EQUAL TREATMENT

NEWSLETTER OF THE TREATMENT ACTION CAMPAIGN JULY 2005

Minister, the treatment plan needs leadership

Laugh It Off's biting satire resulted in a victory for human rights over intellectual property. See page 28. Photo by Aaron Tjoa.

Over 1,500 activists marched to hand over a memo to the South African AIDS Conference on 8 June. See page 18. Photo by Themba Maphumulo.

Thembeka Majali, Reverend John Oliver and Zackie Achmat at a TAC interfaith service calling for food, treatment and better health-care. Photo by Nokhwezi Hoboyi.

Traditional Healers turned out in support of TAC at the Cape High Court where an interdict was being sought against Matthias Rath for defaming TAC. Photo by Iming Lin.

TAC
TREATMENT ACTION CAMPAIGN

EQUAL TREATMENT

July 2005
Issue 16

CONTENTS

Learners at a treatment literacy workshop at Mhelembe High School in Makhasa, Limpopo show their TAC Talking About Antiretrovirals *fact sheets. Photograph by Petunia Nkolele.*

Equal Treatment is published by the Treatment Action Campaign

34 Main Road Muizenberg 7945

Tel: +27 (0) 21 788 3507

Fax for attention Equal Treatment: +27 (0) 21 788 3726

Email: et@tac.org.za

Website: www.tac.org.za

Distribution: 35,000 copies

Editors: Nokhwezi Hoboyi and Nathan Geffen

Layout: Darryl Cotton

Administration: Faniswa Filani

Front cover: TAC members debate with the Minister of Health. Photo courtesy of Mail & Guardian. Taken by Nadine Hutton.

New layout design: Doret Ferreira

Letters to the editor should be 300 words maximum.

Sponsored by Swedish International Development Agency

TAC is committed to providing people with HIV/AIDS, 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.

editorial

MAKE THE TREATMENT PLAN WORK

TAC campaigns for HIV treatment

Central to our campaign are the rights to life, dignity, equality and freedom of every person. These positions of principle are always informed by science. We defend them passionately, animated by the knowledge of lives lost, bodies broken and families destroyed.

Since the beginning of this year studies by Statistics South Africa and the Medical Research Council have confirmed that HIV/AIDS is the leading cause of death in young adults and children in our country. The people who die lonely and miserable deaths are mostly, but not only, poor and black. One in every nine teachers lives with HIV. Nearly one third of teachers with HIV will die over the next three years if they do not get access to antiretroviral treatment. The right to life for many people with AIDS is still a right that is bought.

Stigma, inequality and deliberate absence of leadership are the main causes of AIDS deaths because they are the main obstacles to treatment and prevention.

As I write this, one of my closest friends, Ronald Louw, lies in a hospital in Port Elizabeth fighting for his life. A white middle-class gay law professor with an activist history nearly left it too late. He only found out his HIV status a few weeks ago when his CD4 count was below 100 and he was diagnosed with pneumonia. Now cotrimoxazole and the antiretroviral regimen he has just started give him hope. Ronald has said that when he is better he is going to tour South Africa telling people to get tested early. But, why did Ronald like so many other men in our country have to wait till they are at death's door before admitting their HIV status?

This month's *Equal Treatment* tells of other people who have a chance at life because they have access to treatment, but it also tells the difficult story of Thomas Munyai who is ill and does not know if he will be able to access antiretrovirals. Thomas is one of the statistics on the waiting lists of Limpopo, Mpumalanga, KwaZulu-Natal, Eastern Cape and elsewhere; lists that are the product of bureaucracy and lack of leadership. We salute the courage of Ronald and Thomas. They are both open about their status and fighting for life.

This month's issue focuses on the treatment plan. Government released the plan on 19 November 2003. It was a breakthrough that TAC welcomed and celebrated. It promised over 180,000 people on antiretroviral treatment in the public sector by March 2005. It also committed to hiring more health-care workers, implementing nutritional programmes for people with HIV, a large prevention effort and continuing the implementation of mother-to-child transmission prevention.

Yet we are way behind target. After revising the target without consultation, government acknowledged only 42,000 people were on treatment in public facilities by end of March 2005. Yet the Health Minister was angry that this many people were on antiretrovirals. The programme is hampered by an inconsistent drug supply, fear of reprisals if initiative is shown by health workers, lack of training and too few health-care workers. There is hardly any government driven public education on HIV treatment and too little on prevention. Not enough has been done to keep health-care workers in the system or attract new ones. Furthermore, despite the Minister of Health's talk about nutrition, the nutritional commitments of the treatment plan are not being implemented properly. And, except for the Western Cape, no province has improved on the single-dose nevirapine regimen for reducing mother-to-child transmission.

Heading for a disaster

Thousands of people are benefiting from treatment and the numbers are climbing steadily because of the commitment of government officials in some provinces, dedicated health workers at antiretrovial sites and the vigilance of treatment activists. But given the scale of the problem – 5.6 million people with HIV, half-a-million needing treatment now and 300,000 expected to die this year – the slack implementation of the treatment plan is a tragedy. The rollout is not a disaster but the country will head for disaster if we do not act with urgency, compassion and far-sightedness.

Leadership is what's missing

Underlying all the problems of the treatment plan is a lack of leadership. The Minister of Health shows gross incompetence, neglect and disrespect for life of people living with HIV. She undermines the plan by publicly endorsing unproven treatments and doubting the real benefits of antiretrovirals.

But she is a failure in almost all other respects too. TB is out of control and multi-drug resistant TB has become a problem. Maternal and infant mortality are increasing. There's currently a measles epidemic. She has failed to deliver on the promise of a human resource plan for the health services. She has allowed vested interests such as drug companies and New Clicks to misuse her failures to cover their greed in the courts.

It took years of struggle to get a treatment plan. Now we must make it work.

Treat 200,000 by 2006

The treatment plan committed to treating far more than 200,000 people by end of March 2006. This is still achievable, but it will take leadership and political will. It will also require TAC to mobilise our branches to get people tested for HIV and to campaign for our clinics to make antiretrovirals available. Persistent activism and mass mobilization is the only way to create sufficient leadership. We are ready for this challenge.

Sometimes we show anger as we struggle against denialism, stigma and poor leadership. We are often criticised for this. Some say: Why focus so much energy on antiretrovirals? Why are you so harsh to the Minister of Health? Indeed, the photograph on the front cover of this issue conveys some of that deep frustration.

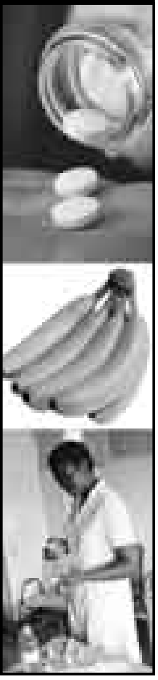
We offer no apology. This is not an abstract struggle for us; it is about life and death. We have seen the difference treatment makes. Hundreds of TAC members – people like Nokhwezi Hoboyi, Vuyani Jacobs and Sindi Godwana – live today because they take antiretrovirals. I am alive because of antiretrovirals.

Over the last few months, our country has seen riots and anger over housing. Foolish politicians have blamed “sinister forces” for these riots. They have threatened people with the National Intelligence Agency. In Free State people who threw stones and burnt tyres were charged with the common law offence of “sedition”. This is shameful. Many of us are celebrating fifty years of the Freedom Charter but we see its ideals as far from realized especially for poor and working people in our country.

Many feel that despite formal democracy, as poor people, especially black people, our dignity and freedom remains diminished by inequality and poverty. Riots are the product of pain and frustration. People living with HIV/AIDS in our country feel this pain and frustration but riots can never substitute for sustained, persistent activism to challenge inequality.

TAC has always shown discipline in our activism. Persistent activism, patient education and mass peaceful action are the basis of our work. We may be tired of denialism but we will fight till the last breath.

Zackie Achmat, TAC Chairperson



WHAT IS THE HIV TREATMENT PLAN?

On 19 November 2003, government published the *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*. This was the long awaited treatment plan that TAC campaigned for. It describes government's strategy for confronting the HIV epidemic in South Africa. Over the next five pages we look at what the plan is all about, what's working and what's not. We also look at the human resources and nutritional aspects of the plan in detail.

Compiled by Fatima Hassan, Julia Cole, Aaron Tjoa, Reid Roberts, Iming Lin, Danielle Dimitrov and Nathan Geffen

The treatment plan caters for the rollout of antiretrovirals, hiring more health-care workers, scaled up prevention programmes, voluntary counselling and testing and better nutrition for people with HIV.

People living with HIV will be provided with services and support at all stages of infection. HIV-positive patients with CD4 counts above 500 will receive CD4 counts once a year. Adults in World Health Organization stage IV of HIV or with a CD4 count less than 200 will receive CD4 count and viral load tests every six months. Antiretrovirals will be given to people who have AIDS-defining illnesses or a CD4 count below 200.

The plan envisages patients will initially be treated at district or regional hospitals. Once their treatment is stabilized, they will be monitored at clinics, and have access to counselling and support groups.

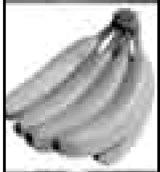
Traditional healers should also play an important role in the treatment plan. The plan recommends that joint training is set up between traditional healers and clinicians to share knowledge and improve monitoring of patients. Traditional healers can mobilize their communities, promote adherence to drug regimens, and provide emotional support for patients. The plan also says that traditional medicines should be tested to ensure their safety, to investigate future treatments and to make sure that there are no harmful interactions with prescribed drugs.

The implementation of this treatment plan should not only provide resources for those affected by HIV, but should impact on and improve the public heath system in South Africa as a whole.

