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### *The Treatment Era: ART in Africa PlusNews Web Special*



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## 1. Introduction - The Treatment Era



Celebrating the opening of an AIDS treatment centre in Katima Mulilo, Namibia.  
Credit: IRIN

As a result of falling antiretroviral (ARV) prices, new sources of international funding and growing political commitment, providing treatment for Africa's HIV-positive citizens is, for the first time, an achievable goal.

In sub-Saharan 3.8 million people need treatment now, but as of June 2004, only 150,000

were on ARVs - less than four percent of that total. The remaining 96 percent - those parents, workers, lovers and children denied access to the life-prolonging drugs will, unless there is urgent intervention, inevitably join the other 30 million people worldwide that the pandemic has claimed.

### Picking up the gauntlet

The enormity of the challenge is daunting for a continent that, over the past two decades, has witnessed the attrition of public services and the deepening of poverty. Even Africa's targets under the World Health Organisation's '3 by 5' initiative - three million people in the developing world on antiretroviral therapy (ART) by the end of 2005 - seem incredibly ambitious.

But, although little more than pilot programmes in many countries, the rollout of ART is underway, and lessons are being learnt on the job. "I genuinely believe [3 by 5] is still within reach, and that the momentum is picking up at country level. I don't want to pretend it's going to be easy, though - it's going to be very tough," Stephen Lewis, the UN Special Envoy on HIV/AIDS in Africa, told PlusNews.

What it takes to deliver ART is already well understood, much of it as a result of the pioneering work of Medecins Sans Frontieres (MSF) in South Africa and Malawi. It involves standardised treatment protocols and simplified clinical monitoring; the delegation of aspects of care and follow-up to more junior healthcare workers and the community; the involvement of community members and people living with AIDS in programme design; and ensuring a reliable supply of affordable medicines and diagnostics.

The delivery platform for national programmes is the overburdened and under-resourced public health system, whose decline has been accelerated by the toll of HIV/AIDS. In Malawi, more than half of all government health posts are vacant and, according to a report by the Regional Network for Equity Health in Southern Africa (EQUINET), 90 percent of public health facilities do not have the capacity to deliver even a minimum healthcare package.

Under such conditions, "without urgent measures to recruit and retain healthcare workers, coupled with a system-strengthening perspective, the public health response to HIV/AIDS will be delivered at the expense of public health in general," the EQUINET report noted.

WHO acknowledges that "major new investment in countries' health systems" will be needed - an additional 100,000 health and community workers for a start. It estimates that the cost of achieving 3 by 5 will be US \$5.5 billion, but points to the ongoing mobilisation of international finance, and the lasting benefits that well-managed increased spending on ART will have on public healthcare in general.

Given Prime Minister Tony Blair's commitment to driving the AIDS agenda forward, both Lewis and South African treatment campaigner Zackie Achmat highlighted in interviews with PlusNews the significance of Britain's chairmanship of the G8 and European Union in 2005.

However, the issue of resources remains politically charged, with activists demanding that the Global Fund to Fight AIDS, Tuberculosis and Malaria be the primary financing mechanism, to avoid duplication with bilateral initiatives such as the United States President's Emergency Fund for AIDS Relief. In a new report Action Aid has also warned that the International Monetary Fund must relax its restrictions on public spending by African governments if they are to be able to effectively respond to HIV/AIDS.

### Build it and they will come?

But where ART is available, stigma, seemingly inexplicably, still influences people's response to treatment.

"Once HIV is perceived as a chronic but treatable condition, one of the factors that amplify stigma - fear of contagion and inevitable death - is lessened. However, stigma is much more than fear of contagion; it is also a tool used by cultures to exclude those felt to have broken extant rules. The dominant stereotype of people living with HIV is a stigmatising one that casts them as immoral," noted an article in November 2004 in the British Medical Journal (BMJ).

The Infectious Disease Care Clinic at Botswana's Princess Marina hospital in the capital, Gaborone, is one of the biggest treatment sites in the world. Many patients travel long distances to get there because of the anonymity the facility provides. Many also arrive sick beyond recovery because they have waited too long to seek treatment, even though Botswana has a well-publicised, amply funded, model ART programme.

It is not just rural people that succumb to stigma. Vodacom, one of South Africa's largest mobile phone

companies, has a free treatment programme, but few workers are reportedly accessing it. "Professional relationships still convey a danger of rejection, especially in contexts of conflict or competition", suggested the BMJ article.

ART should be part of a continuum of care: a comprehensive approach that includes voluntary counselling and testing, prevention of mother-to-child transmission, and other prevention and social support services. A regular supply of drugs, treatment preparedness and literacy are important factors in achieving high and sustained adherence rates.

"Rolling out ARVs is okay, but it has to be done right, otherwise it's dangerous - [drug] resistance will make the problem worse," Zambian HIV-positive activist Winston Zulu told PlusNews. "Here, we rolled out without talking about treatment literacy [or] even about the side effects [of the drugs]. Some people have had terrible side effects and stopped taking their drugs."

### Not everybody wins

A mix of payment systems - free, subsidised or self-paying - are employed by governments, and criteria for access to ART differ widely. What is increasingly clear, however, is the inequity in access, even when the drugs are free.

"Given their limited access to income and other productive resources, women are less likely to be able to participate in self-pay schemes, even with subsidised prices," a report by the US-based Centre for Health and Gender Equity noted.

"Many families cannot afford to have more than one person on ARVs because of the financial implications, so if there is one person that should go on the drugs, it is usually the man, because as the perceived head of household, he is less dispensable," Karana Mutibila of Zambia's Network of People Living with AIDS told PlusNews.

Because of the additional cost of paediatric ARVs, and the difficulty of calculating the correct dose when using adult ARVs, HIV-positive children are another group that are often sidelined by existing ART.

ARVs represent only around 50 percent of the costs of treatment. In Zambia, CD4 count, viral load, liver function, syphilis and TB are just some of the tests required

before ART can start - and they are not free. "People can go to and fro for three weeks [taking tests] before treatment starts, and many of them give up," said Zulu.

A study in Senegal found that when the cost of drugs for opportunistic infections, laboratory exams, consultations and hospitalisation fees are calculated, patients on ART pay an additional US \$130 a year - a significant amount for the majority of people who live on less than a dollar a day, and a reason cited for treatment interruptions.

The "Freeby5" campaign argues that any form of payment disadvantages the poor, while exemption systems are not cost-effective. The signatories to the declaration note that a "prerequisite for ensuring that treatment programmes are scaled up, equitable and efficient, and provide quality care, is to implement universally free access to a minimum medical package, including ARVs, through the public healthcare system".

The unfortunate reality is that not everybody who needs treatment will be able to access it - but if you are rich and live in the cities, you stand a better chance. "What we can look forward to is some treatment, for some people, in some settings," said professor Alan Whiteside at the Health Economics and HIV/AIDS Research Division of the University of KwaZulu-Natal, South Africa.

He calls for an informed debate at national and community level about who should get access to treatment, rather than leaving it to the doctors or the ad hoc rationing caused by limited services. Should there be economic criteria, where only graduates need apply? Should it be based on equity, where the most vulnerable are served? Or on moral grounds - the victims of sexual abuse? Most would agree that health workers should top any list.

"People in the north consider that they have a compact with their governments, which entitles them to a certain level of treatment when they are sick. I don't think that's true in the developing world: if you don't think you are entitled to it, or expect to have it, you die uncomplainingly. This epidemic provides room for building civil society [as a political movement around treatment]," Whiteside told PlusNews.

### [Resources:

- ART Treatment access and effective responses to HIV and AIDS - Providing new momentum for accessible, effective and sustainable health systems - Equinet: The Network on Equity in Health in Southern Africa - <http://www.equinetfrica.org/bibl/docs/BRIEFaids.pdf>
- Treating 3million by 2005 - WHO | World Health Organization - <http://www.who.int/3by5/publications/documents/en/3by5StrategyMakingItHappen.pdf>
- How the Fight against HIV/AIDS is Being Undermined by the World Bank and International Monetary Fund - Action aid U S A - <http://www.actionaidusa.org/blockingprogress.pdf>
- Barriers to better care for people with AIDS in developing countriesbmj.com - electronic BMJ (British Medical Journal) - <http://bmj.bmjournals.com/cgi/reprint/329/7477/1281>
- Gender, AIDS, and ARV Therapies: Ensuring that Women Gain Equitable Access to Drugs within U.S. Funded Treatment Initiatives - Center for Health and Gender Equity - <http://www.genderhealth.org/pubs/TreatmentAccessFeb2004.pdf>
- Free by 5 - University of KwaZulu-Natal - <http://www.nu.ac.za/heard/free/declaration.htm>



## Overview - Focus on Mozambique



Maputo Central Hospital: two lab technicians from Malawi learn to do HIV tests, viral load and CD4 counts.  
Credit: IRIN

Mozambique is a catalogue of the problems that poor countries face when they expand anti-retroviral therapy (ART).

National HIV prevalence in 2004 is projected to be 14.9 percent among people aged 15 to 49, based on sentinel surveillance by the ministry of health and the National Institute for Statistics. The average hides sharp disparities between provinces, ranging from 26.5 percent in Sofala to 8 percent in Nampula. Provinces bordering South Africa, Zimbabwe and Malawi are the worst affected.

Among the estimated 1.4 million people infected, 218,000 need treatment in 2004, according a National Institute of Statistics study.

As of November 2004, 5,900 people were on ART: 4,200 through NGOs, 1,200 at Maputo Central Hospital, a few hundred at provincial sites, and about 50 through private health care.

The goal was to have just under 8,000 people on ART by the end of 2004, with an annual increase to 20,800, 58,000, and 96,000 - reaching 132,000 in 2008.

### Healthcare providers

The first problem is lack of human resources. There are 800 doctors, 300 of them expatriates, in a population of 18.9 million. This means one doctor for every 24,000 people, against one per 5,000 to 10,000 recommended by the World Health Organisation. The 11,000 nurses represent one per 1,700 people, while WHO recommends one every 300.

Healthcare is also unevenly spread: 80 percent of doctors are in Maputo, the capital; among all health staff, those in the provinces have the lowest qualifications.

Due to AIDS-related deaths, Mozambique needs to train 25 percent more doctors and nurses every year just to maintain the existing low levels of staffing, says a study by the ministry of health.

The University Eduardo Mondlane, the new National Health Institute in Maputo, and the new Nursing School in Beira are increasing student uptake, but to retain them in the country after graduation will require better salaries and working conditions.

