MAKE TRUTH POWERFUL:

LEADERSHIP IN SCIENCE, PREVENTION AND THE TREATMENT OF HIV/AIDS

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Closing address: Microbicides 2006

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Speak truth to power but make truth powerful.

Jeremy Cronin: ANC MP and SACP Deputy General-Secretary

When there are so many we shall have to mourn,
when grief has been made so public, and exposed
to the critique of a whole epoch
the frailty of our conscience and anguish,

of whom shall we speak? For every day they die
among us, those who were doing us some good,
who knew it was never enough but
hoped to improve a little by living.

WH Auden: In Memory of Sigmund Freud

In our time, political speech and writing are largely the defense of the indefensible. Things like the continuance of British rule in India, the Russian purges and deportations, the dropping of the atom bombs on Japan, can indeed be defended, but only by arguments which are too brutal for most people to face, and which do not square with the professed aims of the political parties. Thus political language has to consist largely of euphemism, question-begging and sheer cloudy vagueness. Defenseless villages are bombarded from the air, the inhabitants driven out into the countryside, the cattle machine-gunned, the huts set on fire with incendiary bullets: this is called pacification. Millions of peasants are robbed of their farms and sent trudging along the roads with no more than they can carry: this is called transfer of population or rectification of frontiers. People are imprisoned for years without trial, or shot in the back of the neck or sent to die of scurvy in Arctic lumber camps: this is called elimination of unreliable elements. Such phraseology is needed if one wants to name things without calling up mental pictures of them.

George Orwell – Politics and the English Language

In his State of the Nation address on 11 February 2005, President Thabo Mbeki cautiously and carefully described South Africa's health crisis:

> "Broad trends in mortality confirm the need for us to continue to pay particular attention to the health of our nation. With regard to AIDS in particular, the government's comprehensive plan, which is among the best in the world, combining awareness, treatment and home-based care is being implemented with greater vigour."

A little more than a year before, in December 2003, Treatment Action Campaign (TAC) leader and activist Lorna Mlofana was raped some 20 kilometers away from Parliament, the site of President Mbeki's address. When Lorna's rapist discovered that she had HIV, she was brutally murdered.

More than two years later on 16 February 2006 and only after a sustained public campaign by TAC activists in the Western Cape, a man was convicted and sentenced to

life in prison for Lorna's rape and murder.[1] Lorna's HIV-related death – and the deaths of hundreds of thousands of her fellow South Africans each year – cannot be wished away as broad trends in mortality. Instead, they speak to the crisis of violence, illness and death that our HIV prevention and treatment programmes appear unable and unwilling to stop.

In her opening address to this conference, Mrs. Graça Machel passionately conveyed the limitations of current prevention efforts and the need to rethink prevention strategies. In addressing vulnerability, risk and the impact of HIV/AIDS on women in Africa, she highlighted the urgent need for microbicides. While Microbicides 2006 has placed a spotlight on the development of – and the need for – female controlled prevention tools, it has also provided each one of us with the opportunity to assess HIV prevention more broadly. Everyone present realizes that there is a local and global crisis of HIV prevention.

With a few notable exceptions, prevention efforts in South Africa and beyond have largely failed for a complex set of social, political, economic and cultural reasons. And we all carry the responsibility for the failure of HIV prevention –governments, international agencies, business, the scientific community, faith-based organizations, civil society bodies, communities and individuals.

Treatment activism teaches us that prevention is political. HIV prevention advocacy and activism must be placed on the agenda of every scientist, health professional, activist and community leader. HIV prevention advocacy must be scientifically rigorous. It must unequivocally defend the autonomy, dignity and equality of women and girl-children. It must promote the needs and protect the marginalized and vulnerable in every context, whether gay men, sex workers, injecting drug users, prisoners, migrants, refugees or children.

At Sunday's Community Prevention Meeting held prior to the start of this conference and co-hosted by TAC, the Chris Hani Institute, the Gender AIDS Forum, the AIDS Law Project and others, we affirmed these principles. Our demands of the international community, South Africa's business community and our government are clearly spelt out in a memorandum we handed over to this conference. I urge every conference participant to support our demands.