Treatment Plan Implementation Scorecard

✓ = On track ✗ = Failing ½✓ = Not quite there yet

• 22,000 additional employees in the health system by 2008	✗
• At least one treatment centre in every health district within one year	✓
• Access to care and treatment in every municipality within five years	✓
• 53,000 people on treatment and over 200,000 CD4 count tests by March 2004	✗
• A further 138,000 new people on treatment by March 2005 (giving a total of just under 200,000 people on treatment)	✗
• A further 215,000 new people on treatment by March 2006 (giving a total of about 400,000 people on treatment)	✗
• All HIV positive people able to access comprehensive treatment by 2009	✗
• Prevention programmes in schools, healthcare centres, workplaces and communities	✗
• Scaled up condom distribution	½✓
• Integration of traditional healers with public health service	✗
• Improved nutrition interventions	✗



WHAT'S WORKING?

The number of people receiving antiretrovirals in the public sector is far below government's target. Photo by Rodrick Clarence.

Nationally, more than 113 sites were providing antiretroviral treatment to more than 42,000 people as of March 2005. Over 1,500 sites offer mother-to-child transmission prevention. All provinces have made their business, strategic, treatment, and human resource plans public, although some of these plans are very poor. The Western Cape, Gauteng, Free State, Northern Cape, and North West provinces are showing commitment to making the plan work. Limpopo, on the other hand, has shown no commitment whatsoever and the Kwazulu-Natal Department of Health is often reluctant to communicate or share information.

Government almost met its target of a site in each district. By end of March, 50 districts had treatment sites. However, the vast majority of people are still unable to access treatment at a clinic serving them. Consider that there are approximately 4,000 public health facilities in South Africa and only just over 100 provide antiretroviral treatment.

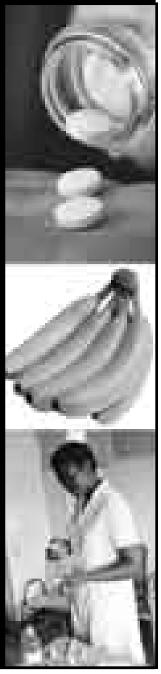
In February 2005, the office of the national manager of the antiretroviral programme released national patient numbers and site details for the first time. This gives us a fairly good idea of the extent of the rollout across the country as of end of January. (See the table for provincial treatment numbers from this report.)

Private Sector

There are probably still more people being treated in the private sector than in the public. The private sector includes people being treated by NGOs such as the American Healthcare Foundation Clinic in Umlazi, companies such as Anglo American and Daimler Chrysler, people on private medical schemes like Zackie Achmat and Edwin Cameron, and people paying out of their own pocket. The Joint Civil Society Monitoring Forum estimated that over 45,000 people were on treatment in the private sector as of October 2004.

Province	**No. of patients assessed by end January 2005**	**No. of patients on treatment by end January 2005**
Eastern Cape	89,657	3,739
Free State		1,115
Gauteng	96,840	9,774
KwaZulu Natal		6,086
Limpopo	3,180	935
Mpumalanga	2,146	936
Northern Cape	2,295	515
North West		2,625
Western Cape		6,660
Total	**194,118**	**32,385**

Source: Statistics by Cluster Health Information, Evaluation, and Research issued by National Department of Health



WHAT'S NOT WORKING?

The treatment plan called for 53,000 people to be on antiretroviral treatment by March 2004. This goal, like most others in the treatment plan, was not achieved.

In 2004, President Thabo Mbeki changed the estimate, promising to achieve the 53,000 goal by March 2005. Current Department of Health estimates place the number of treated at around 42,000, far behind revised targets. If we were on track with the original plan, nearly 200,000 people would already be on treatment.

The lack of strong political commitment to the plan from the Health Minister and the President has left many other goals of the treatment plan unachieved.

Queues outside shack clinics in Lusikisiki. Photos by Nathan Geffen.

- **Drug shortages**
  The procurement process – the process of selecting sources of antiretroviral medicines – remains inconsistent, causing drug shortages (e.g. efavirenz in Mpumalanga).

- **Shortage of human resources**
  There is a severe shortage of doctors, nurses, pharmacists, counsellors, administrators, managers, cleaners and porters. Government has yet to release a national human resources plan. Nor has any information been released indicating whether progress has been made towards hiring an additional 22,000 health-care workers by 2008. The long queues outside public clinics across the country, often starting early in the morning, are a consequence of the health-care worker shortage.

- **Sub-optimal mother-to-child transmission prevention regimen**
  Outside of the Western Cape only the single-dose nevirapine mother-to-child transmission prevention regimen is used. The programme is particularly badly implemented in Mpumalanga and Limpopo provinces.

- **Long distances for patients to travel**
  Most patients outside the Western Cape still have to travel long distances to large hospitals to get their antiretroviral medications, rather than having treatment available at local clinics.

- **Lack of antiretroviral training**
  There is a lack of knowledge about antiretroviral treatment among public health workers, especially when it comes to treatment for children.

- **Poor public messaging**
  Government has distributed no fact sheets on antiretrovirals or nutrition for people with HIV as far as we are aware. There are very few adverts encouraging people to get tested or explaining the treatment plan. In addition, the Minister of Health sends confusing messages that scare people into not taking antiretrovirals.

- **Lack of information**
  Government does not provide enough updates on the state of the rollout and whether or not targets are being met. The timetable of the treatment plan, annexure A, has still to be released.

WHERE IS THE HUMAN RESOURCES PLAN?

Building a strong and capable health sector requires a full staff of health professionals. A survey of the public health sector by Health Systems Trust (HST) shows that South Africa is far from reaching this goal. The report found that in 2003 the public health sector had many unfilled posts.

Nurses of Majosi Clinic, Limpopo. How can we make their lives better? Photo by Petunia Nkolele.

There is an increasing burden on health care workers because of HIV/AIDS, and yet because of staffing shortages, nurses find themselves doing multiple jobs, including cleaning floors and moving patients. At the Western Cape People's Health Summit, Dr. Lydia Cairncross reported that doctors and nurses work for many days without proper food or rest and have to face long queues of patients with little time to see each one. Every day doctors and nurses do not show up to work because they have been overworked, Dr. Cairncross said.

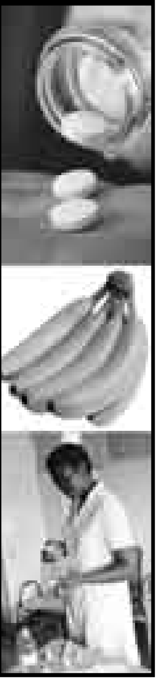
These conditions lead to poor health services, and an emigration of doctors and nurses from South Africa to other countries with better working conditions and salaries.

The Human Resources Plan is supposed to address these issues, but this remains uncertain as a draft of the plan has yet to be completed and made public, despite promises from the Health Minister that the draft would be available in March 2005.

Sources: www.hst.org.za/news/20040813, Lydia Cairncross. "Health Care Workers' Conditions of Work." Western Cape People's Health Summit.

PROVINCE	**PERCENTAGE UNFILLED POSTS**
Mpumalanga	67
Free State	41
North West	33
Gauteng	32
Eastern Cape	28
Northern Cape	27
Kwazulu-Natal	25
Limpopo	13
Western Cape	14

Source: HST



NUTRITION: MUCH TALK AND LITTLE ACTION

For people with HIV, good nutrition slows down the progression to AIDS. Good nutrition is also needed to optimize antiretroviral treatment. The treatment plan has a nutrition policy that targets communities that do not have adequate food.

The plan includes giving nutritional information at local service sites to all people with HIV. It also commits to giving vitamin supplements and food parcels to children under 14, pregnant women, and malnourished people with AIDS who qualify for antiretrovirals.

Because information from each province is not available, it is difficult to assess how funds are being allocated regarding the nutritional policy. However, reports from local communities highlight some of the programme's weaknesses at provincial sites. Vitamins and food parcels are not available at every site. For example at Harriet Shezi Clinic – the largest paediatric treatment site in the country – none of the nearly 2,800 adult and paediatric patients received food parcels in April 2005. Although 6% of children on antiretrovirals at the clinic receive fortified maize meal they do not have access to food parcels.

Lihle Dlamini with her antiretroviral medicines and good nutrition.

Social workers do not always know who is eligible for benefits and the application form is several pages long. There are also no proper nutritional guidelines and no evidence that accurate nutritional information is given to people attending clinics. There is however much evidence of inaccurate information being given by the Minister of Health. For example she makes unfounded claims for the usefulness of certain foods such as garlic, onions, lemons and olive oil.

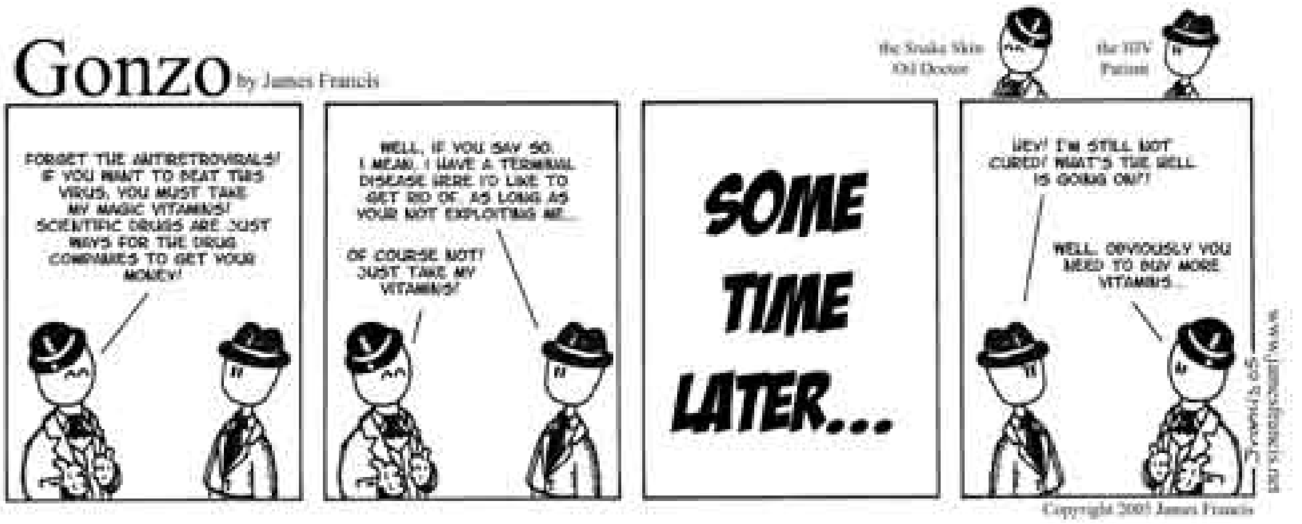
In addition, there is a general lack of nutritionists and social workers in the country, so many people have no access at all to nutrition assistance.