Meanwhile, with donor money to offer monthly salaries of US \$3,000, the government is recruiting 120 doctors in Cuba and India.

### Infrastructure

Another problem is poor health infrastructure. In the provinces, sub-standard facilities and lack of basic equipment is common. Many of the 27 rural general hospitals operate below minimum acceptable standards, says the Health Sector Strategic Plan 2002-2005.

To enable ART, the Italian Catholic NGO, Comunita de Santo Egidio, rehabilitated three molecular laboratories with state-of-the art equipment. The biggest, at Maputo's Central Hospital, cost US \$450,000; those in Maputo and Beira are operational, and Nampula will open soon to serve the northern region.

In the meantime, blood samples are sent weekly from the north to Maputo by courier airplane - run-down inter-provincial roads make some airfreight unavoidable.

The lab in Maputo offers training for health personnel from Mozambique and other African countries where Santo Egidio plans to start ART.

At Maputo Central Hospital, Brazilian cooperation funds ARV training for doctors and nurses, and to date 200 doctors have been trained, so that every province now has ARV-competent doctors.

Dr Rui Bastos is the Mozambican training coordinator. "We are overworked," he says. "We lack diagnosis capacity, drugs for opportunistic infections, nurses, psychologists and resources in general."

Other problems are the lack of legislation on post-exposure prophylaxis and deliberate infection, and the ethical conflict between professional confidentiality versus medical notification to partners, says the HIV/AIDS National Strategic Plan 2004-2008.

### Treatment providers

Two NGOs, Medecins Sans Frontieres (MSF) and Santo Egidio, run model community-based care and treatment projects: MSF treats 1,700 patients in Maputo and Lichinga; Santo Egidio runs 13 sites in Maputo and Beira, treating 2,500 patients.

By 2007 Santo Egidio plans to treat 8,400 persons at 20 sites in five provinces.

In Maputo, MSF is working at full capacity. Its clinic there has 1,500 patients on ART and a waiting list of 1,000. "It is frustrating, but our human and financial resources are limited," says MSF general coordinator Patrick Wieland.

MSF employs 20 medical staff in Maputo, including two Mozambican and three foreign doctors, and 10 non-medical staff. The total annual cost of the programme is \$2.5 million, but, being donor-dependent, MSF can only guarantee five years of treatment, and

continuation hinges on additional funding. Patients must understand this, sign consent forms, and hope.

"It is not our role to treat everyone," says Wieland. "We showed ART is feasible; we can train others, but we cannot substitute for the government."

Santo Egidio operates on a different model, at a lower annual cost of \$2.2 million. The Catholic charity relies on volunteers from Italy and other countries, who pay their travel to Mozambique during holidays and work one month for free at its sites.

The annual treatment cost per patient at Santo Egidio is \$700, broken down to \$300 for generic antiretrovirals (ARVs) and \$400 for tests and other support.

The success of such ART programmes in Mozambique and elsewhere in Africa lies in strong community involvement regarding patient identification, selection, care, support and monitoring. It is labour and capital intensive.

Besides drugs and tests, patients need good food, clean water and a healthy environment; mothers need formula for babies. Santo Egidio distributes food, insecticide-treated mosquito nets, water filters and home-based care kits, while MSF has partners who provide this support.

Can these schemes be replicated by the public health sector?

"As it is, no," says Wieland. "Local solutions are needed - there is no other choice."

Gabriella Bortolot, coordinator at Santo Egidio, says: "We can't export a western model to Africa, but the challenge is to develop an African model of quality care."

Local solutions include using non-medical personnel at all levels. Lay community workers, trained and supported by referral systems, can run pharmacies, do routine follow-up, counselling, and home or palliative care; nurses and clinical officers can offer prescription and consultation, while community health workers can monitor patients for toxicity and clinical failure, freeing scarce doctors to attend mainly to complications.

Eliminating the requirement for viral load and CD4 counts before starting treatment bypasses expensive tests.

## Expansion

Mozambique began planning nationwide ART in 2002 with a degree of reluctance: health authorities knew first-hand the problems involved.

"AIDS should not detract from other health services, it should reinforce them," says Dr Mouzinho Saidi of the National Programme to Fight HIV/AIDS.

The examples of successful ART schemes run by NGOs helped dissolve the initial reluctance, but today the government is under pressure from activists and donors alike to expand treatment access.

"We are resisting donor pressure to increase the numbers because we want to grow in a sustainable way," says Saidi. "If we lose control, drugs will end up [being] sold on the streets and patients will not be properly monitored."

The fear of creating resistant strains of the virus is palpable, as is the fear of donor funds shrinking in the future.

"The government is very conscious that, once we start, we can't stop, so these are reasonable figures reflecting local capacity," says WHO representative Dr Bokar Toure.

The ethical imperative and the practical feasibility of ART in Africa are now widely accepted. The challenge is at what pace and how.

"Scaling-up was decided by donors in foreign capitals, who don't know the on-the-ground reality of treating patients," says Wieland. "Westerners like to do a lot quickly, and have quick impact, but we need long-term strategies to sustain results, not relying on donors and their whims."

## Coordination

Throughout the interview with PlusNews, Saidi stressed one point: coordination. "We can't have disorganised growth or parallel systems for treatment, drug procurement and drug supply," he explained.

Mozambique, like other developing countries, has a variety of health care providers, including the state, NGOs, churches and the private sector.

ART began in Mozambique with NGOs; the public health sector came later. The challenge is to coordinate the whole spectrum of ART providers.

One point of friction is patient selection. The medical criteria - a CD4 count under 200 or stage III/IV of AIDS - are established by WHO. Additional social criteria, which become crucial when need exceeds supply, vary.

The government has not developed national social criteria to select patients. Hence, it clashes with Santo Egidio because the charity provides ART to 100 inmates at a prison in its clinic's catchment area. The government argues that prisoners cannot support treatment with healthy living; the Catholic charity argues that every patient has the right to treatment.

Planning and coordination could have avoided this problem.

## Donor dependency

In UNDP's Human Development Index, Mozambique ranks at 171 out of 177 countries. In 2003 its GNI per capita was US \$210, compared to an average of \$450 in sub-Saharan Africa.

In 2000 foreign aid accounted for 70 percent of all spending on health, 46 percent of education expenditure and 75 percent of the funds spent on infrastructure, such as roads and water.

In 1999 foreign aid provided 52 percent of the \$100 million health budget, notes the Health Sector Strategic Plan. With increased foreign funding for AIDS, the ratio is higher today.

Mozambique is one of the most donor-dependent countries in the world, and its treatment plan echoes this. The government worries about the long-term sustainability of treatment, and the recent wrangle among donors about next year's financial support for the Global Fund to Fight AIDS, TB and Malaria feeds these concerns.

Then you meet Ana Maria Muhai, 43, a dynamic activist in Machava on the outskirts of Maputo. Her miner

husband returned from South Africa in 1998 with a retrenchment bonus and promptly left her and their three young children when she became sick.

In February 2002, Muhai, weighing 29 kg, ravaged by opportunistic infections, bald, with horrible skin rashes and a bad cough, arrived at the clinic. In three weeks ARVs brought her back from the brink of death.

Today, a healthy Muhai helps patients with treatment adherence. When some ask if she is paid by the Italians to say she is HIV positive, she pulls out an old photo. "Then they see it is for real - I know it is not a cure, but I feel cured," she says.

There are 1.4 million people like Ana Maria Muhai in Mozambique, whose contribution to family, community and nation is unique, irreplaceable, and threatened by the virus.

## 2. Delivery

### AFRICA: Show us the money!



AIDS activists have pushed for better access to generics and lower prices for brandname drugs.  
Credit: PlusNews

Protest emails flowed fast and furious in mid-November when AIDS activists at a meeting in Arusha, Tanzania, lobbied against a US-led drive to delay a new round of grants by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

The United States, the largest contributor to the three-year-old Fund, raised concerns about its efficiency and accountability, the absorptive capacity of recipient countries and grants to rogue regimes like North Korea.

A compromise was reached in Arusha and a delayed new \$1 billion round will take place next year. But the problem showcased the uncertainty under which the Fund operates, and the myriad AIDS-related activities it finances from Albania to Zimbabwe.

During four proposal rounds since its inception, the

Global Fund has approved up to US \$3 billion in grants to 128 countries - falling short of raising the \$10 billion a year it set out to raise three years ago.

Meanwhile, the US Congress has set the US contribution to the Fund for 2005 at US \$350 million, or \$200 million less than in 2004. Activists read this as proof of Washington's "go-it-alone" approach to AIDS, eschewing multilateral institutions in favour of George Bush's President's Emergency Plan for AIDS Relief (PEPFAR), launched in 2003.

The controversial five-year \$15 billion PEPFAR programme funds treatment, prevention, orphan and palliative care in 15 developing countries. (Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam and Zambia).

### Brands versus generics

Its two most contentious issues are the preference for expensive brandname antiretrovirals (ARVs) instead of cheaper generic drugs, and abstinence and fidelity over condoms in prevention. Critics charge that PEPFAR protects the interests of big US-based phar-

maceutical companies and the agenda of the Christian religious right.

Before the Arusha meeting, the Ecumenical Pharmaceutical Network (EPN), which represents Christian hospitals and charities in 22 developing countries, criticised PEPFAR's choice of brandname drugs for antiretroviral therapy (ART).

The health services of developing countries normally use generic drugs to treat AIDS. Adding branded ARVs creates a two-tier, multidrug regime system, which complicates procurement and supply lines, while burdening health professionals and community health workers, who have to administer different drug regimes, sometimes to patients in the same family.

Generic treatment uses a 3-in-1 fixed-dose combination pill taken once a day. Branded ART consists of several pills a day, which can complicate adherence and encourage pill sharing among family members, said EPN.

PEPFAR will not use generic ARVs that are not approved by the US Food and Drug Administration (FDA) - not even those approved by the World Health Organisation (WHO). Critics argue that the FDA is not the global arbiter of drug quality, and should reinforce WHO's stringent qualification process instead of shunning it.

Conceding the point, the FDA is fast-tracking approval of 3-in-1 generic medication for 2005. However, the US-based pressure group, Health Gap, says the FDA process is "a bottomless pit of enhanced approval criteria aimed at shutting out generics from approval", that will give drug companies time to develop 3-in-1 brand-name pills.

Earlier this year, generic ARVs got a boost with the release of results from the world's first open clinical study on the safety and effectiveness of a 3-in-1 pill, conducted in Cameroon by Medecins Sans Frontieres-Switzerland and the French agency for research on HIV/AIDS, in which Triomune, a drug produced by Indian manufacturer CIPLA performed as well as brand medicines.

