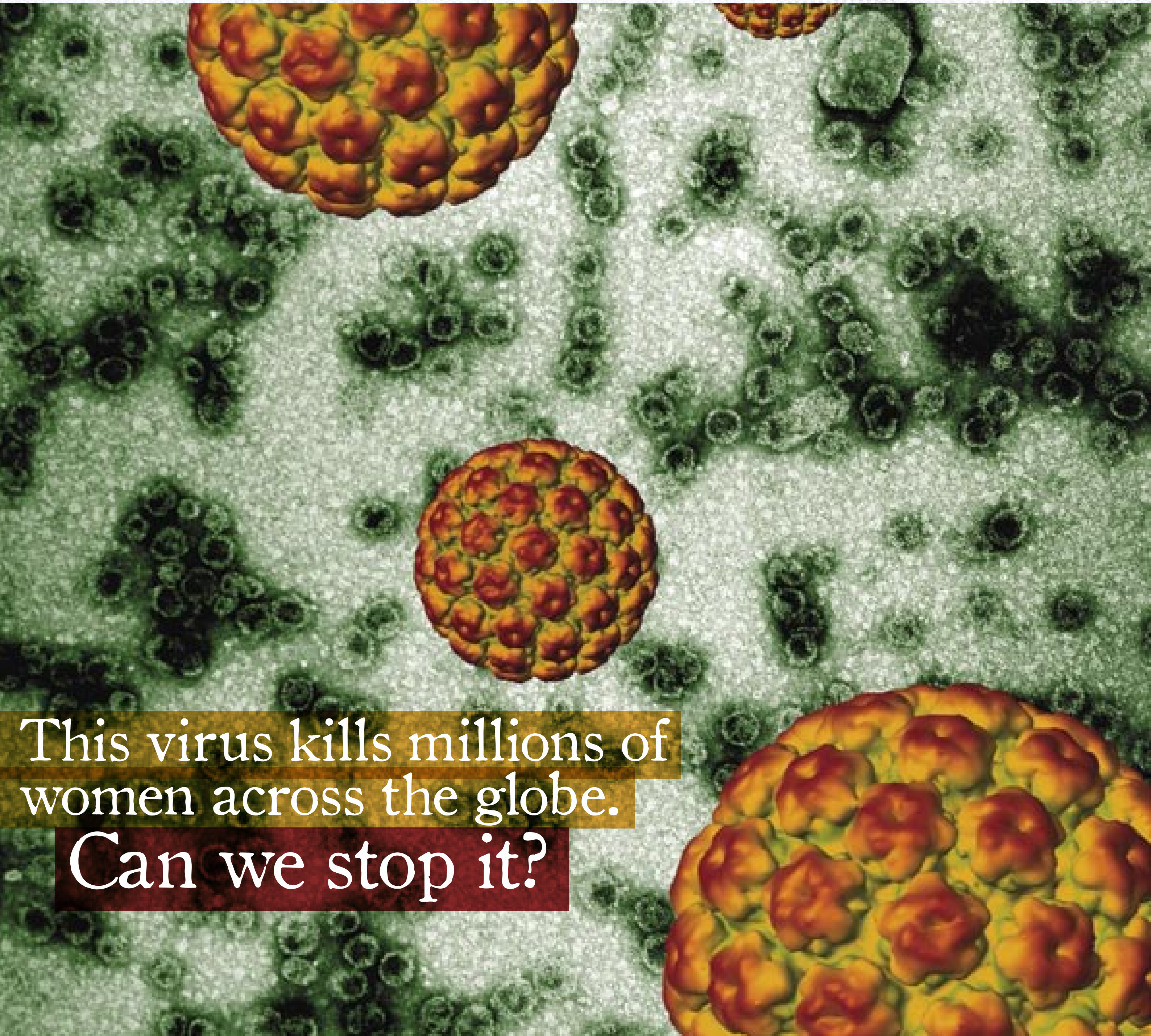
EQUAL treatment

Issue 22 / May 2007



This virus kills millions of women across the globe.

Can we stop it?

CONTENTS

Issue 22 / May 2007

Editors: Nokhwezi Hoboyi and Nathan Geffen

Thank you to Wolfgang Tillmans for allowing *Equal Treatment* to reproduce his photos from the book *Why we must provide HIV treatment information*.

Front cover images by Dr Arvind Varsani, Electron Microscope Unit, University of Cape Town. First published in this issue of *Equal Treatment* and hereby released into the public domain.

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TAC is committed to providing people with HIV, their families and caregivers accurate information about life-saving medicines and treatment. However, TAC and its leaders are independent of the pharmaceutical industry and have no financial interests with it.

TAC
TREATMENT ACTION CAMPAIGN

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page 4-15

HIV education around the world

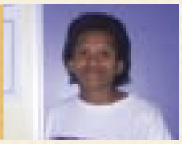
TAC is sometimes perceived as an organisation whose primary work is to toyi-toyi for HIV treatment. While the value of toyi-toying should not be underestimated, most TAC activists will explain that HIV education, often called treatment literacy, is by far the most important work the organisation does. The article also looks at the work of other treatment literacy organisations across the world.

page 18-19

How do we stop drug-resistant TB?

Dr Nesri Padayatchi explains how we need to respond to the drug-resistant TB epidemic.

page 20-22



It's my life

People living openly with HIV tell their stories.

page 23

Give us pap smears!

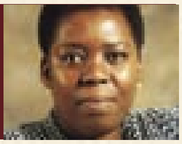
TAC Limpopo members campaign for pap smears in a clinic.

page 24-25

Front cover story: Is the end of cervical cancer in sight?

This fact sheet explains cervical cancer caused by the Human Papilloma Virus.

page 26-28



A plan to save lives

We explain the five year National Strategic Plan for HIV/AIDS and Sexually Transmitted Infections.

page 29

Interview with Josh Hawks

FRESHLYGROUND's bass player explains why they're concerned about HIV and other social issues.

page 30-33

The Media: Messenger of life or death?

We look at the best and the worst of the media's coverage of HIV.

page 34-36

Tenofovir: The MCC and drug companies are failing us

We explain the importance of tenofovir and criticise the MCC, Gilead and Aspen Pharmacare for failing to register it.

EDITORIAL

HIV education for all!

Treatment for HIV/AIDS is being scaled up across the world. With this, comes the need for more people to access accurate information about HIV prevention, treatment and care. High quality communication and education are essential for people living with HIV, their supporters and the general population. With knowledge, people living with HIV can regain their confidence to take control of their lives. It is for this important reason that this month's issue focuses on HIV education, which most people in TAC call treatment literacy.

With treatment literacy, it becomes possible for people to draw conclusions about HIV for themselves and not because they are being told by a priest or doctor, for example that condoms used regularly can prevent HIV infection or that proper eating and taking your medicines correctly will ensure that you live a longer and healthier life. Treatment literacy empowers people living with HIV and those who support them.

We believe that ordinary people can learn the science of diseases and medicine. People who are treatment literate take medicines because they understand the evidence that shows they work, not just because they have been told it works.

Much progress has been made by TAC and our partner organisations in Africa, Asia and Eastern Europe to bring HIV education to communities. We show some examples of these programmes in this issue.

Can we stop cervical cancer?

There is much treatment literacy we all still need to learn. TAC has prioritised women's sexual and reproductive health and we are developing educational materials to support this campaign. For example, this month's front cover has images of the Human Papilloma Virus (HPV), which causes cervical cancer and kills hundreds of thousands of women globally every year. Two new vaccines have been developed and approved in the United States. We need these vaccines in Africa now – and at affordable prices for our governments to buy them. However, questions remain about the effectiveness of the vaccines for the types of HPV we see in Africa. Our fact sheet on HPV explains these issues.

New HIV/AIDS plan brings hope

As we go to press, final changes are being made to the National Strategic Plan. The plan will be sent to SANAC for final approval. If implemented properly, families will be saved from disintegration, millions of people with HIV will live longer healthier lives and hundreds of thousands of new infections will be prevented every year. There is real hope ahead.

Sipho Mthathi
TAC General Secretary

We answer your letters

Winning letter:

Dear Editor

I was diagnosed with HIV on 28 July 2003. I am still healthy. I have not been sick since then. I have tested for TB several times but no TB was found. The only problem is my CD4 count goes up and down and I don't know why because I use a condom when I have sex. It causes me a lot of stress because I'm not willing to take antiretrovirals yet. I want to stay healthy without them for ten years or more, like other people. I don't like to use boosters because I don't trust them. I am taking cotrimoxazole and vitamins. How can I maintain my CD4 count in good condition so that I can be a long term survivor without antiretrovirals? I am not against antiretrovirals, I just want to be a long term survivor.

Xoliswe Melude

Most people do not need antiretrovirals for eight to twelve years after being infected. About one in every 30 people are lucky: they do not need treatment for much longer, even up to two decades. There is some evidence that your lifestyle can have a small but significant effect on your CD4 count and help you delay treatment. Regular aerobic exercise (e.g. running), as well as weight training have been shown to help. So does deworming. Also, a daily vitamin supplement has been shown to help Tanzanian HIV-positive women a little, but it has not been shown to help people in higher income countries like the US. Probably the biggest factor determining when you will need treatment is chance, i.e. your genes and the strain of the virus that you have – things you unfortunately have no control over. But once you need them, antiretrovirals will help you become a long-term HIV survivor.

Incidentally, condoms protect you from getting or transmitting HIV and other sexually transmitted infections. They are also a contraceptive. They do not have any other effect on your health and will not effect your CD4 count.

Dear editor

I want to know why TAC concentrates more on medicines, rather than on the cure itself.

Bongani

The cure for HIV is many years away. But there are medicines available now that can help people with HIV live normal, healthy lives. We must, therefore, concentrate on getting people access to these medicines. However, we take your point and will in a future issue of *Equal Treatment* have a special focus on vaccine research. A successful therapeutic vaccine would be as close to a cure as we are likely to get for a long time to come.

Die Redakteur

Dankie vir die voorreg om aan u te skryf as `n HIV pasiënt. Ek glo en hoop dat daar wel hulp en genesing sal kom indien die navorsers voortgaan om `n teenmiddel te soek.

Wat my egter bekommer, is dat ek as gevangene te Riebeek-Wes, nie voldoende behandeling ontvang nie. Ons medikasie is nie gereeld nie. Ons voedsel is nooit volgens voorskrif nie. Ons het al gepraat en ons besware geopper maar dit val op dowe ore. Slegs leë beloftes en intussen gaan ons gesondheid agteruit. Ons kan dalk net soos so baie ander `n statistiek word van mense wat gesterf het as gevolg van HIV. Dit terwyl ek graag wil leef sodat ek `n statistiek van hoop kan wees.

Ek smeek vir dringende ingryping sodat ons gesond kan leef.

J. Mouries

TAC has asked various organisations and people in the Riebeek Wes area to follow up on this letter.

Write a letter!

In our next issue, if we publish your letter, you'll receive a R100 Pick 'n Pay gift voucher. The best letter will get two vouchers. Keep your letters short and to the point. Indicate if you wish to have your name changed. Remember to include your contact details.

