism was profound: the world's and the country's most beloved hero had aligned himself with our struggle. TAC subsequently won the Nelson Mandela Award for Health and Human Rights, very likely with Mandela's assent.

We decided to organise a massive march at the opening of Parliament on 14 February 2003 to demand that the state implement a treatment plan. Our march poster's salient graphical feature was a photo of Mandela in his HIV-positive T-shirt. I emailed the poster to the Nelson Mandela Foundation, which acts on behalf of Mandela, requesting permission to use the photo, though this was just a courtesy because the photographer had given us

permission already. Both Achmat and I got a go-ahead over the phone from the Foundation's head, John Samuel, though no written confirmation, and so we proceeded. As it became clear that the march was going to be a huge event, Mandela or his Foundation must have come under pressure from the ANC. Two days before the march, the Foundation distanced him from it and alleged that although they had allowed us to use the photo, permission had not been sought to use it for a march at the opening of Parliament. This was a cop-out, because the photo I sent the Foundation was of the march poster. Despite the embarrassment for us, we decided it was best to be gracious: Mandela's support had been clear enough and there was no reason to inflame the situation. We released a conciliatory statement regretting the misunderstanding.²⁴

The march was our biggest until then and possibly since. Between 10,000 and 15,000 people took part, a magnificent cross-section of South African society. White middle-class people from Sea Point and black and coloured working-class people from across the city all joined in. All three trade union federations, Cosatu, Nactu and Fedusa, participated. We also hired a train from Johannesburg which brought several hundred of our members from up-country. This large turnout showed how fed-up ordinary people were becoming with the state's obstruction of treatment. We followed up the march with a statement that we would commence a civil disobedience campaign if the state did not announce a treatment plan and return to the negotiating table at Nedlac with the objective of signing the agreement. We called the proposed campaign 'Dying for Treatment'.

I was nervous about civil disobedience. I was worried that it might backfire, that our membership would not understand why we were drawing on tactics used to fight apartheid and that public opinion, which we had fought hard to win, would turn against us. Achmat, however, was convinced it would work and he was supported by most of TAC's leadership, including Majola, who was more in touch with what the members were thinking than most of us.

Achmat suggested I read *A Theory of Justice* by John Rawls, which put forward a compelling argument consistent with liberal philosophy that

there are occasions when civil disobedience is justified in a democracy. It was at about the time that I read Rawls that Cosatu distanced itself from our planned actions, saying, in contrast to him, that civil disobedience was not appropriate against a legitimately elected government. This was our first serious difficulty with Cosatu, which was a critical ally because it was part of the ruling tripartite alliance and its policy positions had influence over the nearly two million workers who were members of its affiliates.²⁵

We planned our first civil disobedience action for March. It was our finest logistical effort. Somewhat paranoid about being bugged, the five or so people involved in planning it communicated on phones that I had got a friend, Gregg Gonsalves, to hire from an airport cellphone shop so they could not be linked to us. We held meetings with our members where we discussed the purpose of the campaign. It was made clear that being arrested was likely and that anyone who wanted to participate had to be 18 or over and sign a consent form which also committed its signatories not to use violence. Hundreds of our members signed up and a lot of the younger ones on the threshold of official adulthood bemoaned the fact that we would not let them take part. Yet except for a handful of the organisation's leaders, no one knew the final plan until an hour or so before it was carried out. We gave our members enough information to know where to gather, but none of the details.

On the launch day we met at gathering points in Cape Town, Durban and Sharpeville outside Johannesburg and briefed the protesters. Then hundreds of us marched to police stations to demand that the Minister of Health and the Minister of Trade and Industry, Alec Erwin, be arrested for culpable homicide. We implicated Erwin for his failure to use his ministerial powers to bring down the prices of Aids medicines. We had also reliably heard that he was sympathetic to Mbeki's views. We handed over a docket, mainly prepared by Achmat, detailing the evidence against them. The plan was that we would refuse to leave until we were arrested. This took place on 20 March, one day before the commemoration of the massacre in 1961 when the Pan Africanist Congress marched to Sharpeville police station to demonstrate against the apartheid pass laws. This was not a coincidence,

but it was coincidental that the American invasion of Iraq took place on the same day, reducing some of the media publicity we got. Though it was clear that the invasion was coming several days before, we were not willing to change the logistics of such a complex operation at such short notice. It was not the first time international events had overshadowed our plans. Once I phoned the *Cape Times* to inform a good Aids journalist that Sibongile Mazeka, the five-year-old child of one of our members, had died of Aids without treatment. The newspaper had previously carried a beautiful story about Mazeka's plight. 'No ways we can do it,' said the journalist. 'Something too big has just happened.' The date was 11 September 2001.

In Sharpeville, TAC members dispersed not too long after handing over the docket and opening a case against the two ministers. In Cape Town, the police – who at that time got on quite well with us (our relationship has since deteriorated, but that is another matter) – did not want to lock up the demonstrators. Eventually, they symbolically arrested about 60 people and immediately released them. Things were not so cushy at CR Swart Police Station in Durban. The police refused to cooperate and instead TAC supporters were 'tear-gassed, sprayed with a water-cannon, punched, kicked and pushed around with batons'. Five people were hospitalised including Sifiso Nkabinde, TAC's provincial organiser at the time. Human Rights Watch issued a statement condemning the police brutality. Achmat and I flew up to Durban a few days later for a follow-up protest against the cops. It got messy again, though less so. The police brought out water cannons and blocked our attempt to push our way into the station. But they seemed reluctant to use severe force with the media present and eventually showed some contrition.²⁶

So started our civil disobedience campaign. We performed a few more similar activities. On one occasion we held a sit-in at the Department of Trade and Industry offices in Cape Town, demanding to speak to Alec Erwin so that we could ask him why he was not using his ministerial powers to make generic ARVs available. We refused to move unless Erwin came. We knew from the onset this was unlikely to happen. That Erwin was in another city at the time made it even more unlikely. So 17 of us were arrested. We

were charged and appeared in the Cape Town magistrates' court several times before the charges were dropped. On another occasion, a group of us temporarily prevented the Minister of Health from speaking at an event organised by Health Systems Trust at the Holiday Inn in Woodstock, Cape Town. We held placards accusing her of being responsible for 600 deaths a day. I remember being slightly startled by the cathartic release of anger as TAC members chanted 'Murderer' at the top of their voices. People in the audience joined us as we shouted, 'Manto go to jail.' An ugly fracas ensued, with Achmat, Nonkosi Khumalo and the minister exchanging insults. A famous photo was taken of Achmat sneering at the minister. He apologised later for making a personal insult about her wig, inspired apparently by a ditty composed by TAC members which suggested that Tshabalala-Msimang give her wig to Erwin (who is bald). However, none of us involved in the disruption have ever apologised for calling her a murderer.

After the disruption and after the minister had finished her speech, one of our members threw her shoe at what she mistakenly thought was Tshabalala-Msimang's vehicle (it was apparently a decoy vehicle). It landed harmlessly in the road. Several people reprimanded her. Another member, whose mother lay dying of TB in a nearby hospital, had to be restrained from throwing a stone. In all my years at TAC, this was the only time I ever took part in a demonstration where one of our members acted violently towards the person at whom our demonstration was aimed. Despite civil disobedience, occasional police brutality and the sheer number of demonstrations we have organised over our decade-long history, TAC members have – remarkably – restrained their justifiable anger.²⁷

The civil disobedience campaign generated an enormous amount of publicity. We broke the law intentionally, willing to take responsibility for doing so even if this meant going to prison. In our view, the moral cause for which we were fighting, preventing thousands of avoidable deaths, outweighed our duty to abide by the law. But the campaign brought controversy as well. Some journalists who had previously reported TAC's events positively became more circumspect. I was grilled for what felt like hours by a presenter on a call-in radio show. He asked me why TAC

had resorted to what seemed to him such undignified actions when we had successfully used the courts to get the state to implement PMTCT. The question showed a misunderstanding many people have about TAC's litigation and the use of litigation in political campaigns generally.

Court cases are costly and they often take a very long time to conclude. We could not wait so long for a treatment plan while thousands of people were dying. Moreover, there is no guarantee of victory in court. The PMTCT case was as close to a slam dunk as a court case can get. The precise details of the intervention we demanded were clear. An affidavit by the economist Nicoli Nattrass, building on separate studies by Jolene Skordiss and myself, showed that the programme would save the state money, because the cost of caring for HIV-positive children was much higher than the cost of preventing them from becoming infected in the first place. Making similar arguments for a treatment plan was much more difficult. For one thing, ARV treatment is not cost-saving in the strict and easy-to-prove sense that PMTCT is. The Constitution provides for people to have access to health services but it is only a duty in so far as it is within the state's available resources. Nattrass and I, with Chris Raubenheimer, published a paper showing that treatment was affordable. It was well received and made the front page of the *Mail & Guardian*. With hindsight our conclusion was right. Moreover, TAC soon uncovered and publicised a confidential Department of Health presentation which reached the same conclusion. The presentation was apparently based on research, organised by Fareed Abdullah, who ran the Western Cape Aids programme, and officials in the National Treasury. But it was not an argument that was likely to be uncontested in court. Courts are usually conservative and, despite the moral imperative to provide treatment, it was not clear we would win. Even if we did win, governments do not like being ordered to change their policies by courts. The state would most likely have carried out the judgment reluctantly, meeting the bare minimum of requirements to avoid contempt of court proceedings. To some extent this has been a problem with the PMTCT judgment.²⁸

Civil disobedience generates discomfort: that is its point. But Achmat's

judgment was that it mattered more what our members and people with HIV thought than the polite middle class. And it paid off. Deputy President Jacob Zuma met with a small TAC delegation at the Tuynhuys, the Cape Town office of the Presidency. He committed the government to implementing a treatment plan if we ended our civil disobedience campaign. There was some doubt among us that Zuma would keep his side of the bargain, but we nevertheless decided to suspend civil disobedience without going through the same consultations we undertook to start it. This led to much criticism from some of our members. Thankfully, Zuma stuck to his word. In August the Cabinet released a statement, apparently sans Mbeki, instructing the Minister of Health to develop a plan to provide ARVs in the public health system. Whatever Zuma's shortcomings, his intervention at a critical moment helped get ARVs to hundreds of thousands of South Africans.

We set to work to try to influence the plan. The person charged with heading the task team developing it, Anthony Mbewu, proved antagonistic to the TAC. When we requested a meeting with him, he gave us a few minutes in a Wimpy Bar. But others involved in the plan's development, like the Cape Town doctor Ashraf Grimwood, were much more receptive and helped put forward our views. The plan was delivered on 19 November 2003. It included targets and committed the government to making treatment available in every district in the country. While it had many shortcomings, it was the culmination of our work over the previous five years. A small group of us went to Parliament to thank the government. Tshabalala-Msimang walked past our celebration. We cheered her, something that was unthinkable the day before. She responded by sneering at us. Perhaps she did not think our cheering was sincere. (It was.) More likely it was because she was not happy with the plan and she would soon show this.

After the government's statement of commitment, the TAC leadership expected that its focus would shift from national campaigns to concentrating on the details of the treatment plan's implementation at district level. We even sent a letter to all our members at the end of 2003 stressing the

growing need for our branches to advocate that treatment be rolled out in their particular communities. When a couple of months passed, it became apparent that the Department of Health was doing nothing to implement the plan. Beyond a few pilot sites and the largest public hospitals, there was no progress. When we enquired what was going on, the excuse was that the state ARV tender had to be finalised before the programme could proceed. State tenders at the best of times take a long time to finalise. Combined with a lack of political will, they can be delayed indefinitely. So bureaucratic tactics were now being used to delay the ARV rollout. By March 2004 there were still fewer than 2,500 people on the public-sector ARV treatment programme.

Fatima Hassan, acting on behalf of TAC, threatened the minister that if ARVs were not procured in the interim to get the programme going, we would go to court by 18 March. We received a response from the acting director-general, Dr Kamy Chetty, that the minister was out of the country and would respond by 24 March. We began preparing litigation and increasing pressure in the media.²⁹

Elections were coming in April 2004. The government had basked in the positive media coverage that followed the release of the treatment plan. Now this was being undone. A day or so before we intended to file court papers, the minister relented and agreed to start purchasing ARVs even though the tender was not finalised. So the treatment rollout began in earnest. Yet it continued to be obstructed by the bureaucracy. Sites had to be accredited before they could provide ARVs. There was one central accreditation team that moved very slowly. To this day we are still behind the targets set in the plan. The 2003 plan provided for over a million people to be on treatment in the public health system in 2009. Though there are not good statistics available on the number of people on treatment, a serious shortcoming of the programme, the figure is in the region of 700,000, probably no more than 50% of the current need. (Incidentally, a new plan is now in place with a new set of targets.)³⁰

Once ARV treatment began rolling out, Tshabalala-Msimang's support for quackery intensified. Creating confusion and trying to destroy public

confidence in ARVs by supporting alternative treatments proved a key way in which she undermined the rollout. The most important examples of this were her support of Matthias Rath and Zeblon Gwala, the story of which will be told later. As a result, TAC's relationship with government deteriorated even further.

To monitor the ARV programme's implementation, the TAC and ALP brought a group of organisations together to form the Joint Civil Society Monitoring Forum. Over the next few years, these organisations pooled their areas of expertise to push and prod the programme along. TAC concentrated on highlighting instances of hospitals with unacceptably long delays. For example, we spoke out about Mahatma Gandhi Hospital in Durban, which had over 1,000 people waiting to start ARV treatment. At Queenstown's Frontier Hospital TAC members demonstrated against the tardy pace at which the hospital was making ARVs available. Under the leadership of our national organiser, Linda Mafu, a group of members entered the hospital and refused to leave until a commitment was made to provide the medicines. Many of the demonstrators needed ARVs themselves. The police were called in and used batons to force the demonstrators to leave the building. Then, even though the demonstration had dispersed, they started firing rubber bullets at groups of TAC members standing far away from the hospital. The incident was captured on video, which showed the police acting violently without being provoked. Over 70 organisations, including UNAids, condemned the police brutality.³¹

We also publicised the slow accreditation process. I saw personally how ridiculous this was. Once I visited the remote village of Acornhoek on the edge of the Kruger National Park, where Tintswalo Hospital is situated. I met with the hospital staff, who explained that they had everything they needed to proceed with ARV treatment except the ARVs themselves because they were not accredited. TAC had established a treatment fund, mainly to provide medicines to our members who for one or other reason could not obtain them through the public health system. We used this fund to buy treatment for some of the hospital's patients to show the Department of Health that the hospital was capable of running the programme. Though

it took a long time and several protests, eventually the Tintswalo staff managed to get the state to supply ARVs.³²

When the ANC was re-elected in 2004, we hoped that Mbeki would use the opportunity to appoint a new minister of health. Instead Tshabalala-Msimang kept her job. But Mbeki made a crucial error: he appointed Nozizwe Madlala-Routledge to be her deputy. Madlala-Routledge is a Quaker and had been responsible, as Deputy Minister of Defence, for making ARV treatment available to the military. I had previously heard her speak at a gay and lesbian film festival. Here was someone who represented the best side of the ANC: pro-gay rights and straight on Aids. I am not sure why Mbeki chose her. Perhaps he thought appointing someone we liked would reduce the pressure we exerted.

TAC members began having meetings with Madlala-Routledge at which we explained our concerns. She was willing to learn the science of HIV and wanted to improve the ARV rollout. She soon fell out with Tshabalala-Msimang, who began restricting her activities. Once Madlala-Routledge agreed to speak at a TAC event but then received a telephone call from ANC headquarters stopping her. She was desperately upset. She visited Achmat's house to explain this to Siphosiso Mthathi, Achmat and a few others. As she described what happened, the pressure of her dreadful work environment got to her and she broke down. At last there was a politician in Mbeki's government willing to speak out and dedicated to improving the healthcare of the country. For this, there was a concerted attempt to make her life miserable. We would become increasingly close to her over the next few months. In the meanwhile, the ARV treatment and PMTCT programmes were stuttering along.

If there was any slight hope that Madlala-Routledge's appointment was a sign that Tshabalala-Msimang or Mbeki had warmed to us, this was dispelled in early 2006 when we learnt that the government had blocked our attendance at an important special assembly of the United Nations on Aids, known as UNGass. We publicised this, causing the state much embarrassment locally and internationally. Deputy President Phumzile Mlambo-Ngcuka then intervened and facilitated negotiations between

Mthathi and the Health Department. Mthathi was then invited to join the government delegation, an offer she refused. Instead a few international organisations offered some of their positions at UNGASS to us, allowing TAC to send a delegation. TAC's deputy chair was able to deliver a powerful speech to the UN, saying:

My name is Nkhensani Mavasa. I was born in 1978. I come from the village of Thomo in Giyani, Limpopo, one of SA's rural provinces, where too few people are on treatment ... While in the past we have hesitated, debated, restrained our actions, failed to protect vulnerable groups, the epidemic has raged on. A new global response to the epidemic must build on what we have done and learnt. But it cannot aim for less than 100% truth, leadership, accountability [and] universal access to prevention, care, treatment and support.³³

The beginning of the end of the era of denialism occurred at the International Aids Conference in Toronto in August 2006. Here the South African government's stand was one of the most ostentatious, despite being located amid the marketing displays of multinational pharmaceutical companies. It also featured garlic, lemons and African potatoes – the minister's idea of treatment for Aids – but no ARVs. Infuriated TAC members at the conference occupied the stand in protest. I started passing the vegetables around and caused a fracas with the government officials manning the stand. The incident was captured on video and placed on YouTube.

At the same time we had taken the state to court to compel it to provide treatment to inmates at a prison in Durban. During the Toronto conference, one of the applicants died because he was not given ARVs in time. Our anger reached boiling point. Heywood spoke at a plenary session in front of thousands of delegates and called for the minister's removal from office. We supported him by getting people to walk silently on to the stage with banners demanding that Tshabalala-Msimang be fired. She was sitting in the front row, scowling. At the closing of the conference Stephen

Lewis, the outspoken and respected special envoy on Aids to Kofi Annan, castigated Tshabalala-Msimang. While these events unfolded in Toronto, TAC held an illegal protest in Cape Town demanding the arrest of the Health Minister. Over 40 of our members were arrested.³⁴

We considered taking Mbeki to court to compel him to dismiss Tshabalala-Msimang. Though it was unlikely that such an action would have succeeded, we prepared the ground by writing a letter to him asking for reasons why he continued to retain her. Shortly after the conference, John Moore, a leading HIV scientist, and I drafted a letter to President Mbeki, calling for Tshabalala-Msimang to be dismissed. We got 82 HIV scientists and clinicians to sign it and released it in early September. It received a lot of publicity.³⁵

The combined effect of these actions worsened the Mbeki government's already damaged reputation. The pressure we exerted was unprecedented, even exceeding that of our civil disobedience campaign. On 19 September, Phumzile Mlambo-Ngcuka addressed a Cosatu congress and stated that HIV was the major cause of death in the country. She and other government officials also began having discussions with Mthathi, then TAC general secretary, and Heywood. The government compromised and soon agreed to negotiate a National Strategic Plan for HIV (NSP). The plan was to include new targets for prevention, treatment and much else. You might ask why a new plan was needed when we already had the 2003 one, but years of obstruction informed by Aids denialism and support for quackery meant the old plan had lost its shine. Some of its targets were now unachievable and it was also silent on many other important interventions for stemming the epidemic. We needed a new, much more detailed and realistic policy which could galvanise the state and society and on the basis of which we could realistically hold the government to account.

Coincidentally, Tshabalala-Msimang fell ill at this time. She needed a liver transplant and went on long sick leave. Though we expected Madlala-Routledge to step in as acting Health Minister, in February 2007 Mbeki appointed Jeff Radebe instead. At first this seemed promising. We sent Radebe a letter expressing concern about the department's management

of drug-resistant TB. He met with us within days of receiving the letter, something inconceivable during Tshabalala-Msimang's reign. The meeting was positive and he responded with due seriousness to our concerns. The director-general of health, Thami Mseleku, attended too. Formerly the director-general of education, he knew nothing about medicine. Under Tshabalala-Msimang he had been her echo and treated us with contempt. But now he was a different person. Besides being pleasant, he provided detailed answers to our questions. The change of heart proved to be a temporary phenomenon.

Tshabalala-Msimang's departure gave Mthathi and Heywood the space to negotiate the NSP with Department of Health officials. This had the Deputy President's blessing and Madlala-Routledge's behind-the-scenes support. Teams of HIV experts in epidemiology, treatment and prevention as well as economists worked on the technical aspects of the plan. For once civil society was working with government on Aids. It seemed a new golden age had arrived, and Tshabalala-Msimang's and Mseleku's absence from any real involvement in the NSP process reinforced that feeling.

With each subsequent draft the NSP improved. It committed the government to putting 1.5 million people on treatment by 2011 and halving new HIV cases by then, including reducing transmission from mother to child to less than 5%. Together with the Department of Health's chief director of HIV/Aids, tuberculosis and sexually transmitted infections, Nomonde Xundu, Heywood coordinated the final version of the document. In April 2007, a large meeting was held in Johannesburg amid much fanfare to adopt the NSP. Cabinet approved it in May. We released a statement commending the government's commitment to HIV but pointed out that it now had to get implementation right.³⁶

In June 2007 Tshabalala-Msimang, having recovered, returned to office. While she had been away, Madlala-Routledge gave an interview to Michael Specter of the *New Yorker* in which she stated that she had been stopped from speaking about Aids for a year. She also obliquely criticised Tshabalala-Msimang and spoke about Aids in a refreshingly different way from her minister. Then an Eastern Cape newspaper, the *Daily Dispatch*,

ran a scathing exposé of the dreadful conditions at Frere Hospital in East London. Though Tshabalala-Msimang reacted defensively, Madlala-Routledge visited the hospital and admitted there were problems. These incidents undoubtedly angered the President and intensified the war between the minister and her deputy. But as Madlala-Routledge said in the *New Yorker* article, 'It is important that I say the truth, because that is what sustains me.'³⁷

We had been informed a long time before this that Mbeki had come close to dismissing Madlala-Routledge because of her outspoken views on Aids, but Mlambo-Ngcuka had managed to persuade the President not to do so. Finally, in August 2007 he asked her to resign. She refused and so he dismissed her. Mbeki gave Madlala-Routledge two reasons for his decision. He alleged that she had taken an unauthorised R160,000 trip to Spain, flying business class with family members, details of which had been leaked to the pro-Mbeki *City Press* days before she was fired. TAC came to Madlala-Routledge's defence. We pointed out that the purpose of the trip was to attend an important Aids vaccine conference. Madlala-Routledge had indeed travelled in business class and with a family member, but government rules allowed her to do this. She had been told by someone in the Presidency that she had permission to go, but she had not received permission in writing. It was this technicality that Mbeki took advantage of in order to discredit her. That Mbeki was prepared not to honour an oral agreement with someone who worked with him is indicative of the Machiavellian games he played. The other reason that Mbeki gave could have been written in the Soviet Union in the 1930s. 'I have, during the period you served as Deputy Minister of Defence, consistently drawn your attention to the concerns raised by your colleagues about your inability to work as part of a collective, as the Constitution enjoins us to. For the same reason, I have also discussed this matter with you as Deputy Minister of Health.' *Star Trek* fans might be reminded of the Borg.³⁸

Despite his well-earned reputation for being a Machiavellian manipulator, Mbeki badly miscalculated. Our press release, which came out a few minutes after her dismissal was officially announced, called it 'a

dreadful error of judgment'. This became the headline in the next edition of the *Cape Argus*. We quickly organised a demonstration at Cape Talk/702 Radio where Madlala-Routledge gave a live interview in which she pulled few punches about the era of Aids denialism. We also arranged for dozens of organisations and individuals to deliver flowers and messages of support to her at the radio station. While she had been a popular minister, with this live, sincere and honest interview she became a national hero, the woman who stood up to Mbeki on Aids.

This abuse of power by Mbeki was not unique. Once an aide summoned a senior board member of one of our donors. The board member was at the time a fledgling businessman, part of the growing black middle class and dependent on good relations with government. He was asked why his organisation funded TAC. It was a less than subtle message to him to stop doing so. Thankfully he stood firm.

Mbeki's perceived aloofness and dictatorial methods of running the ANC had already made him very unpopular. At the time of Madlala-Routledge's dismissal he was in a race for the ANC presidency with Jacob Zuma, whom he had dismissed as Deputy President of the country two years earlier. Madlala-Routledge's departure exacerbated Mbeki's waning popularity. In Polokwane in December 2007, Zuma trounced him in the ANC elections and became the organisation's president instead.

For a few more months Mbeki remained as President of the country until he was ousted by the Zuma faction in September 2008. Kgalema Motlanthe then took over as President. More reasonable, approachable and decent than Mbeki, he finally removed his most unpopular minister, Tshabalala-Msimang, from her position and stuck her into an unimportant ministerial post where she could do little harm. He replaced her with Barbara Hogan.

Hogan had been one of the few ANC MPs to speak sensibly on Aids. She had also spoken at a TAC congress a few years previously and had often met with the TAC's leaders. In her time as chairperson of the Parliamentary Portfolio Committee on Finance, she had argued, using the costing study that Natrass, Raubenheimer and I had published, that ARV treatment was

affordable. Her independence cost her: the ANC removed her as chair. But now she and Madlala-Routledge were back in favour. The latter was made deputy speaker in the National Assembly.

Hogan made removing the legacy of Aids denialism a priority. At a major vaccine conference in Cape Town, she stated, 'We know that HIV causes Aids. The science of HIV and Aids is one of the most researched subjects in the medical field.' She affirmed her support for the NSP and obliquely denounced the quackery of Matthias Rath. That Fatima Hassan, with the blessing of the TAC and ALP leadership, left her job at the ALP and joined her as an adviser was indicative of the strength of the new relationship between the minister and civil society.³⁹

When Jacob Zuma became President in May 2009, Hogan was replaced with Aaron Motsoaledi, a doctor with scientifically sound views about HIV, who had a positive meeting with Vuyiseka Dubula, TAC's general secretary, shortly after assuming his new position. He has also delivered excellent speeches describing the extent of the epidemic and brought hope and renewed energy to the struggle against HIV. His task is not an easy one. Tshabalala-Msimang left behind a myriad problems: an unchecked drug-resistant TB epidemic, an acute shortage of nurses and doctors, alienated scientists, pending legal actions with various disgruntled bodies (most of which were resolved by Hogan, thankfully), neglected hospitals and clinics, several pieces of bad legislation, a string of qualified audits and a massively overspent budget. Although the legacy of denialism, primarily in the form of quackery gone out of control, will be with us for a long time, Tshabalala-Msimang's management of the country's other health issues, including cancer, diabetes and obesity, was not much better than her response to Aids. Motsoaledi was also saddled with a dysfunctional national Department of Health and the incompetent Thami Mseleku, whom he soon sent packing. Nevertheless, for the first time since TAC's inception, there is regular contact with the minister, respect and the mutual desire of both parties to combat the TB and HIV epidemics using science. We have moved into a new post-denialist age, one fraught nevertheless with pitfalls.

4

Tradition and science

‘You hear people talking all the time about traditional science as opposed to Western science ... This debate does not need to happen in a way that stops people from taking medicine that will save their lives. But it is killing large numbers of our citizens.’

– Nozizwe Madlala–Routledge¹

Andile Madondile’s search for life

Andile Madondile was born in the small town of Sterkspruit when it was part of the Transkei bantustan. Now it is part of the Eastern Cape, a province that offers few economic opportunities: it is predominantly rural, stuck in poverty and a quarter of its active job-seekers are unemployed. So when he was twelve, in 1991, Andile and his mother joined thousands of other Xhosa-speaking people living in the Eastern Cape in what is an ongoing migration to Cape Town. They moved to Khayelitsha, a township created artificially in the 1980s by the apartheid government, far from the city centre and white suburbia. In two decades, it has grown into what is probably the city’s largest township.

Cape Town is attractive for the rural poor, at least compared with the Eastern Cape. It is a far bigger city than any in the Eastern Cape and it functions a lot better. The Western Cape as a whole has a lower unemployment rate than the Eastern Cape as well as better health facilities, schools and universities. Andile’s mother, for example, got work as a

nurse. However, a large chunk of Khayelitsha is a slum, with high rates of HIV, unemployment and violent crime. Thousands of its inhabitants live in shacks cobbled together from corrugated iron and wooden planks. Andile and his family live in one of these in a section of the township called Site B. But there is not just despair; Khayelitsha is also a vibrant place of hope. Driving through its maze of badly tarred and dirt roads, you see a commercial mix of spaza shops, hairdressers, spare parts outlets, shebeens and people selling meat straight off the braai. Tradition merges with modernity: cows and goats share the same roads as minibus taxis; traditional healers share the same patients as private doctors and public health clinics.

Over the next few years, Andile moved back and forth between Cape Town and the Eastern Cape. Because he was dodging school and getting up to mischief in Khayelitsha, his mother insisted that he finish his schooling in the Eastern Cape. In 1997 he matriculated in the town of Tsolo, near Umtata, the former capital of the Transkei, and then returned to Khayelitsha to train as a hair stylist. After his training he got a job with New Look Cosmetics. It was in 2004 that Andile noticed that he had begun to lose weight inexplicably and suffer from diarrhoea, stomachaches, headaches and a rash that appeared all over his body.

‘A neighbour suggested that I go to the clinic to get tested for HIV. It took me two weeks. I did not believe in HIV and Aids. But I went to the clinic and got counselled and tested. The result came back positive. My CD4 count was 34.’

But he had no confidence in the public health system. So he decided to go to a traditional healer in the nearby township of Nyanga. A friend living there had told him that a lot of people were going to her and that he would get better if he saw her.

‘I went on a Sunday. There was a long line to see her, about 60 people. Some were very sick. I could tell because they looked like me. The healer spent some time with me. She was very nice. She explained that somebody in Transkei does not like me and wanted me dead. I paid R40 for a consultation. I had to pay another R250 for the medicines she gave. It was

a dark brown liquid in a two-litre bottle. She told me that I should take half a cup in the morning and half a cup in the evening. I don't know what was in it but it was tasteless and easy to take. She also gave me a black-coloured ointment for my skin that she told me I must apply at night.

'She told me to come back a week after I first saw her, but I got worse and so I decided not to return. Whenever you go back you have to pay. Sometimes the second consultation at a traditional healer is more expensive, about R200. But you don't see any improvement.

'I disclosed my status to Sithembele, who had been my partner since 1999. I told her they had found me HIV-positive, but that I did not believe I was. Our relationship had been good until then. But now it started to get worse. I was drinking too much alcohol at the time and I used to hit her sometimes because of this.'

This is a brave admission. Violence against women is like a cancer in South African society and reducing it has been one of TAC's main campaigns in Khayelitsha. While the macho culture which sees women as subordinate to men is definitely part of the story, surely as important is the erosion of dignity in men like Andile brought on by unemployment, the fear of violence, lack of educational opportunities, hopelessness and a precarious existence.

Andile continued, 'She told me if you are HIV-positive I cannot have a relationship with you anymore. She left me. At the time we had a daughter. She left the child for me to look after.

'I lost my job because my boss told me he could not employ someone who was HIV-positive. I had told him I was HIV-positive because he kept nagging me about why I was going to the clinic.

'I was lonely. My younger brother offered me no support. I was deeply stressed because I could not afford to buy food. I could not work. I was just sleeping on the bed. I could not do anything. I decided that for me to live is no good. I felt useless. That was when I decided to hang myself.'

Unemployed, poverty-stricken, dying of Aids in his mid-twenties and lonely, Andile tried to commit suicide. He stood on a chair and connected a rope from the roof of his shack to his neck and kicked the chair away.

'Luckily for me, I thought I had locked the door, but I had not done so properly. I was starting to get dizzy when my child ran in. When she saw me, she screamed, "My daddy's hanging himself." The neighbours came in and cut the rope. They told me I had to go back to the clinic, which I did. My doctor, Gilles [van Cutsem] of MSF, said my CD4 count was very low. He told me to start ARVs. But I was scared to start them. One of my friends had told me ARVs are not good, that they have lots of side-effects.

'I called my mother, who was at the time in Welkom [in Free State province]. I told her I was HIV-positive and about to start ARVs. She said to me there's somebody in Welkom, a guy from Malawi, who could make people with HIV feel better. She sent me money and together with my daughter I took a train to Welkom. I had diarrhoea even on the train. I had shingles on my face. I was also starting to lose my hair and I was also forgetting things.