After six months, 80 percent of patients, formerly at stage IV of AIDS (where the body's immune system has been incapacitated by the virus), had undetectable viral loads. "We know from our direct field experience that these generic fixed-dose-combinations are prolonging lives," said an MSF statement.

While the price of ARVs has fallen dramatically over the last few years - from \$15,000 a year to \$185 in South Africa - PEPFAR pays premium prices for its medicines. The Wall Street Journal reported in October that PEPFAR was paying more than twice as much for AIDS drugs than the World Bank or the Global Fund - the two other main funding sources for ART. Paying double the price equals treating half the patients, say critics.

It is the fall in drug prices that has brought what Dr Eric Goemare of MSF calls "a seismic shift" in the ability and willingness of governments to treat their citizens.

## Shifting strategy

Reacting to criticism, in May 2004 PEPFAR pledged to harmonise its AIDS work with other donors and governments. Ambassador Randall Tobias, head of the US Office of the Global AIDS Coordinator, promised "to respect local government decisions as to how to manage their HIV/AIDS programmes".

One example is Mozambique: it provides only generic ARVs and wants to stay that way. A multiplicity of drug regimes would further burden the rundown health infrastructure and scarce health professionals in one of the world's poorest countries.

"We can't have parallel systems and duplication of efforts in drug procurement, pharmacy, computerisation, monitoring and training," said Dr Mouzinho Saidi of Mozambique's National Programme to Fight HIV/AIDS. "Just think: patients and their doctors would be confined to the place where a certain ART is available."

The Mozambican government argued that PEPFAR should support the national strategy and not impose another. "We had long, tough, high-level negotiations but, eventually, we reached consensus," Saidi told PlusNews.

PEPFAR agreed to fund the non-pharmaceutical parts of ART, to expand ART sites, train health workers, improve labs, and ensure blood safety. It will also provide branded second-line ARVs (for patients with resistance to generic first-line ones) and paediatric ARVs, the two most expensive drug items.

PEPFAR's commitment to Mozambique for 2004 is \$25.5 million, including funds for prevention, counselling, mother-to-child transmission, orphans and home-based care.

The EPN has recommended that PEPFAR coordinate more effectively with existing HIV/AIDS programmes. As the number of funding sources has grown, so has recognition of the need for harmonisation and streamlining of donor procedures to enable better utilisation of grants.

The so-called "three ones" - one national AIDS action plan, one national coordinating strategy, one monitoring system - are key to preventing duplication and identifying bottlenecks to aid flows, according to UNAIDS.

But the Global Fund has also been recognised as more than a funding mechanism. "The Fund is rewriting the rules on delivering assistance. It tries to marry the best of all other instruments: an emergency spirit, recipient-owned programmes, and participatory processes," Mabel van Orange, managing director of the Brus-



sels-based Open Society Institute, said at the Bangkok AIDS conference.

Among the criticisms of PEPFAR is that it diverts potential financing from the Global Fund. "Donor governments need to view the Global Fund in the same way that they view their other national priorities, like contributions to international peacekeeping, or

investments in domestic school systems," the International Council of AIDS Service Organisations said in a report released earlier this year.

#### [Resources:

- "Stepping Back from the Edge: The Pursuit of Antiretroviral Therapy in Botswana, South Africa and Uganda", (UNAIDS), 2003 -

[http://www.dec.org/pdf\\_docs/PNACU828.pdf](http://www.dec.org/pdf_docs/PNACU828.pdf)

- "Assessment of First Year Efforts of the Global Fund to Fight AIDS, TB and Malaria", United States General Accounting Office -

<http://www.gao.gov/new.items/d03755t.pdf>

- "A Comparative Analysis of the Financing of HIV/AIDS Programmes in Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe", 2003 -

[http://www.synergyaids.com/documents/Finance\\_CompAnalys.pdf](http://www.synergyaids.com/documents/Finance_CompAnalys.pdf)

## AFRICA: Healthcare workers feel impact of HIV



Overworked, overstressed and underpaid.  
Credit: Rick Cadenaro

South Africa's Western Cape region, in theory, provides free antiretroviral therapy (ART) to all who need it. But in the Khayelitsha township, outside Cape Town, more than 500 people who qualify for antiretroviral (ARV) drugs remain

on waiting lists because there are simply not enough doctors and nurses to deliver treatment.

"We have funding and we have strictly no restrictions - our only limiting factor is staff," said Eric Goemaere, head of Medecins Sans Frontieres in South Africa, which already provides ARVs to more than 1,000 patients at three HIV/AIDS clinics in Khayelitsha. "We haven't been enrolling patients fast enough and, as a result, we treat patients too late."

In South Africa more than one in five adults aged 18 to 49 are infected, making this the world's largest population of people living with AIDS, according to the World Health Organisation (WHO).

With such numbers already straining the health system here, Goemaere stressed that it was crucial for HIV-positive health providers to stay healthy. "We cannot afford to lose staff to HIV/AIDS," he told PlusNews.

A new study has shown that healthcare workers in South Africa are likely to be infected with HIV at rates only slightly lower than the overall adult population, raising concerns that such prevalence will have a disastrous impact on efforts to stem the epidemic.

Experts believe the problem may be even more serious in the rest of sub-Saharan Africa, where health infrastructures are already crippled by limited funding and the "brain drain" - the emigration of medical professionals to better-paying jobs in developed countries.

An estimated 15.7 percent of workers in health facilities in four of South Africa's nine provinces were living with HIV/AIDS in 2002, according to the study, published in the South African Medical Journal. The HIV-positive rate was much higher - roughly 20 percent - for both non-professional health workers and caregivers aged 18 to 35.

"In order for developing and middle-income countries to provide adequate prevention and care programmes for their populations, they have to look at the health status of health workers," said Dr Olive Shisana, executive director of Social Aspects of HIV/AIDS and Health at the Human Sciences Research Council in Cape Town. "The healthcare systems are not going to cope without a healthy workforce."

The high prevalence of HIV/AIDS in the health community is particularly worrisome, considering the overall shortage of health workers in sub-Saharan Africa. Africa needs a million new healthcare workers - nearly triple its current capacity - to reverse falling life expectancies and stem the public health crisis, according to a new report by the Joint Learning Initiative research group.

In South Africa alone, the total number of registered nurses grew by only 3.7 percent, to 96,715, between 2000 and 2003, according to the South African Nursing Council.

"One of the biggest challenges we have at the moment is that many of the health facilities, both private and public, are finding it very difficult to fill vacant posts because there aren't enough nurses available," said Hasina Subedar, registrar of the council.

Subedar said the council does not compile statistics on how many nurses are HIV positive, but noted that the vast majority of nurses are women, who tend to demonstrate a higher rate of HIV infection than men.

"It places a greater demand on the number of nurses we need to bring in to the system if we're going to be losing nurses to HIV/AIDS," she said.

The majority of countries in sub-Saharan Africa do not meet WHO's recommended minimum ratio of 20 physicians per 100,000 of population and, according to the most recent data available, 13 countries have fewer than five physicians per 100,000 of population, notes a June report by the US-based Physicians for Human Rights.

The report, 'An Action Plan to Prevent Brain Drain', observed that sub-Saharan African countries generally suffer from a colossal shortage of health workers. In Malawi, for example, a government survey found nurses occupied only 28 percent of the available posts in 2003.

"The prevalence of HIV/AIDS among healthcare workers is having an even worse impact outside of South Africa, because there is a net migration of nurses and doctors from other African countries to South Africa and elsewhere," said Professor David Sanders, director of the School of Public Health at South Africa's University of the Western Cape.

Besides being directly affected, Sanders said, HIV-positive health workers in sub-Saharan Africa are likely to have infected family members, and therefore face considerable strain caring for relatives and attending funerals. Moreover, as HIV depletes the total number of health workers, those left behind have to carry larger caseloads.

The authors of the South African Medical Journal study called for the introduction of ARV programmes

specifically targeting health workers, and "vigorous human resource planning" to replace the workers likely to die from AIDS. They also stressed that health systems must be careful about exposing HIV-positive employees to tuberculosis and other infectious diseases while at work.

"There is absolutely no doubt that the epidemic is impacting, directly and indirectly, on health workers, and thus on the health infrastructure," said Sanders. "It's clearly limiting the ability of the health sector to respond to the epidemic, but it's an issue that people haven't sufficiently taken account of."

Some argue that health systems should begin by doing more to educate and train health workers about HIV/AIDS prevention, as well as treatment.

"Not only do nurses and other health workers not receive enough training about how to treat, identify, or care for people with HIV/AIDS, they don't have enough information about HIV/AIDS transmission to protect themselves," said Holly Burkhalter, US policy director with Physicians for Human Rights.

Burkhalter said health workers are at greater risk of contracting HIV because they often do not have access to proper resources, such as latex gloves, that would reduce exposure. "A midwife delivering babies in the middle of a rural community, without gloves, is exposed to HIV," she noted.

Burkhalter said African nations must aggressively address the prevalence of HIV among health workers while it provides government-funded ARVs to their populations. "It doesn't matter how much money you put on the table for medications if you don't have the staff to deliver them."

## BOTSWANA: Model treatment programme has its problems



Botswana's treatment programme is seen as a model for other countries.

Credit: MASA ARV Programme

When the Botswana government decided to provide free antiretroviral (ARV) treatment to its HIV-positive citizens, the country was hailed for taking such a bold step at a time when some of its neighbours continued to debate the toxicity of the drugs and wrestle with how they would fund their treatment plans.

Two years on, while most countries in Southern Africa have embarked on some form of treatment programme, Botswana has about 35,000 people in the public and private sector receiving the life-prolonging drugs, funded by the Bill and Melinda Gates Foundation and the Merck Company Foundation.

But despite the progress in rolling out the programme, health and government officials are concerned that people still wait until they are very ill before seeking help, making it more difficult and expensive to treat them.

On average, HIV-positive Botswana access treatment when their CD4 count is at 80, according to Dr Ernest Darkoh, operations manager for the national ARV programme. Without HIV infection, the normal CD4 count range is 500-1,500. At 200 and below, a patient is at serious risk and treatment should begin.

At Princess Marina hospital in the capital, Gaborone, the Infectious Disease Care Clinic lies tucked behind the main hospital buildings. With about 12,000 people enrolled, this is one of the biggest treatment sites in the world.

Healthcare workers at the Princess Marina site see over 200 patients a day, many of who are "coming in sick beyond recovery". This has meant that the initiation process, which should take a couple of months to train patients and get them ready to begin taking the drugs, has had to be fast-tracked, Virginia Kebinakgabo, the clinic's sister-in-charge told PlusNews.

