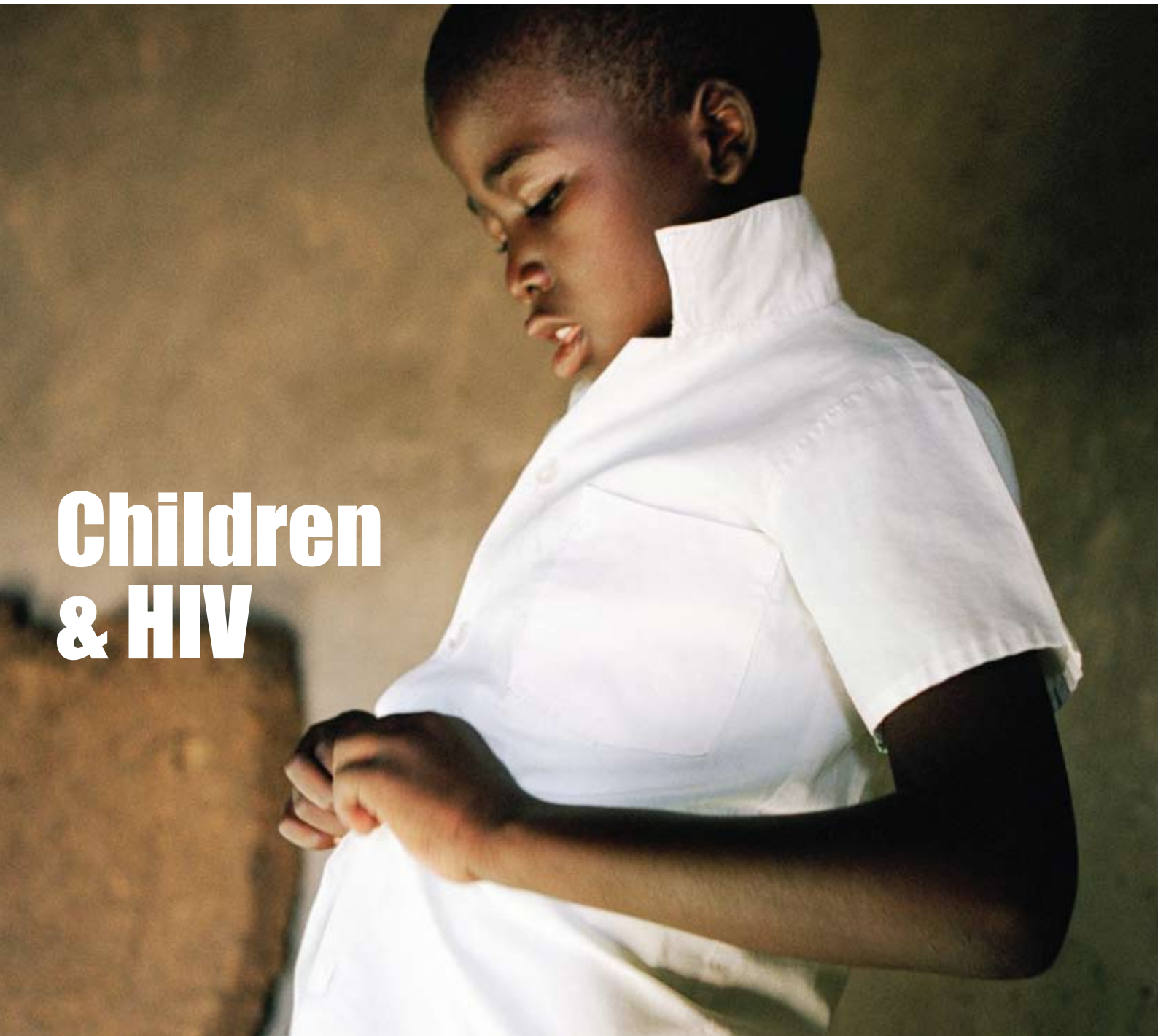
EQUAL treatment

Magazine of the Treatment Action Campaign December 2007/January 2008



Children & HIV

Editor: Nathan Geffen

Front cover photo: Zamokuhle Mdingwe, taken by Gideon Mendel. Thank you to Gideon for donating the photo. Copyright is with Gideon. Thank you to Zamokuhle and his family for allowing us to use photos of him.

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EDITORIAL

We can end the child HIV epidemic!

Ever since I realised the scale of the devastation wrecked by HIV/AIDS across Africa, I became determined to try to bring more attention and awareness to the issue. I don't believe that people living in western nations are indifferent. For the most part, they are simply unaware of what is taking place. As horrifying as the statistics are, it seems that they are in some ways, too vast, too abstract to comprehend.

The issues of the pandemic are highly complex. But what it comes down to is really quite simple – human rights. How much do we value the lives of human beings? Do people have the right to have access to life saving health care or not? The truth is, that if the health care system of a nation is on it's knees, then people are simply left to fend for themselves.

Children are particularly vulnerable. Over 60,000 are infected every year in South Africa. Also, parents die, leaving an elderly generation of grandmothers to take care of their orphaned grandchildren. And if no one is left after that, then inevitably, thousands of children are either abandoned or taken into care if there are facilities.

We can do something about this. We need to make sure that parents get treated so that they can fulfil the hopes and expectations of their own lives and also so that they can raise their children.

Photo: Andrew Warfick. Image is in the public domain.

The South African government's history of AIDS denialism has set back treatment and prevention efforts. If the government is truly committed to the highly acclaimed National Strategic Plan, it can demonstrate this by improving the prevention of mother-to-child HIV transmission programme. We have the technology to virtually eliminate the child HIV epidemic. Now we need the political will.

This issue of *Equal Treatment* examines young children and HIV. The next issue will look at youth and HIV. We hope you enjoy them and learn a lot.

Annie Lennox

Annie Lennox is a patron of Friends of TAC, UK. The proceeds of internet downloads of the song *Sing* on her new album *Songs of Mass Destruction* are being donated to TAC.

Send your letter to:

**Equal Treatment,
34 Main Road,
Muizenberg, 7945,
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et@tac.org.za**

We answer your letters

Tested HIV-positive. Now what do we do?

Dear Editor

Shortly after getting married, my wife and I discovered we were HIV-positive. We are not on medication, nor did we receive any counseling when we tested positive. We don't know how and where we can get medication, and we are worried about how much it might cost. When should we start on antiretrovirals and where can we find a health clinic that will provide us affordable medicines?

Regards

John Smith (name changed)

ET: If you use the public health system you should enroll in the HIV programme at the nearest clinic or hospital offering antiretroviral treatment. You can get a list of these by going to www.tac.org.za and clicking on Antiretroviral Sites or by phoning the AIDS Helpline on 0800 012 322. If you use a private doctor and you are a member of a medical scheme, you should enroll in the medical scheme's HIV/AIDS disease management programme.

You need to have CD4 and viral load counts at least every six months. This is free in the public health system and about R750 in the private health system, but your medical scheme should cover it. If you get a serious opportunistic infection, especially TB, you should start antiretroviral treatment. If your CD4 count falls below 200 you should also start treatment. Antiretroviral treatment is free in the public health system and costs R350 to R700 per month in the private health system, depending on what drugs you take. But again, your medical scheme should cover this cost. Most important, you need to learn more about HIV. Please download our free informational booklets and pamphlets from http://www.tac.org.za/literacy.html.

Serious side-effects

Dear Editor

I tested HIV-positive three years ago. I am on antiretroviral treatment now. I test my viral load every six months. My problem is that I have been losing weight, my breasts are growing, I have stomach problems and my legs are also getting thin. I worry that I am not getting better. My doctor has told me to take vitamins. Should I ask my doctor to give me second line drugs?

Regards

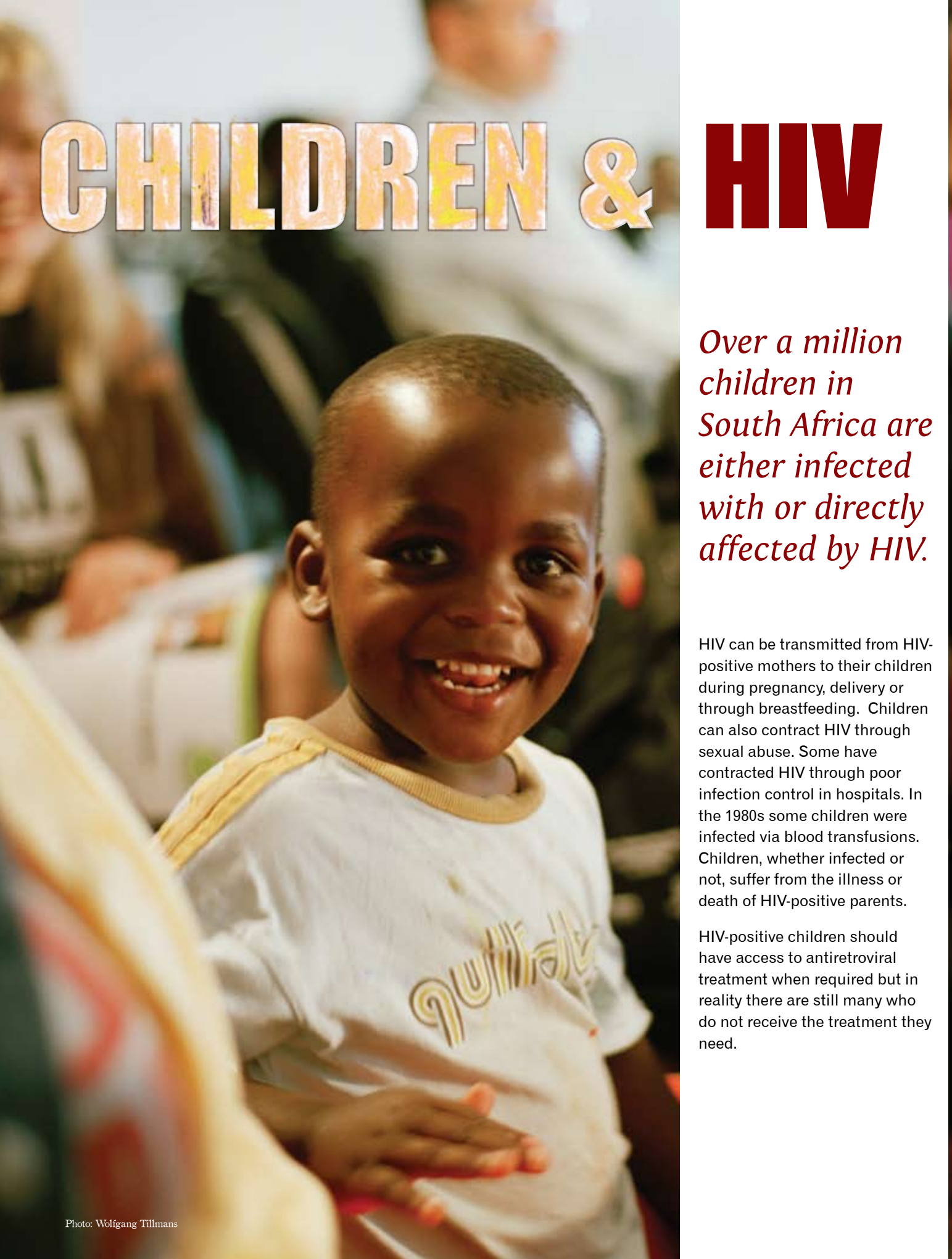
Lindiwe Skhosana (name changed)

ET: It seems that there are problems with your drug regimen. You might have lipodystrophy. This is a side-effect of some antiretroviral medicines used in the South African public health system, especially stavudine (also known as d4T). It is when the fat distribution in your body changes. It could explain why your legs are getting thinner and your breasts larger. You should ask your doctor to consider changing your antiretroviral drugs. It is also possible that the virus in your body is resistant to the antiretrovirals you are taking. You need to check your CD4 count and viral load. If your viral load has increased and your CD4 count has dropped, you need to change all three of your antiretroviral medicines. You should also ask your doctor to check you for TB.