'I went to the healer. He was somewhere between 45 and 60 years old. He told me that someone bewitched me because he was jealous that I had found work. He gave me traditional medicines and made cuts in my skin with a blade. He put the medicine on the cuts. It did not hurt much. He told me not to eat until the next morning. He also gave me an enema.

'I woke up in the morning and went back to the healer, where I vomited. I had to do some other things there as well,' Andile said without specifying.

'I trusted him because I did not know anything about HIV. I stayed in Welkom from September to November 2004. He gave me five litres of medicine. I had to drink three cups a day. He did not tell me what was in it. After I finished the first five litres he gave me a different five-litre mixture. The first one was drinkable but the next one was not.

'I was not getting better. I told my mother I'd heard of ARVs from my doctor. I told her I had to go back to Cape Town to start ARVs. She did not want me to go. She was no longer a nurse and instead worked with traditional medicine. She believed in them. I need to be honest: I had an argument with my mother. I told her I'd never take these medicines again. She gave me money and said I could go back to Cape Town.

'I returned to Cape Town in December. I was nervous to go back to the

clinic because I'd left without notifying the doctor. They did another CD4 count. It had dropped to 9. I needed to go on to treatment but I still had to go through a process of counselling.'

The clinic also insisted that he had to have a friend who reminded him to take his treatment, a treatment supporter. Andile did not have an obvious one. His girlfriend had left him and he was lonely. But luckily he had a friend, Eric, whom he had been working with. 'I called Eric. I told him my problem. I told him I needed someone to come to the clinic to sign up as my treatment supporter.'

In the meanwhile Andile read pamphlets on treatment and began attending a support group at the clinic where he heard stories about people doing well on ARVs.

'I began treatment on 8 March 2005. I remember that day because it is the birthday of my child. After two weeks on treatment, I did not feel any improvement. I thought ARVs might not work. Somebody told me to keep taking them. I also spoke to Sister Mpumi in the clinic. She explained to me they take time but you will be all right. Sometime between June and August 2005 I started seeing the improvements. My diarrhoea stopped, although I still had a rash and was not picking up weight. But by December my skin was back to normal and I began to put on weight. I could see now that ARVs were working.

'I called my mum and told her I was getting better. I also told her I needed money because I did not have a job. She took a taxi to Cape Town and saw me. She saw how the ARVs worked and told me I must go out and teach people about them. I was not ready to do so then.

'[My mom] still believes in ARVs and often tells me to take my pills. She also told me to encourage my little brother and little sister to go for HIV counselling and testing because she did not want them to get sick like me. I told them to get tested, but only my sister has done so. Her result was negative. I encourage her to stay negative and use condoms. She is eighteen now.

'After I saw a documentary on Zackie Achmat on television, I joined TAC in November 2005. I started to attend meetings of Positive Men, a

subgroup of TAC. I became active in 2006 because I now had energy.

'I'm now a community health organiser and a treatment literacy trainer for TAC.

'When Sithembele saw that I was getting better, she came back and apologised to me. She told me she was very scared. I accepted her apology because this was the person I wanted to spend my life with and with whom I had a child. We got married in 2007.

'There is no longer violence between us and has not been since we got back together. TAC has given me a lot of dignity. I have also not got drunk since last year. When I teach people about HIV, I tell them they should not drink.

'Sithembele got tested. She did not want to at first. "I'm not sick," she said. I told her she could still have the virus and that I'd support her whatever the result. The result came back negative. We now have to use a condom whenever we have sex. She is still negative. We decided to have another child and so we washed some of my sperm and in 2007 we had a boy. The sperm washing was paid for by some Swedish guys who did a documentary on me.' (Sperm washing is an expensive procedure that separates seminal fluid from sperm. It is thought to work because sperm cells do not carry HIV, but this is not fully understood.)

I asked Andile what he understood by science and why it is different from traditional medicine. 'Science to me means you can trust the medicine because they will tell you the side-effects and what is in the medicine. There is an expiry date on the medicine. Traditional healers do not tell you this. They don't want to tell people what's inside their medicines because they are making money. Whenever you go to the traditional healer you have to pay. You don't have to pay when you go to the clinic. There are no expiry dates. You can end up taking a very old medicine. I know that ARVs work because they worked for me. My CD4 is now 388 and my viral load is undetectable.'

For Andile the key difference was the openness of scientific medicines as well as the fact that they are tested.

I asked him why he decided to place his trust in the traditional healer in Nyanga rather than the clinic.

'I went to her because I did not believe in the clinic. Most of the people I know would first go to the traditional healer before going to the clinic. There is lots of mistrust of the clinic. There is a belief among men that you are not a real man if you go to the clinic. If you go to the clinic often, you get discriminated against for being weak, for not being a real man. The TAC has started to change attitudes about people going to the clinic. Women usually go to the clinic when they are sick, but we have a lot of work still to do with men. More education is needed, especially to encourage men to go for HIV counselling and testing.

'One of the problems is that there is a belief, which I learnt as a child, that if you go to the clinic they will put your penis on a table, take a hammer and hit it. There is also embarrassment that a woman nurse will look at your private parts. Many men do not want to get treated for their sexually transmitted infections because of this.

'I would not stop people from getting traditional medicines. That is what we grew up with. But at the same time people in the community must not try to convince those who are going to the clinic to instead go to traditional healers. Traditional medicines need to be tested just like the medicines at the clinic.'

Zebulon Gwala's dream

Zebulon Gwala is immaculately dressed. He used to be a truck driver, he explains. He says his travels took him around Africa. He used to have dreams in which his grandfather gave him herbal medicine recipes. One of these recipes was for Ubhejane, which Gwala claims is a cure for Aids. Ubhejane is perhaps the most dangerous of the untested remedies being marketed as a cure for Aids today. I use dangerous in a particular sense. I do not know if the contents of Ubhejane are poisonous; probably they are not. What is dangerous is that Gwala explicitly sells it as an alternative to ARVs. Use either Ubhejane or ARVs, but not both, he and his employees tell patients.

Together with a TAC activist who posed as an interested patient, Jack Lewis's film company CHMT went to Gwala's factory and shop and

filmed what happens there. They also interviewed Gwala. He quite happily consented, probably with the knowledge that he had the protection of senior people in government. The video is available on YouTube.²

His customers first have to deposit about R300 cash into his bank account, for which they get a receipt. They then go to his shop and hand over the receipt. There they are told to take two bottles of a black liquid. One has a blue cap, the other a white one. The blue one, customers are told, 'fights the virus or whatever disease you have' and the other boosts the immune system. Both bottles look identical except for the different-coloured caps. The film showed dozens of receipts on the cashier's desk. Gwala's business was booming and probably still is.

The CHMT crew also filmed the factory where Ubhejane is manufactured. It was filthy and certainly did not comply with acceptable manufacturing practice for a medicine. For one thing, the drums containing Ubhejane are unclosed, so insects and other creatures can easily contaminate the product. The factory door stood open (Durban is hot and humid in the summer) and the raw ingredients lay about haphazardly.

On 13 February 2006, Manto Tshabalala-Msimang's spokesperson released a statement defending Ubhejane. Five days later Tshabalala-Msimang wrote, 'The DA [the official opposition party] has described Ubhejane, a traditional medicine widely used by people living with HIV and Aids, as "a fake Aids cure" that is produced by "a backyard chemist" ... The DA makes this sweeping statement despite the fact that Ubhejane is currently being researched at the University of KwaZulu-Natal to establish the required scientific data on the positive effects that it is reportedly having on patients with HIV and Aids.'³ In fact the testing that was taking place at the University of KwaZulu-Natal did not extend beyond the laboratory. It was a simple test from which nothing significant can be learnt about the safety, quality or efficacy of Ubhejane when used by humans for the treatment of Aids.

A sociologist and special adviser at the time to the Premier of KwaZulu-Natal, Herbert Vilakazi, became Ubhejane's academic praise-singer. He has written several papers lambasting what he calls Western medicine. Instead

he proclaims the benefits of Ubhejane for the treatment of Aids. He also claimed the medicine had been tested, which it has not.

Vilakazi's writing is vitriolic toward things Western or what he perceives as Western:

The rise of Western civilization and its domination of all regions of the world accustomed almost everyone to the view that Western modes of thought, in particular Western science, are superior to all other cultures and systems of thought. Of all cultures African culture was dismissed as most backward and most vacant of scientific content.

Alas! How wrong both suppositions are! It is becoming increasingly clear to a few of us, who are familiar with African culture and Western science in some depth, that African traditional medicine, as theory and practice, is actually the most fundamental critique of the method and logic of modern Western science.⁴

In another paper with the disturbing title, 'A New Model of Health-care Delivery for KwaZulu-Natal', he wrote: 'Traditional Doctor [Zeblon] Gwala has a herbal mixture called Ubhejane, which seems to have remarkable powers for reversing the symptoms of full-blown Aids. Dr N. Gqaleni, Deputy Dean, Nelson Mandela School of Medicine of the University of KwaZulu-Natal, has compiled a report on a preliminary study of Ubhejane which was conducted at the laboratories of the School of Medicine.'⁵

I alerted Salim Abdool Karim, a leading HIV scientist at the university's medical school, to this. He organised for the university to release a statement clarifying matters. It was unequivocal and quoted Professor Gqaleni himself, the man Vilakazi said had tested Ubhejane.

The University recently initiated a research programme focusing on traditional medicines. A part of this programme includes research on traditional medicines and other forms of traditional healing for the treatment of HIV/Aids. Research was conducted by Professor Gqaleni on the activity of Ubhejane on cell-lines in test tubes. 'The findings of

these studies cannot be extrapolated to make conclusions about the potential action of this traditional medicine in humans. The University has not conducted any clinical trial research on patients with Ubhejane and refutes claims that research at the University has found any benefit for Aids patients,' said Professor Gqaleni.⁶

In the CHMT video, Gwala brags that, in contrast to ARVs, patients can go straight to the manufacturer to find out about Ubhejane. Yet the contents of Ubhejane are a secret. The TAC KwaZulu-Natal provincial office sent one of its members to buy Ubhejane and then couriered it to me in Cape Town. I took it to the University of Cape's pharmacology department where Professor Peter Smith explained to me that despite what is shown in the movies it is not possible to determine the precise contents of a chemical mixture, at least not without going to enormous expense and trouble. So I asked him to check if it had nevirapine in it. Perhaps Ubhejane was spiked with ARVs, I thought. But Smith reported back to me that his lab could not find any traces of the drug.

Together with Fatima Hassan I attended a meeting of the Parliamentary Portfolio Committee on Science and Technology. We could only watch because we were not among the invited speakers. Vilakazi was, however. His written report for the committee stated, 'On the basis of the evidence available I am convinced that there is far greater promise of the emergence of a solution of HIV and Aids using as foundation African Traditional Medicine, than from within the framework of Western Medicine.'⁷ He also said, 'There are a few medical doctors, too, who have observed the conditions of Aids patients who opted to take Ubhejane, and they testify about the effectiveness of the mixture in reversing the symptoms of Aids.'⁸

Gwala was also in the room and so was asked to speak. He alternated between Zulu and English. He, like Vilakazi, appealed to nationalist sentiments to promote his product. At the end of his talk, Hassan and I gaped because the MPs, most of them from the ANC, stood up and applauded.

It is hard to exaggerate the level of verbiage and pseudo-scientific nonsense that pervades Vilakazi's writing. I have quoted a small fraction

and there is much worse. Yet Mbeki appointed him to chair a body called the Presidential Council on Traditional Medicine. Much of Vilakazi's argument in favour of Ubhejane is based on the retelling of positive anecdotes about the medicine's alleged success. TAC's policy department has over a number of years given basic journalism training to about 70 of our members. One of them was Sylvia Fynn. She went around Durban collecting testimonies from patients and the surviving families of patients who had taken Ubhejane. Her collection of anecdotes tells a remarkable story: some patients speak about the medicine's wonders, but in several cases families recalled how their loved ones had died while on it. I have also received reports from doctors of patients going off Haart and instead going on to Ubhejane and becoming extremely ill.

At TAC we have an archive of horror stories about Ubhejane that I suspect matches or exceeds Vilakazi's anecdotes of success. But this is not the point. Ubhejane has not been tested. It has not even gone into a phase I safety trial. There is also no basis for taking it into a phase I trial at this point: we do not know its ingredients because Gwala will not reveal them. We do not even know if it is manufactured in a consistent way; on the evidence of the video footage it most likely is not. Medicines cannot simply be tested on humans willy-nilly; they have to go through an extensive pre-testing phase to determine if there is a reasonable chance of success.

Consequently Ubhejane has not been and cannot be approved by the Medicines Control Council (MCC). The country's law forbids a medicine to be sold for the treatment of a viral condition, such as Aids, unless that medicine has been approved by the MCC. The sale of Ubhejane is illegal and the promotion of the product by Gwala, Vilakazi and the former Health Minister is unethical.

My colleague Nokhwezi Hoboyi worked together with me to lodge a complaint about Ubhejane with the Department of Health's Law Enforcement Unit. We sent it to the department in April 2008. To date no action has been taken. I understand that the DA has also lodged complaints about Ubhejane. They too have been rebuffed.

We have had one small success. In December 2007, Gwala advertised

Ubhejane indirectly as a treatment for Aids in *Ilanga* newspaper. Without mentioning HIV or Aids, he claimed Ubhejane would increase one's CD4 count and cure a range of illnesses that were clearly Aids-related. Hoboyi brought the advert to my attention and translated it. On behalf of TAC I lodged a complaint with the Advertising Standards Authority of South Africa (Asasa), a self-regulating institution whose code and decisions all the major newspapers in the country agree to abide by. Gwala's lawyers responded that Asasa had no jurisdiction over him, a pathetic defence which Asasa rebutted because they have jurisdiction over any advertisement in a newspaper that abides by their code, including *Ilanga*.

Asasa upheld our complaint and, as I understand, the advertisements have ended, though I cannot be sure. We released a strongly worded statement following the ruling, titled 'TAC complaint against charlatan Zeblon Gwala upheld by Advertising Standards Authority'. In response to the negative media publicity following the ruling, the Department of Health issued a statement declaring that Tshabalala-Msimang had never supported Ubhejane. It was a lie of course, but nevertheless it was progress.⁹

It was a very small victory. Asasa is not a state institution and has limited power. Ubhejane continues to be advertised in informal ways that Asasa really does not have jurisdiction over. No state body with the responsibility of stopping Gwala has made the slightest effort to do so. He continues to deceive people with deadly consequences.

Busisiwe Maqungo's spiritual experience

Busisiwe Maqungo lost her first baby to HIV. She joined TAC after that. She also became a regular guest on CHMT's television series *Siyayingoba Beat-it*, an HIV education magazine programme. An episode in 2000 shows her visiting a traditional healer named Merci Mancini. Maqungo explains her grief and self-loathing to Mancini, 'There's nothing I do to treat my virus, like taking this or that type of treatment to prevent me from getting sick. I'm just sitting here, waiting for my doomsday, because I know eventually I'm going to die. And ever since my child died, I see no need to struggle to treat myself. I failed my baby.'

They then enter a long poetic dialogue. They enter a trance. The conversation is animated. They talk about Maqungo's ancestors and most importantly about what seems to be her late child. Finally Manci says, 'Okay, do you see that bone? It says you must get a bottle of medicine to drink so that it takes away tiredness. This bone is going to prevent the coughing that you'll have. You're going to steam yourself and wash yourself so it takes bad luck away. But when the bones talk about bad luck, it means there is somebody at home who died. Somebody who died, did you hear me? But you didn't let him or her die; he or she is still inside you. This medicine is oily. It's going to help you with all your problems ... Rub it on your face. And run it on your head. Here it is, my love.'¹⁰

This was a cathartic experience for Maqungo. Manci prescribed medicines, likely placebos, to improve Maqungo's psychological well-being. This was surely a religious (or traditional) experience, not a medical one. It was deeply meaningful for Maqungo. Most medical doctors would not be able to offer Maqungo what Manci did because they would not be able to tap into the belief system that Maqungo and Manci shared from their Xhosa cultural upbringing. Even most Xhosa doctors would not be able to do what Manci did for Maqungo, because of Manci's specific position in Xhosa society.

Maqungo had a second baby. This time around she had access to the PMTCT programme. Her baby was born healthy and free of HIV. Maqungo became a leader in TAC's Cape Town activities and one of the organisation's best treatment advocates. Today she is on treatment and doing very well. Via her own common sense she reaped the benefits of both traditional and scientific medicine.

The role of traditional medicine

We usually seek medicines to treat or cure an ailment or, as is increasingly the case in affluent societies, to improve some aspect of ourselves that rightly or wrongly we find imperfect. Reversing baldness, increasing the size of our muscles and reducing our anxiety are just a few examples of this. For minor illnesses and problems it is often not so important to us

that the medicine we take might be no better than a placebo. Instead, the comfort of a warm-hearted healer or the psychological benefits of being part of some kind of group therapy are our main objectives, even if we do not consciously seek this.

Most of the time, most of us obtain our medicines from sources we trust and whose ideological underpinnings we believe in. For the relief of many kinds of pain as well as minor ailments that are either susceptible to the placebo effect or likely to heal spontaneously, the particular system of healing we choose probably makes little difference: it is more important that we believe in it than that it actually has a scientific basis. So whether you see your homeopath, vitamin guru, chiropractor, reflexologist, sangoma, acupuncturist or medical doctor, you will get more or less the same results, even if the medicines you are given have no physiological benefit, so long as they are not harmful to your health.

However, when it comes to the treatment of serious illnesses, the quality, safety and effectiveness of the medicines you are prescribed become paramount. Placebos have at the very most a secondary, complementary role in the treatment of cancer, diabetes, malaria, TB, cardiovascular disease and Aids. It makes little difference whether the medicine is thought of as traditional or Western: what matters is that the medicine has been tested using a robust scientifically valid methodology and shown to work.

So the dichotomies that see medicines as Western versus traditional, allopathic versus osteopathic, artificial versus natural, are not helpful when it comes to deciding what medicines are safe and effective. Rather, what matters is whether the medicine has been scientifically tested or not. Of course, even science cannot guarantee beyond any doubt that a medicine works. Science, like all human endeavours, is error-prone. Nevertheless, the current scientific methodology for testing medicines includes the period after the medicine has reached the market and has self-correcting mechanisms built into it. So while scientists got Vioxx wrong for several years, partly due to unethical behaviour, it was because of the methods of science that its harm was eventually discovered.

The scientific approach to medicine is imperfect, but it is our best

chance against disease. The results of scientific medicine are obvious: it has contributed to longer life expectancy and better quality of life for billions of people. The usual retort I hear to this is that improvements in hygiene have contributed the lion's share of improved life expectancy over the last three centuries. But these improvements, too, have come about because of improved scientific understanding of how our environment affects our health. For example, the reduction in mortality from cholera is largely due to the implementation of sewerage systems and clean water supplies in cities. But it was John Snow's scientific work in London in the mid-19th century that demonstrated that cholera was a result of contaminated faeces getting into the water supply. We live longer primarily because of science and our ability, albeit deeply flawed, to organise society in a way that can exploit scientific findings.

In cultures across the planet, medicines and treatment techniques are used that have been developed and passed down through the ages. These are usually referred to as traditional medicines. Homeopathy and blood-letting are surely European traditional medical treatments. The former is still extremely popular and the latter has actually made a comeback for some very specific conditions. China and India have rich traditional medicine heritages which are still widely used. Consulting traditional healers and using traditional medicines are not only popular in sub-Saharan Africa but in societies across the world. A white middle-class woman who lives in Sandton, Johannesburg, and sees her homeopath every week is as much a user of traditional medicine as the man in nearby Alexandra township who consults his sangoma.

How many people use traditional medicines in South Africa? It is difficult to say. Much of the industry is informal, unregulated and unknowable. Several surveys, all with limitations, give a range of results. Besides, much of the research is nonsense, albeit frequently quoted. I have tried to stick to reputable research but even this must be treated with great caution.

A useful study that analysed several surveys estimated that 27 million South Africans use traditional medicines (72% of the black African population), 133,000 people are employed in the trade and it is worth R2.9

billion a year. This study also found that people from all income groups and educational backgrounds use traditional medicines.¹¹

A survey by the HSRC in 2005 found that a mere one in a thousand people in South Africa thought of traditional healers as their 'usual source' of healthcare. In another study, Karl Peltzer of the HSRC looked at traditional and alternative medicine use in the province with the highest prevalence of HIV, KwaZulu-Natal. His team questioned over 600 people with HIV before they had started Haart. They were all hospital outpatients. Half said they used traditional or alternative medicines. Nearly one in three were taking traditional herbal medicines and spending on average R128 per month on them. Very few had told their doctors or nurses what they were taking, which is concerning because when they start Haart there might be unwanted interactions between ARVs and their traditional medicines. Interestingly, the vast majority who took traditional herbs said they used them for pain relief. Many also said they took part in spiritual practices or prayers for stress relief. Other studies also show high levels of traditional medicine use in people with HIV.¹²

From these surveys it is reasonable to assume that many people in South Africa see traditional healers regularly, even if they do not perceive them to be their usual source of healthcare and do not expect much more than pain relief. And they consult them for reasons other than physical health – to help them with their anxiety, psychological well-being, for traditional religious purposes, for combating evil or bad luck, or for advice about some aspect of life.

South African law recognises four types of traditional healers. The woman in Nyanga that Andile visited was a herbalist, or *inyanga*. There are also diviners, or sangomas; birth attendants, or *ababelekisi*; and surgeons, or *ingcibi*.¹³

I have often discussed traditional healers with TAC members. I have also participated in TAC workshops on traditional medicine. Views, attitudes and responses to the subject are varied, from embracing it to outright rejection. It is a mistake to believe that black Africans uniformly embrace traditional medicine any more than that whites uniformly embrace

homeopathy or other alternative medicines.

Take Nelson Mandela's former physician Nthato Motlana, who died in 2008. His statements on traditional medicine contrast starkly with Herbert Vilakazi's. Motlana was a co-accused of Mandela during the 1952 Defiance Campaign trial. He was banned and received a five-year suspended sentence. He was a leader in Soweto's politics and active in the 1976 uprising. He was arrested often. He started the first medical scheme aimed at the African market and was a successful businessman. As a role model of the South African revolution, his credentials were impeccable. According to Zackie Achmat, he was also a TAC supporter.

In a speech to graduating medical students at Wits University in 1988 he stated that 'the scientific basis for traditional medicine has not been established'. He called it 'meaningless pseudo-psychological mumbo-jumbo that was often positively harmful'. He went a lot further, even suggesting that he supported incarceration of traditional healers, a point incidentally on which I strongly disagree with him. But here is an excellent suggestion: 'One often gets the feeling that some of my comrades in the struggle and in the professions, thrashing around for some meaningful contribution to the total sum of human achievement by blacks, mistakenly latch on to indigenous medicine as part of that contribution. If so let us first subject indigenous medicine to rigorous scientific examination before there is the beating of drums in the Great Hall of our University.'¹⁴

Motlana's views on traditional medicine had currency in the late 1980s and early 1990s. I vaguely recall hearing him speak to a positive reception at the Grahamstown Festival nearly twenty years ago. The rise of Thabo Mbeki's vehement racial nationalism has made Motlana's views very unfashionable. This backlash is understandable. When a belief system is oppressed, underground support for it can actually grow. When the Soviet Union fell, for example, there was a resurgence of traditional beliefs and practices amongst Jews after decades of suppression. Even though the laws against African traditional medicine were not vigorously pursued, apartheid certainly distorted and suppressed African culture. I suspect the resurgence in African culture, including the public embrace of traditional

medicine, is at least partly a response to this. It is also a response to a public health system that fails to deliver.

In contrast to homeopathy, traditional medicines are not all inert tablets or plain water. Many of them have real effects, not necessarily beneficial. I interviewed a doctor who worked in a paediatric unit in a public health facility in Pietermaritzburg in the late 1990s. He treated children with renal or liver failure because, on the advice of traditional healers, parents would give their children herbal enemas. A study in the early 1980s at a hospital in Garankuwa near Pretoria found that traditional medicines accounted for more than half the deaths of patients admitted to the hospital with poisoning. This is not to say that the active ingredients of traditional medicines are generally harmful. Given that millions of people take them and are not dying of acute poisoning, such a suggestion would be preposterous. However, they should not be thought of as benign either. Some traditional medicines, such as African potato, are dangerous for people with HIV. Yet a survey, which because of its small size must be treated with great caution, found that the African potato was frequently used as a traditional medicine in people with HIV. Others, like St John's wort or Sutherlandia, are possibly detrimental to the level of ARVs in the body.¹⁵

There is a positive side to this as well. It seems reasonable to assume that herbs with useful effects would survive for generations beyond their discovery. Yet knowledge developed across generations is often miscommunicated from one generation to the next especially when, as in southern Africa, the means of communication is usually oral. Nevertheless, it is plausible that some traditional medicines do alleviate symptoms and pain more effectively than placebos like homeopathic remedies, at least for some diseases. Some might be the basis for cures or treatments of serious diseases. There is no reason why traditional medicines cannot be scientific medicines. Conversely it is worth remembering that there are also many medicines developed in the West that are not scientific.

For a few years in the 1990s there was a lot of hype around a plant called hoodia that San people use as an appetite suppressant. It appeared this

might become the model of how traditional medicines could be scientifically tested and commercially produced to the benefit of the original community where it was first used. According to Wikipedia (of which I am a great fan and no longer too snobbish to reference), South Africa's Council for Scientific and Industrial Research (CSIR) licensed it to a British company called Phytopharm to research and develop. The CSIR later also agreed to share any profits from hoodia. Phytopharm entered into a deal with drug giant Pfizer but the deal then all fell apart. The active ingredient, P57, was too expensive to extract and synthesise.

Pfizer's lead researcher on the project wrote in a letter to the *New York Times*, 'There were indications of unwanted effects on the liver caused by other components, which could not be easily removed from the supplement. Clearly, hoodia has a long way to go before it can earn approval from the FDA. Until safer formulations are developed, dieters should be wary of using it.' So much for the hoo-ha around hoodia, for now anyway.¹⁶

Several institutions, including the universities of KwaZulu-Natal and Western Cape as well as the Medical Research Council (MRC), are doing research in the basic science of some traditional medicines. The MRC is developing a database of traditional medicines. Together with scientists at UCT it has also researched the active ingredients of herbs for which there is anecdotal evidence of efficacy against TB and malaria. Unfortunately, so far they have not been able to confirm the anecdotes. Partly this is owing to a lack of funding, but possibly also because anecdotal evidence about medicines is often wrong.

There are pitifully few well-conducted studies of herbal medicines from any continent in the medical literature. A Cochrane review conducted in 2005 concluded, 'There is insufficient evidence to support the use of herbal medicines in HIV-infected individuals and Aids patients. Potential beneficial effects need to be confirmed in large, rigorous trials.'¹⁷ Yet maybe in some African traditional herb there is an active ingredient that will be the basis for an important medicine. The research is worth conducting and gives traditional medicine a real chance for a scientific future. Nthato Motlana would surely have approved.

Some healers are sceptical about subjecting traditional medicines to scientific scrutiny. They argue that cause and effect are considered too differently in science and traditional medicine. Traditional healers typically do not look for viruses and germs to explain the causes of diseases, but instead for moral failures, vendettas and magic. Their methodologies are so different, the argument goes, that analysing traditional herbs using the scientific method is not workable. At the very least, they argue, scientists who test traditional medicines must engage with the belief systems behind the use of these herbs. It is a view that received tacit support from Tshabalala-Msimang. In defending Ubhejane, she declared the Department of Health's intention to legislate different criteria for the registration of traditional medicines. 'In finalising the regulations of these medicines, we are avoiding the pitfall of putting such products in the same regulatory environment as pharmaceutical drugs, whose testing and control is very different.'¹⁸

In another speech, she stated, 'Mindful of the challenge of conventional research methods in the context of the uniqueness of African Traditional Medicines, conventional clinical trials may not be needed to justify the continuing use of traditional medicines, but observational studies and research can add to our body of knowledge of the safety and efficacy of such medicines.'¹⁹ I believe this attitude, if it prevails, will leave traditional medicine without any hope of realising substantial health benefits for its patients.²⁰

The regulation of traditional medicine is in flux. According to researcher Adam Ashforth, traditional medicine was illegal in South Africa 'in virtually all its forms' for over a hundred years, after the Suppression of Witchcraft Act was introduced in 1895 in the Cape. Besides being draconian, outlawing something that is so widely practised is foolhardy. In 2004, Parliament passed the Traditional Health Practitioners Bill, which emanated from the Health Ministry. It recognised and attempted to regulate the field, in part by requiring the registration of practising traditional healers. It is not clear to what extent, if any, the law has been implemented.²¹

In 2008, the Health Department drafted a policy on traditional

medicine. Its focus is on the protection of traditional healers and their products. No attention is given to the protection of patients. Reading it, you get the distinct feeling that it has not been drafted with the interests of ordinary traditional healers in mind, but rather those of companies, with the intention of making it easier to commercialise the sale of traditional medicines. There is barely any concern for the quality, safety and efficacy of medicines, and it is laced with a negative attitude towards scientific medicine.²²

The commercialisation, or perhaps more accurately the industrialisation, of traditional medicine is happening. The number of formal shops selling traditional medicines has grown. As one research group explains, the quality of the packaging is improving but the quality of what is being packaged is probably not. And as I described in chapter 1, many of these commercially packaged products make unsupported claims about the treatment of Aids and other diseases.²³

Working together

‘TAC in the Eastern Cape conducted training for the Xhora Traditional Healers Forum at Madwaleni Hospital. This was a four-day course. The traditional healers came from most of the 39 villages around Elliotdale.’ The healers were taught how HIV affects the immune system, opportunistic infections and how ARVs treat the disease. The healers were mostly positive about the training, although at the beginning of the meeting ‘there was ... a feeling that TAC promotes “western” over traditional medicines.’ The healers agreed they would use their newly learnt knowledge by ‘deploying themselves to the clinics and schools’ in the area.

This story is from the May 2005 issue of the TAC’s magazine *Equal Treatment*, which was devoted to traditional medicine. The training was organised by Phillip Mokoena, now a senior leader in TAC. The organisation has had many training sessions for traditional healers, some of whom have subsequently joined the TAC. Other organisations have done similar things. Besides being able to refer people with HIV to the public health system, healers can also help alleviate the shortage of staff in the

public health system if they are trained to give HIV counselling and even testing. Healers can also often get important information from patients that an overworked or tired nurse does not have the time or patience to extract. Visiting sick people at home, providing for their psychological and traditional religious needs: these are all critical ways of involving healers which the public health system does not have the capacity to do.

The magazine ran an interview with Mkansi Mamayile, a traditional healer whose photograph appeared on the front cover. Her views are enlightening: ‘Since the 1994 elections, it has been much better [for traditional healers]. [We] are more respected and we work more closely with doctors and hospitals. Now I refer people to hospitals if they have chronic diarrhoea, dehydration, or are very weak.’ She explained that she needs training, ‘to improve writing skills because I have to take my patients to the hospitals and clinics directly to explain their problems to the doctors and nurses. If I could write, I wouldn’t have to accompany my patients when I refer them to a hospital.’

If she saw patients with HIV, ‘I would give them traditional medicines but if they do not get better within two weeks, I would refer them to a hospital. If they were extremely sick or weak when they came to me, I would take them immediately to the hospital. That is the policy of the Traditional Healers Organisation.’ She continued later, ‘ARVs are good for people. I have seen people on ARVs who were very weak and have gotten much better.’ She said traditional healers who falsely claim to have cures should have their licences revoked.

But she also said confusing things. The interviewer asked her what she would do if a person taking ARVs came to her and wanted traditional medicines. ‘I would tell them not to mix traditional medicines and ARVs. They would have to choose between the two.’

Equal Treatment’s editorial called for traditional medicine to be modernised. By this it meant traditional medicines should be subject to scientific testing. It also called for rewarding communities from which successfully tested traditional medicines came. On the other hand it said, ‘Some traditional healers spread dangerous messages. They claim they

can treat Aids and ARVs are toxic. Their behaviour gives other traditional healers a bad name. This shows that regulation is needed so that the traditional healing profession will serve patients better. This is something traditional healers should support. If we modernise traditional medicine, it will benefit everyone, traditional healers most of all.²⁴

* * *

‘It’s all about the money,’ said Andile as we walked around Site B. He showed me a pamphlet in Xhosa advertising a treatment for Aids. We also came across an old, poor woman at a stall on the railway station selling traditional medicines. I bought two bottles of medicine from her. They used to contain Klipdrift and Smirnoff. Now they contained even fouler-smelling liquids. Each cost R20 and their homemade labels listed, in Xhosa, dozens of diseases they could allegedly treat. Andile is only partly correct: ideology and belief systems are important too.