The workload can be attributed to fear of stigma and discrimination. Many of the patients travel long distances to get here, preferring the relative anonymity of the facility.

A patient who had travelled 50 km from Molepolole told PlusNews, "That's my home, I don't want them to see me queuing for ARVs."

Consequently, the pharmacy has had to make allowances for patients from outlying villages, who do not

always come for their monthly supply of drugs on the scheduled dates.

Botswana has all the ingredients for turning the epidemic around: political leadership, optimal use of existing resources, and an established treatment plan. But fear of stigma has proved to be an even bigger hurdle.

"People are not yet free to talk about the epidemic. If they can't talk about it, then it will be even harder for them to get help," said Chris Molomo, head of the National AIDS Council.

The size of the population also plays a role - in a country of 1.7 million people, only a handful of individuals have gone public about their status.

### Routine testing as a new strategy

In January this year, the government introduced a policy of routine testing for HIV as part of its strategy for reducing stigma. Healthcare workers now offer HIV tests in public hospitals and clinics, but patients still have the right to refuse.

The change in strategy has been driven by the growing realisation that national plans to provide anti-AIDS medication were likely to fail unless more people knew their status.

"It's time to be much more aggressive and normalise it [HIV/AIDS] like any other condition. In a country where almost 40 percent of the population is [estimated to be] HIV positive, and there is therapy available, not offering an HIV test is tantamount to malpractice," Darkoh commented.

Both Darkoh and Molomo noted that with most clinics now testing about 90 percent of their patients, routine testing had significantly increased the number of people knowing their HIV status.

But human rights activists are concerned that the policy could erode the right of patients to withhold their consent, and that without full knowledge of the procedure and its potential impact, they could be coerced.

"The patient is not in charge. This policy does not treat people as right-bearers who can make their own decisions. It's highly unlikely that a patient will be able to tell a doctor that they want to opt out when they want to," Christine Stegling, coordinator of the Botswana Network on Ethics, Law and HIV/AIDS (BONELA), pointed out.

According to Stegling, the policy was still a political decision "without any technical backup" and it remained unclear how health facilities were implementing it. The public remained largely uninformed

about routine testing and some clinics still did not have access to rapid testing kits.

"They are not addressing anything except their technical difficulty of late entry [in the ARV programme] - even then, I'm not sure how this policy is helping," she added.

What the government should be addressing is the fact that the country was missing a legislative framework that would make people comfortable with their HIV status, Stegling said. For example, Botswana does not have any policy on HIV/AIDS discrimination in the workplace.

Healthcare workers were another problem, she noted, as they projected "their own fears about HIV/AIDS onto the patients".

For Stegling, the bottom line is that "at the end of the day, people are scared to get tested, regardless of ARVs".

BONELA will soon be conducting research into whether people who had tested HIV-positive subsequently enrolled in the national ARV initiative. Until now, this had been very difficult to measure, Darkoh admitted.

## DJIBOUTI: Grappling with the demand for ARVs



In July the government of Djibouti - a small country in the Horn of Africa - announced that, with support from the Global Fund to Fight AIDS, Tuberculosis (TB) and Malaria, funding was available to provide ARVs for those in need until 2007.

The fund provided US \$12 million. Omar Ali Ismael, the head of Djibouti's intersectoral technical committee on HIV/AIDS, told PlusNews the government would also improve treatment and care for those living with AIDS, target vulnerable groups through prevention and care, promote civil society involvement, and improve data gathering and surveillance.

Until now, only 200 people had been receiving free ARVs, Omar Ali said, but with the new funding the number would initially be increased to 4,000.

"Everybody in Djibouti, including refugees and legal immigrants who need ARVs, up to 2007 will be able to receive them free," he told PlusNews.

ARVs improve the quality of life for those infected with HIV and can delay death for many years. According to UNAIDS, wide-scale access to ARVs might help reduce the decimation of workforces and the destruction of families seen elsewhere on the African continent.

With an estimated HIV prevalence of three percent, Djibouti could yet become a success in the fight against the virus. Yet benefiting from ARVs is more complex than initially thought, especially when the complicated issues of training and drug supply are taken into account.

People cannot receive the medicines, for example, unless they are diagnosed with the advanced stage

At one stage, Roda, a 24-year-old woman living in Djibouti, had tuberculosis, a skin disorder, and was disfigured with disease. In March she began receiving antiretroviral therapy (ART) and has started leading a more normal life again.

Roda, who declined to give her second name, is among the more fortunate in Africa. According to figures released by the UN World Health Organisation (WHO) in June, just four percent of HIV-positive people on the continent have access to antiretrovirals (ARVs), the drugs that inhibit HIV.

"Despite the subsequent successes of one-after-another, small-scale pilot projects, few countries have managed to deliver HIV treatment to all, or even the majority, of those in need," the WHO report said.



of HIV and can benefit from easy access to medical advice. Of an estimated 9,000 HIV-positive people in Djibouti, just 1,000 are registered with the medical services.

Many people still do not know that they can get a free test, or that they can receive free treatment, Nazer Kibangou, a Congolese expert at the Centre Yonis Toussaint for Sexually Transmitted Infections, told PlusNews.

A March 2002 survey showed that the national HIV-prevalence rate in Djibouti was 2.9 percent - a figure the country's health authorities say is low by African standards.

The research revealed that 90 percent of those infected with HIV lived in the capital and could therefore be reached easily, and women were more affected than men. Still, it also showed that less than half the population knew condom use reduced the risk of infection.

Staff at a local HIV/AIDS organisation, *Oui a la Vie*, in a scruffy side street off Avenue Treize, told PlusNews it took up to four months to persuade somebody to go for a test.

"They don't want to be shocked by a bad result, and they are full of shame," Ali Barkat Moumin, 34, a volunteer nurse at the centre explained.

Roda was diagnosed with HIV two years ago, but still has not told her mother. The family of Mohamed, once a petty trader and now HIV positive, face a similar dilemma, fending off questions from suspicious neighbours in his quarter.

Now that he is taking ARVs he also feels much better,

though he has had to give up both qat (a leaf chewed as a stimulant) and his beloved shisha pipe, which do not mix well with the medicines.

Houmed Ali Ismael, the chief doctor at Djibouti's Paul Faure hospital for TB, thinks the stigma is linked to death and - in a conservative society - the perceived connection to what he calls "sexual vagabondage".

He added that some visitors at his hospital get angry when they are diagnosed with HIV and not tuberculosis - a curable disease.

Slowly, though, the number of tests is rising - the rate increased by 500 percent during the first nine months of this year, compared with the last nine months of 2003, Ismael said.

Kibangou said just 15 percent of HIV tests were positive at the Centre Yonis Toussaint for sexually transmitted infections and the possibility of ART offered even more encouragement. "That is a big source of hope," he noted.

"The problem is that the sick are poor, and it is difficult to treat the poor," said Hawa Hassan, a counsellor for people with HIV. "If they need medicines which are not in the centre, they have to be bought, and if you ask them: 'Do you have money for this?' then they say 'no'."

## LESOTHO: Not enough staff, poor infrastructure, but ART launched



ARV treatment has just begun at Motebang Hospital in Leribe, Lesotho, but resources are scarce. Credit: IRIN

The office of the Lesotho's HIV/AIDS Directorate, on the 6th floor of an office building in downtown Maseru, the capital, has almost none of the amenities of a modern bureaucracy.

The few computers cannot access the Internet; the bathrooms have no toilet paper, soap, or paper towels. Since this division of the Ministry of

Health and Social Welfare was relocated from the 8th floor two months ago, the office has had no telephone

line because the government has not paid the bill.

Lesotho, a landlocked kingdom surrounded by South Africa, has one of the highest HIV prevalence rates in the world, with nearly one in three adults living with the virus. But drugs that can delay the progress of the disease are only now becoming available through government-subsidised programmes, exposing a woefully limited public health infrastructure in the process.

"The main problem is manpower," said Mateboho Liphoto, one of only two registered nurses who run the directorate's clinical services department, overseeing all public medical programmes on HIV/AIDS and sexually transmitted infections in this nation of 1.8 million. "We really, really need human resources."

Health and Social Welfare was relocated from the 8th floor two months ago, the office has had no telephone

By the end of 2005, Lesotho aims to have 28,000 people on antiretroviral therapy (ART). If successful, the endeavour would cover nearly nine percent of the estimated 320,000 HIV-positive Basotho. But this ambitious plan is still in its infancy.

The first treatment centre to deliver low-cost drugs as part of a national rollout strategy, launched in Maseru in May, is funded almost entirely by pharmaceutical giant Bristol-Myers Squibb. The drug company contributed US \$4.5 million to the first three years of the project, on condition that the government takes over the bulk of the costs in 2007.

The Senkatana Centre originally hoped to enrol 400 people in the first year of operation. Yet in just seven months it has put nearly 600 patients on antiretrovirals (ARVs) and is monitoring another 300, who will probably need treatment soon.

"The influx of patients to this clinic has been overwhelming," said Senkatana's project director, Dr Pearl Ntsekhe. "But because of the ever-increasing numbers, it is very hard on our staff - a sort of fatigue is setting in ... the only solution is to add more staff."

This is difficult in much of sub-Saharan Africa, where many trained medical professionals have left in search of higher-paying jobs in the United Kingdom, Australia, the Middle East, and North America.

The government opened the first of its own ARV clinics in November 2004. Two more are scheduled to open early in 2005, with at least another two to follow by the end of the year. Ultimately, the programme plans to open one public ARV distribution centre in each of the nation's 10 districts, located at an established hospital so as to draw on existing staff.

But some officials question whether the government will reach its target of having 5,000 patients on ART nationwide by the end of 2004. "That's essentially impossible," said Dr Limpho Lekona, director of the new ARV treatment clinic at Motebang Hospital in Leribe, 90 km north of Maseru.

The directorate said efforts to reach these targets would likely have a major effect on healthcare workers. Each of the clinics will have a core team of at least one doctor, a nurse, pharmacist, lab technician and professional counsellor. Considering the thousands of potential ARV patients, it's questionable whether the

limited staff will be able to handle the demand.

"In these teams, there's only one doctor - there's no doubt they will be worn out," Liphoto said. "In order to achieve this goal, we need more hands."

Mat'enase T'enase, the other clinical services manager in the directorate, said the government had already ordered more than US \$830,000 worth of ARV drugs for the launch but, in addition to staff and drugs, other resources are critical to making ART a success.