The continuing increase in new HIV infections is an emergency. Every new infection undermines the rights to life, dignity, access to health care and social services for all. Every new infection means an increased burden of illness on individuals, families, households, communities, the health service and the country as a whole. HIV infection is

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[1] See TAC E-Newsletter 16 February 2006 and other documents at www.tac.org.za for a fuller account of the incident. A woman was also convicted of assault (sentenced to 10 years' prison).

an incurable, life-threatening condition and can only be treated as a chronic illness with antiretroviral therapy for life.

On what do I base my assessment that we are facing a prevention crisis? I want to illustrate with data, experience and reflection from South Africa, because it is my context and home.

South Africa has invested significant financial, human and planning resources in responding to the HIV epidemic. For example, condom distribution increased from about 1 million male condoms in 1994 to well over 400 million male condoms in just ten years. Since a Constitutional Court order compelled it to implement a prevention of mother-to-child HIV transmission (PMTCT) programme in 2002, government – on its own reports – has expanded the programme to more than 1500 sites nationwide. And more than 120 000 people are currently accessing ARV treatment in the public sector.

These huge investments in health have involved great effort. Yet the massive condom distribution amounts to fewer than 35 condoms per sexually active male per year. Government would be the first to admit that the quality of care in – and the implementation of – the PMTCT programme have been highly uneven. And more than 500 000 people in need of ARV treatment still do not have access. But the potential to save lives is there – especially if the PMTCT programme moves beyond the single-dose nevirapine regimen and is properly integrated with maternal and child health programmes, and ARV treatment is easily accessible.

Tragically, the positive developments have been overshadowed by a crisis of leadership, most visible in the form of AIDS denialism – denying the link between HIV and AIDS, and denying the crisis of illness and death. This irrationality has underpinned much of the health ministry's lack of good governance, resulting in unnecessary, predictable and premature deaths. So while our government has placed more than 120 000 people on ARV treatment, its leadership continues to send mixed messages, undermines its own programme and attempts to bully scientists, civil society and anyone who affirms scientific rigour. These actions also undermine HIV prevention.

Despite the crisis of morbidity and mortality, South Africa still sees more new HIV infections every year than deaths. The Department of Health itself estimated that there were 5.6 million people living with HIV/AIDS in South Africa in 2003 (2004 antenatal survey). The 2005 antenatal survey estimated more than 6 million people living with HIV/AIDS in 2004.

An increase of ± 500 000 new HIV infections in one year will place an additional burden of half a million people who will be ill and require ARV treatment in 7 – 12 years. This will mean further suffering for hundreds of thousands of people, and possibly unmanageable demands on the health system and the economy. That this burden of infection, illness,

death and care is disproportionately carried by women and marginalized individuals and groups is not disputed.

In July 2005, the Department of Health published the following breakdown of the ante-natal survey for 2004. **We now have about 1500 new HIV infections each day.** When compared to the mortality data on a provincial basis below, there is a direct correlation between provincial HIV prevalence and death rates.

Province	**HIV prev (CI 95%) 2002**	**HIV prev (CI 95%) 2003**	**HIV prev (CI 95%) 2004**
KwaZulu-Natal	36.5%	37.5%	40.7%
Gauteng	31.6%	29.6%	33.1%
Mpumalanga	28.6%	32.6%	30.8%
Free State	28.8%	30.1%	29.5%
Eastern Cape	23.6%	27.1%	28.0%
North West	26.2%	29.9%	26.7%
Limpopo	15.6%	17.5%	19.3%
Northern Cape	15.1%	16.7%	17.6%
Western Cape	12.4%	13.1%	15.4%
South Africa	**26.5%**	**27.9%**	**29.5%**

Department of Health 2004 antenatal HIV seroprevalence results (published July 2005)

Further evidence for levels of infection – from the Human Sciences Research Council (HSRC) and the Medical Research Council (MRC) – was published during March 2005. After surveying more than 17 000 educators across the country, the HSRC/MRC survey found a 12.7% overall infection rate. Among educators in the age group 25 – 34, the infection rate was 21.4%.