> **The Minister of Health makes unfounded claims about the benefits of some foods.**

Delays in the delivery of food parcels and vitamin supplements to clinics are another problem.

There are some successes, but these are usually NGO driven. In Mpumalanga, the Ndlovu antiretroviral treatment programme, which works with malnourished children and their caregivers, has helped many people grow their own gardens. This project also has its own HIV monitoring lab – the only one like it in the country – which saves a great deal of money. The programme has repeatedly tried to work with the provincial government but the government has not yet co-operated.

In summary, government has provided no information or any evidence whatsoever that its nutritional programmes described in the treatment plan are being implemented.



See James Francis's cartoons on his website, www.jamesfrancis.net.

TOLES © 2003 TheWashingtonPost. Reprinted with permission of UNIVERSAL PRESS SYNDICATE. All rights reserved. See page 28 for information on efforts to legalise gay marriage.

CHAPEL STREET CLINIC: "WE NEED TO ROLLOUT ANTIRETROVIRALS"

By Nokhwezi Hoboyi

Chapel Street Clinic is a community health centre situated in Woodstock, Cape Town. It caters mainly for low-income and unemployed people in Woodstock, Walmer Estate and Observatory. This clinic has not been accredited yet as a treatment rollout site. The nurses at this clinic are friendly and are always willing to assist patients whenever they can.

The majority of the patients here are diagnosed with tuberculosis (TB). The clinic offers voluntary counselling and testing (VCT) and CD4 counts. The staff advise patients to test for HIV once they are diagnosed with TB. There is one lay counsellor who does VCT.

"We test ten people a day and about seven test positive for HIV. About five are females. We need another counsellor to help with the increasing number of patients," said Yolanda the clinic's counsellor. The clinic has been successful at treating TB because it manages to make sure that a high percentage of patients finish their treatment course.

They do not offer mother to child transmission prevention. The nurses are not yet trained to dispense antiretroviral treatment even though they are willing to be trained. The doctor is only available on Mondays and Wednesdays and it is very busy on these days with more than 50 patients. Sister Winnie Nonkonyane, the clinic manager, says that they have a good relationship with their patients. They refer patients with low CD4 counts to the Robbie Nurock clinic for commencement of antiretroviral treatment. The lay counsellor is also not trained on antiretrovirals, so it is difficult to advise patients about treatment. There is no pharmacist to dispense any medication. Instead, the nurses usually dispense medication.

Staff of Chapel Street Clinic. Making a difference to poor people in Cape Town. Photo by Nokhwezi Hoboyi.

Sometimes patients who were referred elsewhere come back to Chapel Street when they have side-effects or untreated opportunistic infections. The clinic's doctor, Kim Narunsky, says, "This is not the best way to treat a patient because one cannot tell whether the side-effects are from TB treatment or antiretrovirals. It would be best if we diagnosed our own patients by giving them antiretrovirals here and it would make it easier for us to manage side-effects or treat opportunistic infections without having to refer them to another clinic or hospital." The staff here believe that they need training about issues relating to HIV/AIDS and antiretrovirals so that they can become accredited and therefore offer more to patients living with HIV/AIDS.

STAFF TRAINING NEEDED AT LEVAI MBATHA COMMUNITY HEALTH CENTRE

By James Dlamini

Levai Mbatha Community Health Centre is situated in Evaton, Gauteng Province. It was opened on 23 March 2001. This clinic does voluntary counselling and testing, mother-to-child transmission prevention (MTCTP) and CD4 count testing. There are six counsellors: two work on MTCTP, two do CD4 counts and the other two counsel. After CD4 counts, patients are referred to Kopanong, Empilisweni or Sebokeng Hospitals depending on the patient's location.

"When it comes to dispensing of antiretrovirals, we have dedicated staff but most of them are under-trained and some are not trained at all. We need training before we can give antiretroviral treatment," said Ms. Ellen Monamadi, the facility manager.

There are some difficult challenges faced by the clinic. Shortage of staff is a critical one. For example, they have only four trained nurses. Also their facility space is limited. "We have problems with some patients, as they have no knowledge about HIV/AIDS or are in denial," said Ms. Maria Seabi.

"Some patients have no knowledge of HIV/AIDS or are in denial."

Levai Mbatha Community Health Centre. Photo by James Dlamini.

Between January and March 2005, the clinic tested 497 people for HIV including 250 females and 247 males.

- **73 females tested positive**
- **58 males tested positive**
- **177 females were negative**
- **189 males were negative**

For MTCTP (between January and March):

- **260 pregnant women were tested**
- **79 tested positive**
- **181 tested negative**

THE STRUGGLES OF DE HOPE CLINIC

A river, too few staff and a lack of ambulances hamper patient care

By Joel Ntimbani

De Hope is a disadvantaged area in Limpopo Province. Goods are only available from tuck shops and there is no transport. The town clinic covers six villages: Nhanganani, Njhakanjhaka, Doli, Matsele, Nkunzana and De Hope. Some patients have to travel more than three kilometres to the clinic and on some parts of the road you have to take off your shoes to cross the river.

The clinic does not have a telephone and there is a shortage of staff. Staff use their mobile phones for emergencies to communicate with the doctors at Elim Hospital. There is only one nurse for voluntary counselling and testing (VCT). When she is upset she does not come to work, therefore no VCT is done until she gets back. If there is a patient that is in a critical condition they have to wait for the ambulance and it takes time to come because it travels for more than 70 kilometres to the clinic.

> **Some patients have to cross a river by foot to get to the clinic which does not even have a telephone.**

Mr. Shikwambani, the senior professional nurse, uses his Toyota to transport patients to Elim hospital. It is a risk because if a patient dies in his car he could be held accountable. But what choice does he have?

MINA NOMSEBENZI WAMI WOBUHLENGIKAZI EMPHAKATHINI

NguThemba Maphumulo

i-Equal Treatment ihambele emtholampilo wakwamakhutha

Ngingumhlengikazi Smangele Mokganye ngisebenzela Kwamakhutha Clinic, umtholampilo oselokishini eningizimu yeTheku. Ngineminyaka engamashumi amabili (20) ngisebenza lomsebenzi ngaphansi kwahulumeni. Ngiwuthanda umsebenzi wami noma unezinselelo eziningi. Ngiyakuthanda ukusebenza nomphakathi emazingeni aphansi kodwa kuliqiniso ukuthi kunzima. Ngiyilunga leNEHAWU ezinyunyaneni futhi iyangixazululela izinkinga engiba nazo emsebenzini wami ngakho ngiyayethemba.

Kuyiqiniso elingephikwe ukuthi uma ngingathola umsebenzi ongcono, ngingashiya. Ngingakujabulela ukusebenza ezibhedlela ezizimele ngoba khona ngathi imali ingconywana kunakuhulumeni. Ezibhedlela ezizimele umsebenzi awumningi njengasemphakathini ngaleyondlela uyakuthola ukukhululeka emoyeni nasemqondweni. Izimo zakhona zokusebenza ziphucuzekile.

Ziningi izinselelo emsebenzini wami, njengokuba umphathi emtholampilo omatasatasa njengalona wethu. Lomtholampilo usiza abantu baselokishini nezindawo eziseduze njengaseZimbokodweni, Umkhazini kanye nengxenye yeAdams Mission ngoba iwona oseduze. Umuntu eyedwa ugcina esenza imisebenzi engenziwa abantu abathathu. Mina njengomphathi womtholampilo kufanele ngibheke ukuthi ozakwethu benza kahle yini, lokho kubuye kube nzima ngoba sesijwayelene. Kodwa kubalulekile ukuthi ngibe umholi oqotho. Indawo esisebenzela kuyona incane kunomphakathi. Ngokunjalo nabahlengikazi bancane futhi abekho abanothando lokuzosebenza kulendawo.

Ukubakhona kwegciwane lengculazi (HIV) nakho kwakha

ATHLONE PARK NEEDS ACCREDITATION AS AN ANTIRETROVIRAL SITE

By Themba Maphumulo

Athlone Park clinic is situated in Umbongintwini suburb on the south coast of Durban. It serves people from Ezimbokodweni and Athlone Park. This clinic treats about 50 people a day, especially on Mondays and Thursdays when it is very busy.

The clinic offers voluntary counselling and testing (VCT), mother-to-child transmission prevention and antenatal care. On VCT, the lay counsellor, Noxolo Luthuli, tests about twenty people a day and usually about ten of them test positive. Patients are referred to Prince Mshiyeni Hospital for CD4 count testing and antiretroviral treatment. They have two registered nurses, one staff nurse, a clerk, one lay counsellor and two cleaners employed by the municipality. There is not much over-crowding as most people use the Kwamakhutha clinic because they have to walk more than twenty kilometres to get there.

The challenge faced by this clinic is that of not being accredited as a rollout site for antiretroviral treatment whereas there is a great need for antiretrovirals by the community. They also need a volunteer to come and give treatment literacy education to the patients on Mondays and Thursdays. The community has a good relationship with the health-care workers because of the good work they do in direct observed treatment support (known as DOTS) for TB. The nurses have asked the TAC Athlone branch to help them with education on HIV/AIDS and antiretroviral treatment.