5

Dr Manto’s quacks

‘The dread of hospitals probably still survives among the very poor, and in all of us it has only recently disappeared. It is a dark patch not far beneath the surface of our minds.’

– George Orwell¹

A macabre duel

Drum is not just a popular, gossipy, glossy magazine. It is a South African legend, which started in the 1950s as a magazine aimed at the black market and soon became a home of African journalistic resistance to apartheid.² On 25 May 2005, *Drum* issued unwittingly a macabre challenge. It featured, on two double-page spreads with photographs and interviews, Edwin Cameron and Nozipho Bhengu. The headline was ‘Can garlic really cure Aids?’ The introduction read, ‘They both look the picture of health. And they’re both living with HIV/Aids. Yet Judge Edwin Cameron and Nozipho Bhengu each do it their way.’³

Cameron is one of the country’s best-known judges who, as an advocate during the 1980s, defended anti-apartheid activists in high-profile cases. He campaigned for gay rights and was involved in Aids work from at least 1988.⁴ Nozipho Bhengu was the daughter of the ANC MP Ruth Bhengu. (To differentiate between them I will use their first names.) Ruth announced to the National Assembly in 2001 that her daughter was HIV-positive. It was a brave statement. At the time Cameron was still the only high-level public official in the country to have disclosed his HIV status to the world.

By 2001 hundreds of mostly poor people had declared their status in the media, at seminars, workshops and conferences. But Nozipho's disclosure was newsworthy and widely reported. She was a middle-class African woman from a well-known family. Her mother was part of the ruling elite. Not only do black women have the highest HIV prevalence in the population but they are also marginalised in South African society. At the time of her disclosure there was a dire need for a well-known public face to represent their struggles.

Ruth explained her reaction to finding out her daughter's HIV status. Nozipho 'gave me the paper on which the results were written. I felt like the whole world had turned dark. She was already in tears. I stood up and asked her to come to me. I put her on my lap and held her close to me. I then told her she was still my child and I loved her very much.'⁵

By imprinting a famous face on the epidemic, Nozipho and Ruth Bhengu helped demystify the hidden nature of a disease that was killing so many of their countrymen and women. By telling the world her daughter's HIV status, Ruth pushed back some of the deadly stigma associated with the infection that causes Aids. If their family could have this dreaded disease, any family could. Ruth also explained that a person in an informal settlement without a plate of food to eat, with no warm blanket to cover her body, no psychological counselling, no soap to wash her body and clothes, who is ignorant about HIV and cannot access information, was far worse off than Nozipho. And indeed, in normal circumstances this would have been true. But there was a catch in Nozipho's case.

Drum magazine explained Nozipho's way of treating her HIV infection. 'Like Health Minister Manto Tshabalala-Msimang, Nozipho believes there is a direct link between nutrition and Aids. But she has gone one step further by testing the controversial diet of garlic, lemons and olive oil prescribed by Manto. Nozipho believes her state of health proves the diet works.' More accurately, the potion Nozipho was taking was actually promoted by Tine van der Maas, a Dutch nurse. However, it was indeed supported by the Minister of Health. *Drum* gave the recipe for the Van der Maas potion:

Take one lemon with peel grated.

Mix with one tablespoon of extra virgin olive oil and one cup of water.

Take it three times a day, reduced to twice daily and eventually once daily as condition improves.

[There's more:]

Take a tablespoon of ginger three times a day, but reduce as condition improves.

Eat ProNutro [a popular South African breakfast cereal] when you've lost a lot of weight. Mix with Maas [sour milk] or plain yoghurt and water.

Take a tablespoon of raw garlic three times a day.

[Then there's general dietary advice:]

Eat lots of beetroot and spinach for their iron content; lots of fruit and vegetables and drink at least two litres of water a day.

Avoid refined foods and those containing lots of sugar (including most fruit juices), alcohol and red meat.

Bhengu said about this diet, 'I'm the scientific proof. I've intensely been taking this since 2002.' By contrast, Cameron explained that a 'holistic approach to the treatment of Aids must include ARVs'. He also emphasised the importance of nutrition but made it clear that it was not enough. ARVs were responsible for the regeneration of his health after he was diagnosed with Aids in 1997, about a decade after being infected with HIV. Bhengu, on the other hand, said she had taken ARVs but her body could not handle the medication and it made her sicker.

The different approaches of Cameron and Bhengu marked the main battle line in South Africa over the response to Aids. On the one side was the approach of President Mbeki, represented by Bhengu. On the other was the approach recommended by medical science, represented by Cameron. Here was a challenge between two opposing ideologies that could be examined through the lives of two individuals. Who would survive? Which remedy would work?

Of course, *Drum* magazine did not explicitly issue such a macabre duel. And of course it would have had no scientific merit. Neither, either or both

could have been killed by a myriad of causes many unrelated to Aids, ARVs or garlic and olive oil recipes. The case studies of two people do not constitute evidence in favour of one or against another intervention. Nevertheless, the experiment was implicit in the article and would have been picked up by astute readers. What science does tell us is the most likely outcome. And it was this outcome that soon occurred. On 19 May 2006 Nozipho Bhengu died of Aids at the age of 32. According to *The Economist*, she 'was writing a book called "From Victim to Victor". She had just two chapters to go.' Probably over 800 South Africans died of the disease that day.⁶

On 24 May, TAC issued a statement. 'Nozipho Bhengu's death shows the urgent need for science, truth, leadership and personal responsibility to lead the HIV and Aids response.' We went on to salute Nozipho for her courage but held Tine van der Maas partially responsible for her death. We also called on the Minister of Health to have Van der Maas and other quacks arrested, explaining that this 'is the only way the Minister can renounce her own culpability in the deadly confusion and the preying on poor and desperate people with Aids by these charlatans'.⁷

This set off a furore. It is culturally taboo in South Africa to talk in a controversial way about the dead and the appearance of TAC's statement close to Bhengu's death undoubtedly increased the outrage. A number of journalists told me that they thought the statement was callous. Senior ANC members secretly supportive of TAC also felt this way. However, the *Mail & Guardian* came to TAC's defence:

The *Mail & Guardian* respects and sympathises with the family's grief over the Aids-related death last week of Nozipho Bhengu ... But there is inescapable truth in [TAC's] charge that the tragedy can be laid at the doorstep of Health Minister Manto Tshabalala-Msimang and her Aids muse, the dangerous Dutch crank Tine van der Maas. The TAC is not, as family members claim, making political capital out of the death. It is merely pointing out that if Nozipho had continued her [ARV] treatment, rather than placing her trust in Van der Maas's vegetarian quackery, she would probably still be alive.

The newspaper then made this essential point about politically supported Aids denialism:

Individuals like Van der Maas ... are not the real problem. In most societies, they would simply be ignored, and would continue feeding each other's sad delusions in small cult groups like the Flat Earth Society. The problem in South Africa is that they have the ear of the president and the health minister ...⁸

At Bhengu's funeral venomous outrage was voiced against the TAC. About four thousand people attended the service at a hall in Edendale just outside Pietermaritzburg in KwaZulu-Natal, the province with the highest number of HIV infections in South Africa. One of the speakers, Peggy Nkonyeni, the provincial health minister, proposed a conspiracy. 'I came to realize that there is this thing called bioterrorism or biological warfare. This is where people can manufacture a virus and target a particular community that will be spread amongst a group of the population. The question is this: What is this HIV/Aids and where does it come from? We need to answer those questions.'⁹ Interestingly, a survey conducted at clinics in three South African cities found that people who held the conspiratorial belief that Aids was developed by whites to control black Africans were less likely to get tested for HIV. And here was the provincial health minister publicly promoting something similar to this bizarre view.¹⁰

She also misrepresented TAC's position on nutrition. 'You know the TAC always amazes me because when we say we have a comprehensive plan which involves prevention, treatment, support, nutrition and care, they say we must not talk about nutrition. But our argument says you can't give medication on an empty stomach to a person. No matter what type of medication one is taking they have to eat. Who has ever been killed by nutrition? We are dealing with an industry that is very shrewd.'

Chriselda Kananda also spoke. She is a popular radio presenter who often expresses scepticism about the fact that HIV causes Aids. She claimed that Bhengu 'had a liver condition and therefore could not take ARVs. Now logic

would say that once you have a liver that is not functioning properly you cannot be on any toxic drug because that means your liver cannot cope with the severe, I say it again, severe side-effects that come with ARVs.' Actually, logic says no such thing and there are many ARV medicines available for people with liver ailments. Quite contrary to Kananda's assertions, some ARVs also double-up as treatments for hepatitis B, a disease of the liver.

The speeches at the Bhengu funeral were indicative of the acrimony of the Aids debate. This was, after all, a life and death fight. But instead of their brave openness being rewarded with sound medical advice, the Bhengus had been met with pseudo-science, mysticism and quackery. Nozipho, who was middle-class, well-off and had access to life-saving treatment, paid a high price for the closeness of her family to a minister of health who was taken in by the deadly delusions of the quack Tine van der Maas.

Knowing the Van der Maas story is essential to understanding the TAC's struggle against Aids denialism. Her influence on Tshabalala-Msimang was considerable and, in turn, she epitomised the ideology Tshabalala-Msimang promoted. In the letters and op-ed pages of newspapers and in television documentaries, the opposing positions that the TAC and Van der Maas represented were portrayed as the contrasting sides of a debate at Nozipho Bhengu's funeral.

The garlic and olive oil evangelist

Burglars urinated on them. That's the explanation Tine van der Maas gave to a journalist to explain why she could not produce the records of 40,000 people she claimed she had treated with her garlic, olive oil and lemon recipes.¹¹

Tine van der Maas and her mother, Nelly, believe their nutritional remedies, ideally mixed with a concoction called Africa's Solution, are a treatment for Aids. They have produced a documentary called *Power to the People* to promote their views. Tine introduces the video by explaining, 'There has been a lot of news coverage on the controversy between on the one side our Minister of Health, Dr Manto Tshabalala-Msimang, on her stance on natural remedies like lemons and garlic and on the other side the

TAC, politicians, journalists, doctors and scientists who relentlessly push for ARVs as the only solution. We are the people being referred to as Dr Manto's quacks, the people behind the wellness programme Dr Manto refers to.'

The video follows the stories of what appear to be very sick people getting better because they went on to the Van der Maas diet. In one scene a drowsy, skinny woman with what her family calls 'the big ill' writhes in bed. A few scenes later she walks about, her previously dull face now beaming. In another story, we are shown a very sick brother and sister. The sister follows the Van der Maas diet; the brother shuns it. The sister gets better; the brother gets worse. And so on. It's compelling viewing. Without an understanding of science, it is hard not to buy its message.

The documentary was shot in the villages in an area known as the Valley of a Thousand Hills, not far from Durban. Tine and Nelly wear no makeup nor do they disguise their grey hair. Their faces are lined and slightly crumpled and red, perhaps the result of the sun and hardship. They wear sandals and simple clothes. Up and down the Valley of a Thousand Hills, in and out of traditional huts, we see them walking, meeting and mixing with poor people. They are tall, muscled, ample and earthy. They speak with earnest self-confidence and exude a genuine naturalness; indeed they are caricatures of Mother Nature. They are friendly and warm.

In Tine's own words, she and her mother treat 'arthritis, diabetes, high blood pressure, high cholesterol, stomach ulcers, HIV-positive people or Aids, skin problems e.g. eczema, tropical fungi where the only solution doctors have is amputating the limbs, yuppie flu, glandular fever, cataracts (we have drops that get the cataracts out after about 2 weeks), epilepsy, MS, depression, unknown health problems where the doctors or even professors don't know ...' She also says, 'as a bonus [we] restore libidos – giving a new meaning to "upliftment program" – you name it – we have done it.' They claim to treat cancer 'whatever route [patients] choose, but even those on chemo treatment do a lot better and hardly suffer from the side-effects of chemo as you keep on detoxifying.'¹²

The Van der Maas advice contains some useful common sense: eat fewer

chocolates and high sugar foods; reduce alcohol intake. But most of it is dubious: eat charcoal to treat diarrhoea, eat ten cloves of garlic a day to prevent thrush and do not wear synthetic T-shirts if you have shingles, 'Women often get thrush in the vagina. Just put one piece of garlic in the vagina before you go to sleep, and usually the thrush is gone the next day.' They have strange medical theories: 'When your body is cold it is much easier for you to get infections. For example TB loves it if your body temperature is 36.5.' They also suggest putting a rusty nail in your cooking pots, presumably so you can get enough iron, and soak chicken livers in milk to 'draw out all the rubbish'.

A particularly interesting component of the Van der Maas wellness programme is a liquid called Africa's Solution Forte sold by a natural health supplement company called Bermins. In her excellent book *Khabzela*, Liz McGregor describes her encounter with Chris Barnard, the man behind Bermins. Barnard makes extraordinary claims about this and his other products recommended by the Van der Maases. Africa's Solution contains several vitamins, grapefruit seed extract and olive green leaf extract. But its main ingredient is hypoxis, 500 mg in every 15 ml. According to one website, this plant has been 'used for centuries in African traditional medicine and recently recognized in the alternative medicine trade as a "wonder cure" for its immune-boosting properties'.¹³ The common name for hypoxis is the African potato. I have mentioned already that it is dangerous for people with HIV. It is no 'wonder cure', as I will soon explain.

The problems with the stories in *Power to the People* are plentiful. No diagnoses are made of the patients' underlying conditions. Although numerous references to Aids or its euphemisms leave no doubt that the context of the video is the treatment of Aids, we do not know if the patients are even HIV-positive, if they really are extremely ill or if they are simply a bit under the weather. Tine even admits they do not ask patients if they have Aids, but describes what she is sure are Aids symptoms. 'Fix the malnourishment and you fix the Aids symptoms,' she tells viewers. We do not know if her patients are taking other medicine besides the Van der Maas food and supplements. The video also shows patients being treated

for tuberculosis, diabetes, epilepsy, asthma, arthritis and cataracts.

It is a textbook example of what is known as counting the hits and ignoring the misses, or hindsight bias. Tine van der Maas only retells, using dubious anecdotes, her successes. Failures are ignored. I corresponded with her in 2005 and asked how many of her patients she followed up. Her answer was breathtaking. 'When you do not hear from patients, they usually are doing well. If they have a problem, they usually phone – this is usually the case when they stopped the programme because they felt so well, they thought why keep on taking it.' I did not have the gall to point out that graves are not usually equipped with telephones, let alone the homes of many people.¹⁴ The Van der Maases give no one in their video CD4 or viral load tests. We have no idea what the state of their HIV progression was before they were treated or after.

HIV is an excellent target for quackery, both because of the typical natural progression of the disease and the stigma surrounding it. It is common for the health of people with HIV to fluctuate. Here's a typical experience: One week you are confined to bed with what seems to be a terrible illness. You have a pounding headache and your whole body aches. You have diarrhoea and you are vomiting. Yet the next week you are living a normal active life with no sign of illness. The desire to believe that you can overcome this lifelong infection, that it is transient, is immense. It is tempting to assign the cause of your recovery to something you might have done slightly differently during your illness: maybe it was the extra intake of orange juice, the 15-minute meditation you did on Tuesday morning or the prayers you said that evening. You grasp the false hope that this is the simple solution you can use in future and that there's no need for chronic medication. You discount the possibility that your body spontaneously recovered because your immune system simply did its job and the illness ran its course.

The stigma of HIV's sexually transmitted nature is profound. Compared with other chronic diseases like heart disease or diabetes, HIV nowadays is generally easier to manage medically and has a better prognosis. Yet many people would find it easier to confront their families with a terminal cancer

diagnosis than their HIV status. What does it mean to tell your mother, your brother or your close friend that you are HIV-positive; that you are sexually active; that you have sex with many people; that you did not use a condom; that you have deviated from the sacred tenets of your upbringing; that your sexual behaviour has caused a lifelong scar inside your body, which through illness will now be worn like the mark of Cain? Or, even in more tolerant secular circumstances, that your premature decrepitude will make public what you do privately? Sex or, more accurately, our attitude towards it is what lies behind our impulse to deny HIV's existence within our friends and within ourselves. For some people this manifests in a strong desire to avoid conventional medicine, because that means a visit to the clinic where the doctor or nurse will tell you that you have to take HIV medicines and remind you about the scarring of your blood. ARVs are unequivocally the symbol of the antidote to HIV, and because they are chronically taken, for life, they are a daily reminder of what many people in our societies still consider transgression and misbehaviour. It is tempting to clutch on to another cause of your illness, perhaps magic, perhaps poor nutrition or the need for a more positive lifestyle. It is this anxiety, among others no doubt, that creates a market for people like Tine van der Maas.

Political support for Tine's recipes

One Van der Maas patient was Nozipho Bhengu. According to Tine, they started treating her in December 2002 when she was hospitalised, had lost 15 kg, had pneumonia, a growth on her spleen and a CD4 count of 55. 'Now', she claimed in 2005, Bhengu was 'a picture of health' with a CD4 count 'around 300'. It was almost exactly a year later that Bhengu died.

Another high-profile Van der Maas patient who died was the DJ Fana Khaba, better known as Khabzela, the main character in Liz McGregor's book. Khabzela spurned ARVs for a multitude of alternative medicines, including the garlic, olive oil and African potato solutions of the Van der Maases. According to McGregor, Tine blames Khabzela's death on whisky and ARVs, not her potions.

But the primary reason for the Van der Maases' popularity was

political. In most modern societies with a developed medicines regulatory framework, quacks like the Van der Maases are consigned to the margins of society, usually treating minor ailments in leafy suburbia. Yet the Van der Maases ran their operation in poverty-stricken rural South Africa with impunity. This was primarily because they had the support of the Minister of Health. They also relied on the unpleasantness of South Africa's health system, which declined dramatically under Tshabalala-Msimang's watch.

Power to the People shows Tshabalala-Msimang visiting the Van der Maases and their patients. The minister gushes when one of them tells her how well she is doing on the Van der Maas programme. At a public meeting where a speaker, one of the Van der Maas patients, shouts 'Viva garlic and ginger', the minister smiles and applauds ostentatiously.

According to Tine, Tshabalala-Msimang visited several of her projects and spoke with many of their patients. Tine claims the minister started talking about her treatments – lemons, garlic and African potatoes – in January 2003 because that is where she first saw their 'Lazarus effect'.

The first time the minister promoted garlic and olive oil for people with HIV in an official speech was actually 28 October 2002. Then she suggested that these home remedies should be part of the government response to HIV. Her only comment about ARVs was to bemoan their exorbitant cost, which her ministry did little about; instead organisations like TAC and the ALP had to campaign to bring down medicine prices.¹⁵

In a speech given on 20 January 2003, Tshabalala-Msimang included African potato in her list of recommendations. She said there was anecdotal evidence that HIV-positive people were benefiting from these products, very likely a reference to her experience with the Van der Maas patients. There was no mention of ARVs in her speech. On 21 August 2003 at a meeting of Soweto home-based carers, in other words in the heart of a community project, she was unequivocal:

In recognition of the importance of food security and good nutrition in mitigating the impact of the disease, and the increasing scientific evidence supporting the efficacy of nutritional supplements for the prevention

and treatment of illnesses such as TB, HIV and Aids, the Department of Health developed a Nutritional Supplementation Intervention strategy for people with TB, HIV and Aids. The strategy includes the dispensing of macronutrients in the form of fortified porridge as well as micronutrient supplements in a pill or syrup form. The Department is investigating the availability of megadose micronutrient supplements to include in the package. The strategy targets all people with TB, HIV and Aids and other chronic debilitating diseases.

In addition to the strategy, the use of alternative remedies such as garlic, lemon and ginger for chronically ill patients is currently implemented in provinces. We should eat garlic because of its antibacterial and anti-fungal properties, lemon because of vitamin C and olive oil as a source of vitamin A and E. All these vitamins are good antioxidants and they are good for everybody.¹⁶

Again, there was no mention of ARVs. In her official speeches, this pattern continued throughout her term: promotion of nutritional remedies, overstating their medicinal value and either ignoring ARVs, mentioning them in passing or bemoaning their prices. Even after she was moved from the health ministry to the less harmful and rather obscure post of Minister in the Presidency, she continued. One of her most incoherent officially recorded speeches was made in her new post in October 2008 to a Methodist church. (I have not corrected grammar and spelling.) 'Remember an apple a day keep the doctor away, raw carrots are good for your every sight, garlic is good and clean the virus, especially thrush in your mouth.' Thrush, incidentally, is a fungal infection, not viral.

There is more. 'It is equally good to treat Shengella when mixed with asprim, and beetroot and lettuce improve your blood content.' But here is the speech's gem: 'There is a Menu on the Cabbage Restaurant, and clubs – the menu is "Minister salad with lettuce, madumbe, garlic, olive oil, beef" this cost R70. You can produce this for less than R 70 and amongst other things it improve your appetite and if you are HIV positive, it prolong the progressive from HIV and AIDs.' This is all precisely from the speech

as it was recorded on the Presidency's website.¹⁷

But merely looking at the minister's official record insufficiently conveys her anti-scientific views. At press conferences and on official occasions she would deviate from her script sometimes to promote garlic and olive oil as alternatives to ARVs. A classic example of the confusion she caused was this: 'ARVs do not cure and they do have side-effects. I do not know of any side-effects of eating proper food.'¹⁸ She was particularly bad in interviews at hiding her real views. Journalists became alert to this and she became an object of satire, known as Dr Garlic. South Africa's leading cartoonist, Jonathan Shapiro, famously depicted her as a vegetable. But Tshabalala-Msimang's scepticism about ARVs preceded her promotion of garlic and olive oil. It went beyond concerns about their cost. In February 2000, she began to echo the President's concerns about their toxicity. It was then that she instructed the Medicines Control Council (MCC) to investigate AZT.

Tine stressed to me that the minister had never funded her, but that on the contrary she had cost them money by requesting her to see patients often at no cost. She maintained that Tshabalala-Msimang asked her to see Nozipho Bhengu. This is highly probable; it is not clear what other route Van der Maas would have found to administer healthcare to a senior ANC family member. One newspaper report quoted Bhengu praising Tshabalala-Msimang, 'I don't care what people say about the minister, she is a leader and a leader is always ahead. In five years' time they will know what she is talking about.'¹⁹

The support that Tine van der Maas received from the minister gave her currency in the media. Astoundingly, *Power to the People* was aired on state television. Van der Maas also got radio time and expounded her views in a prime-time, one-hour interview with one of the country's most popular radio presenters, Tim Modise. On controversial issues, Modise usually had at least two guests with opposing views, but Van der Maas was unopposed, except by the occasional listener calling in.

The Van der Maas message entered the mainstream. An antiseptic manufacturer and popular brand, Dettol, ran a series of television advertisements featuring an HIV-positive man, David Patient, who

recommended garlic and lemon recipes to people with Aids. This was touted as 'positive living', a phrase used repeatedly by the Minister of Health and her supporters, as well as Chriselda Kananda, the Aids denialist radio presenter. Associated with the 'positive living' slogan was advice to eat healthily, exercise and reduce stress if you were HIV-positive.

Encouraging people to eat properly and exercise is good advice, especially with South Africa's high incidence of obesity and diabetes. But genuine nutrition concerns are misused by quacks to make statements based on little or no evidence. HIV and malnutrition interact in complex ways. Many studies show that HIV increases the risk of malnutrition. The most common reason for people with HIV to lose weight – and not in a good Weight Watchers kind of way – is that the virus decreases appetite. This weight loss, coupled with opportunistic infections that cause diarrhoea and poor food absorption caused by the virus, is responsible for the wasting that so often occurs with Aids. Also, as with many infections, people with HIV generally have higher metabolism because additional energy is needed to fight the infection.²⁰

But a person too poor to buy adequate food will not be helped by positive living advertisements featuring garlic and lemon recipes. As for people who can afford to eat enough, there is no evidence that particular foods make a significant difference to the progression of their HIV infection. The time it takes to progress from infection to Aids is for the most part beyond a person's control. Implicit in the positive living campaign is the false and stigmatising message that if you progress from HIV to Aids, it is your fault because you have not been eating healthily, reducing your stress or exercising.

David Patient appeared on television often and gave many talks about positive living. He also equivocated about ARVs. In one interview he described how he used to 'do' the ARV called AZT. By using the same lingo to describe recreational drug abuse, he expressed disdain for ARVs. In another article he wrote, 'Let me make it absolutely clear that I support the availability of medication for HIV-positive people,' and then gave scientifically unsound reasons not to provide them. Patient was probably

a slow progressor, but he eventually became ill with Aids and published a letter in the *Mail & Guardian* in which he stated that he had begun ARV treatment.²¹

Besides the fact that they received state support from the highest level, there is an additional political cause for the ascendancy of quacks like the Van der Maases: the poor state of the public health system. Although South Africa spends more on health than the average of countries with similar per capita GDPs, health outcomes are far worse here. About seven to eight million of the country's 49 million citizens are insured. The rest either pay for private medical care out of their own pockets or use the public health system. About 70% of people say their usual source of healthcare is the latter.²²

The inequality between the two systems is stark. Private healthcare is often as good as anywhere in the world. Public healthcare, on the other hand, is patchy. There are a few pockets of excellence, a few more acceptable facilities, many middling ones and a plethora of really dreadful hospitals and clinics. The insurance system plus out-of-pocket private health expenditure consumes 60% of the country's total health bill. That leaves crumbs for the vast majority of people. Mortality in South Africa is far worse than in countries with similar wealth. The Aids epidemic is largely responsible for this, but the division of resources between the two health systems worsens matters.²³

In Khayelitsha the public health facilities are better than most other places. With the assistance of MSF, Khayelitsha's clinics piloted ARV treatment in South Africa. Yet, even in these model facilities, queues form long before the daily outpatient operations of the clinics open. Photographer Brenton Geach and I did a photo-shoot for a TAC campaign to highlight public versus private healthcare inequalities. We arrived at Khayelitsha's Site B Clinic one weekday shortly after 6 am. The waiting room already had at least 150 people in it. At another clinic, a snaking line had formed outside in the dark. An elderly man told us he had come at 3 am. Others told us that they had to take the day off work because it takes so long to be seen. The waiting rooms are stuffed with the sweating and

coughing ill. Typically a patient will have to wait in at least two queues, one to see a nurse and another for the pharmacy. Although Khayelitsha has become good at integrating various services, it is common in other areas to be referred to a different facility depending on the diagnosis. A patient with TB and HIV could very likely have to get her medicines for each infection at a different place. This and the distance from many people's homes to the clinic they need to go to often mean transport costs are exorbitant. Finally, after travelling and waiting, most of the patients will see a tired, grumpy, overworked nurse on a short fuse for a few minutes.

Much of this is a legacy of apartheid. Although the first post-apartheid government took steps to reverse this mess when it came to power in 1994 and the public health system is now, fifteen years later, large and countrywide, the fact remains that a visit to a South African public health facility is, with good reason, not something most people look forward to.

In contrast, Tine van der Maas is a 'nice' person who cares. She spends lots of time with her patients and shows genuine concern for them. She feeds patients, often using her own money, she claims. A visit from her is a very different experience to a visit to South Africa's public health system. For one thing, the public health system does not do house-calls. The catch of course is that there is a large price to pay for the comfort, warmth and attention offered by Van der Maas. Her remedies simply do not work. For someone used to the worst side of the public health system, there is an understandable temptation to believe that she is offering a viable alternative.

False choices

Tine van der Maas phoned me to try to convince me of the benefits of her remedies. I responded angrily, but then thought about it and decided I could better understand quackery by corresponding with her. In an email I asked her what she thought of ARVs. 'I hate them with a passion,' was her reply. 'If people are taking them and they ask me if they should stop, I always tell them that that is a choice they must make.'

We have seen that controlled clinical trials have shown that ARVs reverse the course of Aids. For the vast majority of people who take them, they

restore health. They allow people with HIV to live much longer, almost normal lives. No other remedies, nutritional supplements or medicines have demonstrated this. So by telling people that it is their choice to take ARVs, Tine is in effect saying to her patients that it is their choice to take, or not to take, the only medicines that have been shown by scientific research to be effective against HIV.

Adults should not be forced to take medicines. People should be free to make their own choices, even if it endangers their health. But this is not really what Tine's patients are asking her. When a patient asks her health provider, 'Should I take this?', the answer she expects is either 'Yes, this will help you get better' or 'No, it will not' or maybe even 'I am not sure'. Most people would be quite perplexed if their doctor's response was 'It's your choice.' Of course it is the patient's choice, but this raises the follow-up question, 'What choice will help me to stay alive?' And it is this question that Tine is really being asked. Her rhetoric of choice is calculated to create the myth that she is empowering her patients.

Van der Maas emailed me a document she distributes. It contains her recipes and theories. Its title is from Hippocrates, 'Let your food be your medicine and your medicine be your food!' It goes on to say, 'Do not believe the TAC or the media when they say you will die if you do not take ARVs. It is not true! They forget to tell you that the drugs will kill you. As long as your body gets ... the right nutrients, your immune system will be strong. This means follow the program every day. You can get all your energy and good health back, but realise that it is a new way of living but not difficult to do.'

Power to the People also attacks ARVs. A toxic warning label on a research formulation of AZT is shown. One patient testifies that she is much better now that she has stopped taking ARVs. Van der Maas says at the end of the video, 'What you've seen here are people who got healthy without medication. They got rid of their asthma pumps. They got rid of their arthritis medication. They got rid of their ARVs.' She explains that sometimes you need medication, but that at other times 'Herbs heal you. Fruit and vegetables heal you.' It is implausible that her patients do not

know her view on ARVs, that she 'hates them with a passion'. She does indeed influence people not to take ARVs.

Manto Tshabalala-Msimang used a similar rhetoric of choice. For example, at a press briefing in 2005 she stated, 'There is no single clear intervention that can solely solve the challenges of people living with HIV and Aids ... I know I get attacked if I say it's nutrition *or* micro-nutrients *or* antiretrovirals and people want me to say, "and", "and", "and". I think we need to give South Africans options.'²⁴

So, like Van der Maas, the minister confused the principle of a patient's right to choose, which was not the issue being contested, with what her duty was as Health Minister or as a person offering care. It was Tshabalala-Msimang's duty to inform patients what medicines would help them so that they would be more likely to choose wisely. Presenting different treatment options as choices, when all but one of them has been shown to work, is disingenuous and irresponsible. It is also a coded way of saying, 'Don't use ARVs. Instead use garlic and olive oil.'

Implausible cures

So what is the evidence for the remedies Van der Maas promotes? The Nutrition Information Centre at the University of Stellenbosch (NICUS) brought out a fact sheet explaining the research on garlic, olive oil and African potatoes for the treatment of Aids. Its findings leave no room for interpretation. 'In summary, there is no convincing or consistent scientific evidence that any one of these foods, singly or in combination, alter the course of disease, any disease.'²⁵

From a scientific research perspective, garlic is the most interesting of these foods. A number of studies have examined garlic's effects on people with high cholesterol and hypertension. A small benefit has been found for garlic's effect on both. An analysis of the cholesterol studies, however, found serious methodological limitations.

I have been unable to find any study of the effects of garlic on HIV in people. Some laboratory (*in vitro*) studies and animal experiments show that garlic *might* have properties beneficial to the immune system.

There are, however, no published studies showing that garlic successfully destroys HIV *in vitro*. Even so, destroying a virus, bacterium or fungus in a laboratory or in animals is one thing, but generalising such successes to what happens in the human body is a different matter. These experiments would merely be the first step in a rigorous array of tests that must be undertaken to show that a medicine is safe and effective in humans.

It is highly unlikely that raw garlic has any significant effect on HIV in the human body. Drugs that defeat HIV have been designed to target specific proteins necessary for its reproduction. It would be an astounding coincidence if garlic happened to have the chemistry needed to do that. Billions of dollars have been invested in HIV research and numerous potential treatments have been tested, most of them unsuccessfully. I would not be surprised if garlic has already been tested *in vitro*, found to be unpromising and discarded without results of the experiment being published.

It is possible, however, that a giant uncontrolled garlic experiment is being conducted because of the spread of Tine van der Maas's and Tshabalala-Msimang's views. François Venter, the president of the Southern African HIV Clinicians Society, works at Johannesburg General Hospital and treats hundreds of people with Aids. 'Often I get patients coming in very ill with extremely low CD4 counts reeking of garlic,' he explains. He suspects they have been trying the Van der Maas diet or some variation of it, and that they have left the public health system as their last option, often too late unfortunately.