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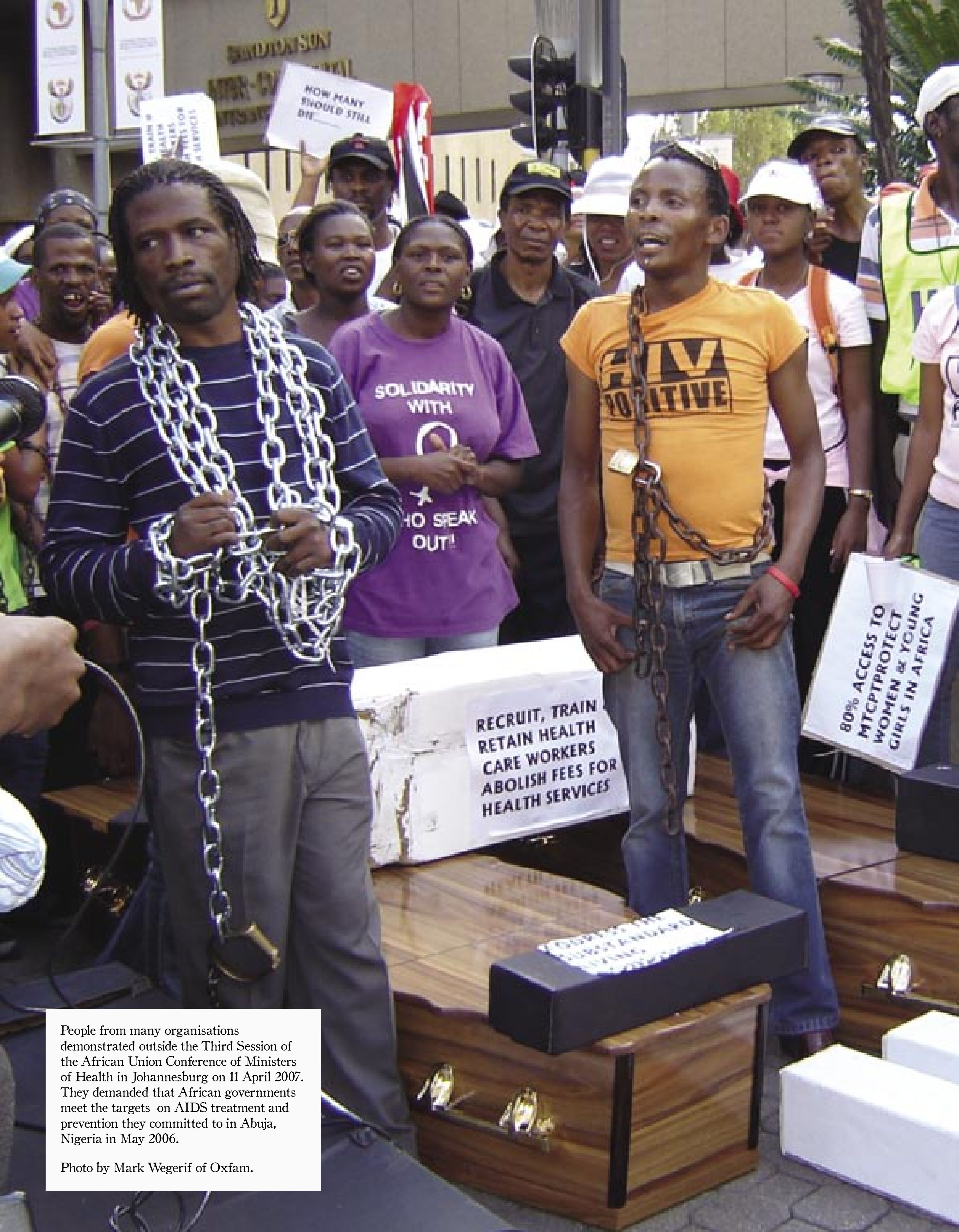


People from many organisations demonstrated outside the Third Session of the African Union Conference of Ministers of Health in Johannesburg on 11 April 2007. They demanded that African governments meet the targets on AIDS treatment and prevention they committed to in Abuja, Nigeria in May 2006.

Photo by Mark Wegerif of Oxfam.

HOW HIV EDUCATION IS CHANGING HEALTH-CARE

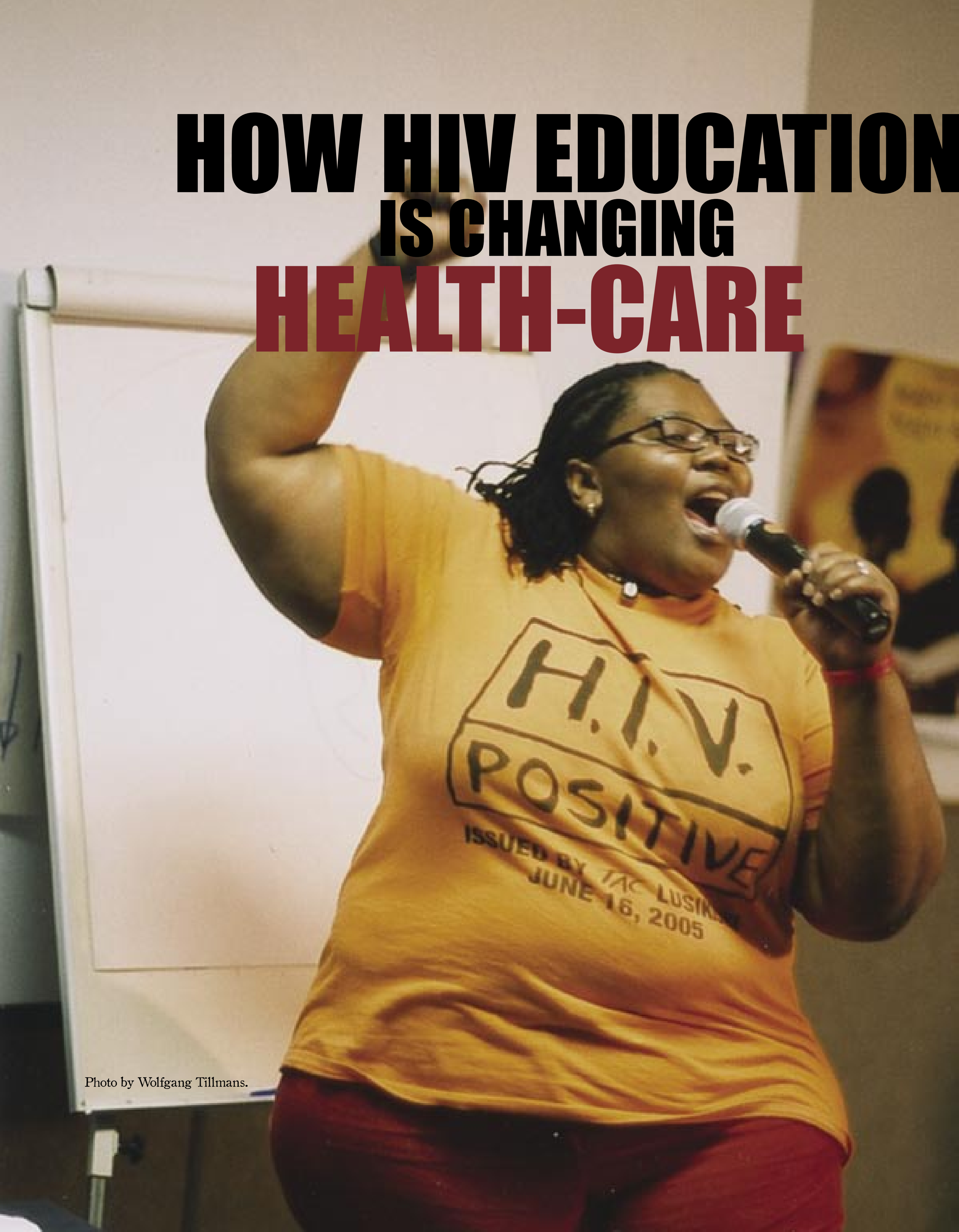


Photo by Wolfgang Tillmans.

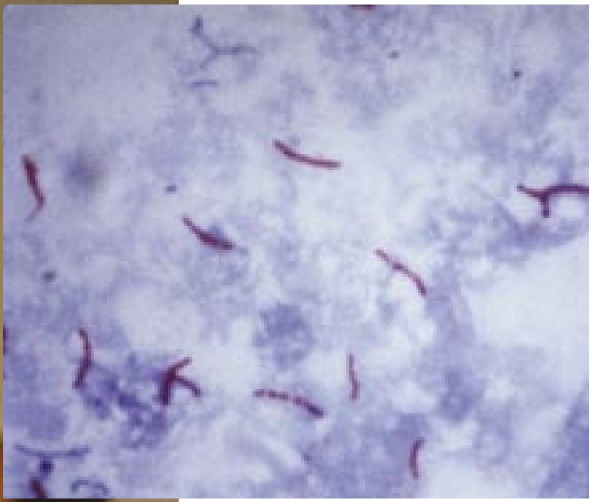


Photo of TB bacteria by Dr George P Kubica. Source: Wikipedia.

Tuberculosis (TB) treatment usually lasts from six to eighteen months. If a patient completes her treatment successfully, she is usually cured.

HIV on the other hand is a lifelong infection. Patients who take antiretroviral treatment must do so for life. Yet if you compare statistics for patients who successfully complete their short TB treatment versus patients who have been on antiretroviral treatment for a long time, the results are surprising. In the Western Cape, the percentage of patients proven to be cured at the end of their treatment course is only 70%. One in ten patients default. But after four years (i.e. eight times longer than the average TB course), 75% of people who started antiretroviral treatment are still on treatment and mostly doing well. The statistics are not directly comparable but no matter how you look at it, HIV patients are generally better at taking their pills than TB patients. Why?

Two completely different approaches are used for the management of these two diseases. People with TB are treated as you would traditionally expect the public health system to treat patients. They are not expected to understand their disease or why they take their pills. They are simply prescribed pills. This is how most diseases are managed, not just TB. But also with TB, everyday, some patients must to go to their clinic and take their pills under supervision.

On the other hand, people with HIV have caused a revolution in health-care. AIDS activism has brought HIV education. They have educated themselves about their disease, how it is treated, side-effects, drugs still being researched, prevention, nutrition and much else. Treatment education teaches people with HIV to have an equal relationship with their health-carers. They ask their health-carers questions: *Why are you prescribing this medicine? What are its side-effects? Are their generic alternatives? Why am I not been given this medicine instead? What diagnostic tests should I take and how often?*

The model of HIV treatment is that patients take responsibility for their own treatment. They are encouraged to have treatment supporters, usually a friend or relative, because it is impossible to supervise that a person takes her pills correctly everyday for life.

In TAC, we call HIV education *treatment literacy*. This reflects the emphasis of TAC's curriculum. However, our treatment literacy programme teaches much more than treatment. Condom use, managing opportunistic infections, mother-to-child transmission prevention, post-exposure prophylaxis, the role of circumcision, patents, the role of sexual abuse in spreading HIV, how trials are conducted etc. – these topics are all part of what we learn.

HIV education has given people with HIV dignity and the knowledge to take control of their lives. While research needs to be done to show more accurately the effects of HIV education, it is clear that it saves lives. It is arguably the most important work that TAC does.

However, we should not be complacent about the mostly good antiretroviral results reported in South Africa so far. TAC's treatment literacy programme cannot keep up with the new numbers of people starting treatment. A programme on that scale must be supported by the state. If we do not scale up treatment literacy, the good results from the HIV treatment programme will probably disappear. And as the South African TB epidemic runs out of control, we had better do the same for TB education that we have done for HIV education.

In this *Equal Treatment* Focus we look at a few treatment literacy efforts around the world run by AIDS activists.

Sources: Western Cape Government Report on Antiretroviral Rollout, South African Health Review 2006.

HOW TAC'S TREATMENT LITERACY PROGRAMME HAS SAVED LIVES

Madwaleni is a remote rural village in the Eastern Cape. It had no treatment site and no resources to educate communities. Stigma surrounded HIV infection.

Since TAC started in 1998, treatment literacy has been at the centre of our work. A big challenge in TAC's early years was our own leadership's lack of knowledge about HIV, so we put an enormous amount of effort into becoming treatment-literate. Assisted by doctors and activists around the world, as well as our own efforts to read and become familiar with medical literature and terms, the organisation developed HIV expertise.

A few years ago, the treatment literacy programme was made more formal and scaled up. Led by Sipho Mthathi, we first trained hard working volunteers to become treatment literacy practitioners, our term for educators. Over the years, TAC has had over 200 treatment literacy practitioners. A group of about thirty treatment literacy practitioners have done advanced training and are called treatment literacy trainers. The treatment literacy programme has reached tens of thousands of people since the programme began.

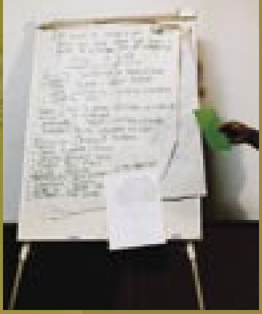
Because of the dire situation in Madwaleni, TAC treatment literacy trainers began working with the community. They started with door-to-door treatment literacy which raised awareness in households. They collected stories of people living with HIV and those of TAC volunteers who are on antiretrovirals. Strong support groups and a TAC branch were built to strengthen the leadership in the area and provide education to the community. Community members became treatment-literate. Activism in the community grew and partly because of the demands of the community there is now an accredited antiretroviral treatment site.