Finally, if your doctor is not taking your concerns seriously, you should change your doctor. Contact Deena Bosch at TAC on 021 788 3507 or the AIDS Helpline on 0800 012 322 to find an HIV doctor near you.

About 5,000 people took part in the TAC/ARASA march on 8 November 2007 in Cape Town for better TB education, prevention, diagnostics and treatment.

Photo: Grant Shapiro, www.grantshapiro.com. Reprinted with permission of the photographer.



CHILDREN & HIV

Over a million children in South Africa are either infected with or directly affected by HIV.

HIV can be transmitted from HIV-positive mothers to their children during pregnancy, delivery or through breastfeeding. Children can also contract HIV through sexual abuse. Some have contracted HIV through poor infection control in hospitals. In the 1980s some children were infected via blood transfusions. Children, whether infected or not, suffer from the illness or death of HIV-positive parents.

HIV-positive children should have access to antiretroviral treatment when required but in reality there are still many who do not receive the treatment they need.

Photo: Wolfgang Tillmans

Child HIV epidemic in South Africa

- Over 300,000 children under the age of 15 have HIV.
- More than 60,000 babies born in 2007 (about 6% of all babies born) became HIV-positive before their first birthday.
- About 38,000 HIV-positive babies were infected at birth. A further 25,000 contracted the virus through breastfeeding.
- Over 50,000 children need antiretroviral treatment now. We do not have any accurate estimates of the number of children on treatment, but it is probably less than 30,000.
- There are over 1.2 million children whose mothers have died of AIDS.
- A child born with HIV who does not access antiretrovirals lives on average two years. A few can live much longer without treatment. Children with HIV on antiretrovirals can probably live almost normal lives.
- The number of children infected through sexual abuse is unknown.

Sources: Mostly ASSA 2003. Also JCSMF. Estimates are rounded.

Johanna's healthy baby

Johanna Ncala, TAC's National Treatment Literacy Co-ordinator, explains how HIV-positive women can have healthy HIV-negative babies.

Hello. I am Johanna Ncala. My hometown is Katlehong, near Johannesburg.

I have been living with HIV since 1993. In 2001 I became sick with TB and my lymph nodes were enlarged. My CD4 count dropped to 16. I was treated for TB for 18 months.

I went on antiretrovirals after I finished my TB treatment. Everyone told me they were very dangerous, except for one doctor. I received my antiretrovirals in the private sector. I first took stavudine (d4T), lamivudine and efavirenz. My CD4 count rose and my viral load became undetectable. My CD4 count carried on rising and by 2004 it was 695.

I really wanted to have a baby, as I was so glad to be alive! So when I met my partner we decided to go for it.

It is recommended not to use efavirenz if you are pregnant. Therefore, before I became pregnant in September 2004, I switched my efavirenz to nevirapine. Becoming pregnant was very exciting but also slightly stressful because some people were judgemental. However, friends in TAC were very supportive.

I made sure I looked after my health. I ate healthily and went to all my check-ups. There was good communication between my gynaecologist and my HIV doctor. I never had any complications but my CD4 went down a bit to 490. This is very common in pregnancy.

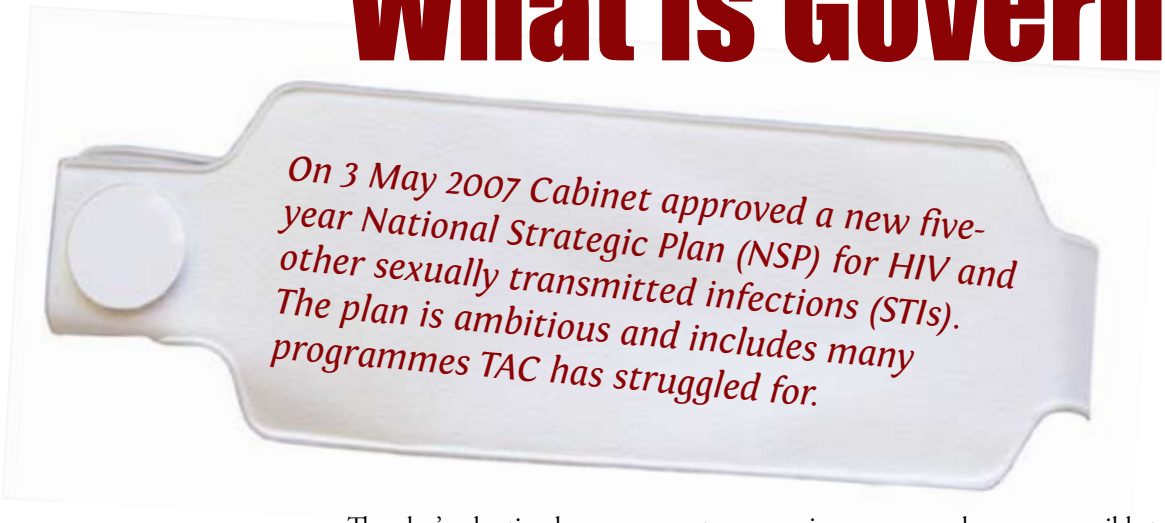
My baby Naledi was delivered by Caesarean section because this reduces the risk of HIV transmission. She is HIV-negative. She is now two and a half and has a mind of her own!

My baby Naledi was delivered by Caesarean section because this reduces the risk of HIV transmission.

The message I want to send to HIV-positive women is this: Look after your health, plan your pregnancy and learn all about HIV and pregnancy. Keeping yourself healthy is the best way to have a healthy baby. And it is necessary if you want to be around to see him or her grow up!

Children and HIV: What is Government's

By Andrew Warlick



The plan's adoption by government was a major political breakthrough and key victory for health activists and people living with HIV. If properly implemented, the NSP will save millions of lives. The 2007-2011 NSP is the most comprehensive HIV/AIDS strategy embraced by government so far. It covers prevention, treatment, care and support. It binds government to clearly defined targets and timeframes.

In addition to government, the NSP also serves as a guide for non-governmental organisations such as businesses, women's groups and organised labour movements. Civil society organisations will have to hold government accountable to the plan's targets. It is therefore important to familiarise ourselves with the NSP's goals and objectives. This article describes the NSP's key targets concerning HIV and children. If you would like to know more about these please visit the TAC website where complete copies of the plan can be downloaded: www.tac.org.za/documents/NSP-Draft10-2007-2011.pdf.

Probably only about half the number of HIV-positive children who need antiretroviral treatment are currently getting it. One of the main aims of the NSP is to increase the number of additional children enrolled in antiretroviral therapy programmes each year. The NSP aims to put 24,000 new children on treatment in 2008 and by 2011 that number is set to increase to 40,000 new children per year. Cotrimoxazole, to prevent infections such as TB and pneumocystis pneumonia (PCP), will also be made more accessible to HIV-positive and exposed children. By 2011 it is planned that 100% of children who have been exposed to or infected with HIV will receive cotrimoxazole treatment.

Expanding access to treatment for HIV-positive children requires a large increase in the number of children and mothers tested for HIV. In 2006 government statistics showed the HIV status of only about 3% of infants born each year in public sector hospitals. The NSP aims to significantly increase testing of children and pregnant women by making sure health workers actively offer HIV tests and counselling to patients. This is called provider initiated testing. According to the NSP, by 2011 provider initiated testing of children born to HIV-positive parents should occur in all public health facilities in the country. By then, 95% of pregnant women should also receive provider initiated testing. Increasing testing will require increased availability of the diagnostic tools discussed on page 14 of this issue. By 2011 the aim is to ensure all facilities can offer PCR tests so that 90% of infants born to HIV-positive mothers will be tested within six months of birth.

Nationally, rates of mother-to-child transmission of HIV remain unacceptably high. The NSP aims to reduce transmission to less than 5% by 2011 through increased access to the prevention of mother-to-child transmission (PMTCT) programme, increased HIV testing and improved access to antiretrovirals for pregnant women.

Plan?

Between 2007 and 2011 the NSP calls for an increase in the proportion of HIV-positive mothers who access PMTCT services from a 2007 target of 60% to 95% in 2011. The aim is to make PMTCT services available at every public health facility in the country by 2011.

The NSP intends to improve the support available for orphans by increasing the proportion of children accessing grants and receiving assistance from community caregivers.

Photo: Gideon Mendel.

Zamokuhle Mdingwe is an HIV-positive child on antiretroviral treatment. The National Strategic Plan aims to put 40,000 additional children onto antiretroviral treatment in 2011.

NSP Targets for Children and HIV

Objective	2007	2009	2011
Increase the proportion of public antenatal services providing PMTCT	85% of all public antenatal facilities	100%	100%
Increase the proportion of HIV-positive pregnant women receiving PMTCT services	60% of all HIV-positive pregnant women	80%	95%
Implement provider initiated testing of children of HIV-positive adults	30% of health service facilities	80%	95%
Increase the proportion of HIV-positive and exposed children receiving cotrimoxazole	65% of HIV-positive and exposed children	90%	100%
Increase the number of children starting antiretroviral treatment	17,000 additional children start antiretroviral treatment	33,000 additional children start antiretroviral treatment	40,000 additional children start antiretroviral treatment
Increase the proportion of children accessing the Child Support Grant	80% of eligible children	90%	98%
Increase the proportion of children accessing the Foster Care Grant	25%	40%	60%
Increase the proportion of children accessing the Dependency Grant	20,000 additional children access it	A further 36,000 children access it	A further 50,000 children access it

Preventing mother-to-child transmission of HIV

By Vikash Parekh, Nathan Geffen and Nosisa Mhlathi

Over 60,000 children are infected with HIV in South Africa every year. Government's prevention of mother-to-child transmission (PMTCT) programme has saved tens of thousands of lives. But by improving it, we can almost end child infections and save the lives of many pregnant women.

A woman's health is most important. A woman has the right to choose to terminate or continue her pregnancy. She also has the right to choose the antiretroviral regimen that makes most sense for her own health.

HIV can be transmitted from mother to child during pregnancy, delivery and through breastfeeding.

The current PMTCT programme includes:

- HIV testing for pregnant women.
- A single dose of an antiretroviral drug called nevirapine offered to HIV-positive pregnant women during labour and to their newborn babies. In the Western Cape and some academic hospitals they are offered AZT as well.
- Antiretroviral treatment for women with CD4 counts below 200 or an AIDS-defining illness, for the women's own health.
- Testing of babies born to HIV-positive women.
- Accurate information is supposed to be given to all HIV-positive mothers about formula feeding and breastfeeding. They are then supposed to choose which they prefer to do.

So, how is the PMTCT programme doing? According to the Actuarial Society of South Africa (ASSA), the number of children born with HIV each year is just under 40,000, and the number infected through breastfeeding is about 25,000. This means that about 6% of children born each year in South Africa become infected with HIV before their first birthday. ASSA probably underestimates the number of new infections because PMTCT has not been implemented as widely as ASSA predicted.

In some areas the PMTCT programme has been very successful. For example, in Khayelitsha less than 5% of HIV-positive women transmit the virus to their children. However statistics from other sites show that the PMTCT programme needs to be improved substantially.

Photo: TAC archive. Image in public domain.

TAC demonstration for mother-to-child transmission prevention in 2000. Seven years later, and the programme still has huge problems.