Province	HIV positive %	No. Educators
Western Cape	1.1	2 134
Eastern Cape	13.8	1 855
Northern Cape	4.3	891
Free State	12.4	1 152
KZN	21.8	3 627
North West	10.4	1 437
Gauteng	6.4	2 772
Mpumalanga	19.1	1 315
Limpopo	8.6	1 905
South Africa	**12.7**	**17 088**

Educators HIV seroprevalence survey HSRC/MRC 2005

One can safely say that the majority of public schools in South Africa have teachers who live with HIV/AIDS, with women educators being disproportionately affected. But education is not alone. The HIV infection rate amongst educators demonstrates the burden that every sector of our economy will face over the next few years. This demands that we review all prevention efforts and redouble efforts to find safe and effective microbicides.

Our understanding of the scale and nature of the HIV epidemic in South Africa is broadened by the 2004 Reproductive Health and HIV Research Unit (RHRU) and loveLife study of youth aged 15 – 24, which remains one of the most important tools to **understand youth prevention work.** The study highlights at least five major factors we must take into account in our prevention work:

- Girls and young women are at greater risk of HIV infection than boys and young men.
- As young men get older their risk for HIV infection increases.
- All schools and communities will have children with HIV/AIDS.
- Most youth (including those with HIV) believe they are not at risk of HIV infection.
- 80% of young people had not had an HIV test.

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Gender	Age	HIV Positive%	Number
Female	15-24	15.5	6 217
Male	15-24	4.8	5 687
Female	15-19	7.3	3 682
Male	15-19	2.5	3 556
Female	20-24	24.5	2 535
Male	20-24	7.6	2 131
All	**15-24**	**10.2**	**11 904**

AGE 15-24 NATIONAL SURVEY 2004 REPRODUCTIVE HEALTH RESEARCH UNIT

The most revealing statistic of the RHRU/loveLife survey is the fact that 73% of HIV negative youth believed that they were not at risk for HIV infection. **Most significantly, 62% of HIV positive youth (who did not know their own HIV status) believed that they were *not* at risk for HIV infection.**

It is a tragedy that 25 years into the epidemic, Naledi Pandor – our Minister of Education — mimics George Bush when she ignores the scientific evidence and refuses to make condoms available in schools. The absence of serious sexuality education also places learners at increased risk of teenage pregnancy, STIs and HIV infection. It violates their rights to education, access to health care services, life, dignity and autonomy. Pandor's immoral position undermines informed choice and places youth at increased risk of harm.

We have a pretty complex and nuanced understanding of the HIV prevention crisis and yet the official response from government is the dangerous, unhelpful and simplistic ABC campaign. As Graça Machel told us on Sunday:

> "The existing methods to prevent HIV infection are failing many women. Asking women to simply **abstain, be faithful, or use condoms** is not practical. Nor is it enough - especially when UNAIDS reports that 75 percent of new infections are acquired from a spouse or regular partner. … Marriage, or being in what a woman thinks is a monogamous, faithful relationship, is sadly, one of the biggest HIV risk factors for many young African women."

The failure of HIV prevention leads to death. In South Africa, children die before their parents because of HIV/AIDS. We know this, as do the Mandela and Buthelezi families, from experience. We also know this from the statistics. In 1997, most adults died in the age groups 65 – 69 (7.38%) and 75 - 79 (7.39%). But by 2003, Statistics South Africa (StatsSA) records that the highest number of deaths occurred in the age group 30 – 34 (9.78%). In addition, infant mortality rose dramatically between 1997 and 2002 – by 40%.

Year	Recorded Deaths	% increase
1997	318 287	-
1998	367 689	15.5
1999	381 902	3.9
2000	413 969	8.4
2001	451 936	9.2
2002	499 268	10.5

Recorded deaths in South Africa between 1997 and 2002 – data from valid death notification forms (Source: StatsSA, 18 February 2005)

The StatsSA data show three clear changes in mortality patterns:

- **early death:** “the figures suggest that there has been a significant increase in the number of deaths amongst men aged 30-44 and amongst women of reproductive ages”;
- **the distribution of deaths:** the provinces worst affected by HIV are experiencing increasing deaths and;
- **the causes of death** have changed dramatically.