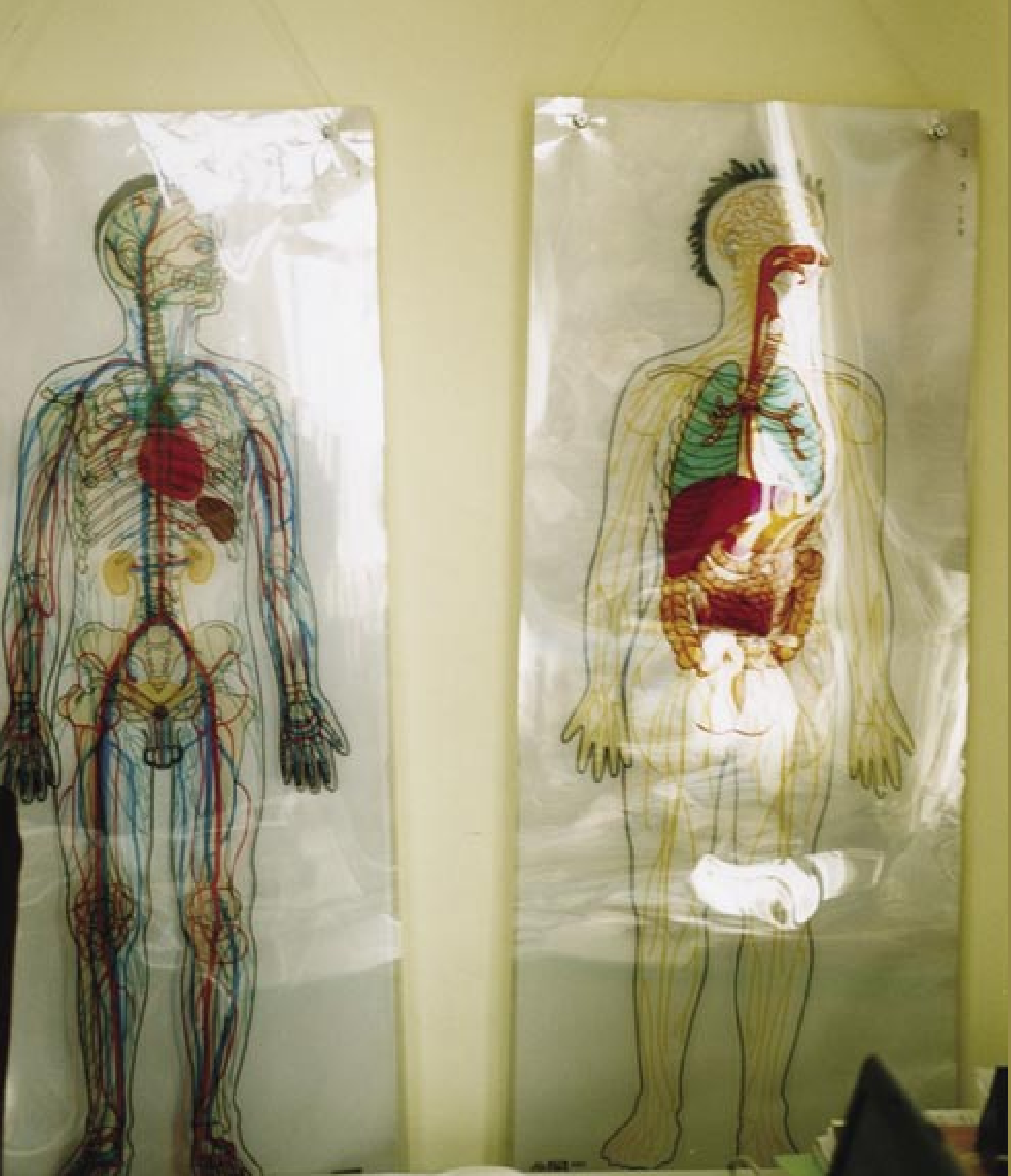
In Gauteng TAC educated six hundred police from the South African Crime Protection unit. Of these, about half went for voluntary counselling and testing after the training.

In Limpopo, doctors distributed the wrong treatment regimens. After TAC's treatment literacy practitioners intervened, this stopped happening.

Treatment literacy materials and techniques used by TAC.

Body map images supplied to TAC by the AIDS and Society Research Unit, University of Cape Town. Photographs by Wolfgang Tillmans.





"The TAC has made me politically strong. When I see something wrong, I see it's time to act. I ask the district organiser to help me push things, to help people get their human rights. If someone was looking well but had third stage illness, and was denied a grant, I could fight for them.

I demanded acyclovir from the clinic in Bisho in June. I was caught by high fever. I developed herpes around my mouth. They took me to Bisho hospital and they gave me anti-fungal tablets. I said it was a viral infection, not a fungal one. She said because you are HIV+, the only thing you must be given is Bactrim. I said that's only for people on stage 3. I went to the village clinic, we argued about the dosage but in the end they gave me what I needed!"

Nocawe Jijimba,
Treatment Literacy
Trainer, Oliver Tambo
District, Eastern Cape

> *"TAC activists stressed that grassroots mobilisation was the key to their success. This was done though AIDS awareness and treatment literacy campaigns in schools, factories, community centres, churches, shebeens and through door-to-door visits in the African townships. By far the majority of TAC volunteers were poor and unemployed African women, many of them HIV-positive mothers desperate to gain access to life-saving drugs for themselves and their children."*

Steven Robins AIDS Activism, Science and Citizenship, Journal of Southern African Studies Vol 30, No 3, September 2004

"We provide education in clinics, in churches, and schools. We teach virology. We show people images of the virus itself. We look at the life cycle of the virus. We look at the body and study the cells, the tissues, the organs, that make up the person. Then we look at the opportunistic infections. We look at what is happening to the body when a person has shingles. Then we look at the treatments that are available in the public health settings.

We use songs to mobilise people, so they know what is happening. Songs can deal with the politics of HIV. Educational songs deal with shingles and they deal with different types of TB. If it is in the head, we point to the head while we are singing.

Here are three songs that we sing in English:

> 'You better change your mind. You better condomise.'
>
> 'You do PMTCT where you are. You do PCR where you are.'
>
> 'All over, the world is talking about antiretrovirals.'

We explain the science of the HIV life-cycle. Then we have the participants act out what is happening in the human body.

We try to simplify the scientific terms so as to reach more people.

We refer to the immune system as the soldiers of the body. What is the role that the soldiers play in the body in protecting you from the invaders? Here comes HIV. Now the soldiers of the body can't function properly anymore. Other people use the example of a football team to show how the virus operates in the body.

We talk about the proteins as the building blocks or bricks used to build other parts of the body. We explain that gp120 is the key that opens the lock so that the virus can come inside the house.

People act out the parts of the human cell and the virus. When the gp120 meets the human cell, the cell opens and the three enzymes and the RNA enter the human cell.

Reverse transcriptase attaches to the nucleotides and changes the RNA into viral DNA. It must be double stranded. Then integrase enters the nucleus. It puts the viral DNA into the human DNA.

Then the nucleus does its work, which starts to manufacture more proteins and more viruses. They come out as a chain of proteins. Then the protease is waiting to cut the chains so the new virus can go off with part of the cell membrane."

Lulekwa Dlelaphantsi and Nombasa Gxuluwe, TAC treatment literacy programme

Evelina Tshabalala stands at the top of Mount Aconcagua in Argentina. She lives openly with HIV and is on antitretroviral treatment. Most people do not make it to the top on their first attempt but Tshabalala did. At 6,960 metres, Aconcagua is the highest mountain in the world outside of the Himalayas. Tshabalala intends to climb the highest mountain on every continent, including the highest mountain in the world, Mount Everest.

Photos courtesy of www.isicongo.co.za.

EvelinaTshabalala

TELEVISION BRINGS HIV EDUCATION TO MILLIONS

Millions of South Africans have watched Siyayinqoba Beat It! on South African television. The programme combines incisive political discussion and HIV-related health information.

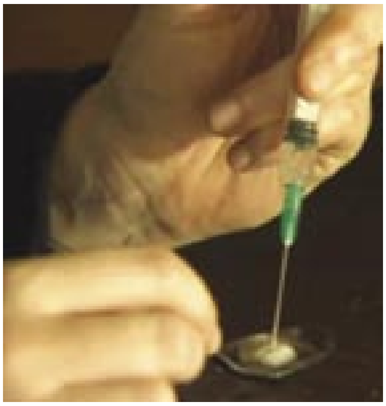
Siyayinqoba Beat It! is produced by Community Health Media Trust (CHMT), a non-profit organisation. The treatment literacy series has received good reviews for its ability to take complicated subject matter and translate it into simple, accurate language. The show often covers TAC or other community events. Every episode features a support group that discusses the episode topic. It has also exposed charlatans such as Matthias Rath, who peddles high-dose multivitamins for numerous illnesses, and Zeblon Gwala, who sells his home-made mixture called Ubhejane as an AIDS treatment.

Siyayinqoba Beat It! is also produced as a standalone treatment literacy series. CHMT uses this as part of a community outreach programme. About twenty TAC trained treatment literacy practitioners work in clinics and explain the contents of the show. Mindset, a health television channel has teamed up with CHMT and set up audiovisual facilities in about 300 clinics and hospitals. The treatment literacy practitioners show relevant episodes to people who use the sites. For example, in maternity clinics a DVD is shown about the importance of getting tested for HIV and how pregnant HIV-positive women can prevent passing the virus onto their babies.

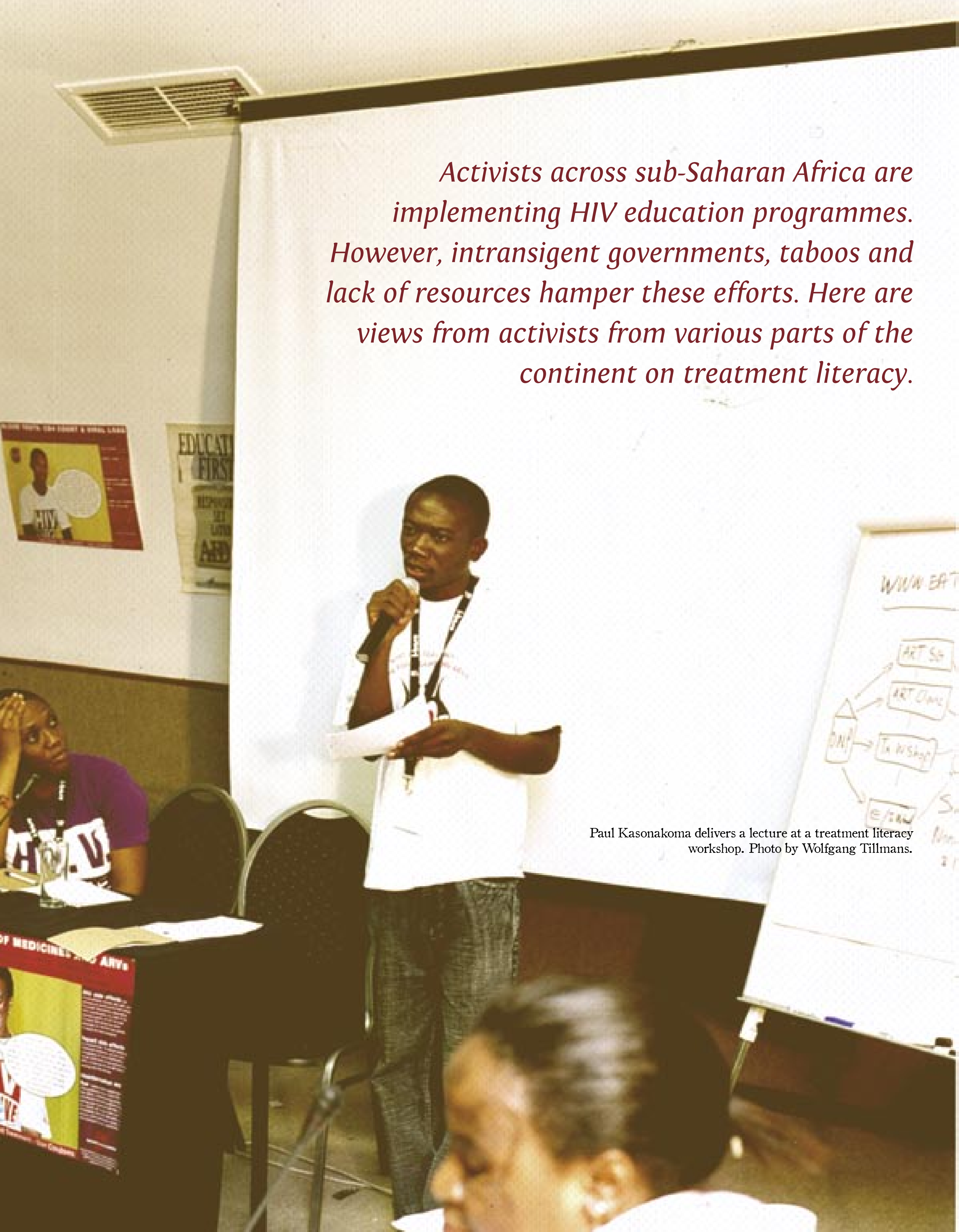
The *Siyayinqoba Beat It!* series is available in Xhosa, English, and Zulu and will soon be translated into Portuguese. For NGOs the series costs R2,350 or individual episodes can be bought for R150. For more information go to www.beatit.co.za or call CHMT on 021 788 9163.

Left: Shalom Ncala, the *Siyayinqoba Beat It!* Presenter, lives openly with HIV. Photo supplied by CHMT.

Below: The *Siyayinqoba Beat It!* series covers a wide variety of HIV-related topics: antiretrovirals, growing food gardens, the effects of alcohol and injecting drugs on HIV transmission, condoms, treatment in prisons, special needs of children and much more! Photos supplied by CHMT.



Activists across sub-Saharan Africa are implementing HIV education programmes. However, intransigent governments, taboos and lack of resources hamper these efforts. Here are views from activists from various parts of the continent on treatment literacy.



Paul Kasonakoma delivers a lecture at a treatment literacy workshop. Photo by Wolfgang Tillmans.

AFRICA DEMANDS HIV EDUCATION

Francina Lusungu Nyirenda. Photo by Wolfgang Tillmans.