Issue	What is the current situation?	How can PMTCT be improved?
Not enough women are treated for their own health.	Pregnant women with a CD4 count of less than 200 or an AIDS illness are supposed to be referred for antiretroviral treatment for their own health. This is often not implemented.	All women with an AIDS illness or CD4 counts less than 350 should be offered highly active antiretroviral treatment (i.e. at least three drugs) for their own health. Women have the right to access health-care and protecting the health of mothers is one of the best ways of helping children to grow up healthy.
Uptake of the programme is low.	Less than half of HIV-positive pregnant women receive antiretrovirals to prevent transmission.	More pregnant women need to be offered HIV testing and access to antiretrovirals in antenatal clinics and hospitals.
We can do much better than single-dose nevirapine.	Outside of the Western Cape and some academic hospitals, pregnant women and the newborn child are only given a single dose of nevirapine. This reduces transmission to at best 8%, but usually much worse.	We need to update our national policy to combine nevirapine with other antiretrovirals, such as lamivudine and AZT. This will reduce transmission to less than 5%.
Not enough babies are tested.	Babies are supposed to be tested at six weeks using a polymerase chain reaction (PCR) test. However, only a small proportion of babies are being tested for HIV.	All babies need to be tested at six weeks. This is important so that HIV-positive children can be treated with antiretrovirals immediately.
Infant feeding policy is confused and inadequate.	Women are offered a choice between breastfeeding and formula milk.	More women need to be told about the advantages and disadvantages of breastmilk and formula milk so that they can make an informed decision. Recent evidence shows that giving women who breastfeed antiretroviral treatment reduces transmission of HIV significantly.
Monitoring and evaluation must be improved.	The monitoring and evaluation of PMTCT is extremely poor.	Better data recording is urgently needed so that government can measure the number of pregnant women tested for HIV every year, the proportion of these who receive antiretrovirals, the number of children born to HIV-positive mothers and the proportion of these who have been tested. This is the only way we can know if the PMTCT programme is working.

Infant feeding

By Polly Clayden

One of the hardest choices for an HIV-positive mother is how to feed her child. She has to consider that breastmilk is nutritionally better than formula milk but also increases the chance of HIV transmission. Here is information that can help women reduce the risk of transmission whichever choice they make.

What do we mean by exclusive breastfeeding, exclusive formula feeding and mixed feeding?

Exclusive breastfeeding – when a baby receives nothing but breastmilk (not even water) except for liquid vitamins or medicines.

Exclusive formula feeding – means feeding a baby only with a formula milk specially made for this purpose instead of breast milk.

Mixed feeding – when a baby receives both breastmilk and other liquids or foods. Try to avoid using this method.

Breastfeeding and risk of mother-to-child transmission

Exclusive breastfeeding is generally the best way to feed an infant but for HIV-positive women, breastfeeding carries a risk of mother-to-child transmission.

Research has shown that 5-20% of babies born to HIV-positive mothers who breastfeed will become HIV-positive through breastfeeding. The risk of HIV transmission increases the longer the baby is breastfed.

If a mother becomes HIV-positive while she is breastfeeding her viral load will be very high and her baby's risk of becoming HIV-positive is even greater.

Breastmilk: the advantages and disadvantages compared to formula milk

From a nutritional point of view breastmilk has many advantages over formula milk. Exclusive breastfeeding provides all the nutrients and liquid that a baby needs until it is six months old. Breastmilk contains hundreds of ingredients, including proteins, vitamins, fats and carbohydrates, perfect for the needs of an

infant. It also contains many antibodies to protect babies from infection. That is why, even in settings with good hygiene, diarrhoea is more common in formula-fed babies than breastfed ones. The composition of breastmilk is so complicated that it is not possible to exactly copy it in formula milk.

The other advantage of breastfeeding is that it is easy, clean and free. Also breastmilk is the right temperature for a baby. This means that a mother does not require formula, bottles, sterilising equipment, access to clean water – all necessary to safely formula feed a baby.

The big disadvantage is that there is always a risk of HIV transmission from mother to baby through breastfeeding. A few recent reports show that treating HIV-positive breastfeeding mothers with antiretrovirals reduces this risk substantially.

The risks and benefits of both types of feeding vary between settings and can be difficult to assess so experts have made guidelines to help with this decision.

Acceptable, Feasible, Affordable, Sustainable and Safe

The World Health Organisation (WHO) recommends that exclusive formula feeding should only occur when it is "acceptable, feasible, affordable, sustainable and safe".

- **Acceptable** means acceptable to the mother, that she is supported and will not encounter pressure or discrimination from her community.
- **Feasible** means she can follow instructions and prepare the formula.
- **Affordable** means that the mother can afford the cost of formula feeding (including all the equipment, fuel etc) or that she is supported by the health system to do this.
- **Sustainable** means that there will be an uninterrupted supply of formula for as long as the baby needs it.
- **Safe** means that the mother has access to safe water, that the equipment required can be sterilised and stored and that the formula is prepared hygienically.

Photo: Nosisa Mhlathi. Image is in the public domain.

Photo: From flickr.com.

Choosing to use breast or bottle is a major decision that HIV-positive mothers have to take. Counsellors should provide accurate information to mothers and then support their decision.

Recent research shows that if you are HIV-positive and breastfeeding, taking highly active antiretroviral treatment reduces the risk of transmitting the virus to your child.

This means that in some settings, where these conditions cannot be met, exclusive formula feeding is not a good idea.

Mixed feeding

Mixed feeding is not recommended. Exclusive breastfeeding for up to 6 months decreases transmission risk considerably (3-4 times), compared to mixed feeding.

When and how to wean

The WHO recommends exclusive breastfeeding for the first 6 months of a baby's life unless exclusive formula feeding is acceptable, feasible, affordable, sustainable and safe.

At six months, if replacement feeding is still not acceptable, feasible, sustainable and safe, the WHO recommends that breastfeeding continues with the introduction of solid foods.

Breastfeeding should stop once a nutritionally safe diet for a young child can be provided. However, mothers should continue breastfeeding babies who are known to be HIV-positive.

A healthy mum, a healthy child

By Vuyiseka Dubula as told to Nosisa Mhlathi

Vuyiseka Dubula is a representative of People with HIV on the South African National AIDS Council. This is her story about how she had a healthy child.

I tested positive for HIV in 2001. When I was thinking about having a baby, I went to my doctor to seek advice and understand my options. He advised me that starting treatment early would reduce my viral load and increase my CD4 count, so I began antiretrovirals in 2004. My CD4 count was 269. I planned to have my child in 2006. I took AZT, lamivudine and nevirapine until I went into labour. My child also got nevirapine syrup after delivery and AZT for seven days after she was born.

Before she was born, I was advised to either exclusively breastfeed or exclusively formula feed for at least the first six months. I chose formula feeding for my child because I knew there was risk of HIV transmission through breastfeeding. I knew that the chances of transmitting HIV to my child were minimal because I had an undetectable viral load but I couldn't take a chance with my only child. I would not be able to live with myself.

Formula feeding requires more cleanliness. When I prepared the feeding I had to sterilize the bottles, I made sure to use boiled water all the time. I was also informed about cup feeding which has less risk for the child being exposed to bacteria from the bottle.

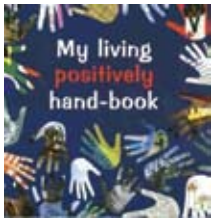
My baby was tested at six weeks and she was negative. I am also healthy and continuing with my antiretroviral treatment.

I believe that women have the right to better prevention options than currently offered by government. The National Strategic Plan aims to halve new infections in children by 2011. It also aims to improve the quality of the prevention of mother-to-child transmission (PMTCT) programme and reduce infections amongst babies to less than 5%. This cannot happen if the PMTCT guidelines are not improved.

Johanna Ncala, Vuyiseka Dubula and Johanna's child, Naledi.

Supporting Children to Live Positively

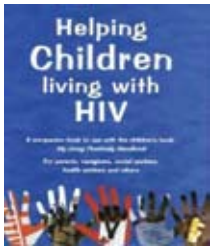
The Children Living Positively Series is a collection of publications by the Children's Rights Centre through which we hope to encourage and support children and their caregivers to learn about their illness and treatment, and actively participate in their own health care.



My Living Positively Handbook

This is a full-colour, interactive picture book for children living with HIV/AIDS. It is suitable for children up to age 12 years. It was written to be used by children together with their adult caregivers. It uses photographs, stories, and clear explanations of medical and psychosocial concepts.

The handbook is intended for distribution to children living with HIV/AIDS through partner organisations, paediatric treatment sites and other organisations supporting children living with HIV. It is currently available in three languages (English, Zulu, and Xhosa).



Helping Children Living with HIV

This is the companion guideline to the children's handbook. It has been developed to help adult caregivers, counsellors, and healthcare workers to use the children's handbook to best effect. It is currently available in three languages (English, Zulu, and Xhosa).

You and Your Child with HIV – Living Positively

You and Your Child with HIV – Living Positively is written for caregivers of children living with HIV/AIDS, and for the children themselves so that they can be partners in their own healthcare. This book is designed to provide further information to understand better what can be done, by whom and how. It is currently available only in English

The publications are available as printed books and CDs. They are also available in electronic format on CRC's website: www.crc-sa.co.za

To request copies, find out about training or get more information around the books please contact:

HIV Project, The Children's Rights Centre
1st Floor, 480 Smith St, Durban, 4001, South Africa
Tel: +27 (0) 31 307 6075 Fax: +27 (0) 31 307 6074
e-mail: info@crc-sa.co.za

What will it cost? *Currently we are able to provide these books free of charge.*

How can I support the project? We are currently raising funds for the translation of the series into more languages and for printing more copies. To donate, please contact CRC or make a donation via our website www.crc-sa.co.za.

This article was provided by the Children's Rights Centre in Durban. Tel: 031 307 6075.

Diagnosing HIV in children

By Sandra Fowler

Without treatment, half of all babies infected with HIV die by their second birthday. Early diagnosis can ensure children get treatment on time.

Recent results from a study carried out in South Africa shows a large reduction in deaths in infants receiving antiretroviral treatment before 12 weeks of age. This means getting infants diagnosed and onto antiretroviral therapy as early as possible is essential. A major obstacle to this is the lack of an affordable HIV test that works in infants.

Diagnosing and treating children infected with HIV/AIDS is more difficult than diagnosing and treating adults. Firstly, the antibody test used to diagnose adults cannot reliably be used for children under the age of 18 months. This is because babies born to women with HIV acquire their mother's antibodies, which can remain in the baby's blood for up to 18 months. Secondly, relying on symptoms as a form of diagnosis is problematic as they may be absent in the early stages of infection or easily confused with other common childhood illnesses.

The current way of accurately diagnosing children less than 18 months old is to detect HIV itself, i.e. not HIV antibodies, in the blood stream. This is done using a technique called Polymerase Chain Reaction (PCR). This PCR test is usually carried out around 6 weeks after birth. It is a complicated expensive test that requires a well-equipped laboratory.

Development of the 'dry blood spot' technique, which uses a small amount of the patient's blood dried onto a piece of filter paper, has improved PCR testing. These samples require much less blood from the baby than normal liquid blood samples and are easier to transport and store. However, the dry blood spot technique still requires complicated PCR equipment and a reliable transport system. Results can take up to two weeks during which patients may be lost to follow up. A simple, affordable and rapid detection test that can be used in settings with little technology and conducted while the patient waits is needed urgently.

Research is ongoing to simplify the test but progress is slow and while we wait, investment by government is essential to improve access to HIV diagnosis for all infants.

Sources: Médecins Sans Frontières and World Health Organisation fact sheets. Helen Byakwaga's commentary on research presented by Annette Sohn at 4th Conference on HIV Pathogenesis.

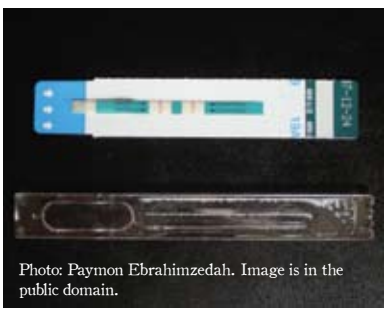


Photo: Paymon Ebrahimzedah. Image is in the public domain.