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Age	1997	1998	1999	2000	2001	2002
0-4	34 779	41 171	40 139	40 768	41 920	48 572
20-24	13 574	15 682	16 892	18 500	19 655	21 838
25-29	18 227	22 797	26 375	30 348	35 667	41 412
30-34	18 903	24 008	28 404	33 909	39 203	46 758
35-39	18 733	23 419	27 118	31 814	36 568	43 020
40-44	18 086	21 816	24 041	27 868	31 893	36 614
45-49	18 530	21 808	23 445	25 452	28 611	31 681
50-54	17 495	20 202	21 596	24 213	26 864	29 613
65-69	23 501	25 733	25 171	24 522	25 719	26 902
75-79	23 525	23 935	22 292	21 830	22 848	23 875

Total Recorded Deaths by Selected Age Groups and Year of Death (Source: StatsSA)

Province	1997	1998	1999	2000	2001	2002
W. Cape	33 292	36 347	38 088	38 540	41 042	43 667
E. Cape	45 345	50 918	53 851	60 602	65 719	73 072
N. Cape	8 495	9 441	9 187	9 847	10 421	11 267
Free State	25 375	30 142	31 625	34 101	36 877	40 715
KZN	70 487	83 048	86 156	95 353	105 256	116 982
North West	25 026	29 458	32 395	35 437	39 723	44 269
Gauteng	67 734	75 993	75 445	80 425	86 213	95 186
MPL	20 122	23 926	25 899	28 273	31 548	35 277
Limpopo	22 338	28 302	29 135	31 263	34 901	38 639
Total including outside RSA	**318 287**	**367 689**	**381 902**	**413 969**	**451 936**	**499 268**

Total Recorded Deaths by Province 1997 – 2002 (Source: StatsSA)

From the tragedy of the death certificate statistics, another very important set of facts can be learned: **the burden of HIV on the health systems**, caused by the increase in disease burden. For example:

- TB deaths increased from 22 021 in 1997 to 50 872 in 2001. In just four years, the disease burden from these deaths more than doubled.

- "Other heart disease" deaths increased more or less in line with population increases from 20 103 in 1997 to 22 602 in 2001, showing that the pre-HIV disease pattern remained high.

This conclusion can be strengthened by comparing every HIV-related cause of death with non-HIV related deaths. For instance, cerebrovascular disease increased from 16 992 in 1997 to 22 577 in 2001. It is unclear what the effect of HIV has been on the increase in this category. But, compare this to deaths due to influenza and pneumonia, deaths that in this age group are indisputably linked to HIV disease. Influenza and pneumonia deaths increased from 11 503 in 1997 to 31 495 in 2001.

Everyone working in the health care sector knows that additional nurses, doctors, clerks, cleaners, managers, dentists or pharmacists were not employed to cope with this demonstrated increase in the disease burden. This has direct consequences for the quality of care and for staff burn-out.

This increasing burden of HIV disease affects people of reproductive age and those who are economically active. People age 15 to 49 are dramatically affected by new HIV infection, illness and AIDS deaths. This has meant an increase in household expenditure on health care and funerals, out of a decreased family income as a result of illness. Tragically, the impact of every death recorded on these death certificate has meant the loss of a breadwinner, a parent or a child.

In the words of Henk Roussouw, who delivered the Ruth First Memorial Lecture at Wits University on 25 August 2005:

> "A death because of Aids, a treatable disease, is a loss for every member of the body politic, from the Union Buildings all the way down to Mathibestad, 70km north of Tshwane, population 21 700."[2]

But instead of a rational response, our government has promoted a conspiracy of silence, attempting to make these deaths invisible. To repeat President Mbeki's words that symbolize the silence, invisibility and obfuscation that surrounds the increase in HIV/AIDS deaths:

> "Broad trends in mortality confirm the need for us to continue to pay particular attention to the health of our nation. With regard to AIDS in particular, the government's comprehensive plan, which is among the best in the world, combining awareness, treatment and home-based care is being implemented with greater vigour."

Tragically, President Mbeki continues to display all the symptoms of denialism. Before his address to Parliament in February 2005, he and his Cabinet had seen the StatsSA report on the increase in certified deaths – from 318 287 in 1997 to 499 268 in 2002. "Broad

[2] Henk Rossouw (2005)

trends in mortality" is his way of describing the epidemic that is causing unprecedented death during his term of office. His silence represents a crisis of leadership. Unfortunately, he is not alone.