"The drugs are there – we don't have a problem with the drug supply. But all our posters and education are talking about prevention – which is OK – but we need information about treatment too. Lately we are moving backwards. The government thinks that if too many people learn about treatment then too many people will demand it and it will create a problem."

Julios Amoako, Ghana.

"In Swaziland, we have a paternalistic approach to HIV treatment. People are just given the pills and told to take them at 8.00 in the morning and at 8.00 at night. There is no explanation at all. "

Sibonelo Mduli, Swaziland.

"You can get people on antiretrovirals, but without information there are problems. We want people to know about the effect of stopping the medications. We want them to know that they must continue for life.

In Malawi, we don't have the information in our local languages that people can understand. We have most of the literature in English, and it is a matter of translating it so more people can understand it."

Francina Lusungu Nyirenda, Malawi.

"There are many taboos in my country and illiteracy is high. If you speak about HIV in Mozambique, they think it is a death sentence. In the rural areas if someone has herpes zoster, they say they were bewitched. We need to educate people. We have community training programmes. We teach people how to identify and treat opportunistic infections and what to do if they see symptoms in their bodies.

But people ask, 'Where did you get this information?' They say, 'You can't tell medical professionals about your symptoms or what kind of medicine you should take.' But we say, 'You are helping the doctor because you are the person who has to take the medicines.' "

César Mufanequico, Mozambique.

"We heard of a person who went to a conference and ran out of his medicine. He then came home and counted the number of days he missed, then took them all at once. He died. He didn't know better.

People are afraid of the drugs. If you ask the average Zambian about antiretrovirals, they say the person with HIV on treatment dies like a pig – fat, instead of skinny like with AIDS. We say, 'Look, we are taking these drugs and we are living.' This makes a lot of sense to people.

We see many side effects with stavudine like peripheral neuropathy and lipodystrophy. People don't have the capacity to go back to the doctor and say, 'This is not working for me.' If people on treatment know how to recognise these symptoms in the early stages, then they can change drugs before it is too late."

Paul Kasonakoma, Zambia

Originally published in *Why we must provide HIV treatment information* by HIV i-Base and TAC.

EDUCATION SAVE LIVES ACROSS THE GLOBE

Although Africa has more HIV infections than any other continent, there are a large number of people living with HIV in Asia and Eastern Europe too. These parts of the world have many of the development problems that Africa has – poverty, shortage of health workers, struggling civil society organisations and weak governments.

Treatment activists from countries as diverse as India, Russia, Thailand, Ukraine, South Africa, Kenya and many others, joined together to form the International Treatment Preparedness Coalition. The coalition allows activists to share resources such as HIV experts and educational materials. This helps improve the quality of HIV education and, hopefully, the health of people with HIV across the globe.

Leading AIDS activists from around the world met in Cape Town in 2006 to share their expertise on treatment education. Photos by Wolfgang Tillmans.

Loon Gangte, India

Artur Ovsepayan, Ukraine

“There is nothing in Hindi for the people who need it.

We are having the first treatment workshop in Delhi. We take treatment information materials from all over on the internet. We will take all this and feed all the wisdom into our treatment handbook. I'm crazy about simplified, non-technical and localised language. I don't yet know how to document all this wisdom into a form I can use. We are observing.

The language people use has changed. They are talking about adherence and side effects now.

In our country you need to translate materials into at least seven languages.”

“In our country, we are not as open and it is difficult to ask people to sing or dance. In our education, we use methods like asking people how they understand HIV and how they learned about HIV.

We always have three main topics that people want to talk about:

‘Is HIV a punishment from God?’

‘Did it come from space?’

‘Is it a result of a pharmacological experiment?’

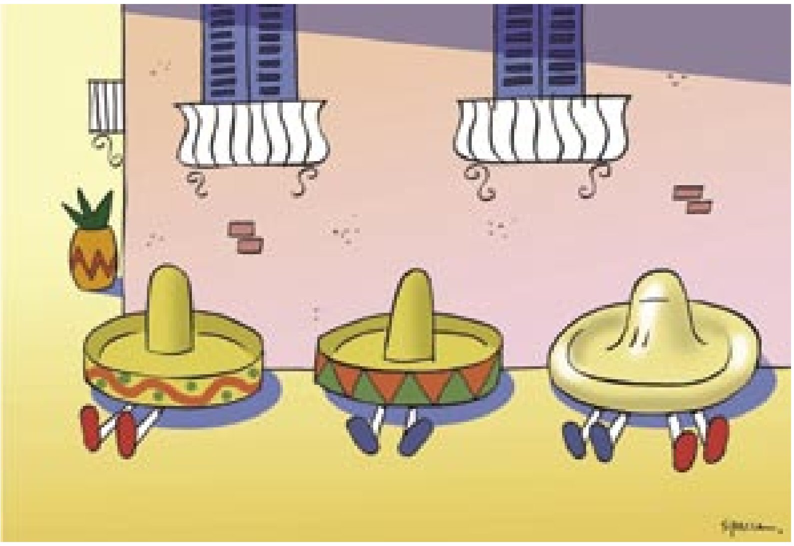
Doctors are not able to explain what they know in ordinary language. So we have doctors participate with HIV-positive people in our seminars. This helps to bring both groups to the same level and get them to come to the same conclusions about how to solve the problem of HIV. So we try to decrease the boundaries between doctors and patients. We use a game as a starting point and then move to more complicated topics.

After we demonstrate the HIV life-cycle we divide into three smaller groups and ask people to demonstrate the different life-cycle stages. After that exercise it is easier to explain the classifications of antiretrovirals and how they work. It is very important that everyone can explain how antiretrovirals work and can pronounce their names. When participants can repeat what you have told them, then the information will stay in their minds longer. ”

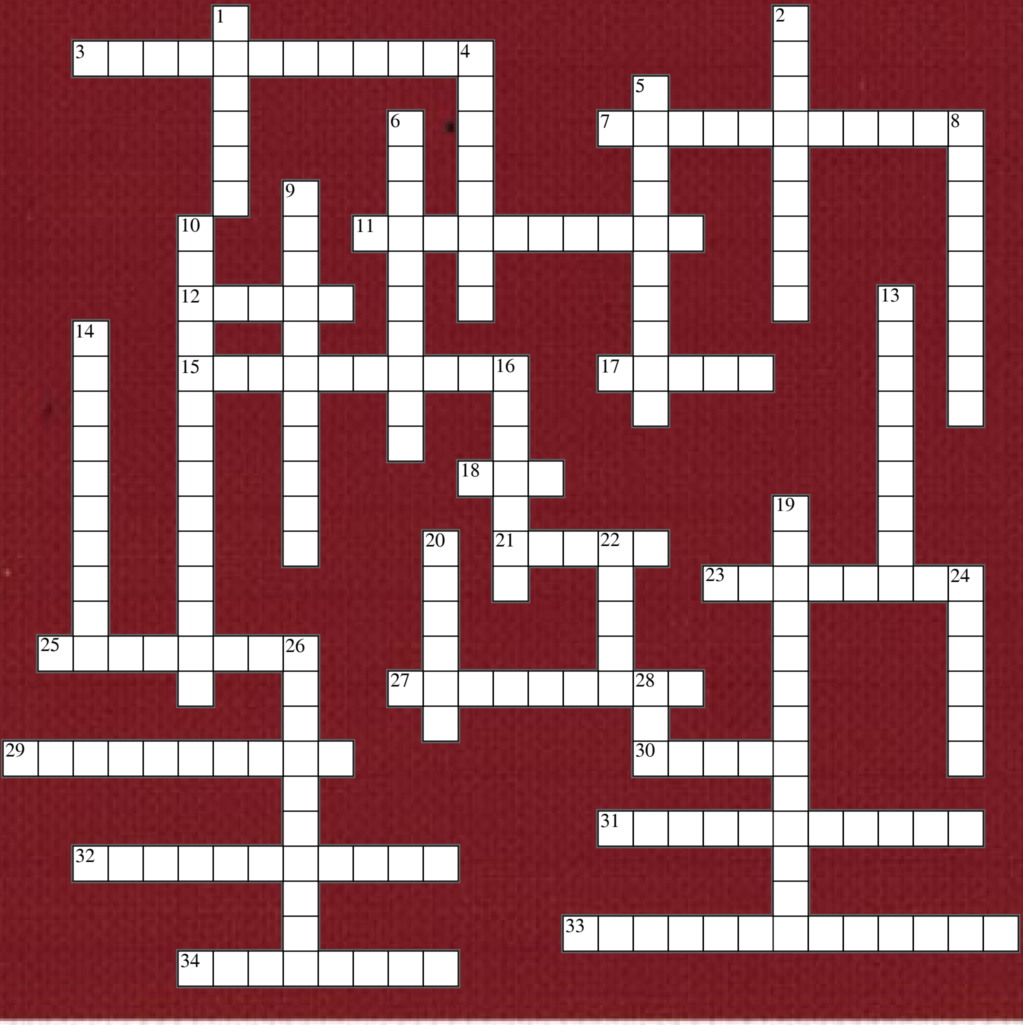
CARTOONS

The Brazilian Ministry of Health, UNAIDS and the International Planned Parenthood Federation recently unveiled "Drawing It Out" – a special exhibition of 300 cartoons by international artists from over 50 countries. The cartoons featured in the exhibition carry an important message about HIV/AIDS – while overwhelming statistics and urgent public health messages can paint a grim picture, there is a colorful and positive vision possible as well. This is an image of society in which laughter is a part of sexuality, where economic circumstances do not determine one's health and where as global citizens, we take up the charge to care for one another.

"Drawing It Out" – a Brazilian Ministry of Health exhibition, supported by UNAIDS and the International Planned Parenthood Federation. See www.ippfwhr.org/drawingitout.html. All rights reserved.



Equal Treatment's Crossword Puzzle



We will give a R200 Pick 'n Pay gift voucher to the first crossword drawn from a hat with at least 30 correct answers.

All the answers can be found in this issue of *Equal Treatment*.

Fax or post your completed crossword, with your name, address and contact number.

Address:
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Muizenberg
7945

Fax: 021 788 3726

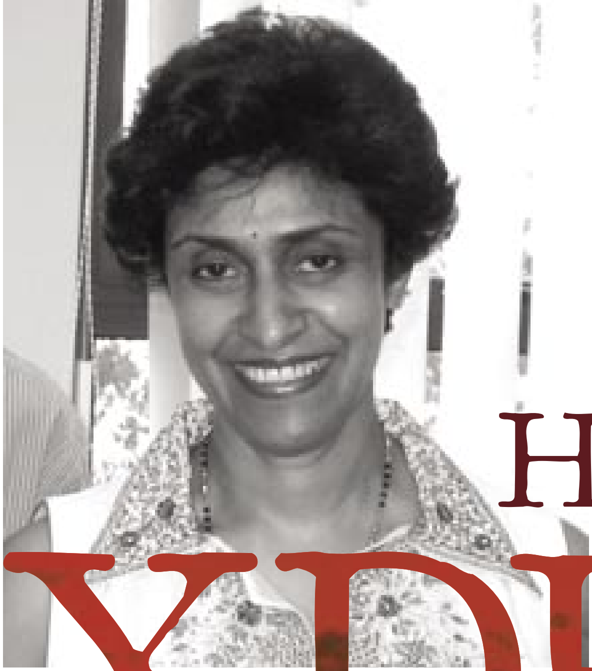
TAC staff members, treatment literacy practioners and their immediate families may not enter.

Across

3. This disease kills more people with HIV in South Africa than any other (12)
7. Nesri Padayatchi believes that this is the most important research needed for TB (11)
11. Monitoring and ________ is a priority area of the NSP (10)
12. Number of times the HPV vaccine must be injected (5)
15. Name of TB drug that people with MDR TB are resistant to (10)
17. Treatment literacy practitioners call this protein a key that opens the lock so that the virus can come inside the house (5)
18. The HPV vaccine is administered over __ months (3)
21. Skin deformities caused by HPV (5)
23. Screening test for cervical cancer (two words) (8)
25. Name of an HPV vaccine (8)
27. The "P" in HPV (9)
29. Another name for ddI (10)
30. CD4 ________ measures the status of your immune system (5)
31. An injectable drug used to treat MDR TB, but which might not work in patients with XDR TB (11)
32. Beat It! television show presenter (11)
33. Famous South African band whose base player is involved in Friends of TAC (13)
34. TAC's name for HIV treatment education is Treatment_____(8)

Down

1. Cartoons in this month's issue come from this country (6)
2. TAC recently held demonstrations around the country demanding the registration of this medicine (9)
4. Government's plan deals with AIDS and _________ Transmitted Infections (8)
5. Device used to be able to see the cells of the cervix (10)
6. One of the four priority areas of the NSP (10)
8. Government has produced a National ________ Plan (9)
9. 52 out of 53 people died of XDR TB here (two words) (11)
10. Medicines that help people with HIV live longer (14)
13. Another name for d4T (9)
14. Surname of HIV-positive woman who climbed Mount Aconcagua (10)
16. First name of Deputy Minister of Health (7)
19. Alfreda Brinkhuis suffered from this side-effect of d4T (13)
20. A US drug company that took years to apply for registration of tenofovir in South Africa (6)
22. Name of Limpopo clinic that claims it can't do pap smears because it does not have water (5)
24. Surname of Acting Minister of Health (6)
26. Indian HIV activist (2 words) (10)
28. Institution responsible for registering medicines in South Africa (3)



HOW DO WE STOP XDR TB?