This HIV rapid test shows a positive result. These tests are accurate for adults and children over 18 months of age. They give a result in about 20 minutes. However, children younger than 18 months might test HIV-positive even if they are HIV-negative because they have their mother's HIV antibodies in their blood. Therefore a test called Polymerase Chain Reaction (better known as PCR) should be used. PCR tests look directly for HIV itself, not the antibodies.

A Paediatrician Speaks Out

Rachel Phillips interviewed Dr Ashraf Coovadia, an HIV specialist in child health at the Coronation Hospital for Women and Children in Johannesburg.

What are the main issues for HIV and children at the moment?

The transmission of HIV from mothers to their babies is fuelling the HIV epidemic in children. We urgently need to improve prevention of mother-to-child transmission (PMTCT).

Also, the status of thousands of HIV-positive children remains unknown. Children are coming too late to hospitals with advanced AIDS. We need to diagnose HIV-positive children before they become sick so that they can receive care from an early stage and be helped to live as normal a life as possible. Our hospital has tried a 'VCT Plus' campaign whereby health workers are taught to ask all adults coming for testing to bring their dependants for testing as well. This has had some success but needs to be championed and scaled up.

Even when children are diagnosed with HIV there is still a reluctance to put them on therapy because health workers do not feel confident enough to give antiretrovirals to children. It is time to change our conservative approach towards treating children.

What needs to be done to improve PMTCT?

The last PMTCT policy document was written in 2001 and has only just been revised as part of the National Strategic Plan (NSP). In general, the NSP is a good document and if we can fulfil its ambitious targets we will achieve a lot. However, the NSP section on PMTCT lacks detail. Recently a group of health workers including myself were asked by government to update PMTCT policy using our knowledge from the field. We have submitted our recommendations (Nov 2007) and hope they will be approved. One of our recommendations, that we are confident will be accepted, is the addition of AZT to nevirapine.

The low uptake of HIV testing among pregnant women is worrying. Less than 30% of pregnant women are being tested for HIV and we need to increase this to at least 90%. Poor uptake is due mainly to a lack of resources and training at health centres. Once women fully understand the benefits of being tested most choose to be tested. All women attending antenatal clinics should be tested for HIV unless they specifically ask not to be.

What are your views on the feeding of babies born to HIV-positive mothers?

A woman's decision should be accurately informed and respected. Both breastfeeding and formula feeding carry risks depending on the circumstances. Our goal is the 'HIV free survival' of children, not just the prevention of HIV transmission. We must be aware of illnesses associated with formula feeding and only carry this out when it is acceptable, feasible, sustainable and safe.

What has been the most important research recently on children and HIV?

The CHER study has been very important and it is already influencing guideline decisions. It confirmed what a lot of us working in the field have known for some time, that HIV-positive children under one year have a high risk of dying and need to be managed aggressively, and that CD4 counts of babies correlated poorly with their risk of death. Our treatment net has been widened by the results of this study.

What issues do you want to see TAC campaigning on?

TAC needs to fight for the price of PCR, CD4 counts and viral loads to come down. The PCR test needed for diagnosing young children is much more expensive than the ELISA test used for adults. TAC needs to continue applying pressure on drug companies to lower antiretroviral prices and manufacture more drugs suitable for children. For example, abacavir and lopinavir/ritonavir can both be used on children but are far too expensive. Also, ritonavir syrup tastes bitter and is difficult to give to children. TAC can help us encourage more pregnant women to be tested for HIV and more adults to bring their children for testing.

When should children start treatment?

By Nathan Geffen

New scientific evidence shows that children should start antiretroviral treatment as soon as we know they are infected with HIV.

Adults with HIV only need to start antiretroviral treatment when they get a serious infection, such as Tuberculosis, or their CD4 counts have dropped below 200. Pregnant women should start treatment if their CD4 count is below 350. It takes several years for most adults to get to this point. Antiretroviral treatment has to be taken everyday for life. But it helps the vast majority of people with AIDS to live almost normal lives again.

In the late 1990s, it used to be thought that adults should take treatment as soon as their HIV status became known. A famous slogan "Hit hard. Hit Early." was used to describe how antiretroviral treatment should be administered. We now know that there was not enough evidence for this. Antiretrovirals have side-effects and the virus can become resistant to our medicines after a while. It makes sense to wait until our immune systems have become weak before we start treatment.

But we now know this does not apply to children. Children need to start antiretroviral treatment as soon as their HIV status is known. This is a new finding based on a study conducted in South Africa. It means that the current guidelines for treating children in South Africa have to change.

The study was called Children with HIV Early Antiretroviral Therapy, better known as CHER. It was sponsored by the leading research agency in the world, the National Institutes of Health. The lead investigators were Dr. Avy Violari of the University of the Witwatersrand and Dr. Mark Cotton of the University of Stellenbosch. The Department of Health was also one of the study sponsors.

The trial included 377 children with HIV between the ages of six and twelve weeks who were still healthy with high CD4 percentages. (NOTE: In children we look at CD4 percentages, not CD4 counts as we usually do in adults. There is a view that we should rather look at CD4 percentages in adults too.)

The children were divided into two groups:

- One group received antiretroviral treatment (AZT, lamivudine and lopinavir/ritonavir) immediately. Some children were to take treatment for 96 weeks and others for 40 weeks. This is known as immediate treatment.
- The other group was to receive treatment only when they developed signs of AIDS (i.e. their CD4 percentage dropped substantially or they became sick with a serious opportunistic infection). This is known as deferred therapy and is the current standard of care in South Africa and many other countries.

Clinical studies have what are called interim reviews of their results. This is when the researchers analyse the results of the study to see that they are not endangering the lives of their patients. An interim review of the CHER study found a massive difference in survival rates between the groups that started treatment early and the deferred group. 96% of the children in the immediate treatment groups survived versus 84% in the deferred group. Therefore the study was stopped and all children given antiretroviral treatment.

This is one of the most important findings about children and HIV. In countries where HIV can be diagnosed in children and where health workers have been trained to give antiretrovirals to children, the status of all children born to HIV-positive women should be found out as soon as possible. If they have HIV, they should be put on treatment.

Source: NIH website: http://www3.niaid.nih.gov/news/QA/CHER_QA.htm

Photo: Gideon Mendel.

Antiretrovirals for children

By Jo Gorton

About 8% or less of HIV-positive children who are in need of treatment in low- and middle-income countries have access to antiretrovirals. In South Africa nearly half of children who need treatment are not getting it.

Antiretroviral treatment for children is more complex than for adults. Different children have to take different doses and types of medicines depending on their weight and age. Also, the funding for developing new diagnostics and treatments for children has been much less than for adults. This is because there are very few HIV-positive children in rich countries where pharmaceutical companies make most of their money. Some antiretrovirals have not been tested on children. Of those that have, some are only available in bad tasting syrups that require refrigeration. Syrups are also difficult to administer cleanly and in the right doses. Some are available in adult doses and have to be cut up for children to use them.

In 2006 the World Health Organisation (WHO) finally published formula guidelines for treating HIV-positive children. It has still not published dosage guidelines. Recently Indian generic manufacturers started developing fixed dose combinations for children and two have been registered with the US Food and Drug Administration. They are not registered in South Africa yet.

The Department of Health currently recommends:

- A child with HIV who is three or less, should start on stavudine, lamivudine and lopinavir/ritonavir (branded as Kaletra). If he or she develops HIV with resistance to this regimen, then switch to AZT, didanosine and nevirapine.
- A child with HIV is over three and more than 10kg should start on stavudine, lamivudine and efavirenz. If he or she develops HIV with resistance to this regimen, then switch to AZT, didanosine and lopinavir/ritonavir (branded as Kaletra).

Photo: Alex Fattal, courtesy of the Children's Rights Centre. Image in public domain.

Opportunistic Infections in children

By Jo Gorton

In general, the opportunistic infections that affect HIV-positive children are the same infections that affect children who are not living with the virus. What HIV does is increase the vulnerability of children to these diseases. This means HIV-positive children are more likely to get sick, more likely to be sick for longer periods of time and more likely to die from infections that children without the virus would normally recover from. This is because HIV weakens the already under-developed immune systems of children. Unlike adults, children do not have any previous exposure to diseases and so they have not built up defences against them.

In Sub-Saharan Africa, the most common illnesses affecting children with HIV are diarrhoea, pneumonia and oral thrush. In addition to these, South Africa also has a large TB epidemic in children. Below is a summary of the main opportunistic infections that affect HIV-positive children:

Pneumonia is the most common reason a child in South Africa visits a hospital. The word pneumonia is a medical term for inflammation of the lung. Symptoms include shortness of breath, chest pain, coughing and energy loss. There are many different types of pneumonia caused by different germs. A particularly common form in Southern Africa is called Pneumocystis carinii Pneumonia, referred to as PCP. PCP is mostly found in children with HIV under one and is marked by coughing, difficulty in breathing and blueness of the tongue and mouth. Lymphoid Interstitial Pneumonitis, another common form of pneumonia, has similar symptoms but is usually found in children older than two.

TB is a disease caused by a germ called Mycobacterium tuberculosis. It is the biggest single cause of death in South Africa (if adults are included), most of it HIV-related. Most TB cases can be cured if children are treated in time. HIV-positive children are extremely vulnerable to TB; one study found that of all children admitted to a large hospital in KZN with TB, 48% of them also had HIV. Other studies show that the number of HIV-positive children who have TB is growing, as is the chance that this TB will be resistant to TB medicines. TB causes prolonged coughing, wheezing, shortness of breath, weight loss, the loss of energy, joint and head aching. TB is almost always passed on to children through their family or someone living in their household. If a child has HIV, it is important that everyone in the family be checked for TB, especially if they have any symptoms or are also HIV-positive.

Acute Diarrhoea is thought to be the most common cause of death in HIV-positive children in Sub-Saharan Africa. Children with HIV will often have prolonged bouts, lasting for over a month. The causes of diarrhoea vary in each region and can be influenced by factors such as hygiene and food availability.

Malnutrition is a special problem for HIV-positive children in some cases because of their living conditions, but more often because of the mouth infections they get. These infections make it difficult for children to eat. HIV can also decrease a child's ability to digest food and absorb nutrients, leading to conditions such as anaemia which occurs when children do not get enough iron into their bodies. Children can even become malnourished in the womb, before birth, if the pregnant mother is malnourished.

Oral problems are common in HIV-positive children. Conditions such as oral thrush or mouth ulcers cause pain and discomfort in the mouth. They also contribute to weight loss.

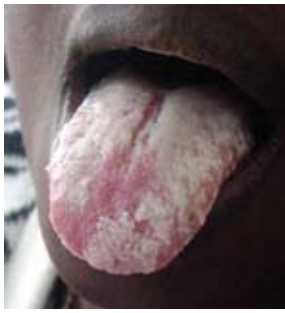
Ear Infections are common and cause a great deal of pain. Doctors will look for liquid coming out of the child's ear and for signs that they have been pulling their ears in pain.

Enlargement of the neck and throat glands occurs frequently in HIV-positive children. This swelling is not usually painful but it may cause permanent disfiguration.

Skin rashes and lesions can occur all over the body. The most common skin lesions are scabies, eczema, ringworm and some forms of herpes. Viruses, bacteria and fungus all cause skin infections that can be painful for children. Many of these skin rashes can be cured in public health facilities.

The mental development of a child can be affected because HIV can damage the brain and nervous system. Slow development is difficult to detect and often goes unnoticed, although some children do suffer from acute and obvious seizures.