It was remarkable to hear our Minister of Health speak on Monday about the ethics of clinical trials. Under the leadership of Professor Peter Eagles (as chairperson) and Dr Humphrey Zokufa (as registrar of medicines), and under her watch as health minister, the Medicines Control Council (MCC) has consistently failed to stop a host of AIDS denialists – Matthias Rath, Sam Mhlongo, David Rasnick, Tine van der Maas – from unlawfully and unethically conducting experiments on people living with HIV/AIDS.

Regrettably, TAC and the South African Medical Association will be in court against our government – including the Minister and the MCC – later this year, seeking an order that it comply with its constitutional obligations and enforce the laws dealing with clinical trials and medicine sales and claims. The efforts of Rath – who claims that his vitamins cure diabetes, heart disease, HIV/AIDS and more recently bird flu – would be laughable if it were not for the state-sponsored AIDS denialism that continues to cause premature and preventable death.

There are many excellent scientists in the Medical Research Council (MRC) producing quality research. But it is disturbing that under the leadership of Dr Anthony MBewu that a once proud state institution (as a co-sponsor of this conference) is now a site of contestation between science and superstition. MBewu has attempted to disguise the fact that the StatsSA report on death certificates shows that HIV/AIDS is the largest cause of death. In a report to Parliament, he pronounced as follows:

> "Before one can investigate the socioeconomic impact of a disease, it is necessary to understand its natural history. This is the first stumbling block – we simply do not understand the natural history of HIV and AIDS."

On 16 March 2005, a month **after** the release of death certificate data that demonstrated to any thinking scientist – beyond any reasonable doubt – that HIV/AIDS has altered life-expectancy and mortality patterns, MBewu "defended the indefensible". He deliberately utilized "modeling data" to confuse parliamentarians intimidated by science and an over-powering executive. Instead of fulfilling a constitutional and statutory mandate, he chose to assist AIDS denialism:

> "Much of the socioeconomic impact of HIV and AIDS arises due to the death of South Africans at a young age, between 25 and 45, an age when they are still economically and socially active as can be seen from these three slides from our Burden of Disease Research Unit at the MRC. To quantify this mortality is difficult as vital registration or certification of death by doctors does not provide an accurate figure for AIDS-related deaths. This is partly due to the reluctance of doctors to write HIV or AIDS on the death certificate. Thus in 1996 the cause of death data estimated 2% of deaths were due to AIDS, and in 2001 2.8% clearly an underestimate. Demographic modelling is therefore used such as the Actuarial Society of South Africa 2000

> model (ASSA2000), which estimated AIDS-related deaths in 2000 to have been approximately 165 000."

There is no science – let alone compassion – in this statement. His obfuscation simply ignores the three million death certificates counted, the graves, the families left behind. In this context, TAC's work, voice, strategy, identity, struggle and community mobilisation remains pivotal to address the crisis of prevention, illness and death in South Africa. But what about the world beyond our borders?

As we all prepare for the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in six weeks it remains important to take the long view of the HIV/AIDS epidemic.

First, HIV/AIDS represents the most critical challenge for humanity and our responses must be based on a vision of social justice, freedom and equality.

Second, science, its methods and rigour must inform the actions of every leader, activist, institution and community. There are no quick fixes – not in science or in social science. Microbicides are essential but they will not automatically create gender equality.

Third, we must promote and demand a feminist response to the epidemic because it is right and because women are subjected to cultural, social, political and economic inequality.

Fourth, the human rights of every person and group disproportionately affected by the epidemic must be respected, protected and promoted nationally and internationally.

Fifth, clear targets for HIV prevention, treatment and care must be set at national level by every country through an open and accountable process. This must include the promotion of accurate messages at every level of society.

Sixth, governments and the private sector have a legal and moral duty to meet the resource demands of the epidemic. This includes the demand that the pharmaceutical industry must invest in microbicides research and development.

Last, learning at every opportunity must be our duty. This conference has been an important learning experience for hundreds of activists in South Africa. The Treatment Action Campaign will join a national community prevention alliance to scale up existing methods and to advocate for new technologies including microbicides and vaccines.

All this requires leadership and exemplary activism. We live in a world that must be changed to survive. As scientists you have a duty to promote and defend science and its uses for public benefit.

Thank you.

[ENDS]