"Even if we were giving out all the doses, the space and the equipment are also problems," T'enase said. "We don't have the computers to keep track of the data."

In the absence of a countrywide treatment programme, some community members are struggling to address the crisis by providing ad-hoc education, counselling and nutrition services on their own.

"Treatment is not widespread," said Bakoena Bernard, a volunteer with Positive Action, the only network of HIV-positive people in Lesotho.

Access needs to be massively expanded and publicised to save those in immediate need of treatment, Bernard said. Despite government pronouncements, programmes have yet to go beyond the planning stages.

"It has become a political issue because the government is paying lip service, to be viewed by the international community that they are doing something," he said. "But on the ground, the question is whether it gets there or not."

At the directorate, Liphoto said none of Lesotho's 22,000 HIV positive children were currently receiving ARV treatment as part of the national rollout, because the kingdom simply does not have the capacity. "There is only one public-sector paediatrician working in the entire country."

## NIGERIA: Restocked rollout expanded



HIV-positive protestors demand sustained funding for ART.  
Credit: IRIN

As Nigeria, faced with one of the world's largest HIV-positive populations, expands its subsidised antiretroviral (ARV) programme, concern is mounting about how funds are being spent.

Two years ago Nigeria launched what, at the time, was a ground-breaking initiative to provide ARV drugs to 15,000 people living with HIV at less than 10 percent of the market price.

But a year later the project ran into difficulties when depleted drug stocks were not replenished and people receiving treatment were given either expired drugs or none at all.

While the 50 treatment centres across Nigeria have since been restocked and the scheme appears to be running smoothly again, fears of similar trip-ups remain strong among people on the treatment programme.

"It is commendable that the government is expanding the treatment programme," Sola Odumosu, an HIV/AIDS activist living with the virus, told PlusNews. "But I just hope they have it all figured out, so that we don't run into scarcities any more."

AIDS has spread steadily in Nigeria. Less than two percent of the population were infected with the HI virus in 1991, but that has risen to more than five percent of the country's 126 million people today.

Babatunde Oshotimehin, chairman of the National Action Committee on AIDS (NACA), said 100,000 people would be enrolled next year in a government scheme providing the ARV drugs that help to prolong life. That represents a six-fold increase on the present number of beneficiaries.

The number of government-run AIDS counselling, testing and treatment centres would double from 50 to 100 in 2005, while a NACA awareness campaign targets 20 to 29 year-olds, who have the country's highest HIV prevalence rate at 5.6 percent, Oshotimehin noted.

With more than six million people infected in Nigeria, health experts fear a three-fold increase in a few years that could cause severe harm to the country's economic and social development.

Some signs of hope have emerged from the last two national AIDS surveys, which showed a drop in the HIV prevalence rate from 5.8 percent in 2002 to 5.0 percent in 2002.

The government is hoping to build on that with a two-

pronged approach of offering help to those infected with the virus, while curbing the rate at which the virus is spreading, Oshotimehin said.

The drive to expand AIDS control activities is being funded largely by a US \$150 million grant from the United States and a \$110 million soft loan from the World Bank.

A World Bank official in Washington told PlusNews that \$16 million of the loan had been drawn down so far. The Bank's programme in Nigeria had recently been entirely restructured to allow the purchase of ARVs in all of Nigeria's 36 states, he added.

The official pointed out that the World Bank loan, denominated in Special Drawing Rights (SDRs) was originally worth just \$90 million, but the dollar's sharp fall against the world's other main currencies had pushed up its value in dollar terms by \$20 million.

The Nigerian government is also expecting \$150 million from the US government's Emergency Plan for AIDS Relief.

"We hope to educate more people, treat more people and generally work to reduce the rate of infection," Oshotimehin told reporters.

More than 700 non-governmental organisations, including faith-based groups, professional associations and networks of people living with HIV, have been enlisted to work with the government to bring a message of care and prevention to the country.

UN agencies, such as the World Health Organisation and the UN Children's Fund, are also helping to influence positive behaviour changes among Nigerians regarding HIV/AIDS.

An HIV/AIDS curriculum for primary and junior secondary schools that is being taught in some schools will be implemented more widely.

NACA is counting on judicious use of the funds from the World Bank and the United States to sustain its campaign to roll back the AIDS pandemic.

But while Oshotimehin expects the foreign aid money to be used wisely, some AIDS activists are less hopeful.

Nsikak Ekpe, president of AIDS Alliance Nigeria, an activist group for people living with AIDS, has expressed fears that many of Nigeria's states were spending their own share of the funds on luxury items, such as flashy cars and big offices, rather than care, support and training aimed at developing a local capacity to deal with the disease.

"The antiretroviral programme in Nigeria is the most

ambitious you can get anywhere," Ekpe told PlusNews. "The only problem is that we have found out that most state governments are playing with the funds and not using them well."

In several states, Ekpe said, the donor money had been used to procure expensive four-wheel drive cars and furnish offices. "This money is for the HIV/AIDS programme, and I don't think that simply means buying jeeps and other expensive goods."

But the World Bank again was reassuring. Nigerian states receiving loans first have to lay out plans, which

are approved by the state and national AIDS committees as well as World Bank experts, the official in Washington said.

"Buying cars and furniture is what people always do first," he told PlusNews by telephone. "But we have seen several of the states start doing some very encouraging work after furnishing the office."

**[Resource:**

- "Scaling Up Antiretroviral Treatment in the Public Sector in Nigeria: A Comprehensive Analysis of Resource Requirements", 2004 - [http://www.phrplus.org/Pubs/Tech037\\_fin.pdf](http://www.phrplus.org/Pubs/Tech037_fin.pdf)]

## SOUTH AFRICA: Lusikisiki - a new model for ARV delivery



Through the Lusikisiki treatment programme, Anoria Samka tells others how her health has improved since taking ARVs. Credit: IRIN

When Anoria Samka's brothers discovered she was HIV positive, they shunned her. But now, when she tells her community that the drugs she takes can stem the progress of the disease, no one ridicules her and no one turns her out. Instead, they listen.

Addressing a hundred men, women and children at the Bodweni clinic in rural South

to promote voluntary counselling and treatment, took place amid the green hills of South Africa's Eastern Cape province, dozens of kilometres from the nearest hospital. Here, in the remote town of Lusikisiki, Samka is one of hundreds of people being treated for HIV, in what has been celebrated as a new model for ARV delivery in resource-limited rural areas.

Launched in October 2003, the programme was designed by Medecins Sans Frontieres (MSF), a humanitarian medical organisation, and implemented in partnership with the local department of health. Unlike many ARV distribution programmes, which tend to be centralised at hospitals, this system delivers most of its services via a network of 11 clinics spread across the countryside.

"The model was to deliver ARVs as close as possible to the home, not to require patients travel to a hospital in a city," says Dr Hermann Reuter, MSF's project coordinator at Lusikisiki.

So far, the Lusikisiki programme has exceeded enrolment expectations, starting a total of 442 residents on ARV treatment in its first year of operation, ahead of its original target of 300. While this is still shy of the roughly 1,500 people that MSF estimates are in immediate need of treatment in the area, the community-based approach could prove to be a successful model for delivering ARVs in poor, underdeveloped communities throughout sub-Saharan Africa.

As in much of the continent, the public health system in South Africa is already debilitated by a significant shortage of resources and medical staff. The Lusikisiki programme is no different: staff say the programme could use an infusion of additional resources, includ-

Africa, Samka says she was very weak before beginning antiretroviral (ARV) treatment in February 2004. Her CD4 count - a measure of the immune system's strength - was only 158. The audience nods solemnly. Many are wearing T-shirts that say: 'HIV positive', and are already aware that a CD4 level below 200 means a patient is at risk of serious opportunistic infections and death.

After receiving ARV treatment for 10 months, Samka says, she is strong and healthy again. "Today, my CD4 count is 421."

Applause and cheers of support erupt from the audience. Then a woman stands up and spontaneously begins the first words of a song, and soon dozens of people join in the traditional melody whose modern lyrics call attention to the epidemic: "It is terrible because we are dying of AIDS."

The gathering, part of the Bodweni clinic's campaign



ing a car to transport patients, and another 50 nurses.

The novelty of the Lusikisiki approach is that it depends on community members to orchestrate the peer counselling and weekly support groups that are the backbone of the programme. At the heart of the model are dozens of volunteers, often HIV positive themselves, who have been trained by their support group.

These volunteers publicly declare their HIV status and attempt to educate community members about HIV prevention, testing, nutrition, and treatment. Reuter believes they are a fundamental reason for the programme's success: "The project is working because of the non-professional staff."

While there is a risk of burnout, many volunteer community health workers are motivated to act because they are living with HIV, and can see the visible improvement of those on ARVs.

"This epidemic is so big, and so many families are affected, people see that they are doing it for the community," Reuter said. "And the model that we are implementing - it's not just a medical model; it's a model for human rights, and ARVs as a part of human rights."

Dr Eric Goemaere, the head of MSF in South Africa, says the agency began the programme in Lusikisiki to build on its experience of delivering ARVs in Kayelitsha township near Cape Town. The Lusikisiki initiative was an effort to transfer the successes of its programme in a resource-limited urban environment to a resource-limited rural setting.

"We went to the most underdeveloped, most remote part of South Africa - Lusikisiki," said Goemaere. "If it works in Lusikisiki, it can work anywhere in South Africa."

Goemaere says the Lusikisiki programme, funded in part by the Nelson Mandela Foundation, expanded "much faster" than MSF originally anticipated and now services between 30 percent and 40 percent of all publicly funded ARV cases in the entire Eastern Cape province.

"People are rushing for treatment," he says. "What Lusikisiki tells us is that when service is available, even in the most remote area, people are queuing for it."

Sarah Mahlangeni, the only professional nurse at the Bodweni clinic, agrees: 23 of the clinic's 340 patients, known to be HIV positive, are currently receiving treatment, and there has been a significant change since the facility began dispensing ARVs in February 2004. Scores of people are now voluntarily requesting to be tested so they can begin treatment as soon as it becomes necessary.

A public demand for testing and treatment is notable in South Africa, where stigma against HIV/AIDS often hampers efforts to educate and treat the more than one in five adults estimated to have the virus. In many communities people say they do not publicly declare their HIV-positive status because they are afraid of being shunned by friends and family.

Nosipho Sivela, an ARV counsellor at the Bodweni clinic, says stigma regarding HIV/AIDS has been largely eradicated in the surrounding rural area because those on ARVs regularly stand up in front of others and explain how their health has improved with treatment.