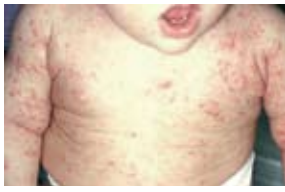
Sources: National Institute of Health, WHO, USAID, Little et al 2007, African Network for the Care of Children Affected by AIDS (ANECCA). With special thanks to Marc Cotton for his revisions.



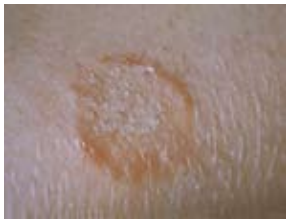
Oral thrush.
Photo: EDHIVtestguide.org

Ear infection. Photo: Taken from a blog by Rachael Brownell.

Swollen glands. Photo: Centre for Disease Control.



Scabies.
Photo: University of Iowa Website



Ringworm.
Photo: http://www.rivm.nl/

Tuberculosis in Children

By Luckyboy Mkhondwane

How children get infected with TB

Children can get infected with TB through contact with a person who has TB. For most children, that person is a family member. Therefore, all family members and close contacts of a child with TB must be screened to find the source of the infection. Younger children are at greater risk of TB germs spreading to other parts of their body because their immune system is not yet fully developed.

TB of the lungs is called *pulmonary TB*.

TB outside the lungs is called *extra-pulmonary TB* and includes TB meningitis (when TB spreads to the brain and spinal cord) and miliary TB (which is when TB is widely spread throughout the body).

Diagnosis

Diagnosis of TB in children can be difficult. Children under the age of 10 years do not easily cough up sputum, which is needed to test for TB. So sometimes gastric aspirations must be done. This involves pushing a tube through the nose into the stomach and drawing fluid out to test for TB. Other ways of diagnosing suspected TB cases in children are:

- Recognising TB symptoms which include loss of weight, a cough for more than two weeks, respiratory infections that do not respond to treatment, swollen lymph nodes, two or more episodes of unexplained fever, vomiting, diarrhoea and blueness of the lips. Sometimes a child with TB may have no symptoms at all.
- Chest X-ray but this is difficult to interpret because the typical X-ray shadow of TB in adults is rarely seen in children.
- History of contact with someone with TB.

Diagnosing TB in HIV-positive children is even more difficult because some diseases can have similar symptoms to TB.

Treating TB in children

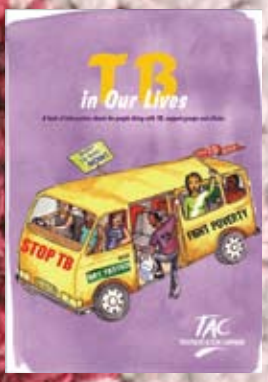
Children with TB can be cured if they take treatment for six months. All children with extra pulmonary TB must be treated in a hospital. Children up to the age of eight years are treated with rifampicin, INH and pyrazinamide for two months and then INH plus rifampicin for four months. Children eight years and older are given rifampicin, INH, pyrazinamide and ethambutol for two months and INH plus rifampicin for four months. Ethambutol is not given to children under eight due to a risk of eye problems.

Preventing TB in children

The policy in South Africa is to give all children the BCG vaccine against TB shortly after birth. The BCG is not very effective in preventing pulmonary TB but it is useful for preventing extra pulmonary TB. Children must also receive all the other vaccines in the immunisation programme because measles and whooping cough can increase the chances of getting TB.

Another way of preventing TB in children is to check all children under five years old who have been in close contact with adults diagnosed with TB.

Sources: Tuberculosis: a Training Manual for Health Workers, TB in Our lives, National TB Control Programme Guidelines.



This article contains only the minimum facts about TB and children. To learn more you can order TAC's new booklet, *TB in Our Lives*, by contacting the organisation using the details on the inside cover of *Equal Treatment*. The book is usually given away free if ordered in small numbers.

Photo: Nosisa Mhlathi

Discovering my HIV while pregnant

By Noluvuyo Ngoboza as told to Sylvia Jacobs

My name is Noluvuyo Ngoboza, and I am from Khayelitsha. When I got pregnant in 2002, I received a positive HIV test. I was very nervous, but when the counsellor gave me my results, he told me to stop crying and just go home.

When I left the clinic, I was scared and confused because I didn't know how I was going to tell my parents about my results. I was scared because my parents were still angry at me for becoming pregnant. Then the next day, I told my partner about my test results. He told me that he would also go for an HIV test. He left that day saying that he was going to get tested for HIV, but I have never seen him since.

One week before I was due to give birth, I disclosed my HIV status to my parents. My mother hugged me tightly, and her eyes were full of tears. I then made the decision to find more information about HIV/AIDS. I eventually gave birth to my son, who is healthy and HIV-negative after having been through the prevention of mother-to-child transmission programme.

I then started working at FAMSA and eventually became a community development worker. I facilitate support groups and workshops on HIV and I now also do HIV counselling in clinics. I am becoming more involved with any cause that fights HIV/AIDS. I am trying hard to learn more about this virus within me. My CD4 count was low in late 2006, so I started antiretroviral treatment in January 2007.

I have been HIV-positive for over five years. I hope that people reading this will get tested so that they will be able to get help early if they are infected. I am happy to know my status because I have managed to save my son's life.

An HIV positive boy's story

By Tandeka Vinjwa and Gideon Mendel

Zamokuhle Mdingwe, the boy on this issue's front cover, has been interviewed by both Tandeka Vinjwa and Gideon Mendel over the last few years. This is what he told his interviewers.

Photo: Gideon Mendel

September 2004

My name is Zamokuhle and I am seven years old. My mother died last year. She had AIDS. I now live with my grandparents and cousins who take care of me. At school I am in grade one. I want to be a teacher when I grow up. I was sick with chest pains and was coughing so my grandmother took me to the clinic for a test – I have AIDS. Every week I go to the support group at the clinic where I meet other people with this sickness. There we learn about medication. I was given lamivudine, nevirapine and d4T (stavudine). It is not difficult to take the drugs as they are easy to swallow. I am very thankful and happy, as I will now live a long life.

November 2004

Every morning, and every evening at supper I take my pills. I can run faster and I have energy. I tell my friends about the pills and they are happy to see me stronger. They know I have AIDS and everybody is kind. At school I am finding that I can learn better, I think my mind is working better now. Yesterday I went with my granny to a big AIDS day meeting where I stood up to talk. I told them my name and how I got AIDS from my mother, because she didn't know she had HIV and breastfed me. HIV was passed to me when I was a baby. She was unlucky because she didn't get the pills in time. I am lucky because I do have the pills that keep me healthy.

November 2007

Zamokuhle is now 11 years old and is in good health. He is adhering well to his antiretroviral therapy. He is in grade 4 and still lives with his grandmother. He likes football and is playing for Mvenyanduku F.C. He sometimes gets minor illnesses like fever but he is not forgetting his treatment. His dream is to have a car of his own.

I take my pills at 6 o'clock in the morning; I'm reminded by the sunrise and in the evening by the shadow of sunset. But during cloudy days I am reminded by the pupils attending morning classes at a nearby high school and in the evening by the arrival of cows at kraals.

Should we circumcise baby boys?

By Sandra Fowler

TAC recommends that baby boys in South Africa should be medically circumcised. Here we explain why.

Results from three scientific studies carried out in Sub-Saharan Africa (one in Orange Farm, South Africa) show that male circumcision can reduce the risk of HIV infection in men by about 50 to 60%. The World Health Organisation and UNAIDS recommends safe medical circumcision as an additional strategy for preventing heterosexual HIV infection in men.

In a high HIV prevalence society there are large health benefits to be gained from circumcision. These far outweigh the small risks if male circumcision is carried out safely and properly.

Male circumcision is a surgical procedure to remove the foreskin of a man's or boy's penis. This practice has been carried out for religious and cultural reasons for thousands of years. By medical circumcision we mean that the procedure is carried out in hygienic conditions, under anaesthetic and by a trained person using surgical tools and techniques approved by the medical profession. Male circumcision is not the same as female genital mutilation. Female genital mutilation is still carried out in some countries. It is a serious violation of human rights and has a negative impact on a woman's health and dignity.

Circumcision soon after birth has advantages over adult circumcision. It is much less traumatic for a man if he is circumcised as a baby. Infant circumcision could be integrated into existing child health care services or the prevention of mother-to-child transmission programme.

There is debate about the ethics of circumcising infants because they are too young to give consent. As with any surgical procedure, medical circumcision carries risks. Complications have been reported in a very small number of cases. Also, there is the possibility that the HIV prevention benefit of circumcising an infant boy today may be unnecessary by the time the child is sexually active if an HIV vaccine is developed. However, we may be waiting for a vaccine for decades. Men who were circumcised as babies never remember it and almost never regret it. Circumcision could make a big difference to the future HIV infection rate in South Africa. Therefore TAC recommends parents to allow their infant boys to be medically circumcised.

The Department of Health must provide accurate information to the public on the role of medical circumcision in HIV prevention so that parents can choose for themselves. Medical circumcision should be offered free of charge at clinics with surgical facilities across the country.

Sources: TAC Electronic Newsletter, Presentation by Godfrey Kigozi at 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention, Sydney, Australia, 25 July 2007.

Never Lose Hope

By Nokhwezi Hoboyi

Equal Treatment co-editor Nokhwezi Hoboyi lives openly with HIV. She could not co-edit this issue because she was on maternity leave. She has however sent this short message for Equal Treatment *to publish on her experience of having a child.*

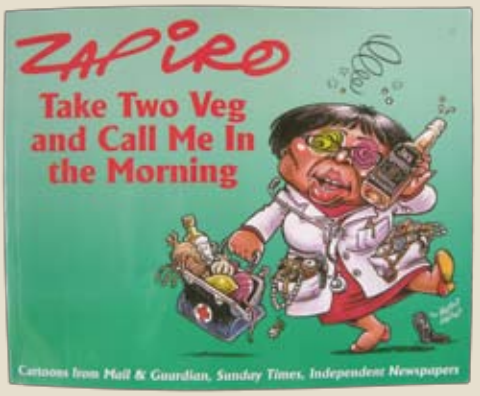
When I lost my second child, I thought that I would never be able to conceive again. As I was HIV-positive, I thought there was no hope for me to become a mother.

Five years later I conceived. I am sure this was possible because I had been taking my antiretroviral treatment correctly. I was so happy to find out that I was pregnant. I had to change my antiretroviral treatment to help my unborn baby. My pregnancy was not an easy one because I had some complications. I had to see my gynaecologist very often to monitor the developments of my unborn child. The support that I received from my family and colleagues helped me so much. My doctor and I agreed on an elective caesarean section to reduce the risk of HIV transmission during delivery.

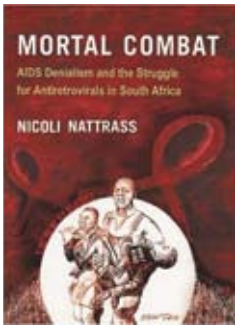
My baby was born prematurely on 9 October 2007. With help from the docotors my son and I are doing fine. He is taking AZT syrup twice a day until he gets tested at 6 weeks. I hope everything goes well and he tests negative. I believe that he will grow into a very strong young man.