The Van der Maases and Tshabalala-Msimang, as we have seen, recommend garlic for thrush. This fungal infection often occurs on the vagina and in the mouth, irrespective of HIV status, but it is more common in people with HIV. However, a terrible opportunistic infection occurs when thrush enters the oesophagus. This is painful and can make it impossible to swallow. It is often deadly. However, only one scientific study has been reported of the effects of garlic on thrush in humans but the statistical sample was too small to prove its efficacy.²⁶ It is conceivable that garlic has some efficacy against thrush. But there is an excellent medicine called

fluconazole, which after TAC's Christopher Moraka Defiance Campaign was made freely available in South Africa's public health system. There is no need to apply a smelly spice to the vagina.

Interestingly, one study noted that the smell of garlic was a limitation on doing human studies of its effect on HIV because this would identify subjects as HIV-positive. Perhaps, also, some people do not want the smell of garlic constantly emanating from them, irrespective of their HIV status.²⁷ There is, however, a very good reason why large quantities of garlic should not be consumed by people whose HIV has progressed to Aids. A study by the National Institutes of Health looked at the effect of taking large doses of garlic pills on a drug called saquinavir in ten HIV-negative volunteers. The garlic reduced the amount of the drug in the body. This might mean garlic supplements reduce the efficacy of some ARVs. While the case is not clear-cut, when it comes to using medical treatments it is best to err on the side of safety. A person with HIV who has developed Aids should be taking ARVs. Supplementing these with garlic in the large amounts prescribed by the Van der Maases is an unnecessary risk. Eating garlic for its usual, culinary purpose on the other hand is fine.²⁸

Then there is olive oil. It is healthy because diets which are high in mono-unsaturated fats, like those found in olive oil, are associated with lower cholesterol. It is therefore perhaps better to drizzle olive oil over your salad than standard cooking oil. Not much more can be said about it when it comes to HIV. There is not the slightest evidence of its having any benefit in the treatment of any disease. It is also expensive, and prescribing it to poor people with HIV is more like a cruel joke than serious advice.

The African potato extract in Africa's Solution is a different story. Several times I have said that it is dangerous. This is because a study has been conducted on hypoxis in HIV-positive people. It had to be terminated early because the group taking hypoxis showed severe bone marrow suppression and significantly lower CD4 counts than the control group after just eight weeks.

You will not be able to find the hypoxis study easily. It is unpublished. I read about it in a NICUS fact sheet. It is referenced in a report for the

MCC on the safety and efficacy of the hypoxis plant extract in HIV-positive patients. I emailed Patrick Bouic, the study's first author, and requested a copy of it. He told me it was confidential and I had to ask the company that sponsored the study, Essential Sterolin Products (ESP). This company specialises in what it claims are natural immune boosters. I contacted them to request the study. They asked me why I wanted it. 'I need it for a book I'm writing on the different types of treatments that have been promoted for Aids in South Africa,' I responded. The response from their representative was curt. 'Having spoken to the Managing Director of the company regarding your request, regrettably I cannot give you a copy of the protocol as it is unpublished and confidential.'²⁹

Pharmaceutical companies are rightly criticised for not publishing failed studies. It is unethical only to publish the good news about a drug and to ignore the bad. Moves are afoot to stop this practice by enforcing a publicly available clinical trial register. Every time a company conducts a trial, it will have to register the purpose of the trial and how it will be conducted. The idea is that it will be easy to spot which trials are unpublished and to shame the responsible companies into rectifying this. But so-called natural health product companies like ESP are no better than pharmaceutical ones. Ironically, ESP's website states, 'We believe that responsible, ethical science is the key to unlocking nature's secrets.'³⁰

Pastoral fantasies

The credits on the *Power to the People* video are revealing. It's a veritable who's who in the denialist zoo. Napwa 'fully endorses this documentary and program'. So does the Traditional Healers' Organisation (THO). The cameraman, Kim Cools, an Aids denialist with evangelical zeal who lives in Inanda, is thanked and shares the copyright. Matthias Rath supplied their tapes. Viewers are also directed to the website of Anthony Brink, Rath's former employee and an outspoken denialist.

An interesting feature of *Power to the People* is the way the camera pans across the beautiful but underdeveloped KwaZulu-Natal countryside. There are occasional shots of a man in traditional Zulu gear who is drumming.

His tribal music is the dominant soundtrack. The Van der Maas document alleges: 'Most medication is made from food, only we have stopped eating healthy [*sic*]. Also the quality of the food is not the same as say 20 years ago, because people are only taking out of the soil, and not putting anything back. To get the same out of an orange from 20 years ago, you now have to eat nearly a whole bag of oranges to get the same in.'

This curious harking back to a bygone era, the rejection of modernity and scientific medicine, and the substitution of a 'back-to-nature' philosophy are common to many purveyors of alternative medicines. Africa's Solution's ethnic branding and its use of a plant endemic to southern Africa emphasise this rejection by offering an alternative to ARVs, which are perceived to be European, American or Western. But Tine van der Maas is not the average seller of New Age remedies to the middle classes that one finds all over the world. The patients in *Power to the People* are poor people in rural KwaZulu-Natal. Life expectancy in the province is a paltry 43. Per capita income is about \$4 per day. Nearly one in three adults are unemployed. These statistics, bad as they are, hide the extent of poverty because of the massive inequality in the province. The situation for Africans is much worse; over 60% live in poverty. And it is worst of all for the rural areas, where over 80% live in poverty. The Van der Maases' target population can barely afford a luxury like olive oil or even garlic in the huge quantities they prescribe.³¹

In her correspondence with me, Tine emphasised how much of their own money she and her mother have spent on their crusade and that they buy the ingredients for patients who cannot afford their concoctions. She also told the same story to Liz McGregor, though McGregor uncovered some evidence of a profit motive. Nevertheless, it is conceivable that the Van der Maases are not driven by profit. Perhaps they are even spending their life savings running their project.

It is highly probable that they truly believe their mission and medical philosophy and that their motivation is primarily ideological not financial. But Tine van der Maas is promoting unproven alternative medicines to deeply vulnerable people facing death if they do not get the right medicines.

She promotes retrograde values to poverty-stricken people in need of better hospitals, proper medicine supplies and more health workers, as well as decent schools, roads and money – in short, people in desperate need of economic development.

Despite her friendliness, her earthy charm, her apparently self-sacrificial behaviour and her genuine concern for her patients, Tine van der Maas is a pedlar of deadly delusions. As we have seen, there is no evidence that her remedies are of particular benefit to people with Aids. On the contrary, Africa's Solution is detrimental. The most optimistic hope for the Van der Maas garlic and lemon concoction is that a clinical trial will show that it is of marginal benefit. In all likelihood it is inert against HIV in the human body. That she offers her remedies as alternatives to ARVs is deeply disturbing. But most troubling of all is that it was the support from the former Minister of Health that sustained the Van der Maas delusions. Thankfully, since Mbeki's and Tshabalala-Msimang's departure from office, the Van der Maases' publicity and influence have waned.

6

The deadly Dr Rath

‘The [medical] experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature ... The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.’

– Nuremberg Code¹

Marietta Ndziba thanks God for Dr Rath

In June 2005, Marietta Ndziba stood up to speak at a press conference at the Holiday Inn in the centre of Cape Town. To her left sat Dr Matthias Rath. At first Ndziba appeared a bit nervous, but her confidence increased with each sentence. ‘Hello, I am Marietta. I am HIV-positive. I was diagnosed in 1999.’² She explained that she had recently had her CD4 count taken at a clinic in Khayelitsha. It was 365: low, but not catastrophically so. Nevertheless, it is not unusual to get very sick at this point. Indeed, Ndziba soon did get ill. She was therefore worried that her CD4 count had dropped and went back to the clinic to ask for another one. The clinic refused, saying she must wait until her next test was due, six months from then.

She started vomiting and got diarrhoea. She had boils under her arms and could not walk or talk properly. It was at this point that her mother met Rath, who claimed his vitamins could treat Aids. Ndziba was hopeful when her mother told her about the doctor. She was sick and she had a family

that she was worried about. The next day she went to her usual doctor. He prescribed medicines, but she never took them because Dr Rath’s people called that day and she decided to rather try their vitamins. After five days, Ndziba could already feel the difference. She proudly told the press conference how much better she felt. And in the video of the conference she does indeed look healthy. She could talk and walk again. ‘I just thank God that he brings Dr Rath here in South Africa to help our lives,’ she said. ‘Why are there people telling lies about vitamins? Because the vitamins help our lives. And the government said to us if you’ve got something to help, eat or drink that thing.’

Ndziba headed a support group for Rath’s patients. For a few months, she was his star patient, recruiting people and publicising how wonderful he and his vitamins were. Four months after the press conference, Marietta Ndziba died in October 2005. One family member insisted that she had died of a stress headache. There was no autopsy. In all probability she died of Aids because she had taken Rath’s multivitamins instead of Haart. Her story exemplifies Rath’s vulturine preying on the desperate. Yet her comments also show the influence of what she understood to be the government position on Aids treatment and the unsatisfactory service she perceived she got from the public health system.

The story of how Matthias Rath, with the support of Manto Tshabalala-Msimang and other politicians, tried to destroy public confidence in ARVs is perhaps, along with Virodene, the definitive example of state-supported quackery during the Mbeki era. While the Virodene story reeks of financial corruption and ultimately led to the destruction of the independence of the Medicines Control Council, it began before the pressure on government to provide ARVs. Rath’s involvement in South Africa started in 2004 at the same time that Haart was being made available. His influence extended to ordinary people. While relatively few people were exposed directly to Virodene, Rath on the other hand took his message directly to the people, with deadly consequences.

Knowing the Rath story is critical to understanding how Mbeki tried to wield influence over the mind of South Africa about Aids. Furthermore,

the public humiliation of Rath, driven primarily by the TAC, was also a humiliation as well as a political disaster for Mbeki and his Health Minister.

But before I tell this story, I need to say more about Rath. Amusingly, the interesting part of his life can be told as a sequence of court cases, complaints and official findings against him. They have taken place on at least four continents and paint a picture of an international charlatan.

A litigious history

Rath was born in Stuttgart, Germany, on 18 August 1955. He apparently holds a doctorate in medicine from the University of Hamburg and is a member of the New York Academy of Sciences. In the early 1990s he worked with the Nobel prizewinner Linus Pauling, researching the effects of vitamin C on heart disease and cancer. He and Pauling co-authored at least two published peer-reviewed papers. They then fell out and ended up suing each other.

A few years ago I emailed Stephen Lawson, who during the time of the fallout was the CEO of the Linus Pauling Institute of Science and Medicine (LPISM), to ask what happened. Lawson explained that Rath ‘accused Linus Pauling and the [LPISM] of interfering with his business relationships’. He continued, ‘We won summary judgment on his lawsuit, which dismissed his claims, and counter-sued him for libel and for interfering with our business relationships. That suit was settled in December 1994 before going to trial. Among other things, the settlement nullified all agreements between Rath and Pauling, some patents were assigned to Rath, and Rath was ordered by the Court to pay \$75,000 to LPISM, which he has not yet done.’

The story of his fallout with Pauling’s institute is important, because Rath drops Pauling’s name frequently. I googled Pauling on one of Rath’s websites and got 484 hits, including a 19-page book chapter titled ‘How I came to work with Linus Pauling’. This is how he modestly describes the start of his collaboration with Pauling: ‘For mankind it was a historic day – the beginning of the end of the cardiovascular epidemic.’ Rath has also claimed that Pauling asked him to continue his life’s work. Here, for

example, is the opening paragraph of an ‘Open Letter by Matthias Rath, M.D. to the Health Food Community in the USA’ written in February 1999: ‘Dr. Rath is the physician and scientist who led the medical breakthrough on vitamins and cardiovascular disease documented in his book “Why Animals Don’t Get Heart Attacks – But People Do”. Two-time Nobel Laureate Linus Pauling stated in his last will in June 1994, “There is no question in my mind that I thought about Dr. Rath as my successor.”’³

Rath has been involved in a host of unsavoury lawsuits and counter-suits with individuals and companies with whom he has fallen out. There have also been a multitude of actions against him for his unsubstantiated medical claims. In October 2002, Rath ran an advertisement in Britain in which he described himself as a world-renowned scientist. He has repeatedly made the same claim in Germany and South Africa. The British Advertising Standards Authority upheld seven complaints against the advert. It found that Rath’s claim that ‘90% of patients receiving chemotherapy for cancer die within months of starting treatment’ could not be substantiated and was likely to distress people with cancer, that the claim that three million lives could be saved if cancer patients stopped being treated with conventional medicine was misleading as was the implication that the pharmaceutical industry was deliberately letting people die for financial gain. Rath had described pharmaceutical anti-cancer drugs as ineffective, poisonous compounds with hazardous side-effects. This was found to be misleading and distressing. The Authority also found that the advert discouraged people with cancer from seeking essential treatment. Finally it found that the claims that Rath’s treatment could control the spread of cancerous cells without damaging healthy cells or that it could prevent the deadliest phase of cancer were unsubstantiated.

Then there was the tragic case of Dominik Feld, a German boy with bone cancer. Doctors had recommended that Dominik undergo chemotherapy and have his leg amputated. Even then, they estimated that he had only a 20% chance of survival. Dominik’s parents, sceptics of orthodox medicine, decided to ignore this advice and let Rath treat him. The boy became one of Rath’s celebrity patients, just like Marietta Ndziba. In 2003, Germany’s

Social Services got a court order for Dominik to be removed from his parents's custody, but this was later overturned.

In January 2004, Rath began treating Dominik with a multivitamin concoction. In an interview Rath said that the boy would become 'a normal adolescent. He will become a doctor.' The boy died in November 2004. He was nine years old. The story generated a lot of negative publicity for Rath. A German television station, SWR, ran a documentary on it in November 2005 and consequently received the European Journalism Prize from the Association of German Medical Journalists. Rath took SWR and a reporter, Beate Klein, to court accusing them of false reporting. He lost, but this has not stopped him from defaming SWR and its former director.⁴

Rath did, however, score a major court victory out of this sorry affair. The *British Medical Journal* erroneously reported in 2006 that Rath was being tried for fraud in relation to Dominik's death. Britain's libel laws are notoriously favourable to plaintiffs, so Rath sued, the *BMJ* retracted and the court accepted its offer to settle for £100,000. I can understand the *BMJ*'s mistake. In dealing with Rath, I often found the court actions in which he was involved incredibly intricate and complex. He sues, gets sued and almost always appeals when he loses. There are cases and cases within cases and they drag on for years, seldom drawing to an entirely satisfactory ending. His lawyers throw up as much sand as possible, confusing courts, journalists and the public. I do not think this is unintentional. Given that much of the action has been reported in German and that the German court system is very different from English ones, the *BMJ* error is understandable. I do not believe Rath could have won this case under American or South African law.⁵

I found at least five other law suits in the US that Rath has initiated. Rath's lawyers have done well off him. The TAC has a deserved reputation for being litigious, but we have nothing on Rath, though thankfully our success rate is well over 90%, while Rath's is not much better than the Bangladesh cricket team's five-day record.

Anthony Mbewu courts Dr Rath

Almost all of the litigation I have described is in the public domain and is easily discoverable with a bit of Internet searching. I did just this when TAC began responding to Rath, so it raises many questions about why officials of the South African government nevertheless proceeded to work closely with Rath from about March 2004. It was then that Rath began meeting Anthony Mbewu, the head of the Medical Research Council (MRC), a statutory body. Minutes of one of the meetings record Mbewu telling Rath that the National Association of People with Aids (Napwa) is a 'good group', while 'TAC is paid by [the] pharma cartel'. He goes on to say, 'Napwa has an open mind and will be a great advocacy tool as a counter-balance to attack.'

The truth is, however, that TAC has never received money from any drug company. On the contrary it has litigated against several of them and been one of the industry's most vehement critics. Napwa on the other hand had received a substantial donation from BMS, the manufacturers of two ARV drugs. Indeed, when Fatima Hassan used the Access to Information Act to compel the Department of Health to produce all its documentation on Napwa, which it funded, Napwa's finances revealed a shady organisation that failed to have proper audits conducted and would take money from whomever it could for unclear purposes. In time, Napwa would become a Rath ally and participate in his activities to undermine TAC's work and the rollout of Haart, as Mbewu had suggested.

The minutes of their meetings also show that Mbewu and Rath planned to conduct a multivitamin clinical trial, apparently for the treatment of cancer. The MRC further agreed to allow Rath to run a series of three one-day workshops at the MRC, for which Rath would pay R200,000. This was all secret. Quite by chance many months later, I came across an obscure line in an MRC publication that indicated that Rath had given it money. I emailed a reliable scientist at the organisation to find out what it was all about. She managed to discover that it was for a workshop but could not find any details. I investigated a bit further but it was not until 2006 that I managed to put the pieces together thanks to a former Rath employee

who provided me with photos of Rath, Mbewu and his wife (also an MRC employee) having meetings and dinner together. My source also gave me the minutes of the meetings, which he took, as well as a letter from Rath to one of Mbewu's aides confirming that money would be transferred to the MRC account. I then gave the information to two excellent journalists, Claire Keeton at the *Sunday Times* and Andy Shlensky at the *Cape Times*. They both did further investigations and ran stories exposing this scandal. TAC placed the evidence on our website. The MRC responded by admitting that it had indeed received R200,000 from Rath for him to run his workshops at their facilities, but that it had returned all but R62,253 because not all the workshops were held.⁶

Mbewu was a Mbeki loyalist who had replaced Malegapuru Makgoba as head of the MRC. Makgoba had publicly disagreed with Mbeki over his views on Aids. In an editorial in *Science* in 2000, he wrote, 'The current political and scientific furore in South Africa, fuelled largely by the dissidents' theories on HIV/Aids and the seeming support of Mr. Mbeki, has much broader implications for South Africa and South Africans than some are prepared to admit.' Mbeki wrote a prickly letter to Makgoba about his views and the two, who were once friendly, fell out.⁷

The path to Mbewu's appointment the MRC was laid in 2001. In that year the MRC produced a meticulously researched report that showed the growing impact of HIV on adult deaths in South Africa. But the MRC board, in cahoots with the Minister of Health, attempted to stop, or at least delay, the report from being published, probably because it contradicted Mbeki's view that the epidemic was being vastly exaggerated and that there were other, larger causes of death. Nevertheless, the report was leaked to the media.

Instead of the news of a growing deadly epidemic galvanising the Minister of Health into action against it, a witch-hunt ensued for the source of the leak. The *Cape Argus* got hold of a letter written by the Health Minister to the head of the MRC board. The vindictive tone of the letter is astonishing. Tshabalala-Msimang accused Makgoba of being the leak. (Makgoba certainly supported the report, having described it in glowing terms.) She

also stated that this was 'not the first time that the MRC president has acted against government'. She demanded that corrective action be taken. The MRC paid a consulting firm called Triumvirate to find the source of the leak. Though the minister denied that she was behind this, the letter showed otherwise. The leak was never found.⁸ Makgoba soon resigned from the MRC and became the vice-chancellor of the University of KwaZulu-Natal.

Rath's advertising campaign

In mid-2004, no one in TAC had heard of Rath and we would not know about the meetings with Mbewu for two years. The first time I came across Rath was when he repeatedly ran an advert in the *Mail & Guardian* newspaper, headed 'Break the Chains of Pharmaceutical Colonialism', which featured a cut-out petition with space for several signatures. The petition declared, 'Natural Health is My Right!' It called for laws to protect the 'fundamental right to free access to natural therapies and traditional medicine'. It also called for the MCC to be disbanded because it was 'an agency whose members are directly or indirectly dependent on the international pharmaceutical industry' and its decisions 'have consistently served these foreign interests at the cost of the health and lives of the people of South Africa'. It ranted against the pharmaceutical industry:

The pharmaceutical business is an investment industry and not a health industry. It is conducting the largest fraud in the history of mankind by deceptively promising health; yet its entire existence is dependent on the continuation and expansion of diseases. The colossal profits of this racket derive from the sale of expensive patented drugs and its trillion-dollar market is reliant on the continuation of human disease.

It accused the industry of genocide and ruining the economies of over 200 countries. It alleged that the 'biggest challenges to the survival' of pharmaceutical companies were natural therapies, which were not patentable and therefore less profitable. In contrast to drugs, these were effective.

The MCC, upset by the attack on its integrity, sent Rath a lawyer's letter demanding a written apology and retraction. Yet the very next day the same lawyers withdrew their demands. I have been informed that the Minister of Health insisted on this withdrawal. Rath's response was to put both letters on his website and gloat.

I discussed the advert with Zackie Achmat and Jack Lewis. We thought it was quite funny and so over-the-top that it was not worth any attention. Rath, whose photo was on the advert, seemed like an inconsequential loony with too much money to spend. We thought that the newspaper's sophisticated readership was unlikely to be influenced by this nonsense.

That all changed in November. First, quite out of the blue, the Traditional Healers' Organisation (THO) with the support of Rath's Foundation announced at a press conference that it was going to demonstrate outside TAC's offices in Johannesburg and Cape Town. This was a new experience for us. We had held dozens of demonstrations against drug companies and the government, several of them with the support of thousands of people. This was the first time we got a taste of our own medicine, so to speak.

For the protest the THO distributed a pamphlet which made some startling allegations (spelling and grammar are unchanged). 'It is mainly women and children who are affected by HIV/Aids and that are being abused by the lack of information on African Traditional Medicines and other treatment options, not to mention being given drugs like AZT and Nevirapin that have devastating side effects.' It went on:

The reason for the picket is that we believe the general public should be fully informed about the deadly side effects of ARV treatments which the TAC, pharmaceutical companies and the media tend to ignore or down play the major side effects and the stringent compliance issues. We are also picketing to let them know that they should promote information on all forms of treatments, not just ARVs. They must stop misinforming the public about the safety and efficacy issues in relation to African Traditional Medicines (ATMs), Complementary Medicines (CMs), supplements and good nutrition. [And so on, in this vein.]

The pamphlet also defended the government, claiming that TAC had intimidated it into providing ARV treatment even though the state had justified concerns about side-effects and long-term health. And this is how the pamphlet described Rath:

Dr Matthias Rath is the world renowned researcher for natural health therapies who led the scientific breakthrough against cardiovascular disease, cancer and viral diseases by natural means. He is the founder of the Dr Rath Health Foundation that is leading the worldwide struggle against the interests of the pharmaceutical investment business with disease and for free access to life saving natural therapies. With his campaign 'Break the Chains of Pharmaceutical Colonialism', the Dr Rath Health Foundation supports the fight of the South African people and the government to make effective and affordable natural health a reality for all.

The pamphlet contained Rath's first attempt to link TAC to the pharmaceutical industry, an allegation he would make repeatedly. TAC, it contended, had been 'financially groomed' by the Rockefeller Foundation. The Rockefeller organisation 'holds shares in over 200 pharmaceutical corporations'. It alleged that TAC also received substantial funding from Atlantic Philanthropies, a member of whose board of directors is the financial adviser of the Rockefeller family. TAC therefore acts in the service of the pharmaceutical industry to promote ARVs. 'Sadly, most low-ranking members and supporters of the TAC are completely unaware that the organisation has been directed to advance the financial interests of the pharmaceutical business with disease.' The conspiratorial logic is extraordinary.

On the day appointed for their protest, 23 November, about 30 traditional healers, dressed in magnificent red uniforms, protested outside our national office in Muizenberg, Cape Town. Two people stood out like sore thumbs: a white woman calling herself Madonna, who by her actions and loud demeanour seemed to be the leader or else positioned herself as such, and Anthony Brink. Madonna had previously attended one of TAC's

biennial national congresses and quite unexpectedly, in a session unrelated to traditional medicines, stood up from the floor and launched a tirade at TAC's leadership for ignoring traditional medicines.

Brink has made the claim to be South Africa's leading Aids dissident. He has also maintained that it was he who alerted Mbeki to the toxicity of AZT. Both claims are plausible. The first is supported by the fact that in the late 1990s and early 2000s, Brink was often in the media promoting Aids denialist views. The second is supported by Allister Sparks, one of South Africa's leading journalists, in his book *Beyond the Miracle*. In an interview Mbeki apparently said that a published debate Brink had sent him 'was the first time I became aware of this alternative viewpoint'.⁹

Brink also wrote a book called *Debating AZT*, which was sold in the country's largest book chain, and was endorsed by a number of public figures. Martin Welz, the editor of a muckraking magazine *Noseweek*, wrote the foreword. Brink also published a written debate between him and the president of the Southern African HIV Clinicians Society, Des Martin.

Brink is an advocate, an incompetent one as will become clear shortly, and a former magistrate. As far as I can ascertain he has no formal university scientific qualification. Indeed, he describes himself as an autodidact. I cannot find any peer-reviewed papers published by him in the medical literature. This is fine. It is excellent when non-scientists learn science to the point where they can explain it to others. What is not fine is when they become so arrogant that they proclaim or imply that almost all the scientists in a particular field have been duped or are part of a conspiracy.

I once debated with Brink on the radio the cause of Aids. Radio debates are seldom won or lost, as there is usually not enough time to explain things properly, but this was an exception. It was like taking candy from a baby. You can form your own view by reading the transcript (the URL is in the footnotes).¹⁰

In his writing Brink tries to hide his scientific incompetence behind the most extraordinary vindictiveness. He has written grotesque personal attacks on Zackie Achmat, Mark Heywood and Edwin Cameron. As an example of this, in a draft of a book he distributed, he referred to Achmat

as a felcher of slave stock. (If you do not know what a felcher is, it is not a word used in polite discussion. Wikipedia has an adequate explanation.)

During the THO demonstration, Brink stood aside from the other demonstrators, appearing very aloof, perhaps even uncomfortable, despite the fact that he has had a significant influence on the Aids debate in South Africa. I watched him as he angrily read one of our pamphlets to someone over his cellphone. He seemed particularly incensed by the part which exposed Rath's shady history.

At some stage of the protest TAC's general secretary at the time, Siphon Mthathi, decided to talk to the demonstrators. As the person who developed TAC's treatment education programme, she combines an excellent understanding of the science of HIV with an ability to explain it to ordinary people. She also understood the racial and cultural dynamics of what was going on in townships around HIV better than other TAC leaders. Except for hysterical ranting from Madonna, Mthathi managed to have a civilised discussion with the demonstrators. It became clear most of them had been misinformed about why they were there and had no understanding of what TAC actually stood for. They had been led to believe that TAC was trying to destroy traditional medicine.

In Johannesburg, the THO march was somewhat more successful. About 500 healers turned up. The atmosphere was much more tense with some ugly spats between TAC members and the healers. I know from my experience in organising TAC marches that a demonstration of this size requires a fair amount of organisation and money. Mthathi received word from her mother, also a traditional healer, that a large meeting had been organised in Gauteng to mobilise traditional healers against TAC. There had been much confusion and many healers walked out of the meeting in protest, including Mthathi's mother. Why, we wondered, had the traditional healers teamed up with Rath? Was the government behind it? The cartoonist Jonathan Shapiro suggested as much by drawing a cartoon of Tshabalala-Msimang hiding behind a wall and releasing the THO, represented by an attack dog, on TAC.

My source, the former Rath employee, has given me a memorandum

of understanding signed between the THO and the Dr Rath Health Foundation. It commits them to a strategic alliance against the pharmaceutical industry. It also commits them to supporting the South African government to 'realize the vision of a new primary health care system based on side-effect free traditional medicine and natural therapies'. It was signed in December 2004 by Rath and one of the leaders of the THO, Nhlavana Maseko.

There is a mistaken perception that the TAC fired the first shot in its battle with Matthias Rath. But it was the THO together with Rath that made the first move. Our first mention of Rath in public was in response to the THO/Rath pamphlet. We also had no intention of engaging with Rath and the THO beyond the events surrounding the demonstration. But we changed our minds on 26 November 2004 when Rath ran a full-page advertisement in the *Mail & Guardian* titled 'Why should South Africans continue to be poisoned by AZT?' It contained a photo of an experimental bottle of AZT with a skull and crossbones logo and a big, bright, red toxic warning on it. This was a liquid form of AZT not distributed to patients. It is used by a research company called Sigma-Aldrich. I had seen Brink talk about this bottle at a meeting in Cape Town. It was his prime propaganda tool against ARVs. The bulk of the advert was dedicated to claiming that there was a 'natural answer to Aids': multivitamin tablets.

This advert marked a turning point in the Rath campaign in South Africa, from unsophisticated anti-pharmaceutical industry rhetoric to an all-out, expensive attack on ARVs and the promotion of an alternative treatment. A few of my TAC colleagues and I began organising a multi-pronged response. We galvanised the support of doctors, including the South African Medical Association and the Southern African HIV Clinicians Society. We asked the *Mail & Guardian* to stop running Rath's adverts; to their credit they did not require any persuading. I also worked with Vuyani Jacobs on a complaint to the Advertising Standards Authority of South Africa (Asasa).¹¹

For an advert promoting a treatment for Aids to be accepted by Asasa it has to be accurate. A second requirement is that the product must also be

registered with the MCC or the advert must be educational and placed by an institution recognised by Asasa as competent to run such a campaign. The TAC complaint took issue only with the advert's accuracy. Neither Jacobs nor I was aware of the second requirement, which was buried in an appendix of Asasa's code. If we had been, perhaps the matter would have been resolved even quicker. But then neither of us is a lawyer.

Brink, on the other hand, is an advocate. He responded by lodging three thick lever-arch files with Asasa to try to prove that HIV does not cause Aids. He failed to address many of the specific inaccuracies Jacobs pointed out. All Asasa would have needed from Brink was one independent expert to support the advert's contentions. Asasa would have accepted anyone with a science degree and some publications on Aids as an expert. Asasa does not itself have the expertise to evaluate scientific claims. This is a flaw in the Asasa code. In today's world of six billion people and millions of PhDs, finding an 'expert' to support even the wackiest contentions is not difficult. Either out of the arrogant belief that he qualified as an expert or from failure to read the code, Brink did not present an expert. Asasa pointed this out, ruled in our favour and the adverts with the specific claims about which we complained had to stop.

Brink therefore got Professor Sam Mhlongo, who was an Aids denialist at Medunsa University, to write a defence of the advert to Asasa. Mhlongo would have met Asasa's definition of an expert except for one thing: his name appeared on one of the adverts as a member of Rath's Foundation. Asasa pointed out that Mhlongo might be an expert but was not independent and therefore Brink's defence was rejected.

Rath did not stop after the first Asasa ruling. He ran adverts in the *Sowetan* and *City Vision*, newspapers with large, black, working-class readerships, attacking Asasa and TAC. He accused Asasa of being an apartheid institution, a biting insult in South Africa, as well as under the influence of the Pharmaceutical Manufacturers' Association (PMA), a member of Asasa. This was a devious allegation. Asasa is a self-regulating authority. Its rulings only have legal force on radio and television. All the country's major newspapers and magazines are Asasa members and voluntarily adhere to its

rulings. So are many other industries, as you would expect if self-regulation is to be effective. So surely it is a good thing that the PMA was an Asasa member. This renders the drug industry subject to Asasa's rulings.

Rath's adverts called us the running dogs of the pharmaceutical industry. He manufactured a web of innuendoes and lies that attempted to link us to drug companies. We threatened legal action against the *Sometan*. Advocate Danny Berger, an expert on defamation law with much experience defending the *Mail & Guardian*, one of the country's most sued newspapers, acted for us. We quickly reached a favourable settlement. *Sometan* apologised and allowed us to run a free advert explaining ARV treatment. We lodged a second complaint with Asasa asking for the maximum sanctions their code allowed. While Asasa could not do very much against Rath, it could stop newspapers from running his adverts again. Once more Asasa granted all our demands. Eventually Rath's newspaper adverts in South Africa dried up because the media started enforcing the Asasa rulings.

Asasa dealt with us professionally and addressed our complaints swiftly. Over the past decade, TAC has tried to use nearly every significant instrument of South Africa's democratic institutions to get justice on various issues: the courts, Nedlac, the Competition Commission, the Human Rights Commission, the Commission on Gender Equality, the Parliamentary Portfolio Committee on Health and the African Union Peer Review Mechanism. The courts have been reasonably good and the rest have ranged from mediocre to bad. Asasa, for its part, was superb.