What can we do about extremely drug resistant tuberculosis (XDR TB)?

Last year researchers found that XDR TB killed 52 out of 53 infected people in Tugela Ferry, Kwazulu-Natal (KZN). Equal Treatment *interviewed Dr. Nesri Padayatchi, the deputy-director of the Centre for the AIDS Programme of Research in South Africa. She has been one of the doctors helping the KZN referral hospitals for multi-drug resistant (MDR) TB, including King George V Hospital, to manage the epidemic.*

ET: How do we know there is an outbreak of XDR TB in South Africa?
NP: We don't know this yet. The term "outbreak" suggests an isolated area where XDR TB has occurred. XDR TB may be widespread far beyond Tugela Ferry, in which case this is not an outbreak. The last surveillance for drug resistant TB was done in 2001-2 by the Medical Research Council. The Department of Medical Microbiology is doing surveillance in KZN currently. Once this is complete, we will have a clearer idea of the extent of the disease.

ET: What is the difference between MDR and XDR TB?
NP: XDR TB is a sub-category of MDR TB. MDR TB refers to TB that is resistant to at least rifampicin and isoniazid. These are two of the most effective drugs that are used to treat 'ordinary' TB.

XDR TB is worse than MDR TB as there is resistance to rifampicin, isoniazid, an injectable drug (either kanamycin, amikacin or capreomycin), and a quinolone [Editor – the drugs used to treat MDR TB].

ET: Are the MDR and XDR TB epidemics getting worse?
NP: My impression is that they are. We will not know this definitively until we have data. Tugela Ferry drew attention to the problem. Health care workers have become more aware of this disease. This means more cases of both MDR and XDR TB are being reported, so there is a bias.

ET: Is XDR TB almost always fatal or are you having any success?
NP: At Tugela Ferry the fatality rate was 98%, but these patients were being treated with TB drugs that they were resistant to. The first patients with XDR TB were started on appropriate treatment in December 2006, so it is too soon to say whether XDR TB is invariably rapidly fatal or not. We will not know until the third quarter of this year. However, the 'best' TB drugs are the ones that these patients are resistant to, therefore I think that very few patients with XDR will be cured. Deaths due to XDR TB appear to have levelled off at this point, but the patients are ill. Two have died from the side effects of the drugs.

ET: Is it a health emergency?
NP: It is a health emergency in the sense that we have to control it now. It is not a medical emergency like a heart attack.

ET: What problems with the management of MDR and XDR TB have you come across?
NP: Access to care, delays in diagnosis associated with technical laboratory capacity to cope, implementation of infection control measures and side-effects of drugs.

ET: What is the connection between the TB and HIV epidemics?
NP: HIV is very prevalent in our community. It causes suppressed immunity. People with suppressed immunity are more likely to get TB. Poor socio-economic conditions also make people more likely to get TB.

ET: What should the state be doing to stop the outbreak?
NP: In the short term – culture and susceptibility testing of all TB patients. [*Editor – these tests identify which TB drugs patients are resistant to*], treating these patients and providing counselling and social support. This will help contain the 'outbreak'.

We need to implement tracing teams to find contacts of MDR/XDR patients and screen them for TB and MDR/XDR TB.

Also we need to implement tracing teams to find patients with MDR/ XDR TB who have defaulted their treatment and implement more measures to control the spread of MDR and XDR TB infection.

We need controlled decentralisation of MDR/XDR TB treatment, i.e. we must carefully make treatment available at institutions with capacity, and after training.

Finally, we must improve counselling and train and retain health-care workers.

ET: Are there special precautions that health workers coming into contact with MDR or XDR TB should take?
NP: There is so much that can be done:

- Cough etiquette (i.e. teach health workers and patients to cover their mouths and cough away from people)
- Separate patients with MDR and XDR TB from other patients and each other
- Reduce overcrowding in wards
- Improve counselling
- Encourage patients to sit in the open

ET: What should civil society organisations like TAC be doing to stop the outbreak?
NP: Educate the public and health care workers.

ET: MDR and XDR drug treatment is extremely complex. Can you explain the main challenges?
NP: There are several:

- The drugs can have serious side-effects such as deafness, nausea and vomiting.
- The duration of therapy is long – 18 to 24 months.
- Patients must have painful daily injections.
- Patients have to keep away from their families and jobs. Often these patients do not feel very ill and cannot understand what the big deal is.

ET: Are there any useful medicines or diagnostics for TB that already exist that you would like to see used more in South Africa?
NP: There is a diagnostic which directly tests for rifampicin resistance on sputum. We need this. We need new good drugs. Unless we get our act together as health-care workers our patients are going to become more resistant.

ET: What are the most important research needs for TB?
NP: Diagnostics, diagnostics, diagnostics! We also need better drugs so TB treatment can be shorter.■

Photo by Nokulunga April.

Finding out about my status gave me a purpose in life

My name is Alfreda Brinkhuis. I am 27 years old and I live in Uitenhage, Langa in the Nelson Mandela Metro District. I am on the Executive Committee of the TAC Langa Branch and a lay health counsellor at Uitenhage Provincial Hospital.

I found out about my HIV status in February 2005 at the Rosedale Clinic when I was being treated for TB and shingles. I started antiretrovirals in October 2005 because my CD4 count was below 200. I was excited when I first got antiretrovirals but I have faced a lot of challenges with them. When I started on the first line regimen of lamivudine, stavudine (d4T) and nevirapine, I experienced joint and abdominal pains and in October last year I had lipodystrophy and started to lose weight. The doctor told me that this was caused by d4T and changed me to AZT instead. My viral load did not improve and it was clear that I was suffering from virological failure. He then changed the whole regimen to didanosine, AZT and lopinavir/ritonavir. I am still taking this combination and my health has improved. I meet my doctor once a month and at any other time when I have a problem.

I met the love of my life after I found out I was HIV-positive. Through my work as a health counsellor, I enjoy helping others develop a positive attitude towards their illness and I am delighted that I am able to call a doctor my colleague. I am now computer literate and part of a committed team of workers. Sometimes I feel over qualified for my job as I find myself educating nurses and sisters about HIV terms such as VCT, PMTCT and the treatment of OIs.

My future plans are to get married this year, adopt a child and to carry on doing what I love - helping others. HIV is no stumbling block but a wake-up call to look after your health and treasure your life and body.

Alfreda Brinkhuis

Yini Umsebenzi Wabahlengikazi?

Singumphakathi sibuye singazi kahle ngemisebenzi ekumele yenziwe abantu, ikakhulukazi izisebenzi zikaHulumeni.

U-Lihle Shozi ohlala endaweni yaseMpembeni uye wagula isikhathi eside ephethwe yisinye esibuhlungu, siphuma udoti. Uthe uma eya emtholampilo eyobikela umhlengikazi, watshelwa ukuthi umuntu obheda kanje usavelaphi. Wanikezwa amaphilisi, wawaphuza ngendlela efanele. Kodwa akazange abe ngcono, okwenze ukuthi abuyele emtholampilo. Uthe uma ephindela wafica loya mhlengikazi futhi, wathi kuye "Usabuya futhi nale sifo sakho socansi, awuboni yini ukuthi unengculazi wena, hamba uyohlola igazi." Lokhu akuzange kumphathe kahle u-Lihle.

Emuva kokuthola ingane, wagula kakhulu kwathiwa akahlolele isifo sofuba ngokuhlola izikhwehlela. Waya emtholampilo lapho imiphumela yabuya ithi akanaso isifo sofuba. Ngokuhamba kwesikhathi waya esibhedlela wahlolwa igazi kwase kutholakala ukuthi unaso isifo sofuba (TB) wase ehlolela negciwane lengculazi, lapha kwatholakala ukuthi unalo leligciwane egazini lakhe. Emuva kokugula kakhulu komyeni wakhe uye waphathwa yi-TB yekhanda (Meningitis) emenze walaliswa esibhedlela sase-Thembeni (Hospice). Amasosha wakhe omzimba (CD4 count) bekawu-110. Ngokuhamba kwesikhathi waqala ukuthatha umshanguzo (ARVs). U-Lihle unxusa abantu ukuthi bahlole igazi kusenesikhathi ukuze bazoqala ukudla imishanguzo ngoba iyasebenza. Abahlengikazi kufanele banikeze iziguli usizo olufanele ngokubachazela ngezinkinga ababhekene nazo.

Nonhlanhla Ngema

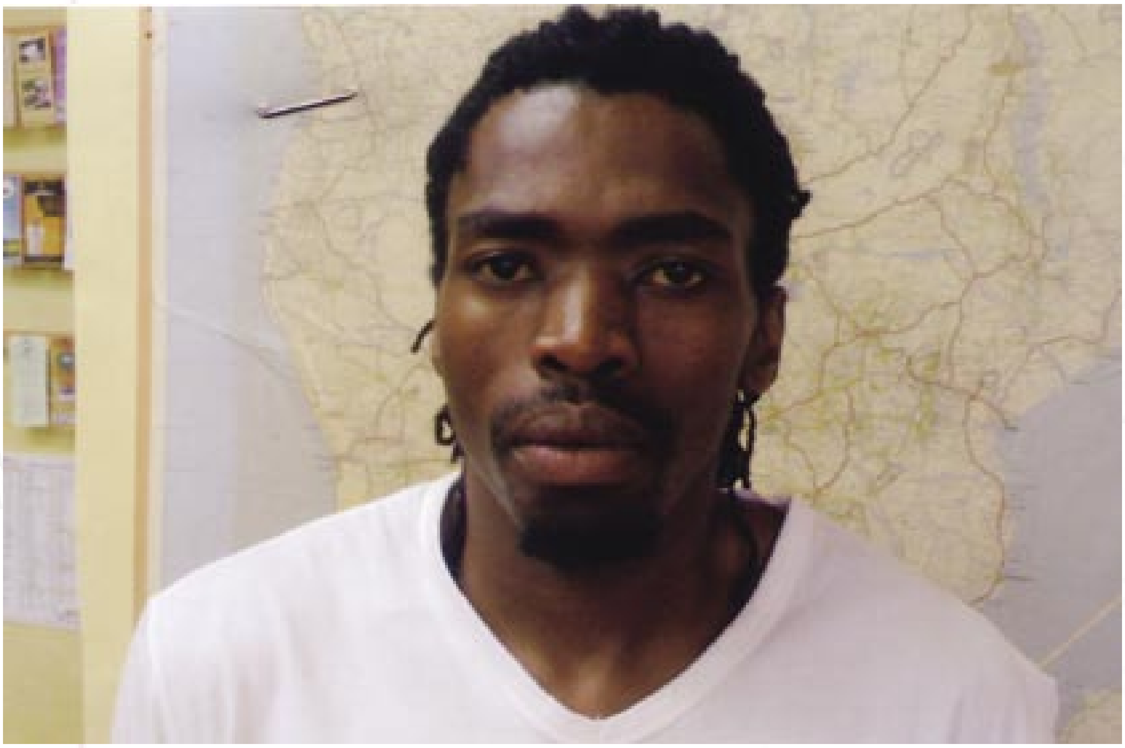


Photo by Thulani Nqambi.

TAC changed my life and helped bring about change in my community

I am Masizole Gonyela from Chris Hani, Queenstown. I am 25 years old. I joined TAC in 2004. I joined, not because I wanted to be popular or get the T-Shirt, but because I felt I had a social responsibility towards my community. I wanted to help and bring about change in my community. In the area where I lived, there was a lot of discrimination and stigma attached to those living with HIV/AIDS. A lot of people were dying in front of my eyes and nobody was speaking out about it. I had to find a vehicle for change and I found that in TAC.

I am now serving as a Treatment Literacy Trainer. I serve on the Provincial Executive Committee and I am a spokesperson for the Eastern Cape. Ever since TAC was introduced in Chris Hani, people living with HIV/AIDS have had access to better health services. They have been given a voice through campaigns, like Access To Treatment, and more work has been done on prevention.

As a result of the work done by TAC, we now have five antiretroviral sites in Chris Hani. Large numbers of people are now accessing treatment and discrimination is no longer a problem. People are now open about their status. All this is the outcome of the commitment shown by the community and TAC as an organisation.

There are still many barriers to combating the HIV/AIDS problem. In many areas, the Department of Education is doing very little especially on prevention. They preach abstinence instead of the use of condoms. Very few men are accessing HIV testing and related services. There is still a culture of gender imbalance. Religious institutions are not taking a hands-on approach to the HIV/AIDS problem.

To solve these issues, we are using the Treatment Literacy Programme to equip communities with information. We are mobilizing communities to stand up for their rights. TAC also has programmes to empower women in and outside the organisation.