Igumbi lokulinda emtholampilo wakwaMakhutha. Isithombe nguThemba Maphumulo.

ingcindezi emsebenzini ngoba bayanda abantu abangenwa ileligciwane. Okubi kakhulu ukuthi eminye imithi ebalulekile ayikho emtholampilo njengoFluconazole no-Acyclovir abantu abasizakali. Asikwazi ukuhlola inani lamasosha omzimba (CD4 count test) kanti baningi abantu abadinga lolosizo. Sinabahlengikazi abane abaqeqeshelwe iHIV/AIDS kanye namaphilisi okudambisa igciwane [antiretrovirals (ARVs)] kodwa awekho emtholampilo asazi noma oke abe khona. Abantu abawadingayo sibadlulisela e Prince Mshiyeni Memorial Hospital kodwa nakhona kunezinkinga.

Umtholampilo wethu awunaye usokhemesi, ithina singamanesi esenza lowo msebenzi saqeqeshwa izinsuku ezinhlanu. Sinaye udokotela osefika zonke izinsuku kodwa kuba yisi khashana. Bakhona abeluleki esikhungweni sokuhlolela igciwane, bathathu kodwa indlu abasebenzela kuyona yinye lokho kudala ukuba bashintshane ngoba kumele kungene umuntu oyedwa ngesikhathi.

Ukuxazulula lezizinkinga umbono wami uthi akwandiswe abasebenzi ezikhungweni zezempilo futhi banikezwe umvuzo othokozisayo (incentives) ukuze bakhuthale futhi bangashiyi baye ezindaweni ezizimele. Kwakhiwe eminye imitholampilo ukuze kunciphe ukugcwala bese kuthi leyo emincane kodwa emumatha kakhulu njengalona wethu unwetshwe. Izinhlangano zomphakathi ezilwa negciwane lengculazi nalezi zonompilo zifundise umphakathi izindlela zokuziphatha nokunakekela impilo. Kufundiswe futhi kuthuthukiswe izindlela zokuvikela ukukhulelwa, izifo zocansi kanye nengculazi entsheni ikakhulukazi ezikoleni.

HARDE WERK ONDER MOEILIKE OMSTANDIGHEDE BY ROCKLANDS KLINIEK

Deur Rodrick Clarense

Daar is 'n baie groot bruin gemeenskap in die Rocklands gebied maar ongelukkig is daar baie diskriminasie teen mense met MIV/VIGS. Hierdie houding verhoed dat mense openlik praat oor hul MIV/VIGS status en maak mense onwillig om getoets te word om hul MIV status uit te vind.

MEER MIV/VIGS OPLEIDING NODIG

Rocklands kliniek is in Mitchells Plain en is nie 'n antiretrovirale middels perseel nie. Maandeliks word vrywillige MIV berading en toetse (VCT) aan meer as 30 mense verskaf. 'n Groot probleem is die tekort aan opgeleide verpleegkunde personeel wat met MIV/VIGS kennis toegepas is. Ek het opleiding by TAC ondergaan en is die enigste personeellid wat opgelei is oor MIV/VIGS.

'n Program vir die verhoed van die transmissie van VIGS van moeder tot kind (MTCTP) word deur die kliniek aangebied. Daar is 'n dokter wat een keer 'n week kom en hy werk met TB en MIV/VIGS pasiënte. Ons het ook 'n raadgewer wat twee keer 'n week vir ons kom uithelp met MIV/VIGS werk.

Verpleegster by Rocklands Kliniek in Mitchells Plain. Foto deur Rodrick Clarence.

'n Groot probleem is die tekort aan opgeleide verpleegkunde personeel wat met MIV/VIGS kennis toegepas is.

TEKORT AAN BASIESE GERIEWE BEMOEILIK MIV/VIGS WERK

Daar is nie genoeg ruimte vir MIV/VIGS kliënte, verpleegsters, dokters of vir die klerk om haar leërs te bêre nie. Die kliniek het nie telekomunikasie geriewe soos telefone of rekenaars nie. Dit word baie moeilik vir personeel om te werk as pasiente kom omdat hulle alles met hul hande moet doen. Daar is tans geen elektrisiteit, nabye toilet geriewe of water nie.

Die kliniek het nie telekomunikasie geriewe soos telefone of rekenaars nie.

MOTHER-TO-CHILD TRANSMISSION PREVENTION SAVED MY CHILD

As told to Skhumbule Hambani

I am Phindiwe Nzanze from kwaLanga in Uitenhage and a mother of two children. The first one is 19 years old and the last one is two years old. In 1999 I was pregnant and tested HIV-negative, but I was amazed because my boyfriend was HIV-positive. I only discovered this after giving birth.

I was frightened as my child was sick until she died at four-months old. The father was also sick. He died two weeks after the baby and they were buried on the same day. I was shocked that my status was still negative and I became anxious to confirm if I had HIV or not. After the funeral I tested again and the results came back positive. I accepted my status but it was tough.

In 2002, I became pregnant again but this time around I was well-informed about HIV/AIDS and what precautionary measures needed to be taken. At the clinic I was told that I would be given nevirapine at seven months to prevent HIV from passing on to my baby. Unfortunately, at six months I had premature labour pains and had to go to the hospital to give birth. In the ambulance I disclosed my status and they gave me nevirapine. My water had already ruptured though I didn't feel any contractions.

I was taken to Port Elizabeth Hospital and still I could not deliver, as I had no contractions. In my clinic card from Uitenhage it was written that they had given me nevirapine. The doctors gave me pills to induce labour. When I started feeling the contractions, the labour pains were intolerable. I thought that the nevirapine's effectiveness had lapsed because I had taken it the previous day. I demanded another pill of nevirapine and the nurse gave it to me. I was then sure that my child could not contract HIV as I have learnt from other TAC members who have had the same experience. *[EDITOR'S NOTE: Single-dose nevirapine only reduces the risk of the child contracting HIV; it does not guarantee that the child will be HIV-negative. There are much better antiretroviral regimens than single-dose nevirapine that reduce the risk even further, but there is no 100% guarantee against transmission.]*

Phindiwe Nzanze and child. Photo by Skhumbule Hambani.

I chose not to breast-feed my child so I used formula milk and cotrimoxazole syrup. My child tested HIV-negative at twelve months and again at 18 months. I am grateful for organisations like TAC because if it was not for them I could have lost my second baby.

Now I am feeling stronger and proud, especially when I educate pregnant women on the mother-to-child-transmission-prevention programme because my child is living proof that nevirapine works.

HOPE FOR TREATMENT

As told to Petunia Nkolele

My name is Thomas Munyai. I am 36 years old and live in Mbokota, Limpopo Province. I was constantly sick so I decided to go for an HIV test. It came back positive. I then joined a support group in Elim, where I learnt a lot and met many people. When I was very sick, Dr. Matthay arranged for my social grant because I am unemployed.

Last year I went for my CD4 count test and it was 60. The nurses did nothing to help me they just sent me home without referring me to a hospital for antiretroviral treatment. After a year my social grant was stopped. When I went back to the hospital I was told to go and speak with the social worker but she was not there. Now I am relying on relatives for food and I am struggling to make ends meet. I hope one day we will be treated.

YINTISO YATIMAKA TA KE ETI ENDLEKA

Yi Petunia Nkolele

Vito ra mina yi-AM, nina 51 wamalembe, nitshama hala Hlanganani township. Hi lembe ra-2004-03-29 ni yile ni teka ngati, hikuva ndzi nga titwi kahle emirini wa mina. Mbuyelo wukumekile kuri HIV-positive, ndzivuye ndziya joyina support group ekaMajosi. Laha ndzi hlangane na Petunia Nkolele nasesi Buyi Ndhlovu va ka Care Group.

Se ani twa kuvava laha ndzi nga kondza ndzi ya exibhedlele ndzi ya kombela ku tekiwa CD4 count. Andzi nga tivi nchumu hi ti mhaka to fana na teto, nkateko wakona iku ndzi vuye ndzikuma ku twisisa endzaku ka loko ndzi hlangana na Petunia. Mbuyelo wa CD4 count wu vuye wuri 110,sweswi niyile ka Wellness clinic, leyi yifambisiwaku hi Dr Nkuna nasista Basani, na vuye vani endla Viral load test kambe ku fika sweswi andzi se kuma mbuyelo.

Endzaku ka loko ndzitekile CD4 count vavuye vani byela leswaku ndziyima ku kondza va ndzi vitana kumbe ku ndzitivisa siku. Kambe sweswi se nkari woleha va ngase ti hlanganisa na mina ndzi yile. Kambe va ri vata na swona ava se ndzi nghenisa eka ntlawa wa lava va faneleke kusungula sweswi ndza vabya swinene ndzi karhatiwa hi milenge ya vava swinene, yatlavatlava. Swa ndzi tikela swinene ndzi ya ndzi yenhla eka weyiti, andzi tika 62 wa ti kilogramu kambe sweswi ndzi tika 57 kilogramu. Ingaku ndzi nga kuma kupfuneka.

MY JOURNEY TO ACCEPT MY STATUS

As told to Sydney Masinga by Isaya Sibiya

I'm 28-years-old now but four years ago I thought I was going to die. It was on a Thursday during December when everyone seemed to be happy for the Christmas holiday. I was at a restaurant visiting my friend who worked there. I bought pizza and a drink but I managed to eat only one piece of the pizza.

After that my body felt tired. I then went straight home and slept. The next day, I vomited for more than two hours. I went to hospital but the doctor told me not to worry and that I would be fine. I stayed in bed for the whole weekend. On Tuesday morning, at around three in the morning, I began vomiting again but this time blood was coming out of my mouth and nose. I began to scream and cry. This time I went to a traditional healer but it did not help. My father took me to a private hospital in Nelspruit where the doctor suggested an HIV test. I was too sick to understand what was going on. The results came back positive. I couldn't believe it; I thought it was a joke. I didn't tell anyone except for my father. After three months I went to another doctor to do a second test and it also came back positive. I went to the local clinic to ask for help; this is where a counsellor told me about the Treatment Action Campaign (TAC).

At present I am not on antiretrovirals but I know that one day I will need treatment.