Despite the Asasa ruling, Rath has continued to place newspaper adverts outside South Africa, including in a Namibian daily newspaper, the *New York Times* and the *International Herald Tribune*. I have seen an invoice for one of his *New York Times* adverts. It was just under \$100,000 – and that was for a relatively modest one. He has run full-colour, whole-page adverts in the *Times*. These I was informed cost in the region of \$160,000. Rath began distributing pamphlets and magazines in Cape Town's townships and later in the Eastern Cape and KwaZulu-Natal too, which made the usual claims. Rath also did several radio interviews, some with extremely gullible presenters. These were only the beginning.

Rath's deadly experiment

Things got much worse. In early 2005 Rath set up clinics in Khayelitsha and other Cape Town townships where his agents began distributing multivitamins as a treatment for Aids. I first found out about this from Mandla Majola, who has for years been running TAC's operations in Khayelitsha. This is probably TAC's most active area in the country. It is where we helped MSF, the City of Cape Town Municipality and the Western Cape provincial government implement the country's first community-based, public-sector PMTCT and Haart programmes. Here people had seen the benefits of ARVs first-hand and now Rath had moved in to try to undo this work.

In March, Majola asked a few TAC members to go to the Rath facilities posing as patients. What they encountered was disturbing. Rath's staff discouraged them from taking ARVs and told them that Rath's multivitamins would strengthen their immune system and make them better. They were also asked to strip down to their underwear so that photos could be taken to show people how patients did before and after they went on to Rath's pills. Rath's employees dispensed pills to them. All of them were instructed to take doses that far exceed the recommended daily allowances for various vitamins. One of the products contained a substance called N-acetylcysteine. This is scheduled, which means it may be sold only by a pharmacist under particular conditions.

Some of the TAC people were told to take 30 of Rath's tablets a day. Some were promised several hundred rands if they returned. They were prescribed one or more of four different products. One of them was Rath's flagship product, Vitacor Plus, which he sells on the Internet for just under \$30 a month. Another, Vitacell, appeared to be developed just for his South African operations.¹² One is not allowed to sell or even give away free an unregistered medicine as a treatment for a viral infection, but that is a law that virtually all Aids quacks breach. But Rath's treatment was much more serious: it had the look and feel of a medical experiment. Our suspicions were confirmed when Rath ran an advert in the *Mercury*, a KwaZulu-Natal daily, in April 2005, his last successfully placed advert in the South African

media as far as I can tell. It was also his worst.

The advert alleged that there was now proof that micronutrients reversed the course of Aids. It showed before and after photos of lesions that had cleared up. Patients testified that their health had improved. Rath wrote:

We conducted a clinical pilot study in HIV-positive patients with advanced Aids. The goal of the study was to show that vitamins and other micronutrients alone reverse the course of Aids, even in its advanced stage ... Thus, it was essential that none of the patients had received any ARV drugs before or during this nutritional programme. The nutrient programme consisted of vitamins, minerals, amino acids and certain other essential nutrients. Blood tests and clinical evaluations were performed at the start and after four weeks on the nutrient programme. The results of this pilot study were so profound after only one month that we decided to publish the data of the first 15 patients without delay. After the completion of the study a comprehensive report will follow.

It is unethical in medical research to publish results as an advert instead of in a peer-reviewed medical journal. A trial that uses just 15 patients to see if a medicine is effective would not pass a peer review. Another problem is that there was no control group, so whatever results Rath put forward were meaningless. Most grievously, it is a grotesque violation of human rights to conduct clinical research on people using untested medicines without receiving the approval of a recognised ethics committee. It is also illegal to do so without the authorisation of the MCC. Any medical researcher should know this.

The advert listed the names of the researchers. These included David Rasnick, a colleague of Peter Duesberg's, who had served on Mbeki's Aids advisory panel in 2000. He has frequently published articles and letters in newspapers supporting the state's non-provision of ARVs and disputing that condoms are needed to prevent HIV infection. Another listed researcher was Professor Mhlongo, who was close to Mbeki.

There were many deaths on Rath's trial. We have already heard about Marietta Ndziba. While investigating Rath, Majola introduced to me to two people who had lost relatives on the Rath trial. Nandipha Sigebenga struck me as a proud woman. She calmly told me how her sister had been recruited to the Rath trial. She was treated for TB in 2004 and needed to go on to Haart. Sigebenga explained that although her sister was sick when she started taking Rath's medicines, her health deteriorated rapidly after that. At one point it seems Rath's people put her on an intravenous drip. 'She did not get better. On the contrary, her body got swollen and she had hallucinations,' Sigebenga testified. Rath's people had given her their contact details in case her sister became very ill. They told her not to call an ambulance if that happened. They also told her it would take two months for her sister to get better. But she did not get better; in fact she was vomiting up the tablets Rath's people gave her. She died on 27 March 2005. Behind Sigebenga's calm façade she appeared deeply hurt and angry.

Zondani Magwebu was a worker on a construction site when Majola introduced me to him. He spoke very poor English and I spoke even worse Xhosa so we had to communicate through an interpreter. Against his advice, his wife had been persuaded to use Rath's pills. She flitted to and fro from Rath to a proper hospital, eventually dying in June 2005 about a month after starting Rath's programme. *The Guardian* recently interviewed him, three years after his wife's death, for a video the paper made on Rath. Surrounded by his three children in dire circumstances, he is a broken man in poor health. 'I have no hope,' he says.

Health-e interviewed several other people who lost family members to Rath. They also found out that two Rath patients, who contended at Rath's press conference that they were taking his vitamins, were actually on ARVs. TAC released an analysis of five deaths on Rath's trials in November 2005. We wrote, 'In two of these cases, Rath is at least responsible for having created false hope. In the other three, Rath is partly responsible for their deaths.' The results of Rath's trial that he has published in newspaper adverts and on his website do not refer to any of these deaths. According to

Rath his programme treated ‘about 748’ patients in the Western Cape and KwaZulu-Natal.¹³

In his work in Khayelitsha Rath teamed up with the local branch of the South African National Civic Organisation (Sanco). During apartheid, civic organisations sprang up in townships across the country to organise against the system. When the ANC was unbanned, they met to try to form a unified organisation under one constitution. So Sanco was born in 1992. It is a vehement ally of the ANC. One of my colleagues describes Sanco as the ANC’s enforcers in the townships. It has a reputation, at least among TAC members that I have spoken to, of being corrupt.

Sanco’s Khayelitsha branch soon came into Rath’s orbit. Its name appeared as co-sponsor of Rath’s adverts and its members distributed his pamphlets and newsletters. Most crucially, they staffed his clinics and recruited patients. Sanco has no medical expertise, yet the organisation’s members involved themselves in Rath’s clinical trial and distributed scheduled medicines.

Nearly all of Sanco’s members are poorly educated, working-class people. Many of them are unemployed and desperate for income. This organisation was ripe for Rath to use in his campaign against ARVs. Sanco’s proximity to the ANC and its heavy-handed involvement with Rath leave me deeply suspicious that it was not coincidental that Rath formed an alliance with the group. My suspicion is deepened by the fact that Rath and Sanco produced newsletters that claimed they had the support of the Health Minister. Did she have anything to do with their alliance?

The involvement of Sanco went beyond their Khayelitsha branch. At one point, at Mark Heywood’s request, I contacted Sanco’s president, Mlungisi Hlongwane. I informed him of what the Khayelitsha branch was doing. Although I thought he was receptive to what I had to say and ready to take action, I was wrong. I did not hear from him again, despite further attempts to contact him.

Sanco produced a book with Rath called *Break the Chains of Pharmaceutical Colonialism*. The book compared the TAC to Nazis and also attacks Cosatu, which, despite being an ANC ally, sided with the TAC

throughout the Rath affair. Hlongwane wrote two pages in the book. He said, ‘I am confident that the decision we took ... to support the work of Dr Rath was a correct one. We recognised that as a community organisation we were not medical experts. But we equally recognised that the economic superstructures are not in favour of the poor, especially those in Africa. Therefore, although we remain ambivalent on the efficacy of ARVs, we are in full agreement with the facts that Dr Rath presents.’ He went on to attack the TAC as well as the media for supporting the TAC.¹⁴ Interestingly, Hlongwane’s successor as president of Sanco was Ruth Bhengu.

How the state aided Rath

I have described Rath’s liaison with Anthony Mbewu and the MRC. There is a lot of other evidence that Rath and the state colluded. In normal circumstances Rath would not have been able to get away with his activities. He broke enough serious laws that had there been the will, the state could have stopped him. Instead it helped him.

Zackie Achmat phoned Peter Eagles, the chair of the MCC, in early 2005 to ask him to take action against Rath. I do not know whether Eagles followed up Achmat’s call, but the MCC made no real effort to stop Rath.

The Department of Health has a law enforcement unit (LEU) whose purpose is to investigate breaches of the Medicines Act and prosecute the offenders. Both Rath’s distribution of medicines and the clinical trial were illegal under this Act. I wrote a complaint about Rath to the LEU in early 2005. It included the affidavits of the TAC people who attended Rath’s facilities and much else. The LEU sent two investigators to the Cape Town office of the Aids Law Project (ALP) to interview me and Fatima Hassan. My impression was that they were serious and intent on stopping Rath. Immediately after our interview, they contacted Rath’s offices, but that is where the investigation stopped. One of the investigators phoned me. He was livid as he described how his boss had taken him and his partner off the case.

In April 2005, the Department of Health held what is known as an *imbizo* in Khayelitsha. This is a public meeting where community members

can ask the government's representatives questions. Rath's activities were escalating in Cape Town's townships, so Majola organised for hundreds of TAC members to attend. I also went along. On the stage were Tshabalala-Msimang, Pierre Uys, the provincial MEC for health, and some civil servants. TAC members dominated the middle and back rows of the hall. In the first few rows were traditional healers. Among them sat Matthias Rath and one of his henchmen. We were not surprised. We had heard a rumour that the minister had met Rath earlier that day and we expected him at the meeting.

After the MEC and minister spoke, the floor was opened to questions. Dozens of TAC members stood up and asked Tshabalala-Msimang to condemn Rath's activities. She refused. She explained that we have a Constitution which defends freedom of expression and that people could choose between TAC and Rath. The meeting was heated. I had a shouting match with some of Rath's employees, who seemed to be German or Dutch. I called them thugs, among other insults. I left shortly before the meeting ended, but Majola told me that TAC members became extremely angry and screamed at Rath. He left in a hurry.

In a written response to a question from the Democratic Alliance in Parliament, the minister admitted to meeting Rath on the day of the *imbizo*. They had 'discussed his concern for people infected with HIV and suffering from the impact of Aids'. She said she would 'only distance myself from Dr Rath if it can be demonstrated that the vitamin supplements that he is prescribing are poisonous for people infected with HIV'.

Later, a source in the government informed Achmat that in September 2005 Rasnick and Mhlongo presented their views and the so-called findings of their clinical study to the provincial ministers and the national Minister of Health at a forum called the National Health Council. Under Tshabalala-Msimang, it had never invited genuine HIV scientists to make such a presentation on the state of the epidemic, the effectiveness of ARVs or similar topics. We released this information to the media and made use of it in our major court case against Rath and the Minister of Health.

Much later, in June 2006, a man contacted me who wanted to remain

anonymous. He had inside knowledge that shipments of Rath's Vitacell had been confiscated by Port Health Services whose job it is to control the importation of food. Port Health had stopped the Rath shipment from getting through because it contained the scheduled substance N-acetylcysteine. The source informed me that the director-general of health, Thami Mseleku, had instructed Port Health to release the shipment. Our lawyers advised us that this was unlawful as Mseleku had no authority to do this.

I contacted Pearlie Joubert, a *Mail & Guardian* journalist. For a few days we worked together trying to obtain more information. Joubert has a disarming guileless voice. It is very deceptive. Watching her at work is a bit like watching Obi-Wan Kenobi order storm troopers around in *Star Wars*. She would phone Department of Health officials, who would simply tell her everything they knew. Peter Eagles, for example, said to her, 'I know the director-general gave permission for these tablets [to be] release[d] by Port Health ... Just phone his office and ask him; he will tell you.' The Department of Health's spokesperson Sibani Mngadi also confirmed that Rath's shipment had been released, though he resisted Joubert's charm sufficiently not to tell who gave the order.

Another official who insisted on anonymity said, 'This is the second time it's happened. The consignment gets withheld because we have problems with the content of the tablets because it doesn't comply with the Medicines Act and then we're told to ignore our concerns and ignore the law we're supposed to enforce. What if something happens to somebody who takes these pills?'¹⁵

Mseleku gave his perspective in an interview with Health-e. 'From our point of view Dr Rath is actually providing vitamins, which are immune boosters just like many vitamins that are there.' He continued, 'If Dr Rath came into South Africa and had this particular product there would have to be a determination as to whether this product is supposed to be a complementary product, or is supposed to be a medicinal product, which then would actually have to be registered in terms of the Medicines Regulatory Act, whereas a complementary product does not have to go

through all those processes.’ It is astounding that a director-general can make such a nonsensical claim about an aspect of South African law for which he is responsible: complementary medicines have to go through the same registration process as any other medicine. The Medicines Act, correctly, does not give any special privileges to complementary medicines.

Mseleku then continued, ‘There have been allegations that Dr Rath was actually using medicine that was not registered in South Africa. And the law enforcement agency says, in accordance with what was pronounced by the Department of Health before about the complementarity of Dr Rath’s vitamins, there hasn’t been anything that was done wrong with regard to that.’¹⁶ He and the LEU would eventually be proved wrong on this point.

Not only did the national government fail to take proper steps against Rath but the Western Cape provincial government, which had helped pioneer a rational response to Aids, also did nothing substantial to stop him. In March 2005 a TAC delegation met with MEC Pierre Uys to ask him to take action. I also called Fareed Abdullah, who was in charge of the province’s HIV programmes. He told me that the provincial Health Department would issue a statement condemning Rath. After much nagging from me, the department eventually released an insipid statement that alluded to Rath’s activities but did not mention him by name. I must emphasise that this was not Abdullah’s fault. He wanted to stop Rath’s activities, but Uys was probably reluctant to have a spat with the national Minister of Health.

A group of doctors also wrote to Uys asking him to act against Rath. Nevertheless, other than sending a file of information on Rath to the national Department of Health, the provincial government did nothing. In September 2005, in answer to a question in the provincial legislature, Uys denied knowledge of Rath’s experiment in Khayelitsha. In a court affidavit I wrote, ‘In my view that ... is not plausible.’ Abdullah eventually resigned his post, partly because of his dissatisfaction with Uys. TAC’s good relationship with the Western Cape government deteriorated as a result of the Rath affair until Uys moved to a new position in 2008.

All these stories very much paint a picture of collusion between Rath

and the state. Instead of investigating and prosecuting him, or at least condemning him unequivocally, officials and politicians met him, struck deals with him, allowed his representatives to present to the country’s health ministers, let his products into the country and made statements supporting him. Nothing was done to stop his illegal clinical trial, his misinformation on Aids or his medicine distribution.

The state’s response was not entirely uniform. According to Health-e, the ANC national health secretary, Saadiq Kariem, condemned Rath, but did so in his personal capacity. Lynne Moeng, who was a director of the national Health Department’s nutrition section, gave an interview to Health-e in which she pointed out the problems with the labelling of Rath’s products. Rath also met with ANC MP Ben Turok and tried to solicit him to support his campaign. Turok thought this was a man looking for business opportunities and wrote a strongly worded letter criticising Rath in *Business Day*.

Rath’s pamphlets were also placed in the pigeon holes of Parliament, promoting multivitamins and attacking the TAC. Kader Asmal, the former Minister of Education, was incensed. He wrote a letter to Rath comparing him to Nazi propaganda minister Goebbels and telling him his ‘kind of quackery deserves the old Afrikaans response: voertsek’. He also defended TAC, saying that Rath’s ‘tendentious and scurrilous attack on an organisation acting in good faith to provide assistance to those on the margins of our country is without parallel in my experience’.

Rath sued Asmal for defamation. He seemed particularly upset by the Goebbels comparison, even though he has compared TAC to Nazis. He also sued several other journalists and the Democratic Alliance for calling him a charlatan. He has since dropped most of these cases, thanks partly to the excellent work of Fatima Hassan then at the ALP. Not one of these cases has gone to court or looks like going to court.

But these criticisms were isolated, made by people with virtually no power to stop Rath. Despite Asmal’s once high standing in government, the ANC did not publicly defend him. The Parliamentary Portfolio Committee on Health, chaired at the time by James Ngculu, has responsibility for

oversight of the Health Minister and her department, yet it did nothing to hold her to account, even though Ngculu was aware of what was going on.

Oddly, despite the fact that I have called Rath a charlatan more vociferously and frequently than anyone else, in radio interviews, press statements and newspaper articles, he has never sued me or TAC.

7

TAC litigates against Rath

‘There is no reason why good cannot triumph as often as evil.
The triumph of anything is a matter of organization.’

– Kurt Vonnegut¹

A few of us sat round a table in Advocate Geoff Budlender’s chambers discussing how to deal with Matthias Rath. We were angered by his human experiments, his deadly disinformation campaign against ARVs, his breaches of the Asasa rulings and accusations that TAC was a drug company front. But here was also an opportunity. There was mounting evidence that Rath was working in cahoots with the Minister of Health. We wanted to expose how the minister was undermining the state’s Haart and PMTCT rollout, something that went far beyond Rath. The meeting included Zackie Achmat and William Kerfoot, our attorney at the Legal Resources Centre. For what seemed like hours we discussed the various litigation routes we could take. It was the umpteenth meeting to discuss how to deal with Rath. I had been confident that the Asasa rulings would put an end to his activities. Instead he had scaled them up. Now we had to find a strategy that would resolve this matter once and for all.

We decided on two court cases. In the first we would ask the Cape High Court to stop Rath from defaming us. We would seek a temporary interdict against him, pending the outcome of a defamation suit. Then we would bring a second case to the same court asking it to find his clinical trial and distribution of unregistered medicines unlawful. In the second case

we would also ask for him to be interdicted from continuing these activities and to stop false advertising. Crucially we would also sue the government in the second case, asking the court to find that it had a duty to stop Rath's activities. I call these the defamation and quackery cases respectively.

We proceeded with the defamation case first because the facts were simpler to deal with and we could pursue it on what is called a semi-urgent basis, meaning that it could be wrapped up quickly – or so we thought.

Pharmaceutical industry funding is pervasive in the Aids world. Many non-profit organisations are indeed funded by the industry. But the TAC has consistently refused to take pharmaceutical money. Our funders wrote affidavits confirming how careful we were about not getting money from drug companies. We explained that once we had merely suspected that a funder was a drug company front we told them not to send us any further money. We also put evidence before the court of our protests and litigation against the pharmaceutical industry.

A few of our branch members testified to the virulence of Rath's campaign against us. Rath's people had put large red posters up across Cape Town's townships headed 'Do you want to march with the TAC?' Thousands of identical pamphlets were also distributed. These alleged that TAC received millions of rands from front organisations for the pharmaceutical industry and, much worse, 'The ARV Pressure Groups demand that the South African government buy Aids drugs that do not cure but actually make people even more sick. They force the government to spread disease and death among the people of our country and at the same time ruin our economy.' A graphic of people dying, apparently of Aids, was linked with arrows to a large caption identifying 'ARV Drug Pushers in South Africa'.

Rath published many variations of this. In an advert he wrote, 'The most notorious of these [Trojan horses of the drug cartel] is the TAC which specifically targets poor communities as markets for the drug industry. The TAC's credibility has been shattered by simply exposing its pharmaceutical funders. Unable to challenge this fact in any court, and in an attempt to silence the truth, the TAC has turned to another Trojan horse of the drug

cartel for help: the Advertising Standards Authority ...'

Another pamphlet was titled somewhat prematurely, 'The last days of TAC'. It maintained that we organised rented crowds for the drug industry and had been mortally wounded by the unmasking of our funding sources. It accused us of money laundering, too. The slurs were not confined to TAC. Our funders, including the Rockefeller Foundation, Bread for the World and Atlantic Philanthropies, were also accused of being pharmaceutical fronts.

TAC is a relatively small organisation when compared with the major political parties in South Africa. At our peak we have had in the region of 17,000 members. Yet we have successfully changed government policy. Our power to achieve this emanates in part from our reputation as an independent organisation that promotes accurate scientific responses to the HIV epidemic in a reasonable way. Rath must have understood this and set about to destroy our reputation. This is why we felt we had to take court action to defend ourselves. Moreover, the allegation of our being in the pocket of 'big pharma' had been made numerous times by our detractors. In 2003, the ANC Youth League spokesperson Khulekani Ntshangase wrote, '[TAC] is just a harmless but very loud pressure group whose salaries are paid by Americans. This is a conglomeration of drug-dealers who serve as marketing agents of toxic drugs which are not even used where they come from, America.'²

The Rath slanders were more than a nuisance. They were published with the endorsement of the Khayelitsha branch of Sanco and the Traditional Healers' Organisation (THO) and aimed right at TAC's heart in Khayelitsha. Combined with the lies spread by the ruling party, we felt we had to set the record straight. We decided to sue only Rath and his Foundation. Suing a Sanco branch and the THO would have been difficult. We were not sure if they were properly registered organisations or what their physical addresses were. What is more, we still wanted to talk both groups out of their support for Rath (something we did not succeed in doing). We also did not think the benefits of taking the THO to court outweighed the risk of alienating traditional healers.

Preparing court papers is intensely hard work. As with many of our cases, TAC members were intimately involved in writing affidavits. This is unusual. Most organisations leave legal papers to their lawyers. This is a mistake in my view. Although lawyers are critical to the process, they are seldom armed with the detailed knowledge needed to construct powerful, unanswerable affidavits. To do this, the clients must get involved. So Doron Isaacs, a law student and TAC volunteer at the time, and I sat up late one night with Zackie Achmat to fine-tune his founding affidavit (this is the main affidavit in a case of this nature, from which all the other affidavits are referenced). We wrapped it up at about 1 am in the morning and drove to Muizenberg police station, a short distance from Achmat's house. It took another half-hour for the several-hundred-page affidavit with all its attachments to be commissioned and signed on every page. After this, Isaacs and I left Achmat at home, feeling that we had accomplished an excellent day's work. About three hours later, Achmat had a heart attack. It became headline news. Aids denialists began asking what role his ARVs had in it.

HIV increases the risk of heart disease. The interaction between ARVs and HIV in heart disease is complex. In general, ARVs reduce the risk, though some ARVs might increase it. It is impossible to know if Achmat's heart attack was induced by either HIV or ARVs. In any case he soon recovered and today he is in excellent health, five years after commencing treatment, which was preceded by a long period of continuously being ill. Nevertheless, Anthony Brink drew up an affidavit that purported to diagnose the cause of Achmat's heart attack (ARVs of course), made findings about his psychological condition and diagnosed his condition as neurological. This was ridiculous. Brink was neither Achmat's doctor nor a doctor at all, had never examined Achmat and barely knew him. Affidavits are supposed to be testimonies to facts known from direct experience or proper evidence. Even non-lawyers learn this when they have to write one, yet Brink is an advocate and seemed not to know it.

Achmat's affidavit in response to Brink therefore included this biting remark, 'A professionally qualified person who (like Mr Brink) expressed such opinions under oath without ever examining the "subject" would

be liable to the discipline of his or her profession. Mr Brink and the respondents appear to take the view that he is able to do so even though he is not professionally qualified in any of the professions concerned.' Geoff Budlender made a similar point when he presented our arguments in the courtroom.³

It was a court case with drama and media attention. At the last minute the THO made a bizarre application to be a respondent along with Rath. We had not cited them, so any finding in the case would not have been binding on them, yet they chose not only to sit alongside Rath, but to accept whatever ruling was imposed upon him in a case which legal experts believed was likely to end in a TAC victory. With better legal counsel they should rather have stayed out of it altogether or applied to be a friend of the court, which means that they could have submitted evidence and argument without being subject to the court's ruling.

The THO advocate, Dumisa Ntsebeza, had been an anti-apartheid activist and commissioner on the TRC. He also collaborated on a book on apartheid crimes with the journalist Terry Bell, who would later write an affidavit supporting our quackery case against Rath. It was disappointing to see someone I'd admired take the side of Rath. Moreover, Ntsebeza's performance in court made me cringe. When he argued, he was bombastic and thumped the table ostentatiously. His arguments were awkward and often downright nonsensical. He would go on to defend Rath in the quackery case as well. His court performances were always poor and he was on the losing side in both cases. Bell had been a good friend of his, but they fell out over Ntsebeza's defence of Rath.

I sat next to Rath on the first day of the case. On my other side sat Achmat. They proceeded to trade insults across me. Also in court were Brink and Rasnick. Achmat traded insults with them during the intervals. Outside court TAC members and Rath's supporters, who included members of Sanco, Napwa and the THO, stood across the road from each other. TAC's placards denounced Rath and the Minister of Health, while our opponents held placards supporting them. Both sides taunted each other. The tension boiled over when Phepsile Maseko, one of the leaders of

the THO, walked into the TAC crowd and said to TAC's Nonkosi Khumalo that we pay people to come to our marches. Khumalo, visibly angry, told the TAC demonstrators what Maseko had said and a scuffle almost broke out. Maseko walked away with a smug smile. I thought she had intentionally wanted to provoke a violent incident.

The outcome of the case was hardly in doubt. From the questions raised by the three judges, it was clear we would get most of what we sought. Yet it took eight months for them to deliver their decision. William Kerfoot contacted the court several times asking when the judgment would be out and continually got assurances that it was imminent. For judgment to take so long in a semi-urgent matter is tardy.

The senior judge in the case, Siraj Desai, wrote the unanimous verdict. He interdicted Rath and the THO from alleging that we were a front for the pharmaceutical industry, received funds from it, promoted ARVs for it in exchange for money or targeted poor people as a market for the drug industry to promote its interests. He also wrote: 'The suggestion that the TAC destabilises democracy is incapable of fair-minded support. The tactics employed by the TAC may be somewhat boisterous and, at least in one instance, abusive towards the Minister of Health. Their conduct, however, does not threaten the security of the state and few, if any, right-thinking South Africans would see it in that light.' The abusive incident was of course Achmat's shouting match with the Minister of Health when we disrupted her speech. Much was made of this in the Rath court papers, though its relevance was hard to understand.

Desai unequivocally cleared our name:

The respondents' allegations with regard to the pharmaceutical industry and the TAC are premised upon conjecture and inferences and, it seems, are underpinned by a conspiracy involving several players. It is an unlikely scenario and no evidence has been disclosed which supports the respondents' position on the TAC's funding. The TAC, on the other hand, has made full disclosure of its income and their source. Moreover, several local and international deponents have confirmed the TAC's policy and practices in

respect of its finances. The respondents' allegations are not supported on the available evidence and the contrary appears to be more likely.

Desai did not grant all the interdicts against Rath's accusations that we asked for. He explained that he was not convinced that all of them were defamatory, but he did not make any finding on whether they were true or not. Nevertheless, we had cleared our name and shown our critics in the ANC and the government that their allegation that we were in the pockets of the drug companies was nonsense. Incredibly, within hours Rath released a statement claiming victory. Here are three telling excerpts:

The Cape High Court found that the reason why the TAC has been fighting against the Dr Rath Health Foundation ... is because they want to spread disease and death amongst the people of Khayelitsha and South Africa as a whole.

In the ruling of March 3 2006, the judges have affirmed that: 'The TAC forces the government to spread disease and death among the people of South Africa ...'

Even the Court exposed the TAC for what it is. The High Court looked behind its 'Mother Teresa' cover and identified its true business as an organisation that among other things is spreading disease and death among the people.

There's nothing of the sort in the judgment. The statement was preposterous. Most media outlets only printed Rath's nonsense to show its absurdity.

The judgment was a victory for us. But with hindsight, it was the other case dealing with quackery that we should have invested more energy in. The defamation case did not get to the core of what was problematic with Rath. More importantly, the Health Minister was not a party to the case though her presence could certainly be felt because of the clear support expressed for her both inside and outside the court by Rath's lawyers and demonstrators respectively.

Furthermore, we were criticised by some people, generally sympathetic to TAC, for running a case that restricted free speech. In particular, Anton Harber, one of the founders of the *Weekly Mail* (now the *Mail & Guardian*), made the troubling point that the interdict was one of three occasions in three months on which the courts had censored material. Harber asked a critical question:

We all accept ... that in our constitutional democracy, prepublication censorship can be used only in extreme cases, the equivalent of ‘shouting “fire” in a crowded theatre’. In a South African context, this might arguably apply to language that provoked violence or race hate, for example.

Does it apply to someone who encourages others not to take medication that can keep them alive? Well, the thing is that it is not quite like that. Rath has not been prevented from discouraging ARV use, but has been prevented from saying certain defamatory things about the TAC. The order against him is an interim measure, pending a full defamation case against him by the TAC. It was one shot in a long and bitter war between the TAC (representing those who want to see our government denounce the Aids dissidents and move faster in providing ARV treatment) and Rath (representing the Aids dissidents).

He was right that the case did not stop Rath from discouraging ARV use – and this was a serious shortcoming of our decision to prioritise the defamation case over the quackery one. Also, it was indeed an interim measure pending the case for defamation and just ‘one shot in a long and bitter war’ between TAC and Aids denialists. The case to sue him has not yet happened and does not seem likely to happen. Neither side has much incentive to proceed to such a costly affair. We made our point and won an interdict. Furthermore, Rath continues to make the same defamatory statements, even though the temporary interdict remains in place. We could possibly lodge a complaint of contempt of court, but it would not be worth our time and money. Rath has since become a spent force because of the quackery case. What we really wanted was the authority of a court

judgment establishing that we were not a front for the pharmaceutical industry. We got this.

Where I disagree with Harber is that if we had done what he suggested, which was to sue Rath for defamation (as opposed to interdicting him first), it would have taken much longer, perhaps years, to clear our name. Rather than an argument in court between our advocates solely on the basis of written affidavits, there would have been cross-examination of witnesses, a much more expensive and time-consuming affair. It would have taken even longer to get to the more important quackery case. But with the temporary interdict granted, we could now proceed with it.

The quackery case

My founding affidavit in the quackery case described how Rath and his agents had distributed advertisements and pamphlets making the false claim that vitamins treated Aids. It explained how Rath had illegally distributed his vitamins as medicines to people with HIV in townships in the Western Cape and how he had conducted a clinical trial on them, by his own admission, without the approval of an ethics committee or the Medicines Control Council (MCC). Our court papers also cited Rath employees and colleagues, including David Rasnick, Sam Mhlongo and Anthony Brink.⁴

More critical, though, was our case against the state. It is surely the government’s duty, not a civil society organisation’s, to enforce the law. Yet the state, instead of doing this, appeared to be helping Rath to break the law. I described the many letters and telephone calls from the TAC to the MCC and Department of Health officials and how they had achieved almost nothing. On the contrary, I showed that the actions of Tshabalala-Msimang and Mseleku had helped Rath.

We had powerful supporting affidavits. François Venter explained the science of HIV. Rob Dorrington, an actuarial scientist, who has led the development of the most respected model for estimating population statistics about the epidemic, demonstrated how we know that there’s a large HIV epidemic in the country. Andy Gray, a pharmacologist at the University

of KwaZulu-Natal, who also sits on an MCC committee, explained how Rath's vitamins actually exceeded the kinds of dosages that would allow them to be distributed without first being registered, how they contained a scheduled substance and how the manner in which he was distributing them, irrespective of their dosages and content, made them medicines. In South African law, a product is a medicine by virtue of the claims made about it. If you sell tea and claim it treats cancer, then it is a medicine. If you own a kiosk and sell AZT, marketing it merely as a sweetie for children, then the AZT is not a medicine. (However, you would still be acting illegally because AZT is a scheduled substance.) This is an essential point to understand about medicines law in this country. Rath and his lawyers and the government and its lawyers never seemed to get it. They responded by arguing that Rath's products were food supplements, not medicines.

Leslie London, an expert in public health, explained in an affidavit that Rath had run a clinical trial and that it was illegal. He wrote:

In conducting biomedical research, researchers are obliged to protect their research subjects and to ensure that their research is conducted in a manner which meets ethical standards.

Provisions to protect research participants were first codified internationally after it was revealed that German doctors had conducted unethical research studies on vulnerable prisoners in the Nazi concentration camps during the Second World War. This led to the adoption of the Nuremberg Code, which sought to regulate the conduct of biomedical research to protect research participants. The Nuremberg Code has laid the basis for an extensive literature on the ethical conduct of research involving human subjects.