For me, TAC has played a vital role in changing not only my behaviour but that of my community. TAC has managed to live up to its own objectives of advancing better health-care for all, treatment for those who need it and ensuring that people become treatment literate. This allows them to make informed decisions and live better lives.

Masizole Gonyela to Thulani Nqambi

Water shortage denies women access to pap smear services

As part of 16 Days of Activism against women and child abuse, the TAC Limpopo Women's Forum gathered on 4 December 2006 at the Thomo Clinic outside Giyani to demand cervical smear services. A Pap smear is a test done on women to check for signs of cancer of the cervix. The cervix is part of a woman's uterus (womb).

More than 70 women from TAC branches all over the province attended in support of this campaign.

TAC members organise at Thomo Clinic. Photos by Adam Malapa.

Eunice Ngobeni, the Provincial Women's Forum Chairperson, said "The main objective for this campaign is to support a national call to fight against women and child abuse and to educate them on health issues. We also want to see if there is a pap smear service available in the clinic."

None of the 70 women who attended the gathering had been able to access the service. The reasons they were given were different from those given by the clinic staff.

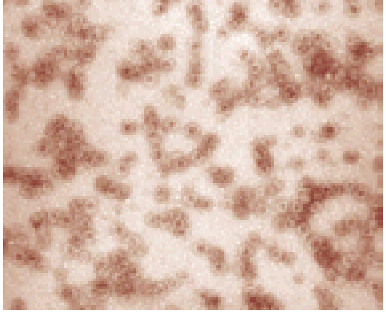
Emma Netshiongole, Acting Provincial Women Organizer, was told that the nurse who conducted the pap smear tests was not available on the day and was, therefore, unable to access the service.

Nkhensani Mathebula, from TAC Mopani, was told that she couldn't access the service because she was meant to make an appointment before turning up.

The sister-in-charge at the clinic had a different story to tell. "The problem is that there is no water in the clinic and in the whole village. We sometimes do not bathe at night because of a shortage of water. I sometimes call someone to bring me water. That is the reason we stopped our pap smear service last November."

Campaign Organiser, Emma Netshiongole responded, "The problem of water is not our baby. It is the Department of Health's duty to make sure that the service is available with all the necessary resources."

Adam Malapa



CAN WE STOP CERVICAL CANCER?

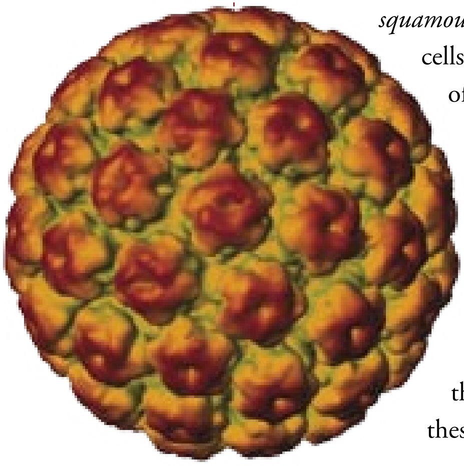
More than 250,000 women died of cervical cancer in 2005, a disease primarily caused by the human papilloma virus (HPV). Most of these deaths were in developing countries. Cervical cancer kills more women in South African than any other cancer. The World Health Organisation expects cervical cancer deaths to increase but new vaccines offer hope that the disease can be overcome.

What is HPV?

HPV is a virus that causes warts on our skin. Over 100 types have been identified. Most are harmless. About 30 types of HPV are sexually transmitted and can cause genital warts and abnormalities to form in the cells of the cervix, the part of the uterus that connects to the vagina. This in turn can sometimes lead to cervical cancer. These high-risk HPV types are the most important risk factor for cervical cancer. In this article we talk about the types of HPV that infect the genitals.

How is HPV transmitted?

Genital HPV is a sexually transmitted infection (STI) so we become infected through skin to skin and genital contact mostly through vaginal or anal intercourse. Condoms will reduce the risk of HPV but are not completely effective. Genital HPV is one of the most common STIs.



A three dimensional representation of the Human papilloma Virus

What is the relationship between HPV and cervical cancer?

Genital HPV types are either low or high risk. Both cause warts. High risk does not mean higher risk of infection but higher risk of cervical cancer. Usually high risk types of HPV go away on their own and do not cause cervical cancer. However, sometimes high risk HPV is persistent (i.e. it doesn't go away on its own). This can lead to abnormal growth of cells on the lining of the outer part of the cervix. The cells that line the cervix are called *squamous epilthelial* cells. Abnormalities of these cells are called *squamous intraepithelial lesions* (SIL). See the box on the opposite page for other words that describe these abnormalities.

There are two types of SIL:

- Low grade is when the changes in the cells on the cervix are just beginning but they still look similar to normal cells under a microscope. This is also called *mild dysplasia* or CIN I.
- High grade is when the cells look abnormal under a microscope. This is also called moderate or *severe dysplasia* (CIN II or CIN III).

If these abnormalities are not detected and treated they can invade deeper into the cervix. This is called invasive cervical cancer.

Is there a connection between HPV and HIV?

HIV-positive women are more likely to be infected with HPV than HIV-negative women, as a weakened immune system can make someone more vulnerable to infection. At lower CD4 counts and higher viral loads, women are more at risk of developing dysplasia. Studies have shown that HIV-positive women also have a greater risk of cervical cancer. Cervical cancer is AIDS defining in HIV-positive women but is easily prevented with diagnosis and treatment.

Why are pap smear tests important?

Women rarely have any symptoms with dysplasia and early stages of cervical cancer. In advanced stages there may be some pain or bleeding between periods. As symptoms are rare until the condition becomes serious, screening for abnormalities is very important. **A pap smear test can detect changes on the cervix.** Sample cells are taken from the cervix using a small brush. The cells are smeared on to a glass slide so that they can be examined in a laboratory. Results are usually available in two to three weeks. HIV-positive women are ten times more likely to have abnormal pap smears than HIV-negative women.

If the test results are abnormal the doctor may repeat the test or you may need a *colposcopy*, which is an examination of the cervix under a microscope. An abnormal smear result does not automatically mean you have HPV or cervical cancer; it can also be the result of inflammation or other infections.

Menstruation and yeast infections such as thrush make it difficult to perform a pap smear successfully so make sure you make the appointment in between your periods and treat any infection effectively.

Screening programmes, such as the British one that was introduced in the 1960s, have been extremely effective. Cervical cancer is rare in countries that have them.

How is cervical cancer treated?

Treatment will vary according to the severity of the diagnosis. For mild dysplasia you will usually be monitored by repeat pap smear or colposcopy as many mild abnormalities will go away of their own accord. But this spontaneous regression (i.e. getting better without medicine) is less common in HIV-positive than HIV-negative women as it depends on our immune response. More severe dysplasia will require treatment. Treatments, for example with a laser, need to destroy the abnormal cells so that they don't progress to cancer. Cervical cancer will require surgery or radiation.

What is the HPV Vaccine?

There are two effective vaccines against HPV. Last year a vaccine against HPV called Gardasil was approved for use in the US for prevention of cervical cancer. The vaccine is active against HPV types 16 and 18, which are thought to cause approximately 70% of cervical cancers. In four double-blind placebo controlled trials of 22,000 women aged 16-26, Gardasil was 100% effective against these sub-types. It also has activity against types 6 and 11 which are believed to be the cause of 90% of genital warts. The vaccine is approved in the US for girls aged 9 to 12 years. It is given as three injections over six months.

Although the vaccine for HPV has great potential, it is not yet clear how protective this will be either for HIV-positive women or for women from parts of the world where 16 and 18 are not the majority HPV types. The vaccine is *not* a replacement for good screening programmes that include pap smear tests. Merck, the manufacturers of the vaccine are marketing it extremely aggressively in Europe. Their behaviour is at best tasteless and likely to undermine trust in vaccines.

HPV causes warts in men but it is not known if the vaccine is effective for men.

More research is ongoing and we urgently need the results.

How is the HPV vaccine administered?

The vaccine is administered as three separate injections over 6 months. The second dose is given 2 months after the first dose, and the third dose is given 6 months after the first dose.

What about the cost?

A serious problem with Gardasil is that it is too expensive. Currently it is sold in the US for over R2,500 ($360) for the three injections. We must campaign for a massive price reduction.

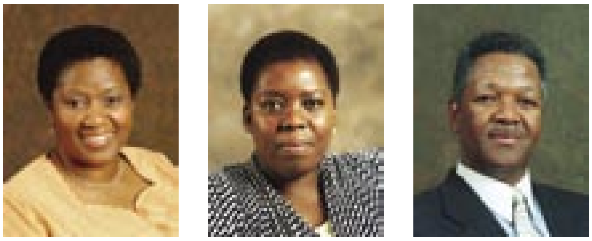
Sources: World Health Organisation, Medical Research Council, HIV i-Base, NIH.

You may hear these terms if you experience HPV-related problems.

- Abnormal cells are called pre cancerous or dysplasia. Dysplasia means cells that look abnormal under a microscope but are not yet cancer.
- Precancerous lesions are also called cervical intraepithelial neoplasia (CIN)

A PLAN TO SAVE LIVES

A different era has opened for people living with HIV and people at risk of HIV infection. As Equal Treatment *goes to print, the HIV and AIDS and Sexually Transmitted Infections National Strategic Plan 2007-2011 (NSP) will be submitted to a new South African National AIDS Council (SANAC) for final endorsement.*



Deputy-President Phumzile Mlambo-Ngcuka, Acting Health Minister Jeff Radebe and Deputy-Health Minister Nozizwe Madlala-Routledge are leading government's new improved response to the HIV epidemic. Civil society must help them keep their promises.

If approved, it will become our country's new national AIDS policy, binding not only government, but all stakeholders who have been part of the process to develop and refine it. This is the government's best commitment yet to confront the HIV epidemic.

The work of every member and supporter of TAC, and our allies locally and globally, over nine years have made this possible. In particular, since July 2006 our work at Westville Correctional Centre, our protests during and after the International AIDS Conference in Toronto and the decision to work with government has succeeded in restoring trust between political leaders and civil society.

This work has also been made possible by the mandate of the Cabinet. The leadership of Deputy-President Phumzile Mlambo-Ngcuka, the Deputy-Health Minister Nozizwe Madlala-Routledge and recently Acting-Health Minister Jeff Radebe was critical to this process.

When SANAC adopts the NSP in a few weeks, there will be genuine cause for celebration. Then the work of implementation will start. TAC must adapt from protest to local pressure (including protest when necessary) for services.

What is the NSP?

The NSP is a political breakthrough and an ambitious plan. It sets out our country's commitment to responding to the HIV epidemic until 2011. It recognises the critical duty of leadership from government, but assigns responsibility to every sector of society for its implementation. It is a source of hope for people with HIV and their families. If implemented properly, it will save millions of lives. State supported AIDS denialism is defeated. The NSP embraces evidence-based and scientific solutions to the HIV epidemic.

Who wrote the NSP?

The process of developing a new NSP started seriously after the 2007 International AIDS Conference. Although initial drafts of the NSP were a good basis for civil society to engage, they had significant shortcomings.

As a result, civil society members of SANAC, together with TAC, SACC, COSATU, FEDUSA, NACTU and business asked government to delay the NSP launch from 1 December 2006 for broader consultation and to ensure that appropriate targets were included. The Deputy-President ensured that the NSP was a genuine consultative effort put together by many different stakeholders. Government, TAC, scientists, economists and many organisations have contributed to the NSP. TAC leaders were part of the final drafting team.

TAC also held community imbizos (meetings) across the country before the government convened the national consultative meeting of 14 and 15 March. The HSRC assisted us with these imbizos which were attended by other organisations and TAC members. The NSP process and objectives were explained at the imbizos. Community feedback from the imbizos was taken to the NSP consultation.

The NSP is more of a statement of intent than a strategic plan. It also should have had more input from government departments other than health. But these are minor criticisms of what is a watershed document.

What is in the NSP?

The NSP describes objectives and sets targets for government and others to meet over the next five years. It starts off with a description of the AIDS epidemic in South Africa and then divides the response to the epidemic into four sections: Prevention, Treatment Care and Support, Human and Legal Rights and Monitoring & Evaluation.

Prevention

The NSP's main prevention target is to halve the rate of new infections by 2011.

This is a noble target, but we must be cautious because it is not clear how it will or if it can be measured.

The NSP includes a number of interventions to do this such as improved programmes to prevent mother-to-child-transmission and post-exposure-prophylaxis for rape survivors.

Treatment Care and Support

The NSP practically commits to the principle of universal treatment. It calls for a nurse-driven treatment programme. It calculates the cost of providing antiretroviral treatment to 80% of people who need it by 2011. It also commits to TB screening for people with HIV, access to nutrition support and other services.

Year	Adults starting treatment	Children starting treatment
2007	120,000	17,000
2008	180,000	27,000
2009	285000	33,000
2010	370,000	42,000
2011	420,000	45,000

People newly starting antiretroviral treatment in the public health system each year
According to the plan by 2011, over one million people should be on treatment.
Source: NSP, Draft 9, pages 79 and 84.