Good news! Nokhwezi's child tested HIV-negative shortly before Equal Treatment *was completed.*

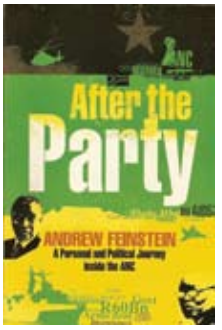
Recommended Reading



Take Two Veg & Call Me in the Morning *is the latest collection of Zapiro cartoons from the Mail & Guardian, Sunday Times and Independent Newspapers. Jonathan Shapiro's brilliant and funny cartoons expose the foolishness and conceit of our public figures, especially the Minister of Health.*

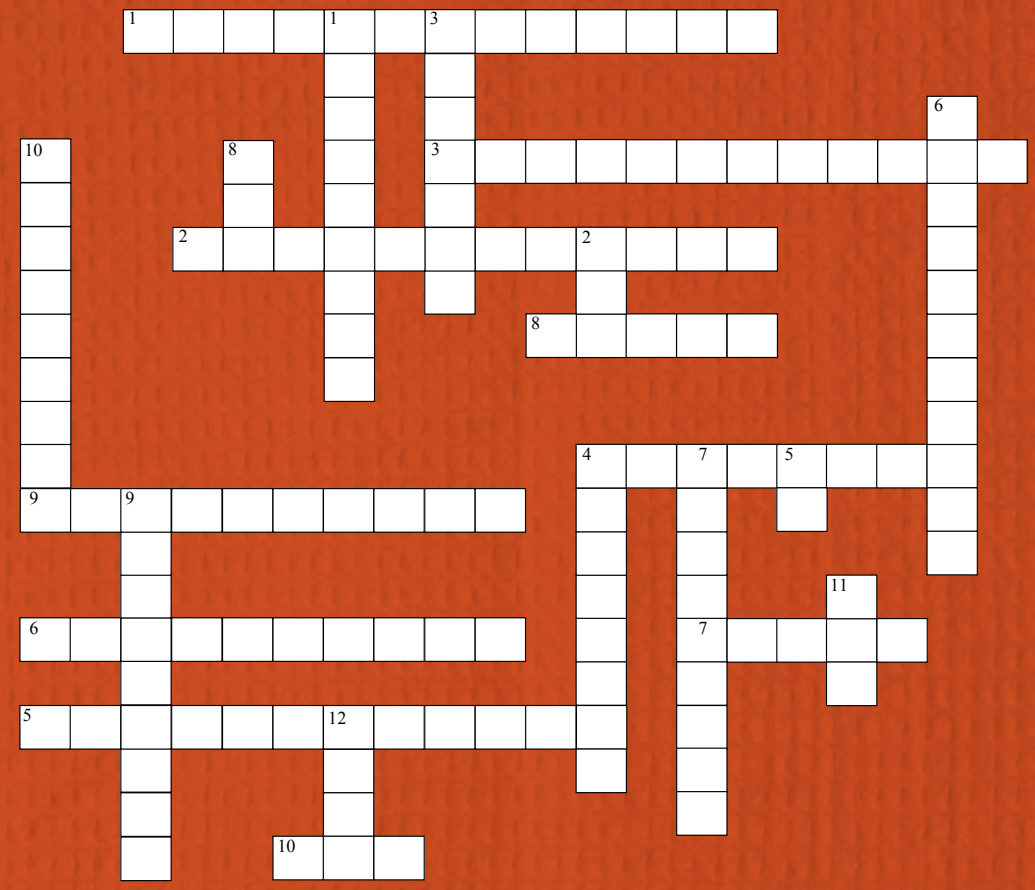


Mortal Combat *by Nicoli Nattrass is a history of AIDS policy in South Africa. It describes the behaviour of the AIDS denialists, including President Mbeki. It shows how denialism delayed the rollout of antiretroviral treatment and prevention of mother-to-child transmission of HIV.*



After the Party *is by former ANC Member of Parliament, Andrew Feinstein. He resigned in protest at the party's handling of the multi-billion rand arms deal. This very popular and well-written book describes the arms deal. It also describes some of President Mbeki's most bizarre comments on HIV/AIDS that Feinstein witnessed.*

Crossword Puzzle



We will give a R200 Pick 'n Pay gift voucher to the first crossword drawn from a hat with at least 20 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:
Equal Treatment
34 Main Road
Muizenberg
7945

Fax: 021 788 3726

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

Composed by Nosisa Mhlathi, Rachel Phillips and Sandra Fowler.

The winner of last issue's crossword was **Xoliswa Melude**. We have sent her a gift voucher.

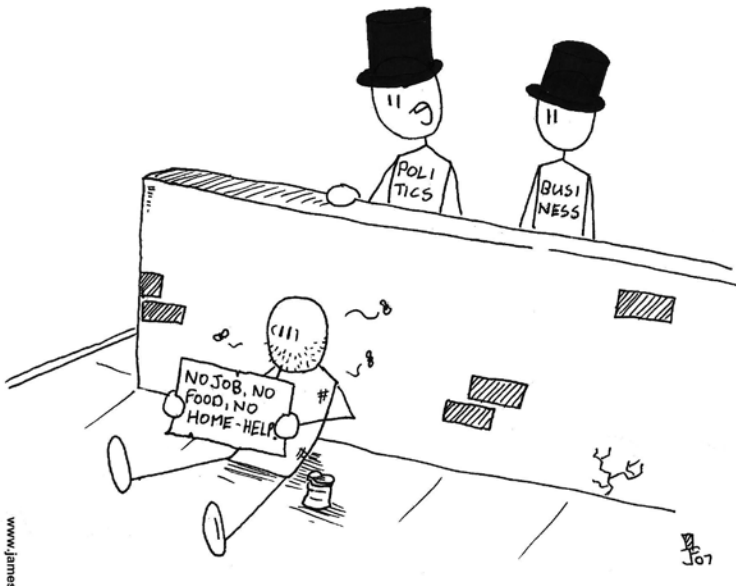
Equal Treatment's

Down

1. Number of times Nandipha's case has been postponed (9)
2. Month in 2007 that Cabinet endorsed the National Strategic Plan (3)
3. HIV-positive women are offered a choice between breastfeeding and this (7)
4. Doing this for two weeks or more is a symptom of Tuberculosis (8)
5. On 8 November 2007, over 5,000 people marched in Cape Town to call for better education, prevention, treatment and diagnostics for this disease (2)
6. She wrote the editorial in this issue of Equal Treatment (5,6)
7. This opportunistic infection is the most common cause for children with HIV in South Africa to be hospitalised (9)
8. This international institution recommends that exclusive formula feeding should only occur when it is "acceptable, feasible, affordable, sustainable and safe" (3)
9. TAC has lodged a complaint against the manufacturer of this drug, Merck, with the Competition Commission (9)
10. If HIV-positive mothers breastfeed they should do it until the baby is this age (3,6)
11. Name of the type of HIV test that should be used on children under 18 months (3)
12. This successful clinical trial on children finished this year in South Africa and shares its name with a famous pop star (4)

Across

1. HIV can be transmitted from mother to child during pregnancy, delivery and _____ (13)
2. Name of the new book by Nicoli Nattress that is recommended in this issue of Equal Treatment (6,6)
3. This is NOT a recommended feeding option for babies of HIV-positive mothers (5,7)
4. City in which the 38th Annual Union World Conference on Lung Health was held in 2007 (4,4)
5. Surgical procedure to remove the foreskin of a male's penis (12)
6. Antiretroviral given to pregnant women to prevent mother-to-child transmission (10)
7. Name of the world's largest drug company (5)
8. Sometimes child medicines are manufactured in this sticky form (5)
9. Dr. Ashraf Coovadia is a _____ in child health (10)
10. ____ blood spots helps with PCR testing (3)



Child Treatment Literacy Training

Do you conduct training on treatment for children living with HIV/AIDS? If so, the Children's Rights Centre would like to hear from you as we are developing a resource list of people who conduct child HIV literacy training, who and where they train. The training may be for community members, educators, health workers, social workers or others.

We are also interested in exchanging experiences and materials, especially with anyone conducting training for community members on child treatment.

If you want to let us know more about what you are doing, or if you wish to exchange information and experiences, please contact:

Meera LeVine, Children's Rights Centre by e-mail info@crc-sa.co.za, phone 031 307 6075 or fax 031 307 6074.

Photo: Jo Gorton. Image in public domain.

TAC members discuss how to mobilise campaigns at district level.

Mobilising Communities for Better Health Services

By Joey Hasson

TAC's campaigns have shown how communities can exercise their rights for improved access to health services. During October, some of TAC's most experienced organisers came together to share their skills and ideas about organising campaigns.

Two conferences brought together more than 100 TAC leaders from all sectors and provinces of the organisation. They produced a document which will be used for training new TAC organisers to become community health advocates.

But these were not just any conferences! Both took place at the Habonim campsite on the beach in Hermanus, outside Cape Town. Surrounded by mountains and the sea, far from any shops, the atmosphere encouraged individuals from different provinces, backgrounds and ages to meet one another, debate and exchange ideas. Delegates discussed a variety of issues affecting organising in TAC such as

- the responsibilities of organisers at branch, district, provincial and national levels,
- how organisers should work alongside other TAC departments,
- how organisers should build and implement community campaigns,
- what technical skills organisers need to plan, budget, evaluate and report on their work,
- how TAC can access and affect local government structures and
- how TAC should run induction workshops for new members.

At each conference, a high level political debate was held. Delegates discussed TAC's five year strategic plans for HIV and TB as well as the National Strategic Plan. TAC's organisational structure was also discussed ahead of the upcoming National Congress in March 2008.

During the conferences, it was affirmed that TAC organisers are the ones who mobilise people on the street to make the demands of their communities heard. It is organisers who bring the community to workshops and meetings. It is organisers who seek out and train new leaders. This important work has been neglected for some time in TAC. But now organising will get the attention it deserves.

The time for building branches, members and leaders has come!

Photo: Pupa Fumpa. Image in public domain.

St Georges Cathedral, Cape Town

29 August 2007

Over 1,500 people gathered at St Georges Cathedral in Cape Town to demand the implementation of the HIV/AIDS and Sexually Transmitted Infections National Strategic Plan for South Africa 2007-2011. They also protested the dismissal of Deputy-Health Minister Nozizwe Madlala-Routledge.

Germiston

5 November 2007

TAC members demonstrated in Germiston to demand improved mother-to-child HIV transmission prevention services in the Ekurhuleni district of Gauteng Province. The national and provincial departments are not improving mother-to-child transmission prevention fast enough. Ekurhuleni district has the resources to implement the improvements discussed on page 8 and 9 of this issue. If government is serious about improving the programme, it can demonstrate this immediately in places like Ekurhuleni.

Photos by Lefa Tlhame. Images in public domain.