He went on to describe international agreements governing medical research on humans, particularly the Helsinki Declaration. He also explained the guidelines that had been established in South Africa for conducting trials. He showed that Rath had not followed these. He examined several affidavits by TAC members who went to Rath's health facilities and showed that they

had not given proper informed consent to Rath's agents. Importantly, London asserted that Rath's experiment had violated an ethical principle known as clinical equipoise. This means that if you are a patient taking part in a clinical trial for a new medicine, you must receive the current standard of care in addition to the experimental medicine. Rath's facilities only gave patients multivitamins; they failed to give patients with Aids ARVs, the current standard of care.

Two doctors, Peter Saranchuk and Kevin Rebe, testified that their patients had stopped taking Haart because of Rath's facilities. Here is an edited description from Saranchuk's affidavit of what happened to one of his patients:

He came to the Nolungile HIV clinic on 30 September 2005 where I treated him. He had been admitted to GF Jooste Hospital on 12 September 2005. According to notes at [the hospital], his baseline CD4 count was 22. This means his immune system was extremely weak. He had advanced Aids. He was also diagnosed with HIV encephalopathy (a condition which causes confusion due to advanced HIV infection) and disseminated tuberculosis.

His patient record at GF Jooste states that there was a two month progressive weakness prior to his presentation at the hospital. I therefore investigated what occurred during this two month period and learnt that he had been a patient of one of the Rath clinics.

I admitted him to an Aids hospice for nursing care on 3 October. My hope was that he would improve, but the reality is that the prognosis for people at his late stage of Aids is very poor.

He died on 8 October 2005 at the hospice.

He never had the opportunity to be initiated on Haart, because he had not sufficiently recovered from his opportunistic infections to commence Haart. It is my professional opinion that the approximate two months in which he was a patient of a Rath clinic resulted in a critical delay, in which the chance of saving his life would have been far greater had he attended the public clinic.

The affidavits of Zondani Magwebu and Nandipha Sigebenga also provided evidence that Rath's trial was killing people.

We cited Pierre Uys, the provincial health minister, for his failure to take sufficient action against Rath. Although Kerfoot and Budlender were not happy with this decision, Achmat insisted. He felt that it was important to expose the fact that Uys had been less than honest in his dealings with the Western Cape legislature about Rath. Kerfoot and Budlender warned us that we had no legal case against Uys because he was not responsible for the legislation that we wanted enforced. We also asked for no relief against him. This was the one aspect of the case we would lose, luckily a rather minor part. Achmat still maintains it was the right decision to cite Uys because it was an opportunity to put it on record before a court. I am not so sure, but in the end it did not matter much. We would win the rest of the case so comprehensively that this was a minor setback.

The South African Medical Association (Sama) joined us as a second applicant. Dr Mark Sonderup was outraged by Rath's activities and was one of the people who drove Sama's involvement in the case. He correctly believed that doctors could not stay silent in the face of such a flagrant attack against medical science. He gave several media interviews condemning Rath and represented Sama at our press conferences. Sonderup informed me that there were board members who were uncomfortable about taking the state to court and at one point I thought Sama might pull out, which would have left TAC looking isolated. I do not know what happened internally at Sama but the organisation kept its nerve and stayed in. I suspect Sonderup was key to this. He has explained to me that Sama's decision to stay in was helped by Kgosi Letlape, then Sama chairman, who had created an environment in the organisation where it was acceptable to criticise the government's HIV politics. He had publicly declared his support for TAC several years earlier and described the state's HIV policy as 'genocide'.

Rath's way of dealing with the court process was to abuse it. We filed our court papers on 25 November 2005. The court rules specified that the answering affidavits had to be filed by 9 January 2006, but it is common for both sides to allow each other extensions, especially when the papers

are voluminous. Brink defended himself separately from Rath and his other employees. He asked for an extension, which was granted, and filed his papers only slightly late, as did the state. Rath, however, delayed and delayed. When our lawyers wrote to Rath's lawyers, Qunta Incorporated, asking when they were filing their response, promises accompanied by lame excuses were made and not kept. In the meanwhile Sam Mhlongo died in a car accident in October 2006.⁵

Irritated with Rath's games, we applied for a court date. Lo and behold, a few days before the hearing, on 20 March 2007 – more than a year late – Rath filed nine volumes, or over 2,700 pages. His court papers included no fewer than four books, none relevant to the proceedings. His own affidavit consisted primarily of a long rant against the pharmaceutical industry and false allegations aligning TAC, Sama and all our expert affidavit deponents with it. It attached numerous scientific papers which according to Rath supported his case, but upon reading them we found that they actually contradicted what he was arguing.

If you file court papers so late, there is no obligation on the other side to accept them. We did not. So at the court hearing, Rath applied for an order condoning their late filing and allowing his court papers to be included. Judge Fourie of the Cape High Court was unimpressed. He said of Rath's excuse for filing late that it 'does not bear scrutiny'. He explained that Rath had shown a 'flagrant disregard of the rules of court'. He gave a punitive cost order against Rath but nevertheless decided to allow his papers to be filed in the interests of justice. This was a good decision that would prevent Rath from excusing his future loss on not having been able to file a response, but it was yet another delay.

While Rath's affidavit was bizarre, reading Anthony Brink's affidavit felt like going through the looking glass into Lewis Carroll's Wonderland. Brink filed 1,289 pages. Once more, instead of testifying about the facts of the case, Brink wrote a polemic that attacked not only our integrity, but the integrity of 51 judges of the Cape High Court as well as the Supreme Court of Appeal and Constitutional Court judges. This is not a recommended method for winning court cases.

He also attacked the MCC, comparing it to the Broederbond, the secret Afrikaner society that had unduly influenced the apartheid government. When it came to Aids, he had no qualifications to depose an expert affidavit, so he described himself as an autodidact. His testimony is replete with self-important descriptions and references to his own self-published, non-peer-reviewed 'scientific' writing. It includes asides about witch burning, donations by a pharmaceutical company to the Nazis and, reminiscent of the *Castro Hlongwane* document, an explanation of Aids as a white racist conspiracy. Could a trained advocate really have thought a court would find this acceptable?

Amusingly he wrote this about an Aids denialist document: 'In recognition of my expertise as a self-trained expert in the subject of ARV pharmacology, I was honoured with a co-authorship of a major scientific monograph.' What is unmentioned is that this 'major' scientific monograph was authored by fellow crackpots and that it had not passed the peer-review process of any reputable medical journal.

At the time he wrote his affidavit, Siphon Mthathi was the general secretary of TAC, the organisation's most powerful position. Achmat had withdrawn from day-to-day work and Mthathi was firmly in control of the organisation. A strong-willed and effective leader with an excellent understanding of politics, she was the main decision-maker and spokesperson for the organisation. Brink had no knowledge of the internal workings of the organisation, yet he chose to write the following racist nonsense under oath: 'The TAC is essentially a cult-of-personality one-man-band practically owned and completely controlled by Achmat, its founder and leader. The Africans hired by the TAC to give colour to its administration are conspicuously mere ciphers echoing their master's voice, with the letters sent out in their name seemingly ghost-written for them.' Mthathi, who writes poetry, publishes opinion pieces, and has an honours degree from the University of the Western Cape and a higher diploma in education from Rhodes University, responded by attaching correspondence she had written to senior people in government. She stated: 'Contrary to Mr Brink's racist assumptions, I can write a letter. I do

not need to have letters or articles ghost-written for me.'

This jargonistic and grandiose passage epitomises Brink's writing:

The ... case set up by the ... TAC ... is plainly intended to achieve a legal imprimatur on the merits of the medical dogmas around which it fundraises for its multimillion rand salary payroll and political activities, and at the judicial abjuration of any rival redemptive philosophy, approach and practice in the field of public health all of which, with submission, makes the case redolent of a politico-religious mediaeval heresy prosecution. I accordingly beg some forbearance in the manner in which I answer the TAC's claims and charges, narrowly or broadly as needs be, and in a forthright prose style to suit, since in my estimation the HIV/Aids paradigm is best understood beyond being a highly lucrative medical theory based on demonstrable junkscience as an essentially reactionary, authoritarian, sex-negative, neocolonial socio-political construct, and a prop to racist ideology, fuelled by middle class moral panic. If my tone is found to be somewhat tart, it's because I think the HIV theory of Aids and its treatment with ARVs is unbelievably stupid. And after reading this affidavit, I expect this court will heartily agree.⁶

For its part the national government wrote somewhat more sane, albeit terribly weak, affidavits. Thami Mseleku's argument centred on his view that Rath's products were foodstuffs, not medicines. He tried to paint the case as a private dispute between Rath and TAC, into which TAC was unfairly dragging the government. He insisted that an investigation had been carried out by the head of the Law Enforcement Unit (LEU), André du Toit, and that he was 'unable to find any sustainable evidence of unlawful activities on the part of any of the [Rath respondents]'. He gave very few details about this investigation. We had asked for details of the investigation frequently but received none. Consequently we amended our court papers, asking the court to find that the state had not conducted a proper investigation and that it should be ordered to do so. I was confident that we were on safe ground with this because a source in the Department

of Health informed me that there had in fact been no investigation.

Finally, two and a half years after filing our papers, the case got to court. The TAC Western Cape office organised protests of about a hundred people against Rath and the Minister of Health every day of the case. Our members filled most of the seats of the court alongside journalists and a motley array of Rath supporters. Rath himself had left the country and did not appear. Brink had approached our lawyers to settle on the basis that neither side would seek costs against each other. Since the case was set down for three days and because we suspected Brink in his madness would very likely take up an enormous amount of time and try to confuse the court, we decided to accept. We reckoned that if we won against Rath, Brink would be irreparably tainted by the judgment. He distributed a propaganda pamphlet to the journalists at the court, but they ignored him. With Brink out of the way, the case proceeded remarkably quickly. The delays had finally come to an end. Because none of the recognisable senior members of the Rath Foundation were present, there was also no visible acrimony once Brink exited from the case.

Exactly three months later, Judge Dumisani Zondi delivered his judgment. He declared Rath's and Rasnick's clinical trial unlawful and ordered them to cease. He interdicted Rath from running further advertisements claiming that Vitacell had medicinal effects on Aids. He then declared that the Minister of Health and her director-general had a duty to take reasonable measures to prevent Rath and his colleagues from running unauthorised clinical trials and adverts claiming that Vitacell had medicinal effects on Aids. He ordered Rath to pay 90% of our costs and the Minister and her director-general to pay 10%. We were ordered to pay the costs for the Western Cape MEC for health.

I have had many happy days in TAC: the successful importation of fluconazole from Thailand, the withdrawal of the Pharmaceutical Manufacturers' Association from its court case against government, the PMTCT court case victory, the huge marches on 9 July 2000 and 14 February 2003, the success of our first day of civil disobedience in March 2003 and the release of the treatment plans. But nothing compared to my

elation on hearing this judgment. For three years my colleagues and I had worked to stop Matthias Rath's activities and to expose how the state had colluded with him. The judgment vindicated that effort.

The most damning aspect of the judgment was the finding that Rath and Rasnick conducted an unlawful trial and that the state should have investigated and stopped it. There are few aspects of the dark side of medical science that conjure up as much revulsion as unethical experimentation. Besides the well-known examples of grotesque Nazi experiments during the Second World War and the Tuskegee syphilis study, books (or, more likely, movies) such as *The Constant Gardener* and *Frankenstein* have imprinted this horror on the public mind. The Rath clinical trial was a real-life version of the story told in Le Carré's novel, except that the bad guys were not our traditional idea of a multinational pharmaceutical company and a Western state – the villains were a vitamin salesman and a developing world government.

There was much irony and vindication in this. For years, Mbeki's supporters had described the distribution of ARVs to people with HIV as treating Africans as guinea pigs. Now the Mbeki government had been implicated in using Africans as guinea pigs – not the TAC, MSF, opposition parties or doctors.

The MCC's failure to take action against Rath's clinical trial is unlikely to have been bureaucratic ineptitude alone. If it was, then there should be no counter-examples of the MCC stopping a trial from going ahead; but there is one. Over the same period as the Rath affair, the MCC went to great lengths to stop a clinical trial that, in contrast to Rath's, was scientifically and ethically sound and extremely important. This was a trial at the University of KwaZulu-Natal to determine whether HIV-positive women particularly in poor communities should breastfeed or formula-feed their HIV-negative newborns. On the one hand, formula milk can be easily contaminated if the water supply is unreliable or the mother lives in squalid conditions. On the other hand, breastfeeding carries a high risk of HIV transmission from mother to child. Researchers at the University of KwaZulu-Natal's Nelson Mandela Medical School, who have been

proponents of exclusive breastfeeding, proposed a clinical trial involving nevirapine that would resolve this problem if it achieved a successful outcome. If nevirapine is safe and effective for this purpose, breastfeeding can be made almost entirely safe and many babies' lives can be saved. The trial was designed by an international multidisciplinary team that included Hoosen Coovadia, one of the country's most respected HIV paediatricians, and was also approved by a recognised ethics committee.

The researchers applied to the MCC for permission to proceed, as they were legally obliged to do. What followed was bizarre. On at least one occasion the MCC lost trial documentation and the researchers promptly gave them new copies. When the MCC asked for additional information, the researchers answered swiftly. Yet over a year later the MCC refused permission for the trial to proceed. The university then appealed against the MCC's decision, as it was entitled to do. It took another eight months before an appeal committee heard their case. The committee agreed to make a decision by September 2005, but only delivered it in February 2006. It ruled in favour of the researchers and ordered the MCC to allow the trial to proceed.

In April 2006, the MCC informed the researchers that they were taking the appeal committee's decision on review to the High Court, a lengthy process at the best of times. Left without a trial two years after first applying for permission, the university sought a court order to allow the trial to go ahead. In April 2007, Judge Mesheck Mabesele ruled in favour of the researchers. So the MCC appealed, initiating another potentially lengthy delay. The researchers therefore approached the court for an interim execution order. This would allow them to proceed with the trial until the appeal was heard. It was granted by Judge Willie Hartzenberg in July. And so the delays went on and on.

Way back in 2004 the trial had been approved by the clinical trials subcommittee of the MCC. This is the committee with the technical expertise to decide something like this. Yet the council overrode its own technical committee. Why? Judge Hartzenberg's judgment provides the likely reasons, 'The emotional cry of [the MCC] that the clinical trial will

lead to the infection of innocent babies with HIV is simply not true. The argument that the experiment is an exploitation of an under-privileged black community for the benefit of more affluent communities is equally unsound.' On the contrary, 'The clinical trial does not place any mother or child in a position worse than what they would have been, had the clinical trial not been done.'

After several more delays, the trial eventually started in August 2008, four and a half years after permission was first sought. Like any trial it might get negative results. But if it does not, a life-saving policy would come into effect four and a half years later than otherwise possible. How many children died because of the MCC's ideologically inspired delays?⁷

What the judgment meant for Rath's advertisements

As far as we can tell, Rath never sold his medicines in South Africa in return for money. His motive appears to have been either to use South Africa as part of an advertising campaign for the more lucrative North American and European markets, or to try to create a market by distributing a large number of free samples and then to start selling the medicines once enough people with HIV believed they were dependent on his vitamins. An alternative explanation is that Rath really believes what he claims and distributes his products free because of an ideological commitment to what he is doing. Against this explanation are his high product prices on the Internet and the way he has litigated against and smeared his competitors. These facts suggest that he is a man whose actions are ruled primarily by avarice.

Rath has been careful not to mention the names of his products in his advertisements. He argued therefore that the advertisements were not in breach of the law because they were statements of fact about any vitamin product, not just his. The court did not buy this and correctly understood that Rath's adverts were linked to the distribution of Vitacell. After all, Rath even admitted in his court papers that patients were given a copy of one of his adverts upon receiving their pills. But the court order is silent on the legality of Rath's continuing ability to distribute Vitacell

once he no longer advertises. Clearly, if Rath had to cease advertising any claims about vitamins, his products would no longer be medicines. But how can something like this be monitored? Who is to ensure that Rath does not continue distributing pamphlets claiming that multivitamins reverse the course of Aids? Moreover, the court did not order him to cease distributing the scheduled product N-acetylcysteine. Nor did it stop him from prescribing vitamins in excess of their maximum dosages.

By the time the judgment came out, Mbeki's presidency was clearly on the wane and his Health Minister could hardly afford any more scandals. Perhaps this was why the state did not appeal against the judgment, as it did in most of our previous cases. Nevertheless, Rath did appeal to the Supreme Court of Appeal in Bloemfontein. We therefore applied to the Cape High Court for what is known as an interim execution order and received it. In a nutshell, this meant the court's order would take effect until the appeal was decided.

The end of Matthias Rath?

TAC member Sylvia Fynn heard that Sanco was continuing, after the judgment, to distribute Rath's medicines in Durban. She went to investigate. She found the premises where this was happening and took photos. She found evidence of Rath's products being distributed, as well as a bin where patients were throwing their ARVs away. I wrote a report with Fynn's information for the LEU. In the meanwhile Barbara Hogan took over as Health Minister. The LEU, now free of the malign Tshabalala-Msimang and instead feeling empowered by Barbara Hogan, investigated and lodged a complaint against Rath and a Sanco official with the police. A shipment of Rath's medicines was also seized.

Rath, or his lawyers, also failed to pursue their court appeal. So we called a press conference in March 2009. Andile Madondile reminded the press of the damage Rath had done in Khayelitsha. I explained that Rath's appeal was out of time. Judge Zondi's judgment therefore stood and our lawyers would begin recovering their considerable costs from Rath. The case was finally over. There may be some residual Rath activities. But his

agents have been driven underground. The damage they can do now is limited. We have stopped him. There was, however, to be one more rude shock for Rath, provoked in part by Anthony Brink's grandiose delusions.

The Guardian case

On 4 January 2007 Brink lodged a complaint of genocide against Zackie Achmat with the International Criminal Court (ICC). He wrote: 'Achmat is guilty of genocide, the gravest crime among the "most serious crimes of concern to the international community as a whole" specified in ... the Rome Statute of the International Criminal Court.' The complaint held TAC responsible for 'an intense coercive, subversive political campaign against South Africa's democratic government to force it to enter into trade agreements with the pharmaceutical industry for the purchase of ARVs, and to provide these drugs in public hospitals and clinics for prescription and administration to the poor, overwhelmingly African. In this project the TAC has been entirely successful.' He explained why his complaint was directed against Achmat alone. 'It is notorious that Achmat completely owns the organization, directs its agenda and operations, and deploys it as his personal executive for implementing them.' Later he explains: 'Achmat's genocidal conduct in pushing these drugs has been committed with deliberate criminal "intent and knowledge" in that, as a direct "consequence" of his actions, thousands of South Africans, mostly black, would likely be killed or seriously harmed in the "ordinary course of events".'

Most of the remainder of the complaint is taken up with the usual Aids denialist misrepresentations of the side-effects of ARVs and a jaundiced retelling of the history of the struggle for Haart. All this is bizarre, but the complaint ends with this sickening explanation of Brink's idea of an appropriate criminal sanction.

In view of the scale and gravity of Achmat's crime and his direct personal criminal culpability for 'the deaths of thousands of people', to quote his own words, it is respectfully submitted that the International Criminal Court

ought to impose on him the highest sentence provided by Article 77.1(b) of the Rome Statute, namely permanent confinement in a small white steel and concrete cage, bright fluorescent light on all the time to keep an eye on him, his warders putting him out only to work every day in the prison garden to cultivate nutrient-rich vegetables, including when it's raining, in order for him to repay his debt to society, with the ARVs he claims to take administered daily under close medical watch at the full prescribed dose, morning, noon and night, without interruption, to prevent him faking that he's being treatment compliant, pushed if necessary down his forced-open gullet with a finger, or, if he bites, kicks and screams too much, dripped into his arm after he's been restrained on a gurney with cable ties around his ankles, wrists and neck, until he gives up the ghost on them, so as to eradicate this foulest, most loathsome, unscrupulous and malevolent blight on the human race, who has plagued and poisoned the people of South Africa, mostly black, mostly poor, for nearly a decade now, since the day he and his TAC first hit the scene.⁸

The British journalist Ben Goldacre has recently published a book called *Bad Science*. He also writes an excellent popular science column with the same name. It is published in *The Guardian* and as a blog. Goldacre debunks bad science and he is funny and good at it. Horrified by this madness, he wrote a column describing Brink's affidavit, his association with Rath and Rath's vitamin peddling activities. About Brink's proposed punishment he wrote, 'I don't think it's out of line to suggest this is particularly vile considering that Achmat is a "coloured" man, by the apartheid government's classification: and let's not forget that Achmat, a longstanding anti-apartheid and gay rights campaigner, was imprisoned under that brutal regime.'

He ended off the column with this: 'Meanwhile this vicious and unhinged hatred, this surrealist charge of genocide, comes from a colleague of the vitamin peddler Rath: from Anthony Brink, from the man who is credited with introducing Mbeki to HIV denialism, who has helped cost the lives of tens of thousands of people needlessly deprived of effective treatments.'

Probably emboldened by his recent out-of-court settlement with the *BMJ*, Rath reacted by suing Goldacre and *The Guardian* for libel. It was a serious mistake. *The Guardian* did not roll over like the medical journal. With resources our lawyers could only dream of, their lawyers flew to South Africa, spent several days researching Rath and Brink and got affidavits from Achmat, Majola and me on Rath's activities in South Africa and the links between Rath and Brink. According to the editor, Alan Rusbridger, the newspaper spent \$680,000 fighting the case.⁹

The Guardian also sent a video team who interviewed some of the families of Rath's victims. The case dragged on for over a year and looked likely to go on for much longer. Goldacre, in the meanwhile, had written a chapter on Rath for his book, but had to exclude it from the first edition while the case was pending.

The Guardian's fortitude paid off, though. In September 2008, Rath withdrew from the case, saddling him with the newspaper's considerable legal expenses. *The Guardian* announced its victory as a front-page headline and immediately released its excellent video. The adverse publicity for Rath was immense. While the quackery case had destroyed his plans in South Africa, his denouncement on the front page of one of Britain's premier newspapers was a fitting *coup de grace* that destroyed whatever was left of his worldly reputation.

* * *

The Rath case was a terribly low point in the ANC's history. The party stood by while Sanco, Tshabalala-Msimang, Mseleku and Mbewu consorted with and promoted a rich and deadly charlatan. Few ANC members spoke out, Asmal, Kariem and Turok being notable exceptions. The Rath affair is laced with irony. He, the state and ANC spokespersons had accused others of being involved with the pharmaceutical industry's unethical practices, especially unethical experimentation, yet the quackery case showed that it was Rath and the state who were complicit in this.

Another irony of the Rath affair was the use of anti-Western medicine

rhetoric and the elevation of traditional medicines. Yet Rath's operations are run from Europe and the over-promotion of vitamins for the treatment of human ailments is a form of quackery with distinctly Western roots.

Though our strategy and tactics were imperfect, our response to Rath had a successful outcome. In conclusion, it is worth reflecting on what would have happened to South Africa's Aids programme and the scientific governance of medicine had TAC not decided to take steps to stop Rath, had we lost one of our two court cases against him or had we collapsed while doing so.

8

How the floodgates opened

'The [Medicines] Act was put on the statute book to protect the citizenry at large. Substances for the treatment of human ailments are as old as mankind itself; so are poisons and quacks.'

– Judge Johann Kriegler¹

A brief history of medicine regulation

Besides the active encouragement of quackery by the Minister of Health and her supporters there were additional shenanigans inside the Department of Health and Medicines Control Council (MCC) that contributed to the market being flooded with quack remedies. To understand this, one needs to know a bit about the legislation governing medicines and the history of the MCC.²

The Medicines and Related Substances Control Act – the Medicines Act for short – was passed in 1965. It established the MCC. Following the thalidomide scandal, many countries tightened their medicine regulation to reduce the risk of unsafe, poor-quality medicines being sold. The Medicines Act went a step further. Besides considering the safety and quality of medicines, it also considered their efficacy. This is spelt out in the first section of the Act. It says that when the MCC determines whether it is in the public interest to allow a medicine to become available, it must only consider its 'safety, quality and therapeutic efficacy ... in relation to its effect on the health of man or any animal'. According to Johan Schlebusch,

the former registrar of medicines whose story is at the centre of this chapter, this criterion was ground-breaking. Today all major medicines regulatory bodies consider efficacy.

Since the Act deals with medicines it is important to know what a medicine is from a legal perspective. Essentially, the Act defined a medicine as any substance that purports to treat or cure illness. There is more to it than that, but for our purposes this is all that one needs to understand. I have already explained this in the chapter on the Rath cases, but because it is so critical it is worth emphasising: a product is a medicine because of the claims made about it, not because of what it is. It is also important to know that the Act established a medicines registry, which can be thought of as a database where medicines, their uses and other details about them are registered.

The intuitive, popular view of a medicine is that it is a complex chemical compound that treats diseases and that must be carefully ingested because of potentially dangerous side-effects, especially if one overdoses. This is not a correct legal understanding, however. Consider morphine, for example. When a doctor prescribes it to relieve pain, it is a medicine. But some people take morphine as a recreational drug, in which case it is not being used as a medicine. In the absence of claims, a product is not a medicine. Nevertheless, even when it is not used as a medicine, morphine is a scheduled substance because of the potential harm it causes if misused. This means that it cannot be sold, stored, distributed or used by just anyone. This is also dealt with in the Medicines Act.

Every antiretroviral has potentially harmful side-effects, especially if misused. So these too are scheduled substances. In fact, most of the medicines your doctor prescribes are likely to be scheduled substances. In South Africa, there is a scale of scheduled substances from 0 to 8. At the one end of the scale a schedule 0 substance can be sold in any shop. At the other end, to prescribe a schedule 8 substance, a doctor needs a special permit from the director-general of health.

One of the purposes of the Medicines Act was to control quackery. There are a few clauses in the Act which deal with this. One of the most

important is Section 14, which states that ‘no person shall sell any medicine which is subject to registration ... unless it is registered’. This does not mean that every medicine needs to be registered. Instead the law gives the MCC the power to make a medicine or class of medicines registrable. ‘The Council may from time to time by resolution approved by the Minister, determine that a medicine or class or category of medicines ... mentioned in the resolution shall be subject to registration ...’

From the late 1960s through to the mid-1970s the MCC published many such resolutions. Every category of medicine for treating major diseases was called up for registration, including antivirals, i.e. any product that purports to treat a viral infection. Since Aids is a virally caused disease, it follows that any medicine that can allegedly treat it or HIV is an antiviral and has to be registered. This legal framework is the key to protection against quackery. If you claim that your product treats cancer, diabetes, HIV or some other dreaded disease, then you have to submit details about your medicine and your claims to the MCC. The MCC must then evaluate it and decide whether or not to register it. Not until it is registered for the treatment of that disease can you make claims about its medical benefits for that disease.

Since before recorded history there have been people afflicted with diseases and people offering remedies. There will always be people claiming to be healers and many of them will use untested medicines as opposed to scientific ones. It would be foolhardy and arguably morally wrong for the state to crack down on every healer, homeopath, chiropractor or other category of alternative health practitioner. What the Medicines Act tries to do is to stop outrageous claims being made, especially in advertisements. It is therefore written in a way that essentially allows traditional and alternative healers to give unregistered medicines to their patients provided they are made by the healers and are not commercial medicines. There are reasonable limits. Healers may not, for example, prescribe scheduled substances (above schedule 0) unless suitably qualified. The Medicines Act does not interfere too far in the private relationship between healer and patient. It is also worth noting that, according to Schlebusch, the MCC did

not try to control traditional medicines until 1993.

The structure of the MCC is complex. It consists of the council itself and several committees made up of experts in several fields relevant to medicine registration. These experts are not employed by the MCC but are reimbursed for their time spent doing MCC work. They are responsible for reviewing medicines and making decisions about their safety, quality and efficacy. The day-to-day grind work and management of the MCC is performed by a secretariat whose members' salaries are paid by the Department of Health.

Two key positions need mentioning. The head of the council is the chairperson. This should be a highly qualified medical scientist or pharmacologist. The key staff position on the secretariat is the registrar of medicines, who is responsible for the administration of medicine registration, the MCC's central task. It is a position that comes with much responsibility.

Despite being a creation of the apartheid government, the MCC became an effective institution with worldwide respect. In 1981 Peter Folb became the chairperson. He is a leading international expert on drug safety and an outstanding scientist. During the 1980s, he was also actively involved in the United Democratic Front (UDF), the coalition of organisations inside the country opposed to apartheid that played a critical role in bringing the regime to an end. Nevertheless, despite his known political involvement, Folb was on several occasions reappointed to the MCC's top position. This confirms my understanding that political interference in the MCC under the National Party, while not entirely absent, was not a systemic problem. The MCC had a job to do and, to the extent that an institution under a racist government can be free of racial ideological baggage, it was.

Schlebusch joined the MCC in 1972. He started as an inspector, or medicine controller, and in 1984 became the registrar of medicines. For nearly three decades he dedicated his life to the regulation of medicines. Folb has described Schlebusch as 'highly competent, trustworthy and most importantly, honest. Furthermore, he had experienced him as loyal in the best sense, which included saying what had to be said.'³

According to Schlebusch, at first homeopaths were the main identifiable alternative sellers over whom the MCC needed to exercise control. But as more types of alternative remedies were submitted to the MCC, the existing Homeopathic Committee was renamed the Complementary Medicines Committee. People selling complementary or alternative medicines had to provide the MCC with the same information as any other medicine with the exception of homeopathic ones. For these, according to Schlebusch, 'We negotiated with the applicants to submit only such information that we would require to exercise meaningful control and surveillance over these products.' If alternative health companies advertised outrageous claims, they would get a telephone call or visit from one of the MCC inspectors. This was almost always sufficient to get the purveyor to behave.

Things became more difficult for the MCC in the 1990s. Alternative health dealers in many countries were becoming bolder and tried to change regulatory frameworks to make it easier to sell their wares. They had success in the US when in 1994 Congress passed the Dietary Supplement Health and Education Act that deregulated the supplement industry, making it easier to sell diet remedies and other dubious products alleged to improve health. According to Schlebusch, the alternative health industry demanded the same in South Africa. He also points out that South Africa started opening up to international trade. 'Countries [such as India] that had been previously unable to trade with us now rushed in to introduce products to the market. We had expected an upsurge in illegal sales of medicines but the scope of activities caught us unawares ... Control of the market, which up to now had been effective, became complicated. However, the market remained under an acceptable level of control.'⁴

When Olive Shisana became the director-general of health under the ANC government, she was sympathetic to the demand of alternative health carers to reduce regulation of their trade. She asked a council representing alternative health practitioners to put together a new Act for complementary medicines. She also chaired a meeting of alternative practitioners in 1996 to discuss their concerns. Schlebusch argues that the authority for such a meeting fell under the MCC, not the Department of

Health, and that by undermining the MCC's authority Shisana created the perception that the control system was about to be changed. 'The sellers of complementary medicines were quick to see the divisions between the MCC and the department and used the uncertainty to allow illegal medicines to pour onto the market. This chaotic situation remained for nearly a year.' Nevertheless, the MCC managed to convince Shisana to change her mind by the end of 1997. Schlebusch won the cooperation of the representatives of the alternative health industry and developed a plan for bringing their market back under control. He says, 'This project would have been an innovative world leader and far in advance of anything else.' But the plan was never implemented.

The purge

In its heyday under Peter Folb, the MCC was an efficient and effective institution. The time South Africa took to register medicines 'compared very favourably with the rest of the world'. It had an international reputation for excellence and the WHO established the MCC as a Reference Centre for the training of regulators of other countries.

All that began to change in 1997 because the MCC, under Folb and Schlebusch, stood firm against Mbeki on the false Aids medicine Virodene. In January and February the MCC suspended a clinical trial of Virodene which had proceeded without the approval of an ethics committee or the MCC. Folb stated, 'There is no one in the world who knows if [Virodene] can offer even a glimmer of hope. No patient is going to be exposed to this chemical until we know if it could be acceptable.' Tension escalated between Mbeki and the MCC, eventually resulting in Folb's dismissal as chairperson, his resignation from the MCC and a purge of its top staff.⁵

On 24 March 1998, Schlebusch and his deputy, Christel Brückner, who had been with the MCC for 24 years, were also dismissed. More accurately, they were threatened with immediate suspension and likely dismissal if they did not take severance packages. 'Staff ... were instructed not to communicate with Schlebusch or Brückner and instructions were given for all the hard drives on computers throughout the Directorate to be copied.