"It's because they trust the ARVs," Sivela says. "They believe that if they know their status, they know how to live with their HIV. It makes them confident because they know that they'll stay alive for a long time."

For Samka, who was abandoned by her brothers when they found out she was HIV positive, the sense of belonging is the most important part of her treatment. Four times a month she makes the 90-minute walk from her village of Mxokozweni to receive her medication and attend a support group, which she calls her "favourite thing" about being involved with the clinic.

"The support group taught me that now I can educate people about HIV anywhere," she says. "Now, I'm a living example. When I talk, I can share things that I've experienced."

## SOUTH AFRICA: Rollout bogs down



Rollout bureaucracy: ART is not just about drugs, but personnel and the health infrastructure.  
Credit: IRIN

One year after the South African government launched its much-anticipated HIV/AIDS treatment programme, there is frustration at the slowness with which the plan is being realised.

In November 2003 the government committed to providing free antiretroviral (ARV) treatment to 53,000 patients by March 2004. The figure is a fraction of South Africa's HIV positive

population, estimated at over five million, but was nevertheless an ambitious beginning to what was to be the world's largest ARV rollout to date.

That target date has since been moved forward a year, and by the end of November 2004 the number of patients receiving the life-prolonging drugs was estimated by the Joint Civil Society Monitoring Forum to be 18,500.

### Call for leadership

The department has attributed the disappointing pace of ARV rollout to a lack of capacity and trained staff at treatment sites, especially in poorer provinces. But leading AIDS activist and outspoken chairperson for the Treatment Action Campaign (TAC), Zackie Achmat, is convinced that the slow pace is less the result of a lack of resources or capacity, than a lack of political leadership stemming from the government's "denialism".

"There are enormous challenges in terms of human resources, but those will never be sorted out without political leadership," he said.

Achmat was speaking at a TAC event in Pretoria in November 2004, aimed at pressuring the government into making public an implementation timetable for its treatment plan that would make the health department more accountable. It is unclear whether such a timetable exists. In its weekly online newsletter, the government responded that TAC was in fact hampering the rollout by wasting officials' time, which could be better spent "at the forefront of service delivery".

The ANC conceded in its newsletter that the process of selecting a manufacturer to provide ARV drugs for the rollout was yet to be finalised. The tender should have been completed by June, and Andrew Boule of the School of Public Health and Family Medicine at the University of Cape Town was not alone in suggesting that the delay had been a factor in limiting patients' access to treatment.

"For the provinces that are weaker, the delay in finalising the tender has been a barrier to getting started because they've deferred setting up their own procurement mechanisms," Boule commented.

Even in the relatively well-resourced urban province of Gauteng, which has made impressive strides with its rollout and is expected to meet its patient targets, the numbers of people awaiting treatment are stretching hospitals to their limits.

Johannesburg General Hospital was among the large inner-city hospitals at the forefront of Gauteng's rollout launch in April. Professor Jeff Wing, who oversees the clinic, said the hospital had been able to halve its waiting list from six to three months since April because, unlike many hospitals, it was well staffed and had a dedicated ward for the clinic.

Despite this, he added, "there's this backlog of patients. I don't know the numbers but it must be millions, so even if we were able to work 24 hours a day, seven days a week, we'd still have a waiting list."

### Good and bad

With its spacious ward devoted solely to antiretroviral therapy (ART), its full-time team of 15 doctors, six nurses and 10 counsellors, and its steady increase in patient numbers since April, Johannesburg General could deservedly be called a model example of how effectively ART can be administered to large numbers of patients.

But then there are facilities like the one at Natalspruit Hospital.

The antiretroviral clinic at Natalspruit services a large area that includes several former townships south of Johannesburg. When it was launched in late July as part of Gauteng's second wave of treatment sites, there was little infrastructure in place to handle the immediate demand for ART.

Four months later, little has changed. Only 180 patients are receiving ARV drugs, compared to Johannesburg General's 1,000, and the clinic is still housed in the small prefabricated structure without air-conditioning that it shares with the hospital's social work department, where the corridor is too narrow to roll a stretcher down.

The lack of space is compounded by a lack of full-time staff: the two doctors, three nurses and one pharmacist at Natalspruit who have received training in ART have to divide their time between the clinic and their responsibilities in other departments. Even the clinic's project manager, Sister Mavis Ngwenya, spends a good portion of her day crisscrossing the hospital grounds between the clinic and the outpatients' ward, which she also manages.

By 3.00 pm on a Tuesday, the one day a doctor is available to prescribe ARV drugs to adults, Ngwenya looks exhausted.

"You feel like not coming back tomorrow," she said, mopping perspiration from her brow with a handkerchief. "It's too much load on one person."

The provincial department of health has so far not made good on its promise to hire additional doctors and nurses. Overworked and overwhelmed by the numbers of patients trying to access treatment, Ngwenya fears that her staff are starting to lose the passion and enthusiasm needed for such work.

Dr Tolela Kitoko, who oversees paediatric treatment at the clinic, shares her concerns.

"There's a need for us to see more patients but, because of our staff, we're limited. We're seeing a small percentage of the people that should be seen. We'd like to have more doctors and nurses on a permanent basis, and a full-time pharmacist, so we could run the clinic more than once a week," he said.

A spokesperson for Gauteng's department of health, Simon Zwane, said his department had made no secret of its recruiting difficulties.

"There is a problem with recruitment that the country as a whole is facing. We're not getting enough applicants, especially for hospitals like Natalspruit that are in township areas."

The national department of health was working towards a programme to train more health workers to administer ARV treatment but, according to Fatima Hassan of the AIDS Law Project, the programme was several months away from being finalised, with no

interim plan in place.

Zwane said Gauteng had managed to recruit 70 per cent of the 214 additional staff needed to implement its rollout through head-hunting, increased pay scales and rural allowances. He denied that any of the 19 facilities currently offering ART in the province had the long waiting lists reported by groups like the AIDS Law Project.

Indeed, despite its lack of space and manpower, the clinic at Natalspruit had so far avoided having to turn patients away. Most patients who qualified for treatment completed their four adherence counselling sessions and began receiving the drugs within two months. Dangerously ill patients could begin treatment in two to three weeks.

But the number of patients arriving at the clinic was increasing weekly, Kitoko said, and without more trained staff, there was a limit to how many could be treated. Meanwhile, follow-up support from the health department had dwindled.

"Initially, when we went through the training course in July, they were very supportive," Kitoko said, "but now we feel like it's losing steam a bit; we feel like we're left on our own."

"They call to get statistics, but they don't come to see for themselves," Ngwenya agreed. "If only they could hire us to work here Monday to Friday full-time, and hire two full-time doctors, we could give ARV treatment five days a week."

#### [Resource:

-Treatment Action Campaign - <http://www.tac.org.za>]

## UGANDA: PLWAs at the centre of AIDS response



Lydia Mungherere speaks with passion about the need for antiretrovirals (ARVs), not only because she is a doctor - the first in Uganda to disclose being HIV positive - but also because she would be dead today if it weren't for the drugs.

In 1999, sick and unconscious, Mungherere was flown home from South Africa where she was working. ARVs pulled her back from the brink of death.

Today Mungherere is a representative of the National Forum of Networks of People Living with HIV/AIDS in Uganda, lobbying MPs and government officials to bring the perspective of people living with the disease into policy issues.

For example, in 2002, when the Uganda AIDS Commission was drafting a national policy on antiretroviral therapy (ART), it asked key stakeholders to review the draft. Among them were people living with HIV/AIDS (PLWAs).

At the time, some 10,000 Ugandans were on ART. The target is to have 60,000 by the end of 2005.

"We made the government realise that to do community mobilisation around treatment, you need us, people with AIDS, to talk to people, to help them with disclosure and treatment compliance," recalled Mungherere.

Because of their lobbying, the policy put PLWAs at the centre of community mobilisation and advocacy around ART. Today, as Uganda scales up treatment, the ministry of health has the Forum as its partner to help people access and adhere to treatment.

Uganda is perhaps the only African country where HIV-positive activists operate at such a high decision-making level in the structures that shape AIDS policy. "It is revolutionary to have people with AIDS at the same level as other stakeholders," said Inge Tack, UNAIDS technical adviser in the capital, Kampala.

This is not surprising - the movement of people living with AIDS in Uganda has a 17-year history of collective organisation and effective activism.

In the late 1980s, when AIDS was taboo in other African countries, several prominent Ugandans disclosed their status in public: a popular musician, an army major and an Anglican priest were among the first. Their testimonies, and those of hundreds of lesser-known Ugandans, helped reduce stigma and discrimination.

Uniquely, Uganda has reversed its AIDS epidemic. HIV prevalence among its 24 million people - over 20 percent in 1992 - has dropped to 6 percent, according to UNAIDS.

Uganda's success is credited to its early, bold and homegrown response; strong and sustained political leadership; openness about the problem; a multi-sectoral approach, and, crucially, the involvement of many actors.

"The government mobilised a lot of players and created an enabling environment for them to operate," said Dr Alex Coutinho, executive secretary of The AIDS Support Organisation (TASO), which, to date, has helped 60,000 PLWAs and their families.

TASO, the first indigenous African group formed by people infected and affected, was set up in 1987, a year after the end of Uganda's brutal civil war. TASO broke new ground in counselling, medical care, social support, training of counsellors, community workers and care providers, advocacy and networking. Its approach has been replicated within and outside the country.

Other PLWA organisations followed, each empowering a different constituency: women, youth, rural and urban, Muslims and Christians. Many of these groups became pivotal players in the national response and role models for similar groups throughout Africa.

As the networks of people living with AIDS multi-

plied, their ability to reach communities became crucial, especially when Uganda decentralised its AIDS response in 1997. Today, at district AIDS task forces and committees, local activists act as advocates, watchdogs and community liaison.

The associations nurtured a significant number of HIV-positive activists, knowledgeable about the evolving science, economics and politics of AIDS, which enabled them to work on all sides of the spectrum: engaging with experts and authorities on policy issues, and with ordinary people in prevention, behaviour change, care, treatment and rights.

One thing was missing, though - a national network. Rivalry, notably between the National Guidance and Empowerment Network (NGEN+) and the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) thwarted attempts at forming a national organisation.

"The scramble for resources led to fragmentation and competition," Major Rubamira Ruranga, head of NGEN+, told PlusNews.

In 2001 the Uganda AIDS Commission (UAC) restructured the response and placed PLWAs in a position to influence policy. The new structure, known as the AIDS Partnership, allowed members to find common positions and elect representatives to interact with UAC.

In May 2003, delegates from 50 main groups founded the Forum. Today it includes 800 associations, from big, professional NGOs to small village support groups.