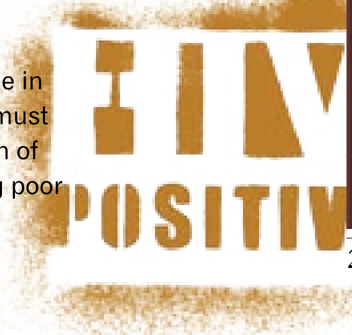
Human and Legal Rights

This describes the implications of the Constitutional right to health. It describes what it will mean to create a social environment which respects the rights of people with, affected by and vulnerable to HIV infection. It proposes nationwide programmes of education on human rights, improving the legal framework to strengthen the government's hand against pharmaceutical companies and looks to improve access to legal systems.

Monitoring & Evaluation

This describes how government will measure the impact of the NSP. For example, government will have to measure condom distribution, mother-to-child transmission prevention, HIV incidence, how the health budget is spent, number of people receiving treatment and how they are doing, number of people taking regular CD4 tests, number of deaths by each disease, social grant uptakes and much more. The Department of Health will not do this alone. Organisations such as the HSRC, the Actuarial Society of South Africa and Stats SA will assist.

TAC branches also have an important role in monitoring and evaluating the NSP. We must monitor and evaluate the implementation of programmes at local level and help bring poor delivery to an end when we encounter it.



How much will the NSP cost?

Implementing the NSP will cost billions of rands each year (see the table). About half this cost is due to the provision of antiretroviral treatment. This is why it is particularly important for TAC to campaign for better and more affordable antiretrovirals, as well as, for example, female condoms and HIV tests. This will improve patient outcomes and reduce the cost to government of the programme. While the antiretroviral rollout does cost a lot of money, over the five year period of the plan, it will be offset to a large extent by reduced expenditure on opportunistic infections if government successfully encourages most people to get tested before they get AIDS-defining illnesses.

Year	2007	2008	2009	2010	2011	% Total
Prevention	643	775	990	1,207	1,427	11%
Reduce sexual transmission	642	773	989	1,206	1,426	11%
Behavioural change interventions	300	400	500	600	700	6%
Condom provision	145	135	212	289	369	3%
Life skills	158	168	177	186	195	2%
Post-exposure prophylaxis for sexual assault	10	10	11	11	12	0%
Sexually Transmitted Infections management	30	60	90	120	150	1%
Reduce transmission through occupational exposure	1	1	1	1	1	0%
Post-exposure prophylaxis for occupational exposure	1	1	1	1	1	0%
Care, support and health system strengthening	4,329	6,075	7,786	9,804	11,893	89%
Scale-up access to voluntary counselling and testing	278	364	451	568	714	5%
HIV testing	278	364	451	568	714	5%
Maintain health of HIV-infected adults	2,724	3,809	4,926	6,309	7,714	57%
Antiretroviral treatment for adults	1,816	2,739	3,791	5,044	6,367	44%
Food support for adults	521	586	652	782	912	8%
Home and Community Based Care	386	483	483	483	435	5%
Address the special needs of mothers and children	1,047	1,343	1,570	1,808	2,064	17%
Antiretroviral treatment for children	285	434	611	816	1,032	7%
Orphan and vulnerable children	452	561	589	618	649	6%
Mother-to-child-transmission dual therapy and infant testing	310	348	370	374	383	4%
Strengthen the health system	280	560	840	1,120	1,400	9%
Strengthen TB programme management	30	60	90	120	150	1%
More and improved community clinics	250	500	750	1,000	1,250	8%
Grand Total	**4,972**	**6,850**	**8,777**	**11,011**	**13,320**	**100%**
Monetary amounts are in millions of Rands						

Cost of the NSP in millions of Rands. Source: NSP, Draft 9, Costing Annexure.

What does the NSP mean for us?

Its real meaning is the extent to which it will be implemented by all arms of government and our communities. As community members, our role is to support the implementation and monitor government's delivery. Every TAC volunteer must read the final NSP. We must organise branch and community meetings to discuss it and understand its relevance at local level to our communities. We will need to work hard at national, district and branch level to hold the state accountable for the plan's targets.

Illustration: Roulé le Roux

John Butler interviewed Josh Hawks the bass player of South African pop sensation FRESHLYGROUND. Josh was one of the first members of Friends of TAC (FoTAC), a group set up to help raise funds and TAC's profile.

Josh Hawks' still fresh life-saving message:

Use condoms & Get tested

Have you been involved with HIV/AIDS work before?
We've been very involved with the Desmond Tutu Foundation and have raised money to pay the wages of staff at an antiretroviral clinic where people living with HIV work as counsellors. Strong treatment literacy has led to 85% of patients taking their drugs correctly. We see this as a model that could be rolled out across the country.

Is enough being done in South Africa to control the epidemic?
Clearly not considering the high number of deaths and new infections that occur everyday. We are all disappointed by the lack of antiretroviral rollout. As a result of TAC pressure, a U-turn by government is taking place.

What can you and FRESHLYGROUND do to help TAC fight the AIDS pandemic?
We can help by using our platform to raise awareness about the pandemic and TAC. FRESHLYGROUND has a broad following of people in South Africa and at concerts we will continue to spread the message: people need to get tested and use condoms.

Have you been doing any work in the local community?
One of the highlights of my week is playing drums in a township community centre with young people who have psychiatric problems, often related to drug use. I provide an amp and a base and we all jam together. Children in townships often don't have the opportunities to do fun things. They live in poverty and it is easy to find problems but not solutions. I'm not saying I have the solutions, but if people give a bit of their time or skills to disadvantaged communities, it would be a great benefit to many people.

Who do you think should be the next President of South Africa?
It's hard to say, but I personally would like to see a woman. I recently saw a lecture that noted the high number of South African women in the 15-24 age category who have HIV. They are taking the brunt of the disease and perhaps a female President would help to inspire change and bring equality for women in South Africa.

"I would like to thank people for supporting FRESHLYGROUND from all stratas of society. We are very grateful. We also hope that more people get involved with TAC and FoTAC and build up the momentum for greater prevention and treatment."

Josh Hawks, FRESHLYGROUND

messenger of life

a look at the media and aids

Many of us learn about AIDS by reading a newspaper report, listening to the radio or watching television. The media helps form opinion on how to respond to the HIV epidemic. But is it getting it right?

The media is not a uniform institution. There are numerous sources of news and opinion. Making generalisations about "The Media" is often meaningless. But we can identify some trends. Most national newspapers in South Africa have been critical of government's response to the HIV epidemic and AIDS denialism. Radio presenters have also been critical. The same, however, cannot be said for SABC television. Nevertheless, the balance of opinion expressed in the media has been to call for the state to improve its response to HIV. Also, every major publication has featured TAC and many newspapers and radio stations consistently report TAC's position on AIDS-related news. TAC's successes would not have been possible were it not for the media.

There are, however, two types of problems that we consistently encounter. The first is that although most reports on the epidemic are well-intentioned, few are accurate. Many journalists are unable to write accurate reports on HIV science. Frequently reports on the epidemic get scientific facts wrong. This is because most journalists do not have adequate science training. Few publishers are willing to invest serious money into improving the science expertise of their staff. In one study carried out by Robert Brand and reported in the Rhodes Journalism Review, 230 stories from a major daily newspaper were examined over a 3 week period. Of those, 92 (40%) were found to contain a numerical element. Of those 92 stories containing numerical data, 26 (28%) were found to contain errors. A deeper analysis would have probably found many more errors.

The second problem is less common, but much more damaging. Some editors and journalists promote AIDS denialism. The problem of poor scientific accuracy is a structural one. However, promoting pseudo-science is a problem of ethics. Pseudo-scientific journalism encourages people to make life-threatening choices, for example to take Tine van der Maas's garlic treatments instead of antiretrovirals, or not to use condoms.

In this *Equal Treatment* feature, we look at the best and the worst reporting of the HIV epidemic.

This feature was compiled by Nathan Geffen as part of a research project funded by the Open Society Foundation (OSF). It is based on Geffen's article Encouraging Deadly Choices: AIDS Pseudo-science in the Media. Available at: http://www.cssr.uct.ac.za/papers/wp182.zip.

The views expressed are not necessarily those of TAC or OSF.

r death?

a journalist's view

We interviewed journalist Susan Smuts, who is responsible for the Everybody Knows Someone *campaign of the* Sunday Times.

ET: What are the positive aspects of the media's coverage of HIV?

SM: HIV is treated as a matter of public importance. The media has run reports on government policies, pressure brought on governement by groups (including TAC) shortcomings in health service, analyses of demographics, actuarial predictions, treatment rollout, etc. These reports have kept AIDS in the public consciousness.

There has also been a focus on personal stories, stories of hope rather than despair. I think this reflects the fact that advances in treatment mean that HIV is no longer a death sentence as well as that courageous individuals have broken the silence.

The *Everyone Knows Someone* campaign in *Sunday Times* has become a platform for people to tell their own stories and the response has been wonderful. Every story is different and readers get to see human beings rather than statistics. And lessons emerge from the stories: We learn that people should seek treatment before it is too late, that it is possible to be in loving relationships even when we are HIV-positive, that people around us will give us support if we ask for it. Many of the contributors who have lost people to AIDS have also expressed thanks for publishing their stories, saying that sharing the story has helped them process grief. Others have written in because they have read a story that made them realise they were not alone, that other people were grappling with similar issues.

ET: What could the media have done better?

SM: It should have been more circumspect about reporting of "cures", and found ways (especially in the earlier days) to report in less negative ways.

We could give more practical information that would enable people to make better decisions, e.g. where to get tested, treated or counselling. We should investigate the availability of AIDS drugs, particularly in clinics.
There is a lot of scope for the media to get involved in campaigns that could help orphans, and poor people whose ability to access help is limited.

ET: What can be done to improve science reporting?

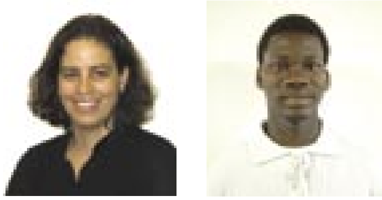
SM: First prize is to have reporters who have science training. But failing that, reporters with a genuine interest in the technical side of HIV reporting and good contacts in the medical fraternity would help. Any good reporter should check their facts, especially when it comes to new or difficult science, with their sources. Reporters on the HIV beat should understand medical advances to date. Reporters could perhaps attend short HIV courses offered by various organisations and institutions. These do not necessarily have to be courses on hard science. They could also sensitise reporters to other aspects of the epidemic.

the good...

Some journalists have published accurate and often groundbreaking articles that have helped us understand the epidemic better or exposed abusive practices.

Exposing the Health department's failure to investigate Rath

September 2005



Khopotso Bodibe & Anso Thom of South Africa's Health e-news network exposed the MCC and the Department of Health's fumbling attempt at investigating the activities of multivitamin businessman, Matthias Rath. They were awarded a CNN prize for their efforts.

Living on the other side of denial

18 March 2007

Sunday Times

Bobby Jordon of Sunday Times reported on a Khayelitsha family six years after both parents started on ARVs. The story explained how their lives improved and how they overcame HIV denial. Articles like this give hope to people living with HIV.

Science for everyone

6 October 2000

Mail&Guardian

Belinda Beresford's Mail & Guardian feature explained how we know that HIV causes AIDS. She debunked the arguments of the AIDS denialists. And she did this in a way that non-scientists could understand.

Reporting statistics

1 December 2005

BUSINESSDAY

Tamar Kahn's lead story explained the Human Sciences Research Council's household survey on HIV accurately and informatively.

Consistent and ethical coverage

CAPE TIMES

The Cape Times has consistently reported on the HIV epidemic and more recently the TB epidemic. Their coverage is solid and informative. The opinion editorials have held government to account for its HIV policy shortcomings.

the bad...

Reports by well-intentioned journalists often contain huge inaccuracies which cause confusion.

New HIV/AIDS pill

In July 2006, a newspaper claimed that a pill, Atripla, that combines three antiretrovirals and only has to be taken once a day was set to hit South Africa within days, pending MCC approval. At the time of *Equal Treatment* going to press, i.e. ten months later, the manufacturer had not even applied for Atripla to be registered here. Reports like this raise false hope.

. . . and the really awful

Here are some of the worst examples of AIDS journalism in South Africa.

Criselda Kananda's denialism

Chriselda Kananda. an AIDS denialist, hosted a radio show called Positive Talk on *Kaya FM*. She often ran shows promoting AIDS denialism. During one show in April 2005 she claimed HIV does not cause AIDS, HIV tests are inaccurate and antiretrovirals are toxic*.* Mindset successfully lodged a complaint against Kananda with the Broadcasting Complaints Commission of South Africa (BCCSA). Kananda now runs a pseudo-scientific radio programme on Metro FM.