The next day TAC was organising a march and I participated in it. From then on I became a full member of TAC. The same year I was voted as the chairperson of the Kabokweni branch in Mpumalanga. I was still afraid to talk about my status. In 2004, however, I accepted my status and spoke publicly about myself. In November 2004, I went to check my CD4 count and it was 460. I went back again in March 2005 and it was 482.

At present I am not on antiretrovirals but I know that one day I will need treatment. This is so that I can live longer in order to make sure that the people of Mpumalanga never have to die without having treatment.

Presently, I am sitting at the Mpumalanga AIDS Council and as a person with HIV sector representative in the Mpumalanga province. I urge everyone to join TAC so that they can get more information about treatment literacy. I have gained a lot from TAC. I wish that my friends and colleagues would come out about their HIV status and help fight the stigma within our communities. All people must know that they have the right to access clinics. They must not be afraid to go to the clinics to get treated for sexually transmitted infections and to have voluntary counselling and testing for HIV. It is our responsibility to campaign for better health-care services in our clinics and to make sure that there is enough medication.

Delegates at a TAC organised Eastern Cape People with HIV/AIDS Conference. Photo by Skhumbule Hambani.

POLOKWANE DEMANDS BETTER HEALTH

By Pholokgolo Ramothwala

On 19 May 2005 about a thousand TAC members, people living with HIV/AIDS, NGOs and COSATU marched to the Department of Health in Limpopo to demand better health care services. The march was led by people whose CD4 counts are below 200. The Traditional Healers Organisation in Limpopo also came in large numbers to support the march.

A memorandum was handed over to the provincial Department of Health and a copy was delivered to the premier's office. Despite pleas for treatment by Grace Ngobeni, who has a CD4 count of 44, and her husband who has a CD4 count of 70, it did not seem that the department was willing to listen to us.

The spokesperson for the department, Phuti Seloba, displayed a remarkable lack of compassion. He said that government has got structures to address all the issues in the memo and TAC just wanted to make a noise. His tone and language undermined the marchers and he kept making the same insensitive statements on radio.

TAC in Limpopo Province is growing and people are beginning to speak out. The lack of democracy and delivery in the province is being exposed and the provincial government, as expected, is acting defensively instead of addressing the problems. But with more pressure they will have to change.

YOUTH LEARN ABOUT HIV PREVENTION AND TREATMENT THROUGH SPORT

About 300 youth from around Khayelitsha in the Western Cape joined the Youth Sports Day that was organised by the youth sector in Khayelitsha.

"The purpose of the games was to bring the youth in TAC branches together and mobilize more young people in their communities to push for treatment and prevention campaigns. We also wanted young people to participate in different activities we run throughout our branches in Khayelitsha and other districts," said Arthur Jokweni, TAC's national youth representative.

The games and sports were used as the educational tool to provide information about the science, prevention and treatment of HIV.

MINISTER OF HEALTH ANGERS KHAYELITSHA TAC MEMBERS

By Vathiswa Kamkam

Traditional healers attending the Khayelitsha Health Imbizo. Photo by Vathiswa Kamkam.

The Department of Health hosted a health Imbizo in Site C, Khayelitsha on 16 April 2005. The Minister of Health Manto Tshabalala-Msimang, Western Cape MEC for Health Pierre Uys and other members of the health department addressed the audience. The event was attended by TAC members, traditional healers and Matthias Rath.

During question time, over 30 people spoke and, with few exceptions, the speakers asked the Minister of Health to support antiretroviral treatment and to criticise the confusing misinformation of Matthias Rath. Some asked if Matthias Rath was a registered doctor in South Africa. Some people also asked why there were medicine shortages.

Instead of doing this, the Minister said "Health Imbizo has turned into an AIDS Imbizo."

She spoke about a healthy life-style and good nutrition as the basis of good health, pointing out the benefits of beetroot. She blamed the shortage of medicine on pharmacists for not placing their orders on time.

About Matthias Rath, the minister said, "I don't know whether Dr Rath is registered or not." She also said that it is a democratic country and people can choose between TAC and Rath. She said "I have chosen the ANC."

TAC members walked out, disillusioned with the Minister of Health.

TAC members became angry at the Minister's response and walked out of the Imbizo, leaving less than half the audience behind.

ACTIVISM AT SA AIDS CONFERENCE

On 8 June 2005, TAC and Medecins Sans Frontieres co-hosted an activist conference in Durban. The conference examined the need to integrate TB and HIV services and what needed to be done to get 200,000 people onto treatment by 2006. The conference was followed by a march past the 2nd South African AIDS conference, where a memorandum was handed over to the conference organisers.

Photo by Themba Maphumulo.

BRAZILIAN GOVERNMENT LEADS THE WAY IN AIDS STRUGGLE

By Aaron Tjoa and Danielle Dimitrov

The Brazilian government has refused money from the US PEPFAR programme and has taken further steps to produce generic versions of more patented antiretrovirals.

In May 2005, the Brazilian government refused 40 million dollars (over R240 million) of AIDS funding assistance from the United States government in order to protest the condition on the money which would require the Brazilian government to publicly condemn sex-work.

Brazil has run a long and successful campaign HIV/AIDS campaign. Over 125,000 Brazilians receive antiretroviral treatment and the government runs a provactive condom campaign. A key reason for their success has been their ability to work with people at high risk of HIV infection such as sex workers. If the Brazilian government accepted the US funding, it would risk alienating sex workers, pushing them away from the reach of government HIV prevention and treatment programmes. Therefore, Brazil refused the money.

The Brazilian government is the first to reject US “moral” policies. It is, however, among a minority of countries that can afford to turn down the funding—less than 2 percent of its HIV/AIDS funding comes from the US government.

Brazil has kept their rate of HIV close to 0.6%, due to their success in giving antiretrovirals drugs to all who need them, distributing condoms, and having a good relationship with people at greater risk of contracting HIV such as as sex workers and gay men.

Important human rights legislation is also moving through the Brazilian parliament. In June 2005, the Brazilian Chamber of Deputies unanimously approved a parliamentary bill which frees the drug patents for all antiretrovirals. The bill must now pass through the Federal Senate. If it becomes law, then all antiretrovirals in Brazil can be produced generically, which will save considerable amounts of money.

President Lula of Brazil

Photo from www.msu.edu/~penzienk/images/lula.jpg

Sources
http://www.guardian.co.uk/brazil/story/0,12462,1475966,00.html
http://www.isn.ethz.ch/news/sw/details.cfm?id=11318
http://news.bbc.co.uk/2/hi/americas/4513805.stm
http://www.aids.gov.br/

John Thorne of the University of Chicago proudly displays a TAC t-shirt at the summit of Mount Kilimanjaro.

HOW DO WE KNOW WHEN MEDICINES ARE SAFE AND EFFECTIVE?

Compiled by Jeff Hoover and Nathan Geffen

Before medicines can be prescribed by doctors to patients, they must go through a series of rigorous tests. Any medicine that has not been tested through an internationally recognized process and then approved by an official regulatory agency should be avoided. If not tested appropriately, there is no way to determine whether medicines are safe and effective.

In South Africa, the Medicines Control Council (MCC) is the government regulatory body that approves all medicines, including HIV drugs, that are legally available in the country.

Medicines are tested through a research process known as a clinical trial. The goal is to determine whether new drugs or treatments are both safe and effective. A carefully conducted clinical trial is the fastest and most thorough way to find out if treatments work and are safe for use in people. Clinical trials are sponsored or funded by medical and research institutions, nonprofit foundations, drug companies, or qualified physicians.

All clinical trials have strict guidelines regarding who can participate. The clinical trial team often includes doctors and nurses as well as social workers and other health care professionals. They check the health of participants at the beginning of the trial, give specific instructions for participating in the trial, monitor the participants carefully during the trial, and stay in touch after the trial is completed.

CLINICAL TRIAL PHASES

There are three main phases to clinical trials, all of which must be documented by the trial sponsor.

Phase 1 - Safety Testing

An experimental drug or treatment is tested in a small group of people (usually fewer than 100) who may be either healthy or patients who might benefit from the drug. These initial studies examine the drug's activity in the body in general and look for side effects.

Phase 2 - Activity Testing

The study is expanded to a larger group of people, perhaps up to 500. The focus is on the medicine's effect on patients with the disease being studied. Different amounts of the drug are commonly given to different people, all of whom are monitored carefully for side effects and whether the drug actually seems to work against the disease.

Phase 3 - Efficacy Testing

This phase only takes place if there is evidence from the previous phase that the drug might be effective against the disease in question. An even larger number of people are given the drug. The goal is to determine treatment guidelines for health workers who will be prescribing the medicine once it is registered as well to compare the test medicine to existing medicines treating the same disease.

If phase 3 data are optimistic, the research group that developed the medicine can apply to a regulatory body for a licence. The medicine can be provided legally to patients only after it is approved.

Control group: Patients in phase 3 are divided into those taking the drug being tested and those taking another drug known to work, or a harmless ineffective pill called a placebo. This allows scientists to use statistics to determine if the test drug actually works. Every phase 3 trial must have a control group.

Double-blind: The ideal phase 3 trial is also double-blind. This means that neither the doctors nor the patients know who is taking the placebo and who is taking the test drug. Only the researchers can determine this. This prevents bias in the results of the trial.

Matthias Rath's vitamin trial in Cape Town does not have a control group and is not double-blind. Therefore, it has no value.

COHORT STUDIES

Clinical trials are important, but they do not give the complete picture of how safe or effective a medicine is. How do we know that a medicine works in practice? Cohort studies help provide the answer.

A key kind of test conducted after a medicine is approved is called a cohort study. Cohort studies are typically massive in scale, involving thousands of patients. Researchers follow the patients for years, collecting specific health-related information that is analyzed to assess the ongoing effectiveness and safety of individual medicines and drug regimens.

Cohort studies greatly assist the ability of clinical researchers to identify new medicines, based on how patients respond to existing ones. Cohort studies also show how a drug performs in practice as opposed to the controlled environment of a trial. Cohort studies can often show that a drug has been disastrous or a stunning success.