"The Forum is the channel for our voices to come through - now we have representation at district, county and parish level," explained Augustine Kishangeaki, coordinator of the Bushenyi District Network of HIV+ People (BUDNET+) in Western Uganda.

The Forum operates at many levels: people like Dr Mungherere work the corridors of power; others in far-flung communities, like Bushenyi, do prevention and treatment literacy, and care for orphans and the sick; Forum representatives sit on local district AIDS Committees and can influence planning and channel funds to PLWA groups.

For example, in its first year, BUDNET+ accessed funds through the district to rent an office and acquire a computer, printer and motorbike. The network offers counselling on positive living and treatment adherence; AIDS prevention through drama and music; home-based care; and training in goat and pig raising, beekeeping and kitchen gardens for income-generation.

Uganda has realised that the scale of activity needed to fight AIDS is too vast for government alone, and PLWA activists are an asset to the national response.



## 3. Access

### AFRICA: Treatment criteria - deciding who gets to live



Ugandan Augustine Kishangaki visits Ely Tumusine, a nurse and HIV-positive activist who just recently started on ARV's after being very ill.  
Credit: IRIN

Every Saturday a bus brings prisoners under armed escort to a clinic in Machava, on the outskirts of the Mozambican capital, Maputo, to get their antiretroviral (ARV) pills.

The clinic, run by the Italian Catholic charity, Santo Egidio, treats 2,500 patients, among them 100 inmates from the local jail.

This has caused friction between the charity and the ministry of health, which has complained that it was not informed of the decision to treat prisoners. Santo Egidio has responded that it was up to the department of correctional services to inform the ministry.

But the real issue at stake is: when the need for antiretroviral therapy (ART) exceeds supply, which patients have priority?

The problem arises because Mozambique has not developed national criteria for patient selection: in their absence, non-government ART providers can make their own choices.

The medical criteria to start treatment - a CD4 count under 200 or stage III/IV of AIDS - are defined by the World Health Organisation, but additional social criteria can vary widely.

The Santo Egidio clinic employs one yardstick, and that is geographical - it will treat any patient in its catchment area. As a Catholic institution, Santo Egidio "places central importance on each and every life", according to its booklet, 'Dream: Treating AIDS in Africa'.

"Every sick person deserves treatment," said Dr Noorjehan Abdul Magid, who works at the Machava clinic. The booklet, however, mentions "priority-setting" for pregnant women, single mothers, teachers and health workers.

The Mozambican networks of people living with HIV/AIDS argue that inmates are unable to live healthy lives and support treatment with good nutrition, exercise, and safe sex, given the prevalence of unprotected anal sex in jail.

"With our scarce resources, it would be better to treat those who have support for compliance from family and associations of HIV-positive people," said Julio Mujojo, executive secretary of the National Network of Associations of People Living with HIV/AIDS.

#### Who comes first?

Social criteria for patient selection in resource-poor settings differ greatly. Botswana, which provides universal free ART through its public health service, prioritises patients with TB, pregnant women, and their children and spouses.

In Uganda it took long debates for members of The AIDS Support Organisation (TASO) to agree that, after medical criteria, seniority of membership would count. TASO, a model support group for HIV-positive people founded in 1987, has 30,000 clients and will start ART in 2005.

At the Medecins Sans Frontieres (MSF) AIDS programme in Khayelitsha, South Africa, a committee comprising health professionals, social workers and representatives of people living with AIDS and the community assesses a number of criteria: residence in the catchment area, regular attendance at the clinic for three months, number of dependents, health and income.

A clinic worker visits the prospective patient at home to check residential stability, alcohol abuse, family support, ability to disclose to at least one family member, and preferably to live openly with HIV, and the degree of community activism.

"Patient selection potentially challenges equity in the delivery of services and, therefore, requires clearly defined and transparent procedures," said an MSF study on Khayelitsha.

#### Gender

Gender disparities also determine who gets treated. The experience in several African countries shows that when treatment is free, more women and children access it. When there is co-payment, however small, men are the majority of patients.

On average, in free ART programmes, 60 percent of the patients are women, 10 percent are children, and 30 percent men. When co-payment is involved, 60 percent are men and 40 percent women.

"In ART, gender should be a constant preoccupation, an obsession," the UN Special Envoy for HIV/AIDS in Africa, Stephen Lewis, told PlusNews.

Abundant literature also documents the plight and vulnerability of widows: dispossession of home, land and children, ritual cleansing and poverty.

Polygamy is another tricky issue. "If only two adults per family can be treated, who has priority - the senior or the junior wife?" asked Florence Mahoro, an HIV-posi-

tive activist at a Parliamentary Forum on HIV/AIDS in Kampala, Uganda, earlier this year.

## HIV-Positive activists

HIV-positive activists often seek preference as a reward for their contribution to the fight against AIDS.

Mali and other West African countries grant fee waivers for ART to activists who disclose their HIV status in public as part of AIDS prevention and de-stigmatisation efforts. Associations of people living with HIV/AIDS see an influx of new members seeking treatment as a result.

In her study, 'Equity in Access to AIDS Treatment in Africa: Pitfalls Among Achievements', author Aline Desclaux wonders if "public disclosure is not a second payment to access treatment, and a form of confession of having a disease still frowned upon."

But rewarding activists reinforces their key roll in treatment programmes, and helps them gain social acceptance. The drawbacks, observers note, can involve power struggles and conflict within organisations.

"It's a terrible position to decide who lives and who dies, and we should leave it to doctors, who make those decisions daily in operations," said Dr Francis Omaswa, director of health at Uganda's ministry of health.

The networks of people living with AIDS in Uganda disagree. They want to be represented in patient selection committees in hospitals, and they want activists to have preference.

"We give a lot back to society," noted Musisi Josephus Gavah, coordinator of the Mukono District Network of People Living with HIV/AIDS (Mudinet) in central Uganda.

Mudinet has 600 members and is a force for community health and welfare in the district. It offers counselling, AIDS prevention, home-based care and treatment adherence; hands out condoms and mosquito nets for malaria control; provides uniforms, school fees and support to orphans; training in making wills and economic planning, and has 50 groups in income-generation schemes.

## Co-payment

Some West African countries require a co-payment for ART proportional to the patient's resources. Senegal, which started Africa's first public treatment programme in 1997, experimented with sliding fees but dropped them in 2001 because the sums collected represented only 12 percent of the costs incurred by the state, and processing the fees was expensive and cumbersome.

Furthermore, studies have shown that co-payment reduced adherence and increased the number of

dropouts. The best adherence rates were recorded among patients treated free of charge, and surveys in Burkina Faso and South Africa have shown similar results.

"In Africa, neither patients nor their families can afford this cost," said Dr Bernard Taverne, medical anthropologist at the Institute for Research on Development in Dakar, Senegal.

If ART becomes a financial burden to patients, the risk is that they will abandon treatment - potentially generating drug resistance - or turn to the informal market for ARVs, traditional medicine and non-approved drugs, or migrate to neighbouring countries offering cheaper ART.

This conclusion led a coalition of relief and development agencies to launch an international campaign in November 2004, called Freeby5, urging all ART-related costs to be free to all patients. (<http://www.heard.org.za>)

"User fees are barriers to equity, efficiency and quality in AIDS treatment," said the campaign's manifesto.

In Mali, Senegal, Burkina Faso and Cote d'Ivoire, ART schemes grant fee exemptions or reductions to certain individuals or groups, such as health professionals, children, HIV-positive activists, patients previously included in research programmes, widows, orphans, pregnant women, retired or destitute persons, and students.

The logic is based on merit, social productivity, dependency, ability to pay, and ethics in research programmes.

The decision-making process includes consensus among programme supervisors, political decisions by health experts, examination of individual situations by multidisciplinary committees, and pre-selection by health professionals, social workers or associations of HIV-positive people.

What emerges from experience and in the literature is the need for checks and balances - otherwise, ART will reproduce existing inequalities, where people with connections have access.

A case in point is Angola, where the state provides free ARVs to 2,000 patients. Since the programme is government-funded, with no external donors, the selection process is less than transparent.

"There are no controls whatsoever in this programme," Rafael Marques, country director of the Open Society in Angola, told PlusNews.

As ART expands in Africa, there will be difficult choices about who gets access to life-saving services, and why. The critical issue of eligibility needs ample discussion among all stakeholders.

"Human rights, law and ethics provide guidance to expanding services in a just and equitable manner," concluded a study by the UN-appointed Commission on HIV/AIDS and Governance in Africa.

## MOZAMBIQUE: People living with AIDS overlooked in response



Activist Honoria Pinto Folano advises patients at the Santo Egidio clinic on nutrition and positive living.  
Credit: IRIN

At a journalism course in Mozambique in 2001, it was hard to find an HIV-positive person to talk to the reporters, and he did so on condition of anonymity. Two years later there were 30 willing to talk, and they gave their names.

From a handful of courageous individuals who went public about their HIV status in 1999 in the capital, Maputo, there is now a nationwide network of 28 associations of people living with HIV and AIDS (PLWAs).

Yet stigma and discrimination persist. Ana Maria Muhai, a community activist with the Santo Egidio clinic at Machava on the outskirts of the capital, tells of sick neighbours who are too ashamed to seek help.

"They don't come out of their homes; they don't go to the clinic, and they die right there," she said.

Muhai, who is HIV positive, was frequently sick from 1998 until she started antiretroviral therapy (ART) in 2002. Her mother and the local schoolteacher helped, but street vendors, afraid of catching the virus, would not take money from her children.

"Stigma is a wall nobody can jump - people look at you like you are an alien," said Julio Mujojo, executive secretary of the National Network of Associations of People Living with HIV/AIDS (Rensida).

Rensida, set up in 2002, has roughly 1,000 members. As the representative of Mozambican PLWAs, it is a partner of the ministry of health, and about a dozen members have been trained and hired as counsellors.

The two largest providers of ART, Medecins Sans Frontieres-Switzerland and the Vatican-linked Santo Egidio, employ HIV-positive activists from the community to identify, support and monitor patients on treatment, and encourage positive living.

"Local people understand the mentality and the culture," explained Gabriella Bortolot, a coordinator at Santo Egidio.

But the evidence from other African countries sug-

gests a lot more could be done by PLWAs in Mozambique. It is widely recognised that HIV-positive people are key to containing the epidemic and caring for those infected.

The greater involvement of people living with HIV/AIDS in anti-AIDS efforts, also known as the GIPA principle, was endorsed by 42 countries at the 1994 AIDS summit in Paris, and reinforced by the United Nations Declaration of Commitment on HIV/AIDS in 2001.