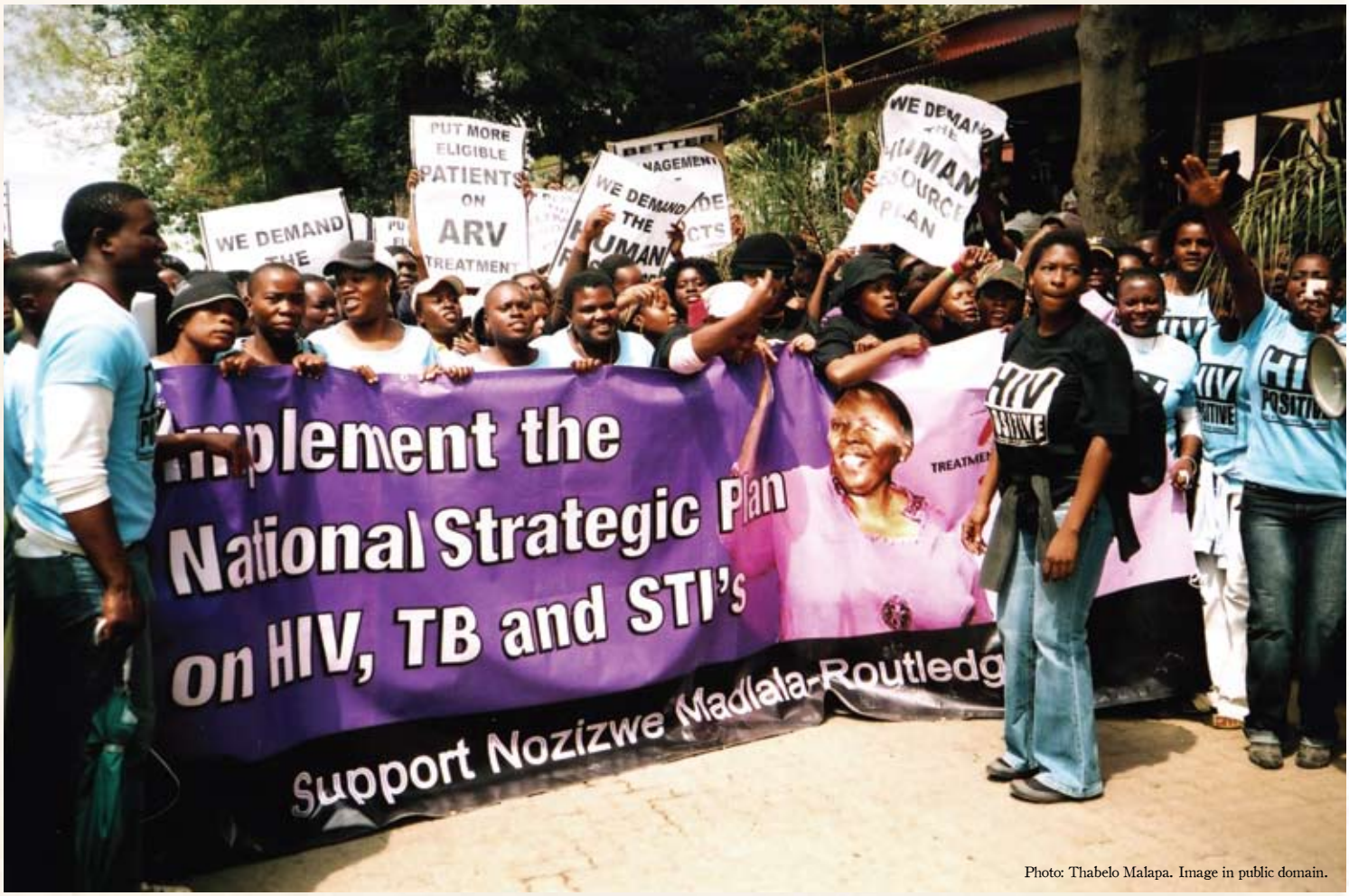


Photo: Thabelo Malapa. Image in public domain.

Mapulaneng Hospital, Mpumalanga

14 September 2007

Over 1,000 TAC Limpopo and Mpumalanga members and community members marched to Mapulaneng Hospital in support of the implementation of the National Strategic Plan (NSP) and in solidarity with principles stood for by former Deputy-Health Minister Nozizwe Madlala-Routledge.

The Impilo antiretroviral unit at Mapulaneng hospital faces many challenges if it is to meet the goals of the NSP. It currently treats about 1,300 clients. Another 1,000 are waiting for treatment. The unit attends to 130 clients a day with one doctor, one nurse trained in antiretroviral therapy, one pharmacist, one pharmacy assistant, one data capturer, a social worker, a dietician and three lay adherence counsellors.

A memorandum was handed in demanding:

- Development of a human resources plan
- Improved clinic infrastructure
- Integration of TB and HIV treatment
- Establishment of a multisectoral committee to monitor roll-out.
- Greater political commitment and leadership

Our Rights in Our Courts

Update on Treatment in Prisons

In our November 2006 issue, we reported on the legal victory regarding the provision of antiretroviral treatment at Westville Correctional Centre. But as that report indicated, we were still concerned about a number of problems in the way government planned to implement the court's order. To date, these issues remain unresolved, despite numerous attempts by TAC, prisoners at Westville and their lawyers – the AIDS Law Project (ALP) – to settle the case. How then, when Deputy President Mlambo-Ngcuka has called for the matter to be resolved, are there still problems with treatment access at Westville?

At a meeting in February this year, the parties, including the Departments of Correctional Services and Health, TAC and the ALP (acting on behalf of the prisoners), agreed to set up a joint task team to reach an agreement. Within a few weeks, the parties reached consensus on the main issues. Lawyers on both sides were instructed to "make it happen". But a few days later, everything fell apart. Despite TAC and the ALP going the extra mile to reach agreement, government's lawyers effectively sabotaged the process. To this day, it remains unclear under whose instructions they were acting.

Since then, not much progress has been made. TAC and the ALP remain committed to reaching an out-of-court settlement. So too does the Deputy President. But until government's lawyers and those instructing them are prepared to negotiate in good faith, a settlement is unlikely. At the time of going to press, plans were on track for the parties to meet once again. If a settlement is not reached, the matter will go back to the Durban High Court, where TAC and the prisoners will argue that government's plan for Westville needs to be improved substantially to comply with both the original decision and the Constitution.

Justice for Nandipha Makeke?

Nandipha was a TAC member who was raped and murdered in December 2005. The trial of her accused has been postponed seventeen times.

In the photo former Deputy-Health Minister Nozizwe Madlala-Routledge is delivering a speech at a TAC meeting in Khayelitsha on 14 November 2007. The meeting was about violence against women and the trial of the alleged murderers of Nandipha Makeke.

Photo: Nosisa Mhlathi. Image in public domain.

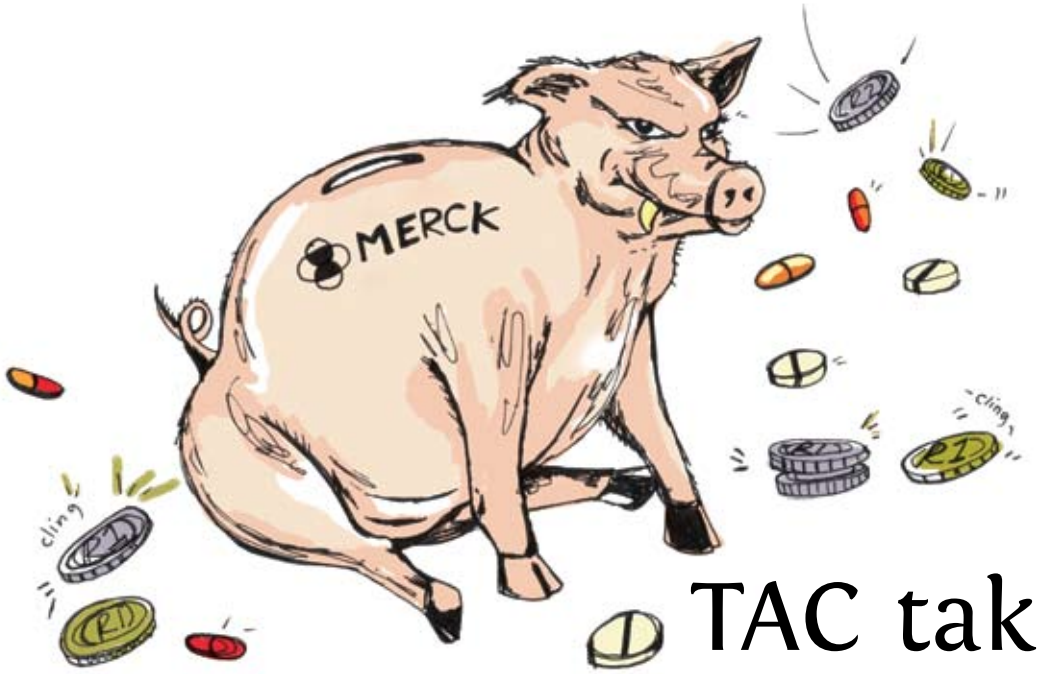


Illustration by Roulé le Roux

TAC takes on MERCK

TAC has lodged a complaint against the pharmaceutical company Merck over its failure to allow some generic drug companies to sell the key antiretroviral drug, efavirenz, in South Africa.

Sixty-four cents in every rand spent by the government on antiretrovirals in South Africa goes to the world's largest drug company, Merck. Merck produces efavirenz, a drug essential in most first-line antiretroviral regimens.

There are two Indian drug companies who manufacture cheaper efavirenz and who have registered it with the Medicines Control Council, meaning the drugs could be available immediately if licenses were granted. Merck has so far refused to grant licenses to these companies. Instead it has granted licenses to two local companies that have so far failed to bring affordable efavirenz to the market.

The AIDS Law Project (ALP) has for six years been acting on behalf of TAC in discussions with Merck's South African company, MSD. Merck has failed to make reasonable compromises. Therefore, TAC filed a complaint at the Competition Commission of South Africa on 6 November 2007. The complaint alleges that Merck and MSD are violating the Competition Act 89 of 1998. TAC is arguing that Merck's refusal to grant licenses to certain generic companies prevents cheaper production and a guaranteed supply of efavirenz.

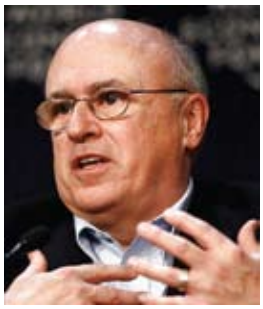


Photo: Taken from Washington Post.

Merck President Richard T Clark. Merck has had one major scandal already in the last few years. The company is facing court actions in the United States for its failure to disclose the deadly side-effects of its drug, Vioxx. However, less known are its actions that have prevented patients in developing countries from getting a wider range of efavirenz products at lower prices.

TAC is willing to negotiate with MSD, as we have no interest in prolonged litigation and would prefer to negotiate a settlement in the public's interest. If a settlement can be reached, TAC is prepared to withdraw its complaint.

Photo by Brenton Geach. Image in public domain.

Government Strangles Health Care in Cape Town

By Andrew Warlick

Western Cape Health Department cuts clinical services at Tygerberg and Groote Schuur hospitals and fails to build key hospitals in Khayelitsha and Mitchell's Plain.

The Western Cape Department of Health has recently taken steps to close 90 beds at Groote Schuur and Tygerberg hospitals in Cape Town. Groote Schuur and Tygerberg are both classified as tertiary health facilities. Tertiary public hospitals provide essential specialist care for poor people. This includes treatment for heart disease, diabetes, cancer, rheumatism as well as emergency services for trauma victims. Some of the services at Groote Schuur and Tygerberg are highly specialised services such as heart and liver transplantation and molecular genetic screening for inherited heart disease, which are found nowhere else in Africa.

This is apparently part of the Western Cape Government's Healthcare2010 Plan. On paper, the plan has many positive points, such as building new hospitals in areas which badly need them such as Mitchell's Plain and Khayelitsha. Yet even though these hospitals are supposed to be running by 2010, not a foundation stone

has been laid for them. It seems that government is implementing the service cuts in the plan, but very few of the improvements.

Healthcare2010 is trying to re-structure public health care delivery in the Western Cape by shifting human, financial and physical resources from tertiary-level to communities. Improving health care at community (or primary) level is critical.

Groote Schuur and Tygerberg are important components of the Western Cape's public health system because they provide essential health services to poor people. They are also academic hospitals attached to the University of Cape Town and Stellenbosch University respectively. Academic hospitals are crucial for South Africa because they train new doctors and health-care workers. The severe shortage of trained health-care workers is a problem for HIV/AIDS and TB services. Each year over 30% of all South African medical school graduates are trained in the Groote Schuur and Tygerberg hospitals and although many of these graduates go on to work in the private sector, some choose to stay in public service. Given the critical role that both hospitals play in delivering health care and training medical professionals their recent bed closures are a matter of serious national concern.

The resources which are being cut from tertiary-level are meant to be re-directed into primary health care. TAC supports government's efforts to expand access to health services, particularly HIV/AIDS and TB services, at the primary level. But it is a bad idea to increase access to primary health care services at the expense of access to tertiary-level services. Both primary and tertiary services need more investment and therefore more money from government.

A strong primary health care system requires strong referral services for patients with complications. The Healthcare2010 plan and the decision to close beds at Groote Schuur and Tygerberg are both based on the needs of the budget rather than the health needs of people. Reducing access to health care at any level of service delivery in the face of public health epidemics such as HIV/AIDS, diabetes, cardiovascular disease and TB is ethically wrong. It is also probably unconstitutional.