Cohort studies regularly confirm, for example, that highly active antiretroviral treatment (HAART) regimens reduce rates of illness and death among HIV-positive people.

TESTING GENERIC MEDICINES

A generic medicine is a copy of another medicine that has already been tested. There is no point in redoing clinical trials on them. Instead we want to know if they are indeed the same as the original. This usually involves doing a bio-equivalence test.

A bio-equivalence test entails giving both the original and generic drug to about 18 to 36 healthy adults.

Before, during and after the participants take the medicines, their urine and blood is analysed to see that the generic drug is acting in the same way as the original.

The generic medicine should be composed of the same kind of chemicals and have the exact same effect as the original drug.

There are numerous medicines available to the public. Some have been tested but many have not, especially so-called alternative remedies. While many medicines are life-savers, there are also many products which are potentially dangerous or harmless but a waste of money. It is essential that activists campaign for all medicines to be tested.

TAC members Nomandla Yako and Matthews Damane with the generic medicines they brought back from Brazil. Before importing them, TAC and Medecins Sans Frontieres made sure the medicines had been through bio-equivalence tests.

LIMITING TRAGIC CONSEQUENCES: WHY CLINICAL TRIALS ARE VITAL

Two high-profile examples, one recent and one from four decades ago, reinforce the necessity of rigorous, regular and ongoing clinical research. In 2004, results from a cohort study pointed to a two-fold increase in the risk of serious coronary heart disease in patients who took Vioxx, a drug used to treat arthritis and other pain, compared with non-users. The drug's manufacturer, Merck, pulled it from the market in September 2004. Merck is currently working with US drug regulators to determine if and when the drug should be made available again.

Even more notorious is the case of thalidomide. In the 1960s, this drug was prescribed to some pregnant women in Europe and Canada to treat morning sickness. It soon became apparent that a relatively high percentage of the women who took thalidomide early in pregnancy were giving birth to children with severe birth defects, including missing limbs. The drug was banned soon afterward, but not until after at least 10,000 children reportedly had been afflicted with thalidomide-related birth defects.

Drug regulators were criticized for approving thalidomide based on weak clinical trial data. The reason the medicine was never approved in the US is because the head of that country's regulatory agency did not believe there was sufficient proof of its safety. The thalidomide tragedy prompted clinical trial sponsors and regulatory agencies around the world to toughen their criteria and oversight, a decision that has greatly influenced the testing of HIV and other medicines today.

It should be noted that clinical trials in the 1980s and 1990s indicated that thalidomide may have a second life: as a treatment for leprosy. In 1998, the US regulatory agency approved the use of thalidomide for that purpose. It also imposed several severe restrictions intended to prevent it from ever being used by a pregnant woman or a female patient's male sex partners.

HIGHLY ACTIVE ANTIRETROVIRAL THERAPY: AN EXAMPLE OF A WELL-TESTED MEDICAL INTERVENTION

Highly Active Antiretroviral Therapy (HAART) which generally consists of three different drugs that work together to slow or halt the replication of HIV, have been among the world's most intensely studied treatment regimens over the past decade.

Numerous independent, large cohort studies have associated certain HIV medicines with various side effects, such as neuropathy. Overall, however, evidence to date indicates that all HAART regimens represent a massive improvement over no treatment at all, unless a patient is resistant to one or more drugs in the regimen.

Example: EuroSIDA Cohort Study

There have been numerous trials and cohort studies demonstrating the effictiveness of HAART. A well-known example of a cohort study for HIV medicines is the EuroSIDA Cohort Study. It is a collaborative effort involving more than 70 clinics and treatment centres in Europe, Argentina and Israel. At least 10,000 individuals are participating in the study, which aims to examine the impact of antiretroviral medicines on patients living with HIV and AIDS. EuroSIDA frequently publishes observations and data that are useful to all patients and providers of HIV treatment and care.

Existing cohort and other clinical studies for HIV medicines will likely continue for several years. Over time they will be joined by additional studies, thereby building an even greater store of information about these medicines.

BEWARE OF UNTESTED MEDICINES

By Nathan Geffen

Not properly tested	Fraud	Untested	Exaggerated claims
Thalidomide	**Vioxx (rofecoxib)**	**Medical claims about onions, garlic lemons etc.**	**Rath's vitamins**
☠	☠		☠
 Source: Thalidomide Victims Association of Canada			
Thalidomide was introduced to the market in the 1960s without having been tested properly. Consequently, thousands of pregnant women gave birth to babies with deformities, such as the child in the photo who has deformed arms.	*Vioxx is a drug used to treat arthritis. It was recently withdrawn because studies found that it increased the risk of heart disease. Allegedly, the manufacturer, Merck, knew about this years before it became public.*	*Garlic, lemons, olive oil and onions are healthy foods. But when the Minister of Health claims they treat HIV, she is making untested medical claims.*	*Some vitamins have been shown to slightly slow the course of AIDS in some people. But Matthias Rath exaggerates their usefulness and prescribes a whole range of vitamins in dangerously high quantities as an alternative to antiretrovirals.*

The lessons of the Vioxx scandal

The Wall Street Journal uncovered evidence that the manufacturer of Vioxx, Merck, knew it increased the risk of heart disease four years before the public found out in 2004. The prestigious medical journal, the Lancet, also accused the US regulatory authority, the Food and Drug Administration, of negligence in its handling of the Vioxx affair. The lessons to be learnt from the Vioxx scandal are:

1. Drug companies and regulatory authorities are not to be blindly trusted. Consumer bodies must be vigilant and demand operational data on all medicines.
2. Cohort studies are critical for determining if medicines are actually safe and effective in practice. Clinical trials have limits.
3. There are numerous untested so-called alternative, complementary, traditional and natural health remedies being sold to consumers. Some of these are probably dangerous and studies are needed to identify which ones.

WHY TAC IS CALLING FOR GOVERNMENT TO TREAT 200,000 BY 2006

TAC has called for at least 200,000 people, including at least 20,000 children, to receive antiretroviral treatment in the public health sector by the beginning of 2006. Here we explain why.

TAC members hold placards showing the organisation's main campaign until March 2006. Photo by Iming Lin.

According to the best available estimates (provided by the Actuarial Society of South Africa and Statistics South Africa):

- Between 1997 and 2002, the number of reported deaths in South Africa rose from just under 320,000 to just under 500,000, a massive 57% increase. Most of those who died were babies and young adults.
- Over 5 million people are HIV-positive in South Africa.
- Over 300,000 people died of HIV in 2004. Even more are expected to die in 2005.
- About 500,000 of the 5 million people living with HIV are sick enough that they need to start antiretroviral treatment now.

South Africa has a large HIV epidemic. Many people have died of AIDS and many more will die unless treated. When people with HIV develop AIDS, they must begin taking antiretroviral treatment to reverse the effects of the disease in order to live much longer. Good nutrition, support and care from family and friends and treatments for opportunistic infections such as TB and pneumonia are also very important. Some vitamins taken in combination as supplements are also useful, and are provided by public health clinics.

But without antiretroviral treatment most people who develop AIDS will die within two years after experiencing many avoidable illnesses and much suffering.

With antiretroviral treatment, the vast majority of people with AIDS can resume normal lives. We do not yet know the average number of additional years of life that antiretroviral treatment gives. It is at least five and probably much more, especially for people who adhere to treatment and refrain from substance abuse. Many people who take antiretrovirals experience some side-effects. A small number experience serious side-effects and consequently have to change their antiretroviral regimens. A very small number of people die from the side-effects.

However, the benefits of antiretrovirals far outweigh the disadvantages. Without antiretrovirals, people with AIDS will die. With antiretrovirals, they have an excellent chance of regaining their health.

The Cabinet committed to rolling out antiretroviral treatment in August 2003. On 19 November 2003, the Department of Health published its operational plan that included rolling out antiretrovirals, hiring an additional 22,000 health workers by 2008, providing better nutrition to people with HIV and continuing to roll out the mother-to-child HIV transmission prevention programme, amongst other interventions.

The plan committed to treating approximately 50,000 people by March 2004, a further 135,000 people by March 2005 and a further 215,000 people by March 2006. This would still have left many without treatment, but it would have been a good start and saved many lives. TAC therefore welcomed the plan. Yet at the end of March 2005, only about 42,000 people were on treatment in the public sector. We estimate that another 45,000 to 60,000 are being treated in the private sector. This is not good enough.

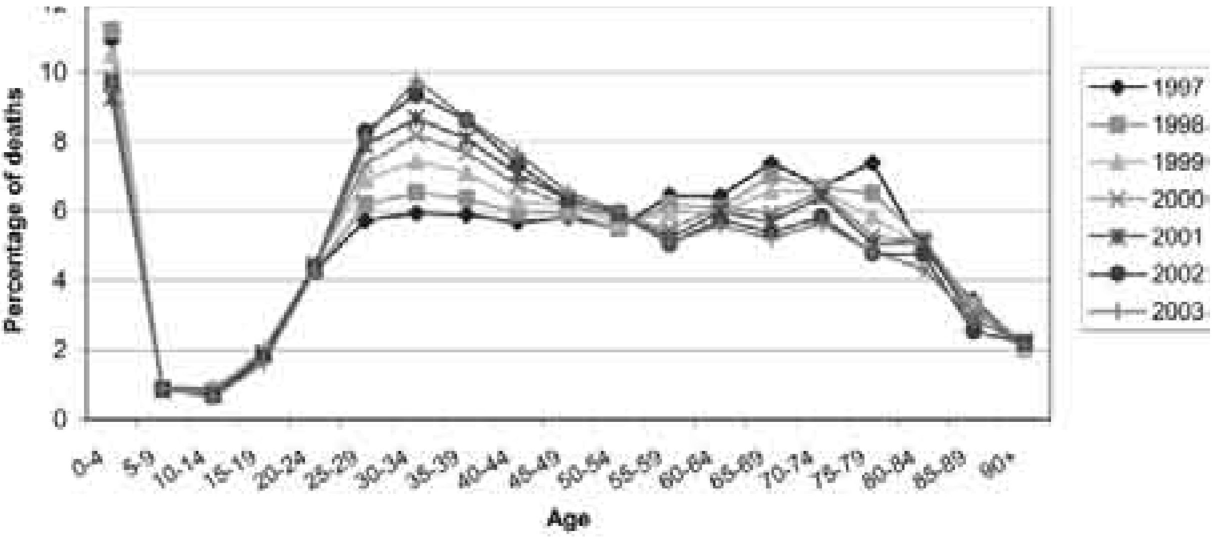
Sufficient funds have been set aside for the rollout by Treasury, but the rollout's pace has been hampered by a lack of leadership by the Minister of Health. Her confusing public messages on AIDS have undermined the programme.