Guards were placed in the passage outside Schlebusch's secretary's office and the locks to his office were changed.'⁶

Folb's and Schlebusch's opposition to continued trials on Virodene was, of course, not the reason advanced by the state for purging the MCC of its top people. Instead it had set up a review team to assess the institution. This was a stitch-up. Folb damned it in the following way:

The modus operandi of the review team was astonishing. It completely disregarded the normal process of taking and testing evidence. The team failed to take into account important information given it, while reaching without apparent good reason conclusions that would have been different had they considered the materials with which they were provided. In a number of significant respects the review team inexplicably acted outside its terms of reference, thus precluding anticipation of such action by those giving them information and opinion ... The result was that the team passed judgement on matters it had considered inadequately. In retrospect, and with the knowledge of the report, individuals (including senior members of the secretariat) were confronted with a 'raw file'. This refers to allegations made by others against them to which they were expected to respond without being given any insight into the content of what had been said. Most disturbing of all, the review team submitted an additional secret report to the Minister of Health. On the basis of the latter, action was taken against the two most senior staff in the secretariat without those affected having access to its content. This was a violation of the rights of the individuals concerned and a remarkable departure from the principles of fair play and natural justice. It significantly taints the report, and brings into question the competence and fair-mindedness of the members of the review team. In general, there is indication that the review team selectively neglected to take account of information and material provided, with the result that the team reached decisions that might have been quite different had it considered open-mindedly all that was presented to it. The evidence that was collected by its members was biased, selective and superficial.

Those who had been dismissed took their case to the Commission for Conciliation, Mediation and Arbitration (CCMA), whose job it is to arbitrate in labour disputes. Although it is ordinarily difficult for an employee to prove constructive dismissal – when an employer wilfully makes your life so miserable that you leave without being fired – Schlebusch and Brückner succeeded.

In their case the CCMA award is an indictment by a disinterested party of the behaviour by state officials towards all three, Folb, Schlebusch and Brückner. Its details are fascinating. Many people once in state service, some of whom I have worked with over the last decade and respected, are severely criticised by it. It is beyond the scope of this book to retell the story in detail. However, I recommend you read it to gain insight into the Machiavellian workings of a state bureaucracy that had fallen under undue political influence.⁷

One critical detail described in the CCMA award is very much part of our story. Schlebusch's successor, Precious Matsotso, testified on behalf of the state against him. One of the allegations she made was that when she took over from him, there had been a large unprocessed backlog of applications for registration, about 400 to 800 she claimed. The CCMA arbitrator turned this allegation on its head:

[Matsotso] said, however, that she had no knowledge of what is an acceptable backlog in terms of international standards. She acknowledged that since she had taken over, the backlog had increased to about 2600. When put to her that South Africa had had, during the term of office of Schlebusch, one of the fastest turn-around times in registration of medicines, she said that she did not believe this. She attributed the increase in the backlog during her term of office to the resignation of key staff members.

Schlebusch told me that during his time the MCC took an average of 13 months to register a new medicine. This is quick. By contrast, the process today is appallingly inefficient and slow and it often takes several years for an application to be decided.

The removal of Schlebusch, Folb and Brückner meant that the people with the responsibility for driving Schlebusch's plan to control the proliferation of untested medicines were no longer around. On the contrary, according to Schlebusch, the MCC formally decided not to implement his plan. Worse, the industry was informed of this. It sent a clear message that quacks would have more leeway. The departure of Schlebusch and Brückner appears to have caused the implosion of the MCC. Sixteen other staff members left. Schlebusch has described it elegantly:

It seems as if the institutional memory of the entire organisation simply disappeared ... With the subsequent confusion and disillusionment ... and an apparent lack of trust in the regulator, the floodgates finally opened. There was now no way to rapidly and easily [manage] the sale of illegal products. Whatever had held sellers back previously from acting illegally was now gone and everybody, including many of those who had [previously abided by the rules], in order to compete in the marketplace, simply put products on the market illegally. The result is the present widespread chaos.

The CCMA award reinstated Schlebusch and Brückner. The Department of Health responded by asking the Labour Court to review the CCMA award. On 6 August 2001, the Labour Court dismissed the department's case, vindicated the CCMA arbitrator whom the department had alleged was biased, and made the CCMA award an order of court. Consequently the department reached a monetary settlement with Schlebusch. However, it still continued to refuse to reinstate Brückner in an appropriate position, so she brought a contempt of court case against the department, the minister and the director-general. Brückner won. On 20 October 2003, the court sentenced Manto Tshabalala-Msimang and Ayanda Ntsaluba to 15 days in prison for contempt, but the sentence was suspended. Brückner was reinstated and she is still there today. Apparently she is not assigned any substantive work.⁸

The Labour Court judge's words are devastating:

I should say something about the public accountability of those whom the state employs to serve the citizens of our country. Harm has been done in this case to the principle whereby the abuse of power should not be tolerated by any instrument of state. Harm has been done to the laudable objective, articulated by the Constitution that guarantees fair labour practices to employees. Harm has been done to the administration of justice and to the requirement that disputes should be speedily and expeditiously resolved, because of the inertia or arrogance of officials who did not bother to reinstate the applicant in her previous position. Harm has been done to the confidence with which the public may accept the reassurance that court orders will be complied with and implemented forthwith. Harm has been done to the applicant, who for almost four years has had to endure the uncertainty whether an unresponsive Department will reinstate her in her previous position. I do not know whether this incident with which I have had to deal is an isolated one. I certainly hope that it is.

The Virodene affair triggered a purge at the MCC with dire consequence. Measures to control quackery went unimplemented and a large backlog developed of medicines waiting to be registered. The authority that the MCC had had over the regulation of medicine eroded and the market began to flood with quack remedies.

The 2002 call-up notice

But matters got much worse. In its attempt to rectify the chaos the MCC swallowed a spider to catch the fly. In 2002, it published a notice in the *Government Gazette* that was deeply flawed and superseded all previous calls for registration of medicines in the same class. The first flaw was that it was difficult to understand. Here is its key clause: ‘All ... substances that fall under the definition of a medicine, including ... nutritional substances that purport to have therapeutic or medicinal effects ... shall be subject to a call-up process instituted as a primary step towards registration of such medicines and shall be submitted to the MCC within 6 months of the date of publication of this notice.’

If you do not understand this, do not worry, interpret it as you wish, because that is what alternative health dealers have done. I have had a public skirmish with the sellers of one such product. They claimed their product, albeit not properly tested, could treat Aids. I am not sure I properly understand their argument in defence of what they are doing (and this is why I am not identifying them). But it seems to me to be this: they have lodged an application for their medicine with the MCC. Even though their application has not been processed, they seem to believe that this is all that is necessary in terms of this notice.

The notice also stated: ‘The data compiled from this call up will enable Council to compile an audit of all products currently available in the market place. Council will review the claims of safety, quality and efficacy for all identified products and will determine whether any such claims constitute a public health hazard and act accordingly.’ This has never happened, nor has any serious attempt been made to make it happen. The notice was passed at a time when the number of quack remedies masquerading as Aids treatments began escalating. It was a godsend for quackery.

During the Rath quackery case we, our lawyers and the judge tore our hair out trying to make sense of this notice. Geoff Budlender, our advocate in that case, and Jonathan Berger of the ALP have explained to me that the call-up notice does not allow sellers of the products referred to by the notice to make claims willy-nilly. On the contrary, they have to wait for the MCC to evaluate the product. This is also the interpretation of a law enforcement person in the Department of Health I have spoken to. However, without the resources or political will, this interpretation has meant nothing. The same source told me that within the six-month period specified by the notice, about 7,000 applications for remedies meeting its criteria were sent to the MCC. To make matters worse, the legally stipulated six-month period was not enforced, and even in 2009 dossiers are still being submitted. In total, there are, according to my source, about 20,000 alternative medicine applications sitting with the MCC, unprocessed and with no plan to process them. The numbers were conveyed in a casual telephone discussion and are likely to be inaccurate, but clearly there is a huge backlog and a big problem to solve.

Nor have manufacturing licences, an obligatory requirement, been issued to the importers and manufacturers of these medicines. Consequently, the quality and stability of these medicines are not being monitored.

In August 2008, the Department of Health proposed the introduction of regulations dealing with the registration of complementary and alternative medicines differently from scientific medicines. The effect of these, if they come into force unchanged, would essentially be to create a separate registration system for these medicines. This is very problematic. Whether Tshabalala-Msimang and Mseleku orchestrated this for ideological reasons or in an attempt to resolve the backlog created by the 2002 notice is unclear.

The medicines registration system, whatever its faults, is designed to ensure that medicines that come to the market have been tested properly so that we can be reasonably sure they are safe, effective and of good quality. It is a system that has been developed in large part as a consequence of the hard experiences of thalidomide and other drug disasters. From a patient's perspective, quality, safety and efficacy are important for all medicines. There is no reason why a category of medicines designated as complementary or alternative should be dealt with more leniently than other medicines.

Pharmacies and the dispensing fee regulations

Nicoli Natrass has told me of her suspicion of an additional cause of the quackery floodgates opening. If she is right, TAC is partly responsible. As I have already explained, in 1997 the government introduced wide-ranging changes to the Medicines Act which the pharmaceutical industry opposed, resulting in years of litigation. Eventually, as a result of TAC's efforts the drug companies withdrew from the court case and the law eventually came into effect. At the risk of oversimplifying a long story, one of the changes it has brought in is that pharmacists no longer add a mark-up, usually 50%, to prescription drugs. Instead they have to charge a dispensing fee, which is capped at a relatively low amount.

The law has had a profound effect on the prices of medicines, keeping their once-spiralling costs under some control. It has come with side-

effects, though. In order to maintain their previous levels of profitability, pharmacists have had to increase their sales substantially to make up for the lower margins. Pharmacists should not be confused with pharmaceutical companies. Many pharmacists are sole proprietors struggling to make ends meet. Some have not been able to do so following the new law and have therefore gone out of business. So to compensate, Natrass argues, pharmacists have probably resorted to selling more unregulated or lightly regulated products like vitamins, so-called immune boosters and non-prescription quack remedies. There are no legal restrictions on the prices they can charge for these.

No survey has yet been published to confirm Natrass's argument, but it is compelling. My local pharmacy is packed to the brim with quack remedies and it has a large advertisement for Secomet in the window, one of the most aggressive marketers of a quack remedy for Aids (usually coded as an immune booster). From my experience at other pharmacies, marketing quack remedies is standard practice.

If Natrass is right, this does not mean that the new pricing mechanism for pharmacists was wrong. The control of medicine inflation is a major benefit to society. Moreover, pharmacies are but one source of the increased availability of quack remedies, and if the law was properly applied, the pharmacies would not be able to get away with their advertisements making grotesquely inflated claims.

The new Medicines Act

It is my fear that another overhaul of legislation, about to come into effect, might worsen matters. The Medicines Act was revamped in 2008, but it has not yet been brought into force. It replaces the MCC with the South African Health Products Regulatory Authority, which I will refer to simply as the Authority. The chairperson and the council members of the MCC, who are expert scientists, will be replaced by paid staff headed by a CEO who will report directly to the Minister of Health. The draft version of this legislation stripped the Authority of its independence from political interference from the Minister. The TAC and the ALP opposed

the offensive amendments. Our submission to the Department of Health stated:

[The draft Bill's] enactment would signal the final death knell of the scientific governance of medicines and clinical trials in South Africa. In our view, this is the latest attack on the evidence-based regulation of medicines and clinical trials, which began in early 1997 when the then independent and internationally respected MCC intervened to stop unauthorised and unethical trials on the industrial solvent Virodene.

This latest development, made in the name of improving effectiveness and efficiency, seeks to destroy what to date has only been weakened. It does so by proposing an amendment to the [Medicines Act] that will effectively allow the Minister of Health ... to block the registration of medicines of proven quality, safety and efficacy, as well as to allow the sale and provision of untested 'treatments' and 'cures'.

Jonathan Berger, who is a meticulous and thorough lawyer, wrote improved versions of the amendments and, together with Andrew Warlick, tried to convince Parliament to adopt these. Dealing with the Parliamentary Portfolio Committee on Health under the chairmanship of James Ngculu was always difficult. Ngculu, usually an Mbeki loyalist, had little interest in holding the Health Department or its minister to account, despite this being a key purpose of the committee. This was aggravated by the problem that most of the MPs on the committee lacked either the skill or the desire to come to terms with its requirements, such as reading technical documents. (The committee was a lot more effective under Ngculu's predecessor, the late Abe Nkomo.) Nevertheless, Warlick and Berger were partially successful thanks in part to the diligence and persistence of one opposition member of the committee, Mike Waters, but the new Act remains problematic.

Schlebusch explained to me another potential flaw, one we understood too late and therefore did not address in our submission. Under the current system, the MCC's expert subcommittees are essentially self-correcting. If one committee misses a problem with a medicine's application, another is

likely to catch it. It might seem counter-intuitive, but this system of reviews being conducted by multiple committees, when it actually worked properly, until 1998, was very efficient. Why? Because committee members were not petrified of making mistakes that resulted in a flawed medicine being registered. They could depend on their colleagues in other committees to catch errors they had missed. So they did not sit on registrations indefinitely, out of fear that they might allow a flawed registration.

Often when new bureaucratic systems are introduced, what worked well in the old system is thoughtlessly replaced. With the implementation of the new Authority, there is the risk that this system of committees reviewing each other's work will be destroyed. Instead it is possible that the work currently done by expert subcommittees will be carried out by paid officials. Attracting high-quality scientists who understand medicine registration to work full-time for the Department of Health will be a particularly difficult challenge. Without the peer review of multiple committees, the registration staff might be hesitant to make decisions and the backlog of medicines awaiting registration could build up.

There is good news, though. After the legislative quagmire left by her predecessor, Barbara Hogan set up several technical task teams, one of which had the task of examining the legislation and problems discussed in this chapter. It is headed by Precious Matsotso and includes experts like Berger, Folb and Andy Gray (one of our experts in the Rath quackery case). The team has consulted widely and, from what I understand, past enmities have been put aside under Matsotso's competent leadership. I am confident that if the task team's recommendations are adopted and implemented with genuine political will, the proliferation of untested remedies can be brought under control again. Time will tell.

The aftermath

‘We must know our medicines by name, how they were found to be effective, and how and where in the body they work; their side effects and how they can be managed; how to monitor the safety of medicine; what food to take and not to take with them. That way we can feel we have some control over our health. We must also follow new scientific research that sheds light on how best to use the drugs we take. All these things are part of what we call “treatment literacy”.’

– TAC¹

In this book I have not attempted to explain the reasons for Mbeki’s denialism. Far more important to understand is how his views or, perhaps more accurately, the perceptions of his views were overcome and how they managed to influence the country’s response to HIV in the first place. Unfortunately, few if any commentators have attempted to answer these critical questions, which penetrate to the essence of the strengths and weaknesses of our nascent democracy. I therefore want to make a short preliminary attempt.

Treatment literacy and the defeat of Mbeki

There were many outspoken critics of the state’s Aids policies, including the opposition political parties. However, what distinguished TAC’s position was a realisation that we had to convince ANC supporters that the state was

wrong about Aids. This was a considerable challenge. ANC structures on the ground, their branches, the ANC Youth League branches, Sanco, the Communist Party and Cosatu dominate political life in townships and in the workplace. Of these, only Cosatu was a reliable partner against Mbeki’s denialism. On the other hand, both Sanco, through its alliance with Rath, and the ANC Youth League, with its close connection to Peter Mokaba, actively campaigned against TAC.

Nevertheless, the TAC broke Mbeki’s hegemony on Aids. Key to this success was a multi-pronged approach. We had a well-run national campaign that made effective use of the media and the courts. Good research was essential for this part of the campaign to succeed. Our partnership with the Aids Law Project, led by Mark Heywood, and its excellent team of lawyers provided us with high-quality legal research. Heywood also invested enormous energy in developing a good relationship between the TAC and Cosatu.

We also put a lot of effort into our relationship with the media, organising hundreds of interviews between journalists and TAC members. We gave workshops explaining HIV science to reporters. We would spend hours explaining our court cases and actions, such as our highly controversial civil disobedience campaign. This reaped rewards. Most journalists were highly critical of Mbeki and very favourable to the TAC.

Throughout the worst periods of our relationship with government leaders, we tried to open doors to senior politicians and ANC leaders, often with success. During our civil disobedience campaign, we had fruitful contact with Jacob Zuma. When Tshabalala-Msimang reiterated her support for quack remedies at the 2006 Aids conference, we began extensive communication with Deputy President Mlambo-Ngcuka, which ultimately led to the development of the National Strategic Plan for Aids.

Underlying TAC’s success was an almost unsung programme that consumed about half of our budget: our treatment education programme. In my first formal TAC meeting a handful of us in the Cape Town central branch gathered in a poky office. Hermann Reuter explained the risk of contracting HIV from needle-stick injuries. A few weeks later I was at a

meeting in Gugulethu where Mandla Majola and Sipho Mthathi answered inquisitive questions about HIV from women in the community. I once attended a branch meeting in a hot, overcrowded shack where Vuyiseka Dubula, TAC's present general secretary, enthralled the branch members with her explanation of how HIV invades CD4 cells and hijacks the cell's machinery to reproduce itself. She in turn had once been a learner in similar TAC workshops, where she acquired her expert knowledge of the disease.

Mthathi was the person who developed the treatment literacy programme and made it work. With assistance from British and American activists as well as local doctors and nurses she developed a curriculum on HIV treatment. We called this education programme 'treatment literacy'. It was through treatment literacy that TAC developed a membership that could explain, discuss and debate HIV. The programme became formal and eventually we started paying first a few dozen and ultimately about 300 people to train full-time. Most of our treatment literacy practitioners, as we called them, were placed in clinics where they would explain the importance of HIV testing and treatment to crowded waiting rooms. The very good practitioners were promoted and became trainers, responsible for training the other practitioners. Andile Madondile is one of them. Like Andile, many of TAC's treatment literacy practitioners are HIV-positive and have survived Aids because of ARVs. Their stories have resonated through the townships where they live and inspired others to get tested.

Song has also been a crucial vehicle for community learning. When TAC members are together, you can bet that songs will be composed with tunes borrowed from the struggle against apartheid. There was even a formal TAC choir, The Generics, which released an album produced by Jack Lewis. Recently The Generics provided backup vocals for Annie Lennox's song *Sing*. The content of TAC's songs is often educational, such as this one (translated, a bit roughly, from Xhosa):

We know AZT protects children from HIV, globally

MTCT Prevention

We know nevirapine protects children from HIV, globally

But more often they were political:

What did we do to you, Thabo Mbeki?

We want AZT

We want Biozole

We want Nevirapine from you, Thabo Mbeki

Thabo Mbeki, what is our debt?

What is our sin?

Is it Aids?²

Sindiswa Godwana's work exemplifies the importance of treatment literacy. She received her HIV education from the TAC and rose through the ranks to become its organiser in Queenstown in the Eastern Cape. From even before Haart was available, Godwana would go to hospitals and clinics explaining the importance of opportunistic infection medicines like fluconazole to nurses. Sometimes she successfully organised for clinics to obtain fluconazole, either from the TAC through our Christopher Moraka Defiance Campaign, or from the Pfizer donation that I described in chapter 3.

Other organisations have started emulating the TAC's treatment literacy programme, a compliment to its perceived efficacy. But the treatment literacy programme has its problems. Misconceptions occur and, unfortunately, sometimes become widely believed. Moreover, the programme is not as strong as it once was. Nevertheless, it was pioneering and crucial to the success of the first large Haart projects, such as the ones in Khayelitsha and the rural areas served by the small town of Lusikisiki in the Eastern Cape.

Very little quantitative research has been done on the benefits of treatment literacy for Haart adherence and uptake. This is a great pity. It is true that a number of studies have been done that taken together can be used to make an argument for the success of treatment education. Furthermore, several programmes in which treatment education has been lacking have failed to do well, suffering from low uptake and poor adherence. Nevertheless, no compelling study has been done. Over the

last decade, as TAC's fame grew, we were often swamped with interview requests and demands from researchers. Yet no one has done a proper analysis of the effects of treatment literacy.³

Our branches, which implemented our treatment literacy programme, were also vital. It is here that a critical mass of working-class people in townships learnt enough of the science of HIV to be able to realise that the denialist message, promoted by Mbeki and filtered down through the ANC's structures, was wrong. Coupled with this were the Haart and PMTCT pilot projects in Khayelitsha and Lusikisiki run by Médecins Sans Frontières. Other leading implementors such as Johannesburg General Hospital, the Perinatal Unit at Chris Hani Baragwanath and the sites run by organisations like Absolute Return for Kids (a charity ARV service provider) and the Desmond Tutu HIV Centre were also critical. All these programmes were integrated into public sector clinics. They showed that HIV is treatable. There is little as compelling as seeing your nearly dead child or friend recovering their health after starting Haart. The treatment literacy programme popularised these programmes and made sure the communities in which they operated understood their success.

All this helped create a consensus that Mbeki's policies were wrong, which was critical to us in defeating him, first by winning the court case to compel the state to roll out PMTCT, then by getting the Cabinet to instruct the Minister of Health to implement Haart, and finally by defeating the forces of unreason, epitomised by Matthias Rath, with which the state collaborated to try to undermine these programmes. Key to achieving this has been our credibility. Many of our members and leaders are ANC supporters, a point we have emphasised. We are also a civil society movement, not a political party. This means the TAC could not be dismissed as just another group trying to embarrass the ANC in order to wrest power from it.

The TAC's effective court cases, demonstrations and use of the media have been built on top of large-scale community education. We would have no demonstrators, no substance in our court cases and nothing compelling

to tell the media without our treatment literacy programme.

Finally, I would be remiss if I failed to point out that a campaign such as TAC's was feasible because South Africa is a democratic country with a Constitution that contains a Bill of Rights enforced by an effective court system. There is freedom to organise politically and express one's views in opposition to state policy. This was not the case before 1994, nor is it the case in many other developing countries with large HIV epidemics. Aids denialism and quackery would not have been defeated without these freedoms and rights.

Why did Mbeki's views on Aids prevail for a while?

There were forces at work in South African society promoting quackery before Mbeki embraced Virodene and Aids denialism. I have already touched on this in the previous chapter. Moreover, traditional leaders and healers certainly exerted influence on our politics. Yet these forces were not particularly powerful, not necessarily more powerful than the countervailing forces from South African scientific and medical institutions or individuals like Nthato Motlana. More importantly, no significant forces directly promoted Aids denialism. The representatives of the alternative health industry and traditional healers could not have realistically expected their products to be recognised as anything more than complementary to ARVs. Mbeki could perhaps even have given them political support without going so far as to deny the cause of Aids or the efficacy of ARVs. The reasonable conclusion I draw from this is that the adoption of Aids denialism was Mbeki's personal ideological choice.

So how did this personal ideological choice prevail, at least for a time? As president of the ANC and by far its most powerful member, Mbeki was able to impress his personal positions on the organisation. Despite an essentially democratic structure – branches and sectors elect their leaders, who in turn elect the organisation's leadership at provincial and national level – the ANC has much within its culture that is anti-democratic and renders it vulnerable to and easily manipulated by the personal views of its strongest leaders.

Mbeki's public statements on ARVs and Aids, his support of Virodene, Peter Mokaba's bullying tactics at ANC conferences, the distribution of the *Castro Hlongwane* booklet to ANC branches and the open support of Rath by Sanco created an understanding within the party that opposing Mbeki's position on Aids would be politically costly. To make matters worse, the proportional voting system, by means of which all ANC MPs are beholden not to their constituencies but to the party bosses, creates an additional disincentive to speak out against poor leadership decisions. Indeed, when ANC MP Pregs Govender spoke out against the state's policies, she resigned shortly thereafter from Parliament. Barbara Hogan was also marginalised by Mbeki when she spoke out.

The ANC together with its allies liberated South Africa from apartheid. It is recognised and admired as the liberator by about two-thirds of the voting population. This enables it to exert a powerful hegemony over South African society. Some conservative political commentators create the impression that South Africa's ANC-supporting electorate unthinkingly follows the ANC irrespective of its serious shortcomings, either out of undying loyalty to the party of revolution or out of racial solidarity. This is false as anyone who attends political discussions in townships can easily find out. But most South Africans certainly look to the ANC for direction and leadership. Most black South Africans are also correspondingly sceptical of opposition parties, in particular the Democratic Alliance, with whom many associate the promotion of white privilege. Nevertheless, what follows from this is that the president of the ANC has immense influence over the party's positions and that the ANC has immense influence over South African society. Consequently, Mbeki's views on Aids, as well the views of people acting on behalf of Mbeki or perceived to be acting on his behalf, carried enormous weight.

Mbeki and his allies packaged Aids denialism and quackery by appealing to African nationalist sentiment. His Fort Hare speech epitomised this, but the rhetoric of local solutions, traditional methods and Western imperialism came from Tshabalala-Msimang and many of the quacks themselves, even those from Western countries like Tine van der Maas and Matthias Rath.

Deaths due to Aids denialism and quackery

Can the damage done by Aids denialism and quackery be calculated? Partially, yes. Indeed, two studies have calculated the number of excess Aids deaths due to the delayed rollout of Haart and PMTCT. Nicoli Natrass analysed what would have happened if PMTCT had been rolled out from 1998 instead of 2001 and if the Haart rollout had taken place throughout the country at the same rate as in the Western Cape, the province credited with the most expeditious implementation. She compared these scenarios using the Actuarial Society of South Africa's high-quality Aids model and estimated that 343,000 deaths could have been averted.

Pride Chigwedere and colleagues at Harvard School of Public Health used a slightly different method. They argued that reduced drug prices and the availability of resources from programmes like the Global Fund and the US government made it possible for the South African government to implement PMTCT and Haart earlier than it did. They used a UNAids estimate of Aids deaths to determine the number of people who were eligible for Haart but did not receive it. Their model calculated that the delayed Haart rollout caused over 330,000 deaths. Delayed PMTCT resulted in over 35,000 excess paediatric infections.

Both studies were intentionally conservative. For example, Chigwedere assumed a low estimate for additional life-expectancy on Haart. Both studies assumed that even with timely implementation, coverage rates would have been sub-optimal. Neither took into account less tangible parameters such as deaths due to the promotion of quackery or infections due to poor state condom messaging and equivocation on the cause of Aids, which might have resulted in riskier or poor health-seeking behaviour. Chigwedere concluded, 'Access to appropriate public health practice is often determined by a small number of political leaders. In the case of South Africa, many lives were lost because of a failure to accept the use of available ARVs to prevent and treat HIV/Aids in a timely manner.'

Even though they used different methodologies, these studies both calculated very similar estimates for the number of lives lost due to Mbeki's policies. Neither Natrass nor Chigwedere was aware of each other's work.

This increases confidence in their findings.⁴

How many people died specifically because of quackery as opposed to the delayed Haart and PMTCT rollouts? As a direct cause of death this is unmeasurable. We cannot know how many people, like Andile Madondile, tried a range of unproven remedies, instead of seeking care from the public health system. We do not even know the precise numbers of people killed directly by the activities of quacks like Zeblon Gwala and Matthias Rath, nor how many such quacks there are or were.

This is, however, not the point. Millions of young adults and children lay dying of Aids in South Africa during the Mbeki era. In questioning the causal link between HIV and Aids, Mbeki's Health Minister had to offer something to the dying, their friends and families. What was offered was quackery. The delayed and obstructed rollouts of Haart and PMTCT were inseparable politically from the offer of alternatives: traditional medicines, nutrition and multivitamin tablets.

If Mbeki's response to HIV had been based on science and respect for the constitutionally defined human right to access healthcare, the state's response would have been very different. It could easily have begun providing PMTCT in 1999 and Haart in 2000. This could have been coupled with a massive public information campaign exhorting people to get tested and treated, as well as to practise safer sex and reduce their number of sexual partners. It could have ensured that the prices of opportunistic medicines and ARVs were brought down quicker than they were. A plan to address the country's shortage of nurses and other health workers could have been developed and implemented. Tens of billions of rands could have been invested intelligently into combating the epidemic.

Chigwedere's study contrasted South Africa's response with Botswana's, where the Haart rollout began in 2000. But South Africa, more than any other African country including Botswana, had much greater capacity to implement a high-quality treatment and prevention response to HIV. We should have been the trailblazer that set the example for Botswana, Cameroon, Zambia, Malawi and many other countries, which have, instead, set examples for us. When you think about it this way, far more

than 330,000 of the more than two million people who died of Aids under Mbeki's watch could have been saved.

What does the future hold?

State-supported Aids denialism is dead in South Africa. Thabo Mbeki was booted out of office. Tshabalala-Msimang is no longer Health Minister. In the run-up to the 2009 elections the political rhetoric from the two largest political parties was unequivocal that HIV causes Aids. On 28 October 2009, ten years after Mbeki's speech expressing scepticism of AZT to the National Council of Provinces, President Jacob Zuma delivered a speech to the same forum in which he acknowledged the devastation that Aids has caused and committed his government to fighting the disease with renewed energy and focus. This marked the end of a terrible era.

But there are still short-term and long-term concerns. Zeblon Gwala continues to sell Ubhejane as a cure for Aids. Most of the country's provincial Aids councils, potentially useful structures for assisting the national government with implementation and holding it to account, are dysfunctional. Parliament has been unresponsive, especially the Parliamentary Portfolio Committee on Health, but I think this situation will improve.

On top of this, the public health system is broken. Drug procurement is erratic. There are not enough nurses or doctors to run the Haart programme properly. The PMTCT programme is patchy. Monitoring and evaluation of the state's Aids programme are poor. Not enough money has been allocated to the Health Department or else what has been budgeted is being poorly spent – probably both. During Tshabalala-Msimang's reign most competent national department staff left and many incompetent ones stayed on or joined.

The Medicines Control Council is dysfunctional. There are not enough law enforcement staff to police the Medicines Act. Thousands of quack remedies for Aids and other diseases have flooded the market. This all means that the confusion generated from the era of state-supported Aids denialism will be with us for a long time.

Despite Mbeki's defeat, there is still a long way to go. Quackery has run amok. By failing to curb the worst behaviour of the alternative health industry, Mbeki's government let a dangerous genie out of the lamp, and putting it back will require substantial political will.

Here is an idea that civil society can implement to help bring quackery under control. In 2006, the TAC together with UCT's Aids and Society Research Unit called a meeting of some of the top Aids researchers and people concerned with medicine regulation to discuss quackery. We formed an informal Coalition against Fraudulent Claims about Medicine. The coalition released a couple of statements, including a condemnation of the infamous British quack Patrick Holford, who visited South Africa and made outlandish claims about the benefits of vitamin supplements. Unfortunately the coalition has otherwise withered away. I suggest this coalition be formally reconstituted, perhaps slightly differently and with some financial backing. It should identify a few of the worst charlatans and litigate them out of business in high-profile court cases, as TAC did against Rath. This should send a message to other quacks that they have to curb their worst excesses.⁵

The TAC has in recent years gone through a difficult period. After nine years of non-stop fighting with the pharmaceutical industry and government, the TAC leadership, worn out and cranky, had an unpleasant internal fight in 2007, resulting in several high-level resignations. Having been involved in that argument, and having the utmost respect for my colleagues with whom I fell out, I will not say more on this. But putting the pieces back together has been difficult. We have also struggled financially, and the global economic downturn will not make matters easier. For a decade the organisation ran on the stamina of dedicated activists, but our lack of management skills and proper systems became a problem. After reducing our size, streamlining our activities and hiring a professional chief operating officer, the organisation's internal situation has improved, but our capacity to hold the government to account on Aids indefinitely is not assured. All of this represents a stern warning for doctors, nurses, patients and other activist groups in South Africa: be vigilant. Aids denialism and

quackery need to be watched closely.

Recently, Nozizwe Madlala-Routledge has called for something analogous to the post-apartheid Truth and Reconciliation Commission to deal with the era of Aids denialism. Edwin Cameron has also made a similar call and I have asked for an independent commission of inquiry in an article published in the *Journal of Aids*. Hundreds of thousands of lives were lost due to Aids denialism; it is a scourge which needs to be exposed, and those responsible for its damage must be held accountable. Whether any prosecutions should follow this inquiry, or whether it would instead be an opportunity for seeking amnesty and repentance, is a matter for debate.

Many of the leading quacks and Aids denialists should be called to account before such a commission including Zeblon Gwala, Matthias Rath, Anthony Brink and Tine van der Maas. So should some of the senior people in the ANC who had the power to alleviate the effects of Aids but did not: Thami Mseleku, the former director-general of health; James Ngculu, the former head of the Parliamentary Portfolio Committee on Health who consistently failed to hold the Health Minister to account; Alec Erwin, the former Minister of Trade and Industry who could have used his powers to make drugs more affordable; and Ngconde Balfour, the former Minister of Correctional Services who blocked Haart for prisoners. Peter Duesberg and David Rasnick, who offered a scientific veneer for Aids denialism, also have a case to answer.