Together with allied organisations including NEHAWU, COSATU, the South African Medical Association and the AIDS Law Project, TAC is trying to protect poor people's access to specialised medical services by challenging the cuts and bed closures at Groote Schuur and Tygerberg hospitals. We are also campaigning for improved services at primary care level. Numerous demonstrations and meetings have taken place in Cape Town over the past few months. There are signs the campaign is working: the Western Cape Government has just announced an extra R332 Million has been allocated to the provincial Department of Health. This should be used to halt the current bed closures.

Photo: From UCT website.

Groote Schuur Hospital in Cape Town. Unique specialist services at the hospital are under threat. More resources are needed at primary health care level, i.e. in local communities. But the more primary care improves, the greater the demand will become to refer patients with complications to hospitals like Groote Schuur. Funding needs to be increased, not shifted crudely from one facility to another.

Photo: Nathan Geffen.

In June 2007, public sector workers across the country went on strike. There is not enough investment in the public health system. Consequently, health workers have poor conditions of service.

GLOBAL CALL TO ACTION FOR THE 38TH ANNUAL UNION WORLD CONFERENCE ON LUNG HEALTH

SAVE LIVES: TRANSFORM TB PREVENTION, DIAGNOSTICS AND TREATMENT

The 38th Annual Union World Conference on Lung Health was held in Cape Town on 8–12 November 2007. It was the first time in its 125 year history that the conference was held outside of the northern hemisphere. This is important as southern Africa is experiencing an extremely large and deadly TB epidemic, fuelled by an HIV epidemic. The response has been inadequate; new infections and needless deaths continue unabated.

TAC and ARASA led a march calling on the delegates to adopt the following Global Call for Action and Declaration on TB:

1. Every year TB kills more than 2 million people worldwide. In Southern Africa it is by far the greatest killer of people living with HIV.
2. In South Africa, over 70,000 death certificates recorded TB as a cause of death in 2005.
3. Despite regional governments declaring an emergency in 2005, TB control and AIDS programmes in Southern Africa are failing to adequately deal with the twin epidemics of TB and HIV.
4. This inadequate response is no longer acceptable.
5. Current diagnostic techniques and drugs are out-of-date; we need simpler, more effective and accessible tools for testing and treating TB.
6. TB prevention, care and treatment programmes must adopt a decentralised, patient-centred approach with treatment literacy, adherence support and community education.
7. More resources for TB research are desperately needed.
8. Provision of a decent public health system that is based on the right of every person to life, dignity, health and equality is the duty of every state and the advocacy work of every HIV/TB activist.
9. Access to decent housing, employment, social security and nutrition are indispensable to the elimination of TB.
10. The TB crisis has caused tremendous suffering and generated confusion, fear and stigma. Protecting public health is not incompatible with promoting a human-rights approach to dealing with this contagious epidemic. It requires a plan and community consultation not repressive measures against individuals.
11. Support services for health professionals and allied workers engaged in saving the lives of people living with TB must be researched and funded immediately.
12. This conference must serve as a platform for consensus on key issues related to the treatment, prevention and care of TB, including MDR and XDR TB. We must review and update our national TB and HIV plans and through partnerships commit the necessary resources to begin implementing the following key areas for action:
    - Improving infection control
    - Getting more people living with HIV tested for TB and people infected with TB tested for HIV
    - Integrating and decentralising TB and HIV services
    - Preventing and treating drug resistant TB (MDR/XDR TB)

We demand vision, research, funding, action and activism on TB/HIV and the crisis in public health now!

Endorsed by: Agency for Cooperation and Research in Development Kenya, Africa Japan Forum Japan, African Civil Society Coalition on HIV and AIDS Nigeria, African Services Committee USA, Dr. Michaell Kazatchikine, CEO, Global Fund, African Council of AIDS Support Organisations Senegal, AIDS Action Baltimore USA, AIDS Care Watch Campaign Japan, AIDS Institute USA, AIDS Law Project, AIDS Rights Alliance of Southern Africa Namibia , American Medical Students Association Africa Action, USA, Artists for a New South Africa, USA, Asia Pacific Network of People Living with HIV and AIDS Malaysia, Asian Peoples Alliance to Combat HIV/AIDS Malaysia, Association morocaine du lutte contrele SIDA Morocco, Batanai HIV/AIDS Support Group Zimbabwe, Botswana Network on Ethics Law and HIV and AIDS Botswana, Cameron Psychology Association FOCAP Cameron, Canadian HIV and AIDS Legal Network Canada, Community HIV/AIDS Mobilization Project USA, Democratic Nursing Organisation of South Africa, Dignitas International-Canada, Economic Justice Network, Economic Justice Network, Ekuphumeline ZION Church, Empilweni, EMPOWER India, Endorsements from South African Organisations, Estonia Society for Positive People Estonia, European Aids Treatment Group Belgium, Gay And Lesbians of Zimbabwe, Global Health Advocates Switzerland, Global Justice USA, Habonim Dror Southern Africa, Health Connection International USA, Health Global Access Project USA, HIV Medicines Association USA, HIV/AIDS Task Force Japan Forum Japan, Humanity for Orphans, Youth and Widows Initiatives Kenya, i-BASE United Kingdom, International Foundation for Alternative Research in AIDS USA, Jewish Outlook, Kenya Treatment Access Movement Kenya, Lebanese AIDS Society- Lebanon, Loving Hand- Zimbabwe, Médecins Sans Frontieres, Mother Africa and Child Care Organisation Ghana, National Council of Disabled People of Zimbabwe, National Network of People Living with HIV/AIDS in Rwanda, Nokwala Educare, Pan African Treatment Access Movement Morocco, Panos Southern Africa, Zambia, Pinoy Plus Association Inc. Philippines, Positive Action Foundation Philippines Inc., Positive Families Network, USA, Positive Malaysian Malaysia, Project Inform USA, Project Ring Japan AIDS and Society Association Japan, Rape Crisis Centre – Khayelitsha, SA Development Fund, USA, Sonke Gender Justice, South African Council of Churches, Southern Africa Treatment Access Movement Zimbabwe, Southern African AIDS Information Dissemination Services Zimbabwe, Stamp Out Poverty United Kingdom, Student Global AIDS Campaign USA, Tanzania Network of People Living with HIV/AIDS Tanzania, TB Care Association, TB Patients Support Self Help Group Kenya, The Centre Zimbabwe, Treatment Action Campaign, Umtha Welanga, Universities Allied for Essential Medicines Canada, Women AIDS Support Network Zimbabwe, World Aids Campaign Netherlands, Zibonele Radio Station, Zimbabwe Activists on HIV and AIDS Zimbabwe, Zimbabwe National Association of People Living with HIV/AIDS Zimbabwe , Zimbabwe Network of Positive Women Zimbabwe.

get tested for TB it can be CURED

TB can be prevented

Everyone can do something to prevent the spread of TB:

- Get tested for TB if you have any symptoms, especially if you are coughing or losing weight.
- If you are HIV-positive, ask your clinic to check you for TB regularly.
- Cover your mouth when you sneeze or cough.
- If someone near you is coughing, look the other way and cover your mouth.
- Open windows, especially in crowded rooms and taxis.
- If you have TB, you must take the right medicines. You must take them on time everyday, even after you feel better.

We say to the Department of Health: Integrate HIV and TB treatment. Clinics should treat both TB and HIV.

I had TB.
I got tested and treated.
Now I am cured.

Fikile Boyce

Symptoms of TB

Coughing for two weeks or more

Coughing up thick liquid or blood

Chills, fever, nausea or night sweats

Weight loss and loss of appetite

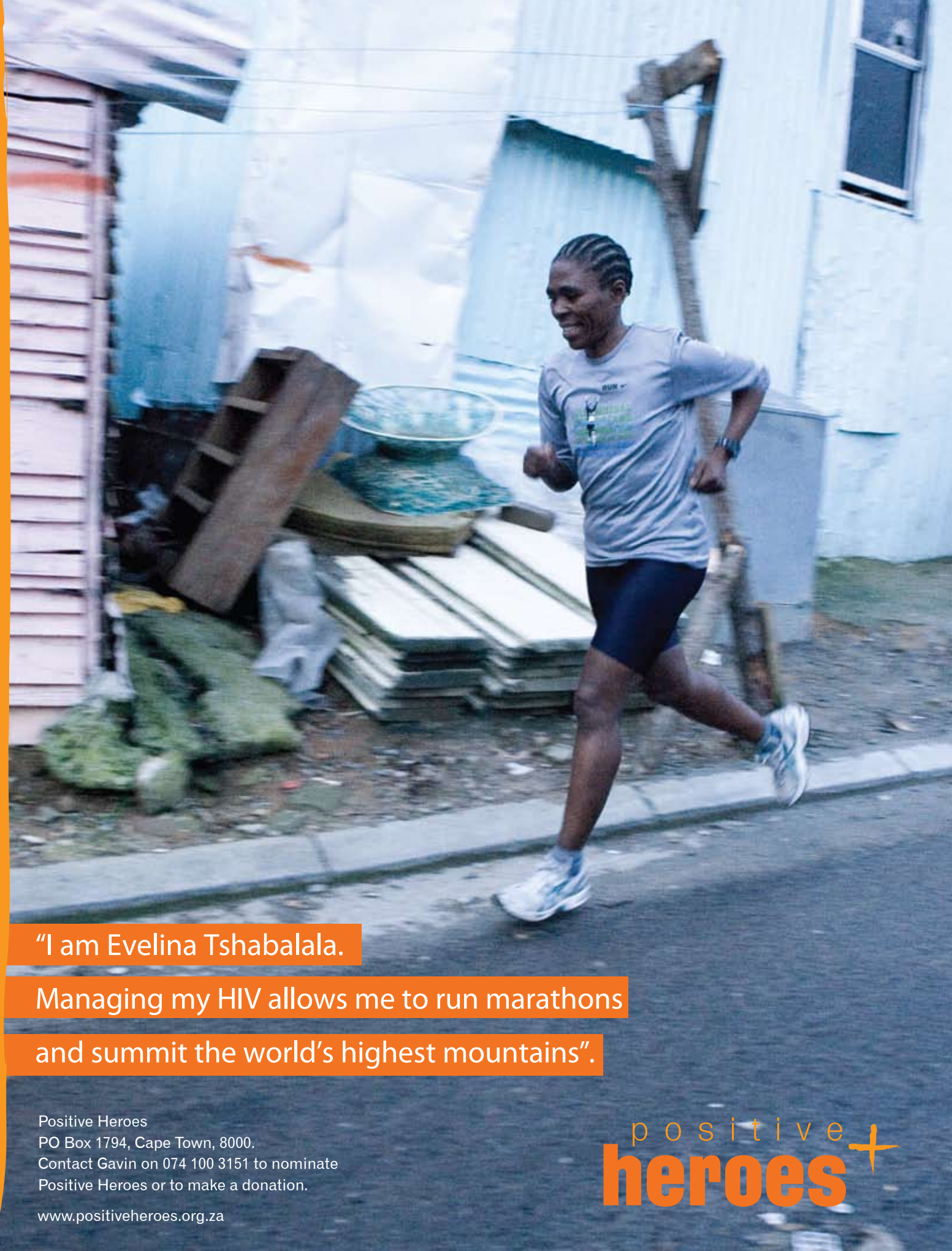
Chest pain or problems breathing

Pain or swelling of your tummy

Pain or blood when you pee

Aches and pains in spine or joints

Reproductive problems



Positive Heroes
PO Box 1794, Cape Town, 8000.
Contact Gavin on 074 100 3151 to nominate
Positive Heroes or to make a donation.

www.positiveheroes.org.za

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