How not to report statistics

Martin Welz's Noseweek magazine has frequently run AIDS denialist articles. In December 2003 Noseweek printed an article by Rian Malan claiming there is not a substantial AIDS epidemic in Africa. The article contained numerous errors. Although Welz printed a response to Malan's article, in February 2007, the magazine again ran a Malan piece, also full of errors.

Deadly Advice

The Citizen ran an opinion editorial on 7 April 2006 by AIDS denialists David Rasnick and Sam Mhlongo claiming that HIV is not transmitted by heterosexual sex. They claimed that condoms were unnecessary for preventing HIV transmission, though they conceded they were useful for preventing the transmission of other curable sexually transmitted infections.

We asked for comment from the editors of the publications we criticised above. Only Martin Williams of *The Citizen* responded with integrity. Here is an edited version of his response:

We publish a wide range of views, whether we agree with them or not.

I must also point out that the articles by Rasnick and Mhlongo were not solicited by us, and we have turned down far more from them than we have published. TAC is also welcome to submit articles but, again, we are not soliciting nor guaranteeing publication.

We do not campaign for or against anyone on this matter. However, we do stand for free speech. There is a possibility that in your eagerness to do good your are inadvertently leaning towards the stifling of debate.

To silence all voices but your own would be unfortunate."

Williams identifies the crux of this debate: are we restricting freedom of expression by saying that it is wrong to publish articles that promote AIDS denialism? We do not think so. Newspapers have the right to publish AIDS denialist articles without fear of state repression. This is what the Constitution guarantees. However, the right to publish should not be confused with the idea that it is right to publish. Freedom of expression does not free publishers from responsible journalism. And when they get it wrong, they should expect very strong criticism.

Most publishers follow some ethical standards. For example, ethical publishers do not publish news articles which they know have factual errors in it. Articles on science should be subject to the same ethic.

Unfortunately, very few editors have the necessary science training to identify errors in science articles. Therefore, they should be extremely cautious before publishing articles that claim to overturn the consensus of most of the world's scientists and all authoritative scientific institutions. The place for such revolutionary articles is in scientific journals where they can be properly evaluated, not in the mass media, where they can only cause confusion. There are many interesting debates about HIV the media should host, but whether HIV causes AIDS is not one of them.

TENOFOVIR URGENTLY NEEDED

Tenofovir is a life-saving AIDS medicine. So why isn't it available to most South Africans with HIV?

Medicines for AIDS and most other serious illnesses can be sold in South Africa once they are registered with the Medicines Control Council (MCC). The MCC makes sure that a medicine is safe and that it works (effective) before it registers it. It is an important institution with important responsibilities.

Tenofovir is a life-saving antiretroviral medicine for treating people with AIDS. It is not a cure for AIDS; it is a lifelong treatment that has to be taken with other antiretrovirals. It has many advantages over other antiretrovirals, but it is not registered in South Africa. Therefore very few people can get it. Yet tenofovir has been available in the United States since 2001. It is unfair that a life-saving medicine should not be available in South Africa, which probably has more people living with HIV than any country in the world.

Tenofovir is manufactured in South Africa by Aspen

Pharmacare. It is patented (owned) in the US by a company called Gilead. TAC holds the MCC, Aspen and Gilead jointly responsible for the delayed registration of tenofovir. On 22 February 2007 TAC held country-wide demonstrations to highlight the delayed registration of tenofovir.

Facts about Tenofovir

Tenofovir is an antiretroviral that we need to have registered in South Africa, so it can become part of the public sector treatment programme, especially as an option to another antiretroviral called stavudine (also known as d4T). Studies have shown tenofovir has fewer side effects than d4T. Also, people resistant to other antiretrovirals can often use tenofovir. Additionally, it is only taken once a day, making it an easier drug to adhere to.

HIV doctors have called for the South African treatment guidelines to be updated to include tenofovir, so that public sector patients can access it, but this can only happen once tenofovir is registered. Another advantage of tenofovir is that there are pills that combine tenofovir with other antiretrovirals. These must also be registered because patients taking them will have to take fewer pills, which is the most important factor for good adherence.

There are three classes of antiretrovirals available in South Africa: nucleoside reverse transcriptase inhibitors (e.g. AZT, d4T), non-nucleoside reverse transcriptase inhibitors (e.g. nevirapine) and protease inhibitors (e.g. lopinavir/ritonavir - better known by the brand-name Kaletra).

Tenofovir is a nucleotide reverse transcriptase inhibitor (NRTI). NRTIs help prevent HIV from reproducing inside CD4 cells by stopping reverse transcriptase, a protein used by HIV to reproduce itself. The World Health Organisation has recommended that tenofovir is a possible replacement for d4T for people taking ARVs for the first time.

What are the advantages of tenofovir over d4T?

Results from various clinics and hospitals around South Africa show that antiretrovirals are saving many lives. For example, a Western Cape Government report found:

By four years duration on [antiretroviral treatment], 7 out of 10 treatment-naive adult patients are still in care. Without treatment almost all of these patients would have died in this time period.

However, d4T has serious side-effects for some people that in rare cases can be life-threatening. For example, d4T can cause lactic acidosis, a sometimes fatal condition, particularly for overweight women. It also causes neuropathy and lipoatrophy. Tenofovir has a lower risk of causing these serious side-effects.

On 22 February 2007, TAC held demonstrations around the country against the Medicines Control Council, Aspen Pharmacare, Gilead Sciences and the Department of Health. We demanded the registration of tenofovir.
Photos provided by Sylvia Fynn.

What are the problems with tenofovir?

All powerful medicines have side-effects. Tenofovir is no exception. Studies have shown that tenofovir has a low risk of causing kidney damage, but this can be monitored by checking what is known as creatine levels. Tenofovir can also have a small effect on bone toxicity in the first year that you take it. However this problem did not get worse

> *"I developed resistance to my first-line treatment and I got peripheral neuropathy from d4T. So my doctor advised me to switch to tenofovir, lamivudine and lopinavir/ritonavir. My CD4 count increased dramatically after the switch."*

Nokhwezi Hoboyi, *Equal Treatment* co-editor. Photo by Designs for Development.

in patients followed up over five years. There is also, as yet, no formulation of tenofovir for children to take.

How often is tenofovir taken?

Tenofovir comes in 300 mg doses and should be taken once a day, with or without food. It must be taken in combination with other antiretrovirals.

Combination drugs that include tenofovir

Tenofovir is also manufactured as one pill with another antiretroviral known as FTC (branded as Truvada).

Critically, tenofovir is one of the three drugs that make up the world's first one-pill-a-day antiretroviral regimen. This all-in-one pill consists of tenofovir, FTC and efavirenz (branded as Atripla in the United States). Reducing the number of pills patients need to take has been shown in a South African study to be the best way to improve patient adherence.

These formulations are not licensed or registered in South Africa. TAC will campaign to change this in 2007.

Does tenofovir have other uses?

Tenofovir is being tested to see if it can prevent transmission from mother-to-child.

It is also being tested as a microbicide and as chemoprophylaxis. This means it is being tested to see if it can prevent the sexual transmission of HIV.

However, it has not yet been shown to be effective for these uses.

Interactions between tenofovir and other drugs

Like many medications, tenofovir can interact with other drugs. Taking tenofovir with didanosine (ddI), another antiretroviral, increases ddI levels in the blood above what they are supposed to be. This can therefore increase the side-effects of ddI. So tenofovir and ddI should not be taken together.

If you take tenofovir with the antiretroviral atazanavir, then you must also take an antiretroviral called ritonavir, else the levels of atazanavir will be decreased below their correct amount and it will not be effective against HIV.

Is tenofovir available at all in South Africa?

Currently you can only get tenofovir under what is known as a section 21 authorisation from the MCC. Your doctor would have to make a special application to the MCC on your behalf. This is time-consuming, complicated and impractical on a large scale. Also, the South African antiretroviral treatment guidelines cannot include tenofovir until it is registered. Only by registering the drug can it become available to most people who need it.

Is tenofovir too expensive?

Yes. The price of tenofovir in South Africa is likely to be at least R120 per month. This is more than the price at which the government buys all three current standard antiretroviral medicines for someone taking treatment for the first time. TAC will campaign for the price to be brought down. For this to happen, other drug companies must make tenofovir and sell it in competition with Gilead and Aspen. Also, the more suppliers, the less risk there is of running out of stocks of tenofovir, as has happened occasionally with other antiretrovirals.

TAC appeal for funding

In South Africa we have over 5 million people living with HIV.
500,000 people will die if they don't get antiretroviral treatment soon.
TAC campaigns for access to treatment, a people's health service
and community driven prevention strategies.

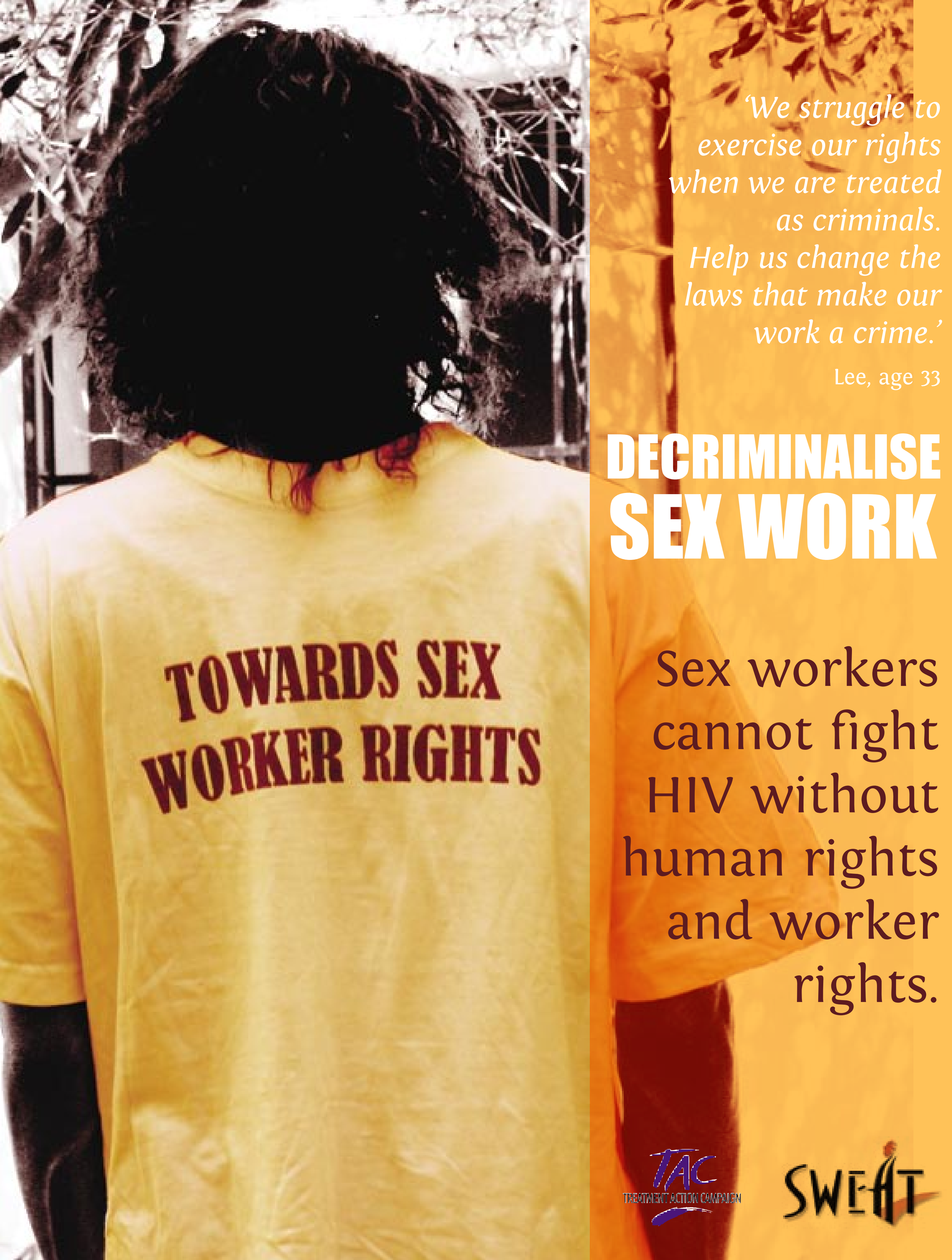
SUPPORT US TO SAVE LIVES

Donate at your nearest bank OR www.tac.org.za/donatenow

DONATE NOW

TAC
TREATMENT ACTION CAMPAIGN

Treatment Action Campaign
Bank: Nedbank, Braamfontein Branch
Account no: 128 405 1870
Branch code: 195 005



> *'We struggle to*
> *exercise our rights*
> *when we are treated*
> *as criminals.*
> *Help us change the*
> *laws that make our*
> *work a crime.'*
>
> Lee, age 33

DECRIMINALISE SEX WORK

Sex workers cannot fight HIV without human rights and worker rights.

TAC
TREATMENT ACTION CAMPAIGN

SWEAT