DEATH CERTIFICATES SHOWS HOW SERIOUS THE HIV EPIDEMIC IS

Statistics South Africa has released a report which shows that the number of registered deaths in South Africa between 1997 and 2002 increased by 57%. When population growth and improved registration of deaths are taken into account, the increase in the number of deaths is 42%. By 2002, the age-group at which the majority of adults died was 35 to 39.

Statistics South Africa acknowledged that these increased deaths are primarily due to the HIV epidemic.

The graph below shows how from 1997 to 2002 the proportion of deaths among young adults grew. Also, increasing numbers of babies and young adults are dying.



Percentage distribution of deaths by age and year of death, 1997-2002. Source: Statistics South Africa P03093.

CASE STUDY:
ANTIRETROVIRAL TREATMENT IN KHAYELITSHA

Currently, three Khayelitsha clinics treat nearly 2,000 adults and children with antiretrovirals. The average CD4 count when patients started treatment was below 100 (i.e. advanced AIDS). After three years on antiretrovirals, four out of five patients are still alive. Without antiretrovirals half would have died within a year. Almost all deaths were due to the advanced stage of disease. In three years, only one in ten patients had to change their drugs due to side effects. Only four of the deaths were due to drug toxicity.

Source: Medecins Sans Frontieres

ANTIRETROVIRALS MAKE THE DIFFERENCE

People with HIV do not need to start taking antiretrovirals until their immune systems become very weak. But when they do become ill, antiretrovirals make the difference between life and death.

A study conducted in Cape Town examined the life-span of people who took antiretrovirals versus those that did not. The findings of the study demonstrate unambiguously the benefits of antiretrovirals.

For example, about 70% of people who developed AIDS (WHO stage IV) and then started taking antiretrovirals were alive after two years. But for people who developed AIDS and did not take antiretrovirals, less than 20% were alive after two years.

The study looked back all the way to 1992. Since treatments have improved tremendously since then, the benefits of antiretrovirals would be even greater today.

Source: Badri M., Bekker L. G., Orrell C., et al. (2004) AIDS. 18(8): 115

WHAT'S NEEDED TO ACHIEVE 200,000 BY 2006?

All our organisations need to step up our campaigns on HIV. Here are some suggestions:

- Mobilise in our communities by handing out pamphlets and running educational workshops that encourage people to get tested.
- Make sure our local clinics and hospitals offer HIV testing to people who are ill or who are being treated for TB.
- Campaign for the swifter rollout of treatment, improvement of clinic services and, critically, improved conditions of service for health-care workers so that they are attracted back to the public health service.
- Organise community action days. Help hand out pamphlets on HIV, clean up clinics and run workshops on HIV treatment, prevention and nutrition.

QUESTIONS FROM *BEAT IT!* VIEWERS

The names of letter
writers have been
changed to protect
their privacy.
Some letters are edited.

Vitamins, garlic pills and antiretrovirals

I would like to know if it is advisable to take multivitamins (i.e. complete A-Z; garlic tablets) with antiretrovirals? The reason I'm asking this is because one doctor said it's a bad idea but when my medical aid dispatches my treatment they do include multivitamins which confuses me.
Linda Watson

TAC responds:

You can take some vitamins with your antiretrovirals. These are available for free at the public treatment sites. But it is not a good idea to take just any multivitamin tablets because their interactions with antiretrovirals and with HIV might not be well understood. It is not recommended to take garlic tablets with antiretrovirals because a study has found that garlic lowers the level of at least one antiretroviral in the blood. Eating garlic in normal amounts in food should be fine though.

Acyclovir and herpes

I suffer from herpes and told my doctor. He prescribed acyclovir. Do I have to take these tablets for life? They are expensive and I cannot buy them with a medical aid. They have been very effective.
Tantaswa Nkolele

TAC responds:

The treatment for herpes is a short course; you do not have to take them for life. Acyclovir is very expensive and we must campaign for price reductions. Some public clinics distribute acyclovir for free, but not many.

Exercise and antiretrovirals

Is it possible to gain weight when you take your treatment, as well as go to gym three times a week?
Matthew Booysen

TAC responds:

Yes. Once your health is restored, you should be able to do all the things you usually do. If you eat a balanced diet you can gain weight. And you can also gain muscle weight from exercise. Exercise is recommended for people living with HIV/AIDS. A woman with HIV is intending to run the Comrades marathon this year!

**Watch SABC 1 on
Thursdays at 10h30
and Sundays at 13h30**

The TV programme for everyone living with HIV and AIDS, our partners, families, and friends.

SABC Education SABC 1 CHMT

OUR RIGHTS IN OUR COURTS

Laugh It Off wins freedom of expression court ruling

The Constitutional Court upheld the right to freedom of expression when it ruled that a t-shirt produced by the *Laugh It Off* t-shirt company was not an infringement of South African Brewery's (SAB) trademark. The t-shirt mocked the SAB's Carling Black Label advert (see photo) by saying "Black Labour – White Guilt." Justin Nurse, the owner of the tiny *Laugh It Off* company almost went out of business as a result of the protracted court action that SAB initiated against him. Nevertheless he has scored an important victory for freedom of speech.

The case is important for the right of access to essential medicines. It can be used to show that intellectual property rights, such as trademarks and patents, must not unreasonably and unjustifiably limit constitutional rights such as access to health-care services.

Justin Nurse, owner of Laugh It Off, *proudly wearing the t-shirt that caused all the trouble. Photo by Aaron Tjoa.*

Right of HIV-positive people to confidentiality

Three women represented by the AIDS Law Project sued Patricia De Lille, Charlene Smith and a publishing company for printing their HIV status without their consent in Smith's biography of De Lille. The Johannesburg High Court judge ruled that the publishing company was liable for refusing to remove the women's names when they complained about the book and awarded the women R15,000 each. However, he found that De Lille and Smith were not liable. The three women have applied to court for permission to appeal the decision. The publisher has also requested permission to appeal.

The right of gays and lesbians to marry

The Constitutional Court recently heard two cases dealing with the right of gay and lesbian couples to be able to marry and thereby share exactly the same privileges and rights as heterosexual married couples. It also considered whether the law may provide the same protections in a separate form of relationship, such as domestic partnership or whether the institution of civil marriage must be expanded to include same-sex couples.

A ruling is expected later this year.

Sowetan shows its integrity and apologises to TAC

The Sowetan newspaper ran a number of Matthias Rath's adverts that made false and defamatory allegations against TAC. TAC therefore threatened to sue the Sowetan. However, Sowetan displayed integrity and reached an amicable settlement with TAC. Sowetan apologised to TAC and ran two free advertisements. The two adverts, on nutrition and antiretrovirals, appear on the inside back and back cover of this issue of Equal Treatment.

UPDATES ON OUR RIGHTS IN OUR COURTS

Latest news from human rights court cases we have reported on in previous issues

TAC v. Matthias Rath

By the time this issue of *Equal Treatment* hits the streets, the outcome of TAC's interdict court application against the vitamin salesman, Matthias Rath, will probably be known. TAC has asked the court to stop Rath temporarily from claiming TAC takes money from drug companies until the outcome of a trial to sue Rath for making these false allegations.

TAC is hoping that by the end of these court cases, Rath will not be able to make these claims ever again and will have to apologise for the harm that he has caused to TAC.

TAC demonstrators outside the Cape High Court during the court case against Matthias Rath. Photo by Nokhwezi Hoboyi.

Amphotericin B price comes down

In issue 15 we reported on efforts to reduce the price of the Bristol-Myers Squibb (BMS) medicine, amphotericin B. BMS have since agreed to sell amphotericin B for just under R26 per vial (VAT inclusive) to both the private and public health sectors from 1 July 2005. The price was previously R145 per vial in the public sector and R192 in the private sector. This means that patients with cryptococcal meningitis should get optimal treatment.

This successful campaign was a joint effort of the AIDS Law Project, the Southern African HIV Clinicians Society, the Desmond Tutu HIV Centre and TAC.

Compulsory licence applications

Issue 15 of *Equal Treatment* reported that TAC and the AIDS Law Project (ALP) started legal action to compel drug company MSD to allow generic companies to produce or import efavirenz. This is mainly to ensure sustainability of supply. To date, there have already been a number of stock shortages of efavirenz. The ALP on behalf of TAC has since sent a letter of demand to the Minister of Health which was copied to pharmaceutical companies MSD and Abbot demanding that she issue licences to generic companies for efavirenz, as the law empowers her to do. Since getting an unsatisfactory response from Abbott a second letter was sent to the Minister demanding that she issue licences to generic companies for the antiretrovirals ritonavir and lopinavir/ritonavir.