The two people who must take most responsibility for the catastrophic consequences of state-supported Aids denialism and quackery are Thabo Mbeki and the late Manto Tshabalala-Msimang. It is they who unleashed an ideology of deadly delusions upon the South African population in the time of Aids. Some analysts have accused them of genocide, one of 'genocide by sloth'. It is true that they had the power and responsibility to prevent hundreds of thousands of Aids deaths, but instead acted to worsen the effects of the disease. Yet, the term genocide is too easily used in today's political discourse.

The Rome Statute of the ICC, to which South Africa is a signatory, defines the 'intentional infliction of conditions of life, inter alia the

deprivation of access to food and medicine, calculated to bring about the destruction of part of a population' as a crime against humanity. Mbeki and some of those working for him intentionally delayed and obstructed access to ARVs. I doubt they believed that this would destroy part of the South African population, but they certainly had enough information available to them to have known that this would be the outcome. Mbeki chose to contest that information, an act of extreme hubris. I am not sure if his actions fit strictly into the ICC's definition of a crime against humanity, but there is certainly a case to be made. What does seem incontrovertible to me is that by failing to exercise their power and responsibility to stop so many deaths, Mbeki and Tshabalala-Msimang were at least guilty of mass culpable homicide.

Interestingly, for TAC's civil disobedience campaign in 2003, we debated this very question at a meeting in the Western Cape, to decide what complaint to lay against Tshabalala-Msimang and Alec Erwin. The majority felt that genocide was the appropriate charge, but Achmat, I and a few others were adamant that this risked overstating our case. So that is why the final complaint we laid with the police was a charge of culpable homicide.

Jacob Zuma took over the presidency with his integrity in doubt and his commitment to the Constitution and women's rights especially in question. As Deputy President he headed the South African National Aids Council and failed to run it properly. Although he was acquitted of rape, his claim during the trial that he showered after unprotected sex with his accuser, an HIV-positive woman, to reduce the risk of contracting HIV was met with ridicule – and rightly so. The behaviour of his supporters in the rape trial towards his accuser was frightening. But there are things to be said in his favour. He apologised for his shower comment and it was he who negotiated with TAC during our civil disobedience campaign. He came through on his promise that the government would deliver a treatment plan. And as President he has banished Aids denialism.

In April 2009 Andile Madondile, along with 65% of the country's voters, returned the ANC to power. I asked him why he voted ANC (which, incidentally, was not always his party of choice). He explained that it is the

party of Mandela, that its manifesto was good and because he did not like the new breakaway party, COPE, made up of disenchanted Mbeki supporters, who Andile says were responsible for the ANC's service delivery failures over the last decade. But his vote is not something the ANC can count on indefinitely. 'If they don't deliver, I will vote for the opposition next time.'

* * *

I drive Andile and his two-year-old boy, Onako, a few kilometres from his house to Radio Zibonele, Khayelitsha's community station. Here, for an hour every Monday morning Andile answers questions over the air about Aids, with Onako sitting playfully next to him. This morning I sit next to Andile in the studio as he gives a short introduction on the human papillomavirus (HPV) which causes cervical cancer. He explains that it is a particularly serious problem for HIV-positive women and that they should have pap smears at their local clinic once a year to look for abnormal cells.

Then the calls come in, one after another, almost non-stop. Most of the callers are women. One asks him questions about ARV side-effects, another about the blisters on her skin and another about the gland that has enlarged to the size of an eye on her vagina. He answers the questions assuredly but without pretence or hubris. He ventures his own guesses but then insists his callers should go to the local clinic to see their doctor. To one caller he has to explain that ARVs do not treat everything. He also talks about his own side-effects after five years on treatment, primarily mild peripheral neuropathy, while 230,000 people listen to him. He has given out his cellphone number, so people constantly SMS during the show and call him afterwards.

Because of science, because of TAC, because of his daughter and because of his own fortitude, Andile Madondile is alive. And others live because of him.

Endnotes

Chapter 1

- 1 Actuarial Society of South Africa, *ASSA2003*.
- 2 Mbeki, 'Declaration of partnership against Aids'.
- 3 Natrass, *Mortal Combat*.
- 4 Myburgh, 'The Virodene affair'; also see Myburgh's shorter explanation in Cullinan and Thom, *The Virus, Vitamins and Vegetables*.
- 5 Myburgh, 'The Virodene affair'; Myburgh in Cullinan and Thom, *The Virus, Vitamins and Vegetables*; Forde, 'Mbeki link to toxic cure'.
- 6 Myburgh, 'The Virodene affair'.
- 7 De Visser and Grierson, 'Use of alternative therapies by people living with HIV/Aids in Australia'; Standish et al., 'Alternative medicine use in HIV-positive men and women'.
- 8 Some of this section was originally published as Geffen, 'Why Ozone Rectal Therapy is not the next cure for Aids'.
- 9 Garber et al., 'The use of ozone-treated blood in the therapy of HIV infection and immune disease'.
- 10 Johnson and Richman, 'Just another day at the world's biggest hospital' and Chris Hani Baragwanath Hospital, 'General information'.

Chapter 2

- 1 Jaffe, 'The early days of the HIV-Aids epidemic in the USA'.
- 2 Keele et al., 'Chimpanzee reservoirs of pandemic and nonpandemic HIV-1'; Levy, *HIV and the Pathogenesis of Aids*; avert.org, 'The origin of HIV and the first cases of Aids'; Gao et al., 'Origin of HIV-1 in the chimpanzee Pan troglodytes troglodytes'; Lemey et al., 'Tracing the origin and history of the HIV-2 epidemic'.
- 3 Wolfe et al., 'Naturally acquired simian retrovirus infections in central African hunters'.
- 4 Zhu et al., 'An African HIV-1 sequence from 1959 and implications for the origin of the epidemic'.
- 5 Worobey et al., 'Direct evidence of extensive diversity of HIV-1 in Kinshasa by 1960'.
- 6 Sher, 'HIV infection in South Africa, 1982–1988: a review'.
- 7 Shilts, *And the Band Played On*.

- 8 Jaffe, 'The early days of the HIV-Aids epidemic in the USA'.
- 9 Clumek et al., 'Acquired immune deficiency syndrome in Africans'.
- 10 Shilts, *And the Band Played On*; Hooper, *The River*; Hooper, 'Sailors and star-bursts, and the arrival of HIV'; McKay, 'The Vancouver connection: revisiting the 'patient zero' myth of the North American Aids epidemic'.
- 11 Many of the stories of the first people to be diagnosed in 1981 in the US have been told. We know a lot about how Aids was discovered in the US as well as the UK and France. But a detailed history of the beginnings of the South African epidemic does not, so far as I can tell, yet exist, at least not in a convenient form. It can be pieced together from archives of the country's major newspapers, the *South African Medical Journal* and various academic theses. Many of the people involved in the early response to the epidemic are still alive and willing to share their memories and anecdotes. It is worth interviewing Deon Knobel and Lance Michell, two doctors involved in the early epidemic; Leon Linz, who was at the time a young gay activist; Mike Bazazza and Gordon Isaacs, who were leaders in the gay community; and Edwin Cameron, Jack Lewis and Zackie Achmat. Unfortunately, large reservoirs of information that resided in people like Reuben Sher, Ivan Toms and Ronald Louw are no longer available. Particularly challenging will be to try to find stories on the early epidemic in the African community. Also see the media scrapbooks collected by Leon Eksteen in the South African Historical Archive. Descriptions of particular cases of people with Aids starting in 1984 are given in an essay by the late John Pegge, who helped pioneer Aids counselling in South Africa, in Cameron, *Defiant Desire*. Also see Webb, *HIV and Aids in Africa*; avert.org, 'The history of Aids up to 1986'; and Mbali, *The Treatment Action Campaign and the History of Rights-based, Patient-driven HIV/Aids Activism in South Africa*.
- 12 Ras et al., 'Acquired immunodeficiency syndrom: a report of 2 South African cases' and Fourie, 'One burden too many'.
- 13 *Cape Argus*, "'Homosexual" disease kills SAA stewards'.
- 14 *Cape Argus*, 'AIDS can be cured, claim homeopaths'.
- 15 Sher, 'HIV infection in South Africa, 1982–1988: a review'.
- 16 Department of Health, *Report National HIV and Syphilis Prevalence Survey South Africa 2006*; and Actuarial Society of South Africa, *ASSA2003*.
- 17 Cameron, 'Restrictions on migrant workers, immigrants and travellers with HIV/Aids: South Africa's step forward'; Linz, 'Private archive of newspaper clippings'.
- 18 McNeil Jnr, 'Aw, c'mon, you don't really believe those Aids myths?'
- 19 Jaffe, 'The early days of the HIV-Aids epidemic in the USA'.
- 20 Overbaugh, 'HTLV-1 sweet-talks its way into cells'.
- 21 Barré-Sinoussi et al., 'Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (Aids)'.
- 22 For much of this section I depended on Andersson, *The Discoveries of Human Papilloma Viruses That Cause Cervical Cancer and of Human Immunodeficiency Virus*.
- 23 See an excellent set of videos explaining retroviruses at Gallo, 'Virus basics'.
- 24 A CD4 cell has a CD4 receptor on it. It is this receptor that HIV binds to when it invades the cell. While all T Helper Cells have CD4 receptors, some other cells also have CD4 receptors.

- 25 Ewings et al., 'Survival following HIV infection of a cohort followed up from seroconversion in the UK'.
- 26 *Time Europe*, 'Mbeki: Africa's challenges'.
- 27 Shisana et al., *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005*; Weiser et al., 'Food insufficiency is associated with high-risk sexual behavior among women in Botswana and Swaziland'; and Rollins, 'Food insecurity: a risk factor for HIV infection'.
- 28 Sewankambo et al., 'Mortality associated with HIV infection in rural Rakai District, Uganda'.
- 29 Ainsworth and Over, *Confronting Aids: Public Priorities in a Global Epidemic*.
- 30 Much of the explanation of how AZT was discovered, tested and marketed is from Yarchoan, *The Story of AZT: Partnership and Conflict*.
- 31 *Sunday Times* of London, *Suffer the Children: The Story of Thalidomide*.
- 32 See an excellent explanation in Goldacre, *Bad Science*.
- 33 FDA, 'Memorandum from David J. Graham, MD, MPH, Associate Director for Science, Office of Drug Safety to Paul Seligman, MD, MPH, Acting Director, Office of Drug Safety entitled, "Risk of acute myocardial infarction and sudden cardiac death in patients treated with COX-2 selective and non-selective NSAIDs"'.
- 34 Fischl et al., 'The efficacy of azidothymidine (AZT) in the treatment of patients with Aids and Aids-related complex. A double-blind, placebo-controlled trial'; and US Public Health Service, 'Approval of AZT'.
- 35 Aids denialists consistently misinterpret the Concorde trial as evidence that AZT is toxic. This is nonsense. To see why, go to <http://www.aidstruth.org/new/denialism/myths> and read myth 9.
- 36 Duesberg, 'Can epidemiology determine whether drugs or HIV cause Aids?'; and Chiu and Duesberg, 'The toxicity of azidothymidine (AZT) on human and animal cells in culture at concentrations for antiviral therapy'.
- 37 FDA, 'AZT advisory meeting.'
- 38 Jordan et al., 'Systematic review and meta-analysis of evidence for increasing numbers of drugs in antiretroviral combination therapy'.
- 39 aidstruth.org, 'Debunking denialist myths'.
- 40 Montaner, DeMasi, and Hill, 'The effects of lamivudine treatment on HIV-1 disease progression are highly correlated with plasma HIV-1 RNA and CD4 cell count'. Information on when drugs were registered was obtained on the FDA website. Information on all drugs registered by the FDA can be found at <http://www.fda.gov/search/databases.html>.
- 41 Goozner, *The \$800 Million Pill*.
- 42 For other simple but slightly more detailed explanations, see avert.org, 'Introduction to HIV and Aids treatment' and TAC, *ARVs in Our Lives*. For a more detailed explanation, see aidstruth.org, 'Structural biology of HIV'.
- 43 Jordan et al., 'Systematic review and meta-analysis of evidence for increasing numbers of drugs in antiretroviral combination therapy'.
- 44 It is also worth noting that before SMART it was thought that Haart was responsible for some cardiovascular disease and organ failure. SMART showed that on the contrary it is HIV that is responsible for these and Haart provides a protective effect against them.
- 45 Here are just a few examples: Mocroft et al., 'Decline in the Aids and death rates in the EuroSIDA study'; Palella et al., 'Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection: HIV outpatient study investigators'; Jaspán, Berrisford, and Boule, 'Two-year outcomes of children on non-nucleoside reverse transcriptase inhibitor and protease inhibitor regimens in a South African pediatric antiretroviral program'; and Severe et al., 'Antiretroviral therapy in a thousand patients with Aids in Haiti'.
- 46 For a good review of the evidence on PMTCT, see US Department of Health and Human Services, 'Updated U.S. Public Health Service guidelines for the management of occupational exposures to HIV and recommendations for postexposure prophylaxis'.
- 47 US Department of Health and Human Services, 'Antiretroviral postexposure prophylaxis after sexual, injection-drug use, or other nonoccupational exposure to HIV in the United States'.
- 48 Government of South Africa, 'Response to former President of the United States: Jimmy Carter's comments on HIV/Aids strategy'.
- 49 Mbeki, 'Address to the National Council of Provinces'.
- 50 For a timeline of events on the mother-to-child transmission court case, see http://www.law-lib.utoronto.ca/Diana/TAC_case_study/additionalinformation.html. See also Cherry, 'South African government rejects AZT advice'.
- 51 Mbeki, 'The complete text of South African President Thabo Mbeki's letter to world leaders on Aids in Africa'.
- 52 BBC, 'Thabo Mbeki answers your questions'.
- 53 Volmink et al., 'Antiretrovirals for reducing the risk of mother-to-child transmission of HIV infection'.
- 54 For a good summary of the data on this, see El Beitune et al., 'Antiretroviral therapy during pregnancy and early neonatal life'. Also see Benhammou et al., 'Incidence of cancer in children perinatally exposed to nucleoside reverse transcriptase inhibitors'.
- 55 Bjelakovic et al., 'Antioxidant supplements for prevention of mortality in healthy participants and patients with various diseases'.
- 56 Irlam, Visser, and Rollins, 'Micronutrient supplementation in children and adults with HIV infection'.
- 57 Fawzi et al., 'A randomized trial of multivitamin supplements and HIV disease progression and mortality'.
- 58 Quoted in Rollins, 'Affidavit in TAC and Sama versus Rath and Others'.

Chapter 3

- 1 *ANC Today*, 'HIV/Aids: lend a caring hand of hope'.
- 2 Myburgh, 'Are you or have you ever been an HIV-denialist?'
- 3 TAC, 'HIV/Aids Treatment Action Campaign 10 December 1998: Day of Action International Human Rights Day'.
- 4 For some of the details on Napwa's and the Department of Health's joint financial mismanagement, see TAC, 'TAC statement on Auditor-General's qualified audit opinion'.

- of the Department of Health'. For a story on Nxesi and Doro's thuggish behaviour, see Heywood, 'Condemn the threats by Napwa against Aids activists'.
- 5 TAC, 'Electronic newsletter' and 'Christopher Moraka Defiance Campaign importing life-saving fluconazole'.
 - 6 ALP, 'Competition Commission settlement agreements secure access to affordable life-saving antiretroviral medicines' and TAC, 'What has happened to the Bristol-Myers Squibb \$1/day offer?'.
 - 7 This paragraph is largely taken from Geffen and Cameron, 'The deadly hand of denial: governance and politically-instigated Aids denialism in South Africa'. The price quoted for Cameron's monthly drug bill excludes VAT. ARV private-sector price list supplied by Medprax updated regularly on the TAC website, <http://www.tac.org.za/community/node/2021>, accessed 23/4/2008. 2008 public-sector prices are from KwaZulu-Natal Provincial Depot, 'ARV Catalogue and Price List 8.1.2008 (RT71-2004)'.
 - 8 Mthathi, 'Founding affidavit in court case between TAC and Others versus Minister of Health and Others'.
 - 9 It has been said that TAC's leadership is predominantly gay. I point out that besides Achmat and me, there have been no other gay members of the TAC secretariat. Jara is heterosexual.
 - 10 Schoofs, 'Flirting with pseudoscience'.
 - 11 Presidential Aids Advisory Panel, 'Presidential Aids Advisory Panel Report'.
 - 12 'Durban Declaration' and SAPA, 'Aids declaration "useless" – state'.
 - 13 SAPA, 'Drugs court case over, Aids patients to wait longer'.
 - 14 Feinstein, *After the Party*.
 - 15 Mbeki, 'Address at the Inaugural Z.K. Matthews Memorial Lecture'.
 - 16 TAC, 'Mother-to-child transmission prevention court case'.
 - 17 Constitutional Court of South Africa, 'Judgment by the Constitutional Court of South Africa in TAC and Others versus Minister of Health and Others'.
 - 18 TAC, 'A response to Minister of Health on mother to child transmission'.
 - 19 For details of the PMTCT case, see Heywood, 'Preventing mother-to-child HIV transmission in South Africa: background, strategies and outcomes of the Treatment Action Campaign case against the Minister of Health'.
 - 20 Leon, *On the Contrary*.
 - 21 Natrass, *Mortal Combat*.
 - 22 My retelling of the PMTCT case here, one of TAC's most important actions to get access to treatment, is superficial. I recommend Mark Heywood's *Preventing Mother-to-Child HIV Transmission in South Africa*. Edwin Cameron and I also dealt with it at some length in *Witness to Aids*.
 - 23 TAC, 'TAC welcomes Cabinet statement on HIV/Aids' and 'TAC condemns delays by government and business at Nedlac'.
 - 24 TAC, 'Press statement on use of Nelson Mandela's photograph on march poster'.
 - 25 Nevertheless, the relationship was soon repaired.
 - 26 TAC, 'TAC civil disobedience campaign update'.
 - 27 In 2008, there was violence at a TAC-organised march to Parliament against xenophobic violence. Hundreds of Somali immigrants, distraught and angry at having been displaced

- from their homes and businesses, tried to storm Parliament. The event got very ugly, but no one was seriously injured. However, the demonstrators who used violence were not TAC members and had no initiation in TAC's non-violent culture.
- 28 Natrass, 'Affidavit in TAC and Others versus State and Others' and Deane, 'The price of three million lives'.
 - 29 TAC, 'TAC sends letter of demand to Minister of Health'.
 - 30 Johnson, 'How big is the need for antiretroviral treatment?' estimates that in mid-2008 about 450,000 were on treatment in the public sector and another 100,000 treated by NGOs and in the private sector.
 - 31 TAC, 'Electronic newsletter'.
 - 32 TAC, 'Long waiting list for antiretroviral treatment at Mahatma Gandhi Hospital in Durban' and 'Treat 200,000 by 2006'.
 - 33 Mavasa, 'Nkhensani Mavasa's speech at the opening plenary of UNGASS today'.
 - 34 AFP, 'South African Aids activists arrested for "illegal" protest'.
 - 35 Abdool Karim et al., 'Letter to South Africa's President Thabo Mbeki'.
 - 36 TAC, 'HIV/Aids National Strategic Plan (NSP)'.
 - 37 Specter, 'The denialists'. Web links to the story can be found here: TAC, 'President Mbeki: do not dismiss Deputy Minister Nozizwe Madlala-Routledge. Can our people trust you on HIV/Aids?'.
 - 38 Ibid. and Mbeki, 'Letter to former Deputy Minister of Health, Ms Nozizwe Madlala-Routledge'.
 - 39 Hogan, 'Speech by the Minister of Health Ms Barbara Hogan at the HIV Vaccine Research Conference'.

Chapter 4

- 1 Specter, 'The denialists'.
- 2 CHMT, *Ubhejane*.
- 3 Tshabalala-Msimang, 'Traditional medicine is here to stay' and Department of Health, 'DA undermines indigenous knowledge'.
- 4 Vilakazi, 'African traditional medicine and modern science'.
- 5 Vilakazi, 'A new model of health-care delivery for KwaZulu-Natal'.
- 6 University of KwaZulu-Natal, 'University of KwaZulu-Natal statement on claims that its studies promote traditional medicine "Ubhejane".'
- 7 Vilakazi, 'HIV/Aids, suffering, death, science and responsibility'.
- 8 Ibid.
- 9 TAC, 'TAC complaint against charlatan Zebon Gwala upheld by Advertising Standards Authority' and Department of Health, 'Health on Ubhejane advertisement in Ilanga newspaper'.
- 10 CHMT, 'Siyayinqoba Beat-It!'
- 11 See Chapter 13 by Manders et al. in Health Systems Trust, *South African Health Review 2007*.
- 12 Shisana et al., *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005*; and Peltzer et al., 'Use of traditional complementary and

- alternative medicine for HIV patients in KwaZulu-Natal, South Africa’.
- 13 Department of Health, Medical Research Council, and Council for Scientific and Industrial Research, ‘National Reference Centre for African traditional medicines: a South African model’.
 - 14 Ashforth, ‘Muthi, medicine and witchcraft’.
 - 15 Venter and Joubert, ‘Aspects of poisoning with traditional medicines in southern Africa’; Babb et al., ‘Use of traditional medicine by HIV-infected individuals in South Africa in the era of antiretroviral therapy’; Brown et al., ‘Impact of traditional medicinal plant extracts on antiretroviral drug absorption’; and Mills et al., ‘Impact of African herbal medicines on antiretroviral metabolism’.
 - 16 See Wikipedia, ‘Hoodia gordonii’; Morris, ‘Little research behind claims that hoodia is safe, effective for losing weight’; and Bindra, ‘A popular pill’s hidden danger – The *New York Times*’.
 - 17 Liu, Manheimer, and Yang, ‘Herbal medicines for treating HIV infection and Aids’.
 - 18 Tshabalala–Msimang, ‘Traditional medicine is here to stay’.
 - 19 Tshabalala–Msimang, ‘Speech by the Minister of Health Dr Manto Tshabalala–Msimang at the Research Colloquium on African Traditional Medicine’.
 - 20 Wreford, ‘Traditional African healers in biomedical HIV/Aids interventions’ and ‘Collaborative efforts between biomedicine and traditional healers’.
 - 21 Ashforth and Natrass, ‘Ambiguities of culture and the antiretroviral rollout in South Africa’.
 - 22 For example, the Executive Summary states, ‘It is recommended that legislation on African Traditional Medicine be enacted to provide an enabling environment for African Traditional Medicine in its entirety and scope, covering but not limited to: the regulation of African Traditional Medicine in South Africa; registration and regulation of African Traditional Medicines and Medicinal Products in South Africa; protection of African Traditional Medicine knowledge and Intellectual Property rights; and the protection of the rights of persons involved in the discipline of African Traditional Medicine in South Africa.’ Note the absence of concern for patients. It also characterises scientific medicine as a Western colonial import, ‘The draft policy is premised on the following: ... The reality that African Traditional Medicine in South Africa has been at the centre of the livelihood of South African people long before colonialism and western civilisation touched the shores of the African continent, bringing with it western medicine and western ways of treating diseases ...’
 - 23 Mander in Health Systems Trust, *South African Health Review 2007*.
 - 24 TAC, ‘Equal treatment’.
- Chapter 5**
- 1 Orwell, ‘How the poor die.’
 - 2 The movie *Drum* was released in 2004 and stars Taye Diggs.
 - 3 Molakeng and Jasson, ‘Can garlic really cure Aids?’
 - 4 Cameron, *Witness to Aids*.
 - 5 Bhengu, *Debates of the National Assembly*.
- 6 *The Economist*, ‘Nozipho Bhengu, victim of Aids and quackery’.
 - 7 TAC, ‘TAC statement on the death of Nozipho Bhengu’.
 - 8 SAPA, ‘Bhengu family upset by “insensitive” TAC’ and *Mail & Guardian*, ‘Dangerous quackery’.
 - 9 In South Africa, provincial ministers are called Members of the Executive Council, or MECs. Thus, Peggy Nkonyeni was the MEC for Health in KwaZulu-Natal. The text, translated by Nokhwezi Hoboyi, is from CHMT, *Nozipho Bhengu’s Funeral*.
 - 10 Bogart, Kalichman, and Simbayi, ‘Endorsement of a genocidal HIV conspiracy as a barrier to HIV testing in South Africa’.
 - 11 Brits, ‘Burglars “peed” on Aids records’.
 - 12 Email correspondence between Nathan Geffen and Tine van der Maas. Also Geffen, *Encouraging Deadly Choices: Aids Pseudo-science in the Media*.
 - 13 See McGregor, *Khabzela*. The definition is from Singh, ‘The genus Hypoxis’.
 - 14 See ‘Examples of postdiction’.
 - 15 Tshabalala–Msimang, ‘Rooting out stigma: combating discrimination’.
 - 16 Soweto is South Africa’s biggest black township.
 - 17 Tshabalala–Msimang, ‘Speech by Minister in the Presidency Dr Manto Tshabalala–Msimang on the occasion of partnership consolidation with the church: celebrating the elderly people’s month and health awareness’.
 - 18 SAPA, ‘Aids patient backs Manto’.
 - 19 Ibid.
 - 20 Hsu et al., ‘Macronutrients and HIV/Aids: a review of current evidence’.
 - 21 Patient, ‘All pigs fed and ready to fly!!’
 - 22 Shisana et al., *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005*.
 - 23 Health Systems Trust, *South African Health Review 2007*.
 - 24 AFP, ‘Manto rolls out “Aids mantra”’.
 - 25 NICUS, *HIV: Should We Review Our Current Recommendations and Prescribe Food Combinations?*
 - 26 I did a search of the words garlic and candidiasis on 9 October 2008. The trial is described in Sabitha et al., ‘Efficacy of garlic paste in oral candidiasis’.
 - 27 Motsei et al., ‘Screening of traditionally used South African plants for antifungal activity against *Candida albicans*’.
 - 28 Piscitelli et al., ‘The effect of garlic supplements on the pharmacokinetics of saquinavir’.
 - 29 Personal communication with Carol Thomson of Essential Sterolin Products.
 - 30 Essential Phytosterolins Inc., ‘About us: Moducare’.
 - 31 Using Stats SA’s strict definition, the unemployment rate is 28%. Using the broad definition it is 38%. Provide Project, ‘A profile of KwaZulu-Natal: demographics, poverty, inequality and unemployment. Background paper 2005:1(5)’. The province’s Gini coefficient, the standard measure of inequality, is 0.71, which is worse than the already appalling national average. Also see Mahlatsi, ‘A review of KwaZulu-Natal socio-economic development’.

Chapter 6

- 1 US Government, 'Nuremberg Code: directives for human experimentation'; also see World Medical Association, 'Declaration of Helsinki'.
- 2 Rath Health Foundation, *Rath Health Foundation Press Conference: Marietta Ndziba*.
- 3 Rath, 'Open letter by Matthias Rath, M.D. to the health food community in the USA'.
- 4 SWR, 'Der Fall Dominik'.
- 5 *BMJ*, 'Dr Matthias Rath'.
- 6 For full details, see TAC, 'Release of documents showing collusion between some government officials, including Anthony Mbewu, and Matthias Rath'.
- 7 Makgoba, 'HIV/Aids'.
- 8 *Cape Argus*, 'Minister demanded "corrective action" at MRC'.
- 9 Sparks, *Beyond the Miracle*.
- 10 SAFM, 'Transcript of debate between Nathan Geffen and Anthony Brink on Tim Modise show on SAFM'.
- 11 George Stacey also lodged a complaint independently of TAC. Asasa consolidated the two complaints into one.
- 12 Gray, 'Affidavit in TAC and Sama v. Rath and Others'.
- 13 Dr Rath Health Foundation SA and Sanco, 'Micronutrients in controlling immune deficiency and Aids'.
- 14 Sanco and Dr Rath Health Foundation Africa, *End Aids! Break the Chains of Pharmaceutical Colonialism*.
- 15 Joubert, 'Health Department DG frees seized Rath drugs'.
- 16 This chapter uses the affidavits in *TAC and Sama v. Rath and Others*. See Geffen, 'Founding affidavit in TAC and Sama v. Rath and Others' and TAC, 'The wrongs of Matthias Rath'.

Chapter 7

- 1 Vonnegut, 'Sirens of Titan'.
- 2 Ntshangase, 'Pagad and TAC two sides of the same coin'.
- 3 Achmat, 'Replying affidavit in TAC versus Rath and Dr Rath Health Foundation'.
- 4 Unless otherwise stated, all references to the quackery court case in this chapter can be found in the court papers. A full copy of the court papers is available at the Cape High Court. A copy of the papers is also in the TAC national office, but they may not be removed from the premises and viewing them would have to be arranged in advance. Some of the papers, including most of TAC's affidavits, the heads of argument and the judgment, can be found at TAC, 'The wrongs of Matthias Rath'.
- 5 It is worth mentioning Quanta Incorporated, the law firm that acted on Rath's behalf in South Africa. Christine Quanta, the senior partner in the company, has been a supporter of Mbeki, particularly his racial nationalism, which permeates her own writing. Mbeki appointed her to a presidential task team on African traditional medicines along with Anthony Mbewu, Herbert Vilakazi and two others. Quanta has herself been implicated in quackery by TAC. She was one of the directors of a company called Comforter's Healing Gift. A TAC member, Emma Baleka, worked together with two journalists to sting the

company. They went to its premises in Uitenhage. The sign outside read 'Our mission is to fight all Aids-related illnesses'. One of the journalists, Nompumezo Makinana, pretended to need treatment for AIDS. Quanta's co-director, Freddie Isaacs, ran the facility. He offered her pills and some other potion for which they paid R210. He told her these would cure Aids and that she should not take ARVs because they would not help. He told Nompumezo that if she used these medicines and went for a CD4 test, the doctor would never say she's HIV-positive again. On the wall of Isaacs's office was a photo of him and Tshabalala-Msimang when he launched Comforter's Healing Gift. Quanta later denied any knowledge of what Isaacs was doing.

- 6 Brink, 'Affidavit in TAC and Sama versus Rath and Others'.
- 7 Hartzenberg, 'UKZN v Medicines Control Council [2007] JOL 20137 (T)'; HIV Prevention Trials Network, 'HPTN 046: Phase III trial to determine the efficacy and safety of an extended regimen of nevirapine in infants born to HIV infected women to prevent vertical HIV transmission during breastfeeding'; Msweli, 'Launch of HPTN 046 study'; and personal communication with Hoosen Coovadia.
- 8 Brink, 'In the International Criminal Court at the Hague criminal complaint against Abdurrazack "Zackie" Achmat'.
- 9 Rusbridger, 'A chill on The Guardian'.

Chapter 8

- 1 Krieger, 'Administrator, Cape v Raats Röntgen & Vermeulen (Pty) Ltd 1992 (1) SA 245 (A)'.
- 2 This section is primarily based on three sources: an interview I conducted with Johan Schlebusch; Schlebusch, 'Short history of the regulation of complementary medicines'; and Hiemstra, 'Schlebusch & Brückner vs. the Department of Health'. The first two of these are not in the public domain.
- 3 Ibid.
- 4 See Specter, 'Miracle in a bottle' and Schlebusch, 'Short history of the regulation of complementary medicines'.
- 5 Myburgh, 'The Virodene affair'.
- 6 Hiemstra, 'Schlebusch & Brückner vs. the Department of Health'.
- 7 Ibid.
- 8 Labour Court of South Africa, 'Public Servants Association of South Africa obo Schlebusch and Brückner v Department of Health (J6086/99) [2001] ZALC 125'; Labour Court of South Africa, 'Brückner v The Department of Health and Others (J1510/02) [2003] ZALC 129'.

Chapter 9

- 1 In Clayden, 'Adapting i-Base materials'.
- 2 These songs are available at TAC, 'The Generics – Jikilele'.
- 3 Healthlink, 'Treatment literacy: empowering communities to access Aids treatment'.
- 4 Chigwedere et al., 'Estimating the lost benefits of antiretroviral drug use in South Africa';

Nattrass, 'Aids and the scientific governance of medicine in post-apartheid South Africa'.

This section is based on Geffen, 'Lost benefit of ARVs in South Africa'.

5 Coalition against Fraudulent Claims about Medicines, 'Patrick Holford'.

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