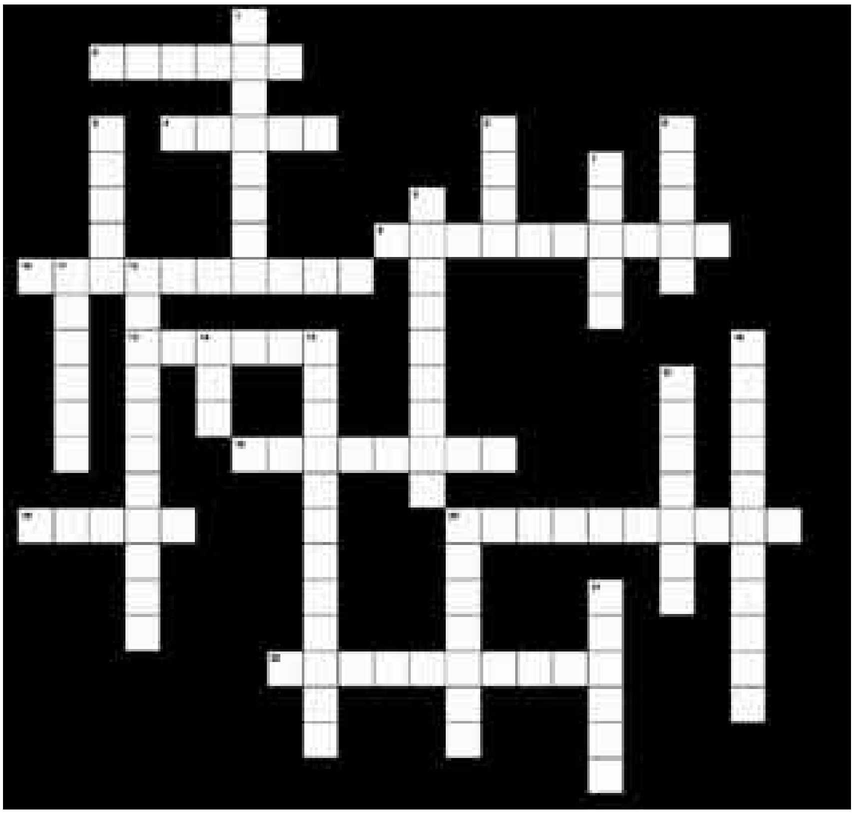
Sources of political party funding remain unknown

In issue 15 we reported on the Institute of Democratic Alternatives in South Africa's (IDASA) court case to compel political parties to disclose their funding sources. The Cape High Court has ruled against IDASA. The judge said that IDASA had not shown why it needed the information to exercise its rights and that Parliament should pass legislation dealing with party funding.

TAC is very concerned about this judgment as it appears to be a significant setback for political transparency. It is unlikely that Parliament will pass legislation that will truly compel political parties to say who their funders are.

EQUAL TREATMENT'S REALLY TOUGH CROSSWORD PUZZLE!

This month: learn about social welfare (solution in next issue)



Down

2. If you are in need of urgent assistance, you can apply for______ relief, which should assist you from the time of application for 3 months.
4. The three grants available for children are foster care, care dependency and _____ support.
9. Someone who accesses a social grant but does not actually need it.
10. If you are over 18, HIV positive, and have a CD4 count under 50, you can access which grant worth R780/month?
13. All employees in South Africa in the formal sector have to make a compulsory monthly contribution to the unemployment ________ fund.
18. The ruler who introduced social security into the first modern state.
19. The approximate percentage of South Africans living in poverty who do not have access to social grants.
20. If someone else will be picking up your grant money for you, you will have to register that person as a ________.
22. The three state social grants are old age, war veterans and ________.

Across

1. In 1948 Britain introduced free health-care for all known as the ________ Health Service.
3. What test do you need to qualify for a social grant?
5. The unemployment benefit paid to people in Britain
6. The disability grant application should take under how many months to process?
7. When Britain introduced the welfare state, it was based on the concept that the state should protect citizens from the cradle to the ________ .
8. If your clinic refers you for special medical treatment but you don't have money to get there, you can apply for a ________ relief to cover travel costs.
11. What does the means test calculate?
12. After approval, you should be given grant money from your date of ________ onwards.
14. What is the abbreviation of the name of the proposed grant to provide R1OO/month to all South Africans?
15. What document guarantees qualified individuals access to social grants?
16. Which Government department oversees social grants. Social ________ ?
17. The first modem state to introduce retirement and disability benefits (i.e. the first social welfare state).
20. The monthly payment given to an old person by the state.
21. The name of the report which made recommendations for social security in South Africa

HELP TAC SAVE LIVES!

Make a regular donation to the Treatment Action Campaign.

Account details:
Nedbank current account: 1950521738 (branch code: 195005)

TAC will not accept funds from pharmaceutical companies.

Section 21 registration: 2000/029181/08. Audits available on www.tac.org.za

TAC members are mobilising across the country to get at least 200,000 people on treatment by 2006. Photo by Nokhwezi Hoboyi.

Conducting a door-to-door campaign in rural Eastern Cape. Photo by Masizole Gonyela.

Making sure the key political issues are addressed at the recent AIDS conference in Durban. Photo by Themba Maphumulo.

LISTEN

By Isaac Skosana

Listen to the words of wisdom
Listen to the truth
Listen to the message
Listen, Listen and Listen

We fought the battle together
Together we saw comrades dying
Treatment accessibility was still a dream
We took a stand and fought for treatment
Listen as I tell, Listen

Listen Oh! Comrade I tell you
Listen my friend as I tell you
Listen oh fellow brothers and sisters
Lies and confusion are a problem and situation
Caused by denialists and money mongers
Our people are being misled
Listen I tell, Listen

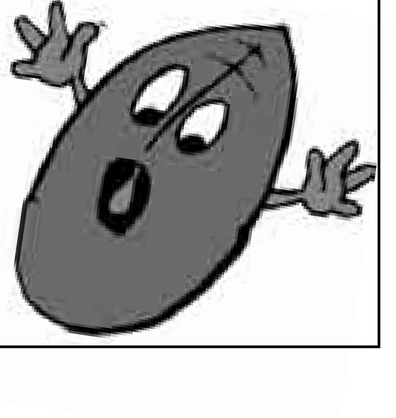
People are still being misled
Opportunistic infections are now denialists themselves,
I mean Matthias Rath, Anthony Brink and others
ARVs are accessible but people still die
They are being confused by these denialists
Listen as I speak because I know
Yes Listen, just listen to the truth

Africans listen as I tell
I tell, as I know the truth
I tell as I feel the pain of losing loved ones
Life is precious and irreplaceable Africans
Let's protect life and do the right thing
ARVs do work, Listen as I tell
Listen to the voice of the witness
Listen from the horse's mouth
Listen to the words of wisdom
ARVs do save lives
Listen and fear not, rather find the truth
Stand bold and firm
Listen as I speak knowledge
Listen Oh listen

OOPS, WE WERE WRONG

Errors in the May 2005 issue of *Equal Treatment*

- In *Life after testing HIV-positive* on page 9, Nokhwezi Hoboyi states that after starting antiretrovirals she had some side-effects and opportunistic infections. Of course antiretrovirals do not cause opportunistic infections; they reduce their likelihood. The article unintentionally implied that antiretrovirals can cause opportunistic infections.
- In *Our rights in our courts* on page 12, we stated that we were seeking a compulsory licence for amphotericin B. This was wrong because amphotericin B is no longer under patent and therefore there is no need to seek a compulsory licence for it. We were seeking a price reduction. See this month's *Our rights in our courts* for an update.



TALK ABOUT

nutrition & HIV

Nutrition and antiretrovirals are both important.

Good nutrition is very important if you are living with HIV. Antiretrovirals are the medicines that treat HIV. Most people with HIV only need to start taking them after a number of years, when they develop AIDS. Antiretrovirals help most people who take them live much longer, healthier lives. They have to be taken everyday for life. Nutrition is not a replacement for antiretroviral treatment. But good nutrition can help you stay healthy for longer so that you can start taking antiretrovirals later. Once you start taking antiretrovirals, good nutrition will improve their benefits.

Eat a balanced diet.

Foods fall into the following three groups:

Body-building foods (protein): *beans, soya, peanuts, eggs, meat, fish, chicken.*
Energy-giving foods (carbohydrates and fats): *maize, millet, rice, potatoes, sugar and oil.*
Foods with vitamins that protect against infections: *fruit and vegetables.*

Try to eat food from each of these groups every day. This ensures a balanced diet. Also try to eat at least three times a day.

Since your body has to fight HIV as well as other infections, it needs more energy. Foods that many people eat everyday like pap, bread, rice, potatoes and mngqusho contain lots of energy.

Eat lots of energy foods to prevent losing too much weight due to HIV.

Make eating an enjoyable event.

Many people living with HIV are badly informed about nutrition. We have been told, "do not eat this or don't eat too much of that". To wonder the whole time whether we are eating the right thing is not good. It makes us feel insecure and guilty. Eating should be an enjoyable, relaxed event.

What matters most is that you eat enough.

People with HIV often lose their appetites when they are sick. However, fighting HIV increases the energy needs of our bodies. Make sure you eat enough when you are ill even if you have lost your appetite.

If you cannot afford to buy enough food to eat, find out if you can apply for a social grant. Join the campaign for the Basic Income Grant so that everyone can have enough money to eat.

HIV causes poor nutrition. Poor nutrition makes HIV worse. A vicious circle.

HIV reduces absorption of food, which weakens the body's ability to resist all kinds of diseases. Poorly nourished people are much more likely to get severe diarrhoea, TB and other infections.

Vitamins

Public clinics give people with HIV vitamins pills. These are often useful for people with HIV. But they are NOT a substitute for antiretrovirals. You should eat lots of fruit and vegetables to ensure you get enough vitamins.

Reduce alcohol and smoking.

Large amounts of alcohol makes HIV worse. Alcohol can also interact very badly with antiretrovirals. Drink small amounts of alcohol or do not drink it at all.

Smoking causes many illnesses, especially chest infections. People often smoke instead of snacking. This is unhealthy if you have HIV. Try to give up smoking.

TAC

treat
200 000
by 2006

This pamphlet was issued by the Treatment Action Campaign. Tel: 021 788 3507 or 011 339 8421 Email: info@tac.org.za

MONGEZI NONYUSA

"I started taking antiretrovirals in December 2002. I feel healthy and strong. ARVs DO work."

MEDECINS SANS FRONTIERES

TAC
TREATMENT ACTION CAMPAIGN

**treat
200 000
by 2006**