UNAIDS charts the extent of GIPA in a six-tier pyramid that ranks, in ascending order, target audiences or beneficiaries, contributors, speakers, implementers, experts and, at the top, decision-makers. Analysts put Rensida's involvement at the middle level of the pyramid, among the speakers and implementers.

"We attend meetings, we listen more than we speak, and we have little influence," said Arlindo Fernandes, a founding member of Kindlimuka, the first association of PLWAs, which now has 370 members.

Elsewhere in Africa, people living with AIDS are central to the national AIDS response.

In Botswana, the Coping Centre for People Living with HIV/AIDS (Cocepwa) trains members as 'treatment buddies', who help others on antiretroviral drugs with disclosure and adherence. Counselling centres and hospitals refer HIV-positive people to Cocepwa.

In Zambia, teams from the national network of HIV-positive people run workshops on positive living and human rights for groups of PLWAs.

In Burundi, between 1999 and 2000, HIV-positive associations successfully lobbied the government to remove taxes on AIDS drugs, allow the import of generics, and set up a national fund to subsidise treatment through the healthcare schemes of public servants and the armed forces.

When PLWAs become partners in their own treatment, and informed users of healthcare, they develop valuable expertise that can complement that of professionals in their communities.

"Where others handle with fear, we handle with care," explained Musisi Josephus Gavah, an HIV-positive activist in Jinja, Uganda.

Public visibility of people with AIDS has marked a turning point in controlling the epidemic. Their testimonies have been a powerful way to make AIDS real, lend credibility to prevention messages, and turn denial into action.

Because of stigma, very few middle-class, let alone prominent, Mozambicans have come out in public. This hampers the ability of Rensida to be a strong actor, lobbyist and watchdog.

However, through workshops and exchange visits, the Brazilian-funded project 'Npwanano' (integration, in the Shangaan language), is strengthening the lobbying skills of Rensida activists, and expanding not only their knowledge of human rights, but also the science, economics and politics of AIDS.

"We have lots of experience in NGO participation in policy-making, lobbying, and supporting the 145,000 patients on ART in the public sector," said Brazilian project coordinator Fernando Sessner.

Rensida needs such skills to claim its rightful space at the decision-making level.

## SENEGAL: Free ARVs not enough to ensure access



Research in Senegal shows the main reason patients were not adherent was that financial problems led to treatment interruptions.  
Credit: Bristol-Myers Squibb

Although Senegal provides antiretroviral (ARV) drugs free of charge to people living with AIDS, health workers say this simply is not enough to ensure proper access.

Bernard Taverne, who heads the ARV programme at the French Development Research Institute (IRD) in the capital, Dakar, told PlusNews that free ARVs without free screening was a catch-22 situation, as the cost of the laboratory tests - from blood to x-rays - that determine whether a person will receive the drugs, was too expensive for most people.

"This is a major obstacle to ARV access," said Taverne. "Some patients, who could have access to free ARVs, can't afford the preliminary tests or the drugs to treat opportunistic infections, and die as a consequence."

Taverne is one of the authors of the "Free by 5" declaration (free access to a minimum medical package, including ARVs, by 2005), issued on 10 December 2004 to mark the end of World AIDS Week. Its backers say a new global strategy is needed to support HIV positive people. [<http://www.ukzn.ac.za>]

"We believe that a prerequisite for ensuring that treatment programmes are scaled up, equitable and efficient, and provide quality care, is to implement universally free access to a minimum medical package, including ARVs, through the public healthcare system," the declaration reads.

Senegal was the first country in Africa to introduce ARV treatment, and 2,700 people are receiving

drugs free of charge under the programme known as ISAARV, which has won international praise. But the World Health Organisation estimates that 12,000 people - more than three times as many - need ARVs.

A study, quoted by the Free by 5 campaign, found that when the cost of drugs for opportunistic infections, laboratory exams, consultations and hospitalisation fees are calculated, patients on ARVs in Senegal pay an additional \$130 a year - a significant amount for the majority of people who live on less than a dollar a day.

"Research in Senegal shows the main reason patients were not adherent was that financial problems led to treatment interruptions," the Free by 5 declaration noted.

"The biggest and most recurrent problem is the failure to provide free biological tests," said Seynabou Mbodj, spokesman for a non-governmental organisation, the National Alliance Against AIDS (ANCS).

"It's all very well handing out free drugs - now we need to provide free tests and free treatment for opportunistic illnesses," he said.

Senegal's last available national survey, carried out in 2003 among high-risk populations in 12 sentinel surveillance sites, showed 93,000 people infected with HIV, with more than 150,000 expected to be HIV-positive in 2010. The Muslim country has a prevalence rate of 1.5 percent - one of the lowest in Africa.



## SOUTH AFRICA: Poverty, stigma and ignorance blights ART



Two years ago Judith Nkambule (not her real name) gave birth to baby girl, but something was wrong - the child was sickly, vomiting, had diarrhoea, and eventually died.

This year, when she fell pregnant with her youngest child, the fifth of five sons, she agreed to be tested.

"I found out I have HIV in February, and my son was born in May," said Nkambule, 32, who lives in the Nancefield township of Musina in Limpopo Province, South Africa.

A predominantly rural province, Limpopo is plagued by poverty, drought and inadequate access to basic services. Primary healthcare use is very low and the HIV/AIDS programme is trailing other provinces. The provincial government spends only 16 percent of its budget on health, in contrast to an average of 22 percent in other provinces.

More than one in five South African adults - an estimated 5.3 million people - are infected with HIV, according to 2003 data from the World Health Organization and UNAIDS. The majority of those infected, about 2.9 million, are adult women.

Like the vast majority of HIV-positive South Africans, Nkambule is not on antiretroviral treatment (ARVs), the drugs that can significantly prolong the lifespan of those living with the disease. In fact, she didn't know medicine for HIV-positive people existed.

"If the doctor gives it to me, I won't have a problem taking it," said Nkambule, who has not told anyone other than her husband she is HIV positive. "I never tell anyone because, here in Musina, all the people are scared of you [if you are positive]."

A lack of popular education about HIV/AIDS persists in Limpopo, where government-funded ARVs are only now becoming available. Nkambule, a poor woman burdened by rampant societal stigmas about the disease, is the one who will suffer, lost in the chasm between the South African government's strategy to treat AIDS and the reality of people living with it.

Nationwide, the number of individuals on state-sponsored treatment is miniscule. According to a consortium of civil society associations, including the relief agency, Medecins Sans Frontieres, only 18,500 individuals were receiving ARV treatment at public facilities as of November 2004.

This number is well short of the Department of Health's original goal of enrolling 53,000 South Africans in state-sponsored ARV treatment programmes by March 2004. With such low figures, the deadline for meeting national and provincial targets has been pushed forward to March 2005.

### The curse of stigma

In Limpopo, where the public treatment programme was only launched in August this year, the Department of Health's plan calls for 6,965 individuals to be on ARVs by March 2005.

But so far only around 130 people are receiving treatment, according to Phuti Seloba, spokesperson for the provincial Department of Health and Welfare.

Seloba said he believed the province would meet the March enrolment goal, but the primary obstacle to the government-sponsored ARV plan was finding qualified candidates.

Stigma was one of the factors preventing patients from sticking to the treatment plan. The provincial department screened prospective recipients to determine whether the neediest applicants would adhere strictly to the drug regimen, Seloba explained.

"For ARV treatment you need a lot of people to come out and speak of their condition, because when they go home they need a big support system," he said, pointing out that it was crucial that, once enrolled in an ARV program, patients had to take the drugs consistently or risk becoming fatally ill.

Seloba said some applicants were not enrolled because they were considered too likely to abandon the programme, but noted that the province had the ability to deliver services to those who qualified.

"The low numbers have no relationship with our capacity to deliver service, it only has to do with people not coming forward," Seloba commented, adding that the province effectively had no waiting lists for treatment.

Since the start of Limpopo's treatment rollout, according to the hospital's coordinator of HIV/AIDS treatment, Elizabeth Tshidzumba, around 40 adults and one child have been put on ARVs at Siloam Hospital in Makhado, one of Limpopo's eight accredited treatment sites.

About 20 people were currently on a waiting list for treatment at the site, she said, and would soon be visited at home, "to make sure they can go through with the [programme], not just theoretically, but practically."

Oupa Fazi, provincial organiser of the Treatment



Action Campaign (TAC), a South African AIDS activist organisation pushing for greater access to treatment, said the government was in part responsible for the very stigmatisation it claimed was hindering its programme.

"The thing is a lack of understanding of issues here in Limpopo," Fazi said. "You are finding people being stigmatised because there is not more information being distributed to our communities."

Proceeding at the current pace, Fazi said, meant it would be impossible for Limpopo to reach its goal of 6,965 people on ARV treatment by March 2005. "I don't think Limpopo will meet even a quarter of that target."

Outside a health clinic in Musina, 46-year-old Maria Delekisa said the community knew many of its residents are HIV positive, but shunned those who publicly admitted to living with the virus.

"In this community, people are scared and don't want to talk about it," remarked Delekisa, who lives in nearby Mushongoville. "If you go to approach someone who is sick, they will refuse, and say, 'I'm not HIV positive, I'm diabetic', or something like that. Once you tell someone you are HIV positive, you have lost all of your friends and family."

## SOUTH AFRICA: The two sides of workplace HIV/AIDS treatment programmes



Derrick Khathi - battling with his employer for HIV/AIDS treatment.  
Credit: IRIN

The fear of stigma and discrimination is preventing many HIV-positive employees from accessing workplace care and treatment programmes.

Vodacom, one of South Africa's most lucrative mobile phone companies, has put in place care programmes, but few workers are willing to access the freely available treatment.

According to Mark de Clark, an administrative coordinator at Vodacom, the company has some of the most comprehensive AIDS treatment programmes in the country, second only to that of mining giant Anglo-American.

"Employees seeking to determine their HIV status need only present positive identification and a letter of employment at any laboratory, or make use of the mobile voluntary counselling and testing (VCT) facilities, available at the company's premises at least once a week," De Clark told PlusNews.

Should an employee test HIV positive, the workplace programme covers basic lifestyle and health management, antiretroviral (ARV) therapy, and treatment for any opportunistic infection accompanying the virus, such as tuberculosis (TB), pneumonia and diarrhoea.

Delivery of medication has been contracted to a chronic drugs courier, Direct Medicines, as part of maintaining the programme's confidentiality clause.

### 'Arrogance of management'

HIV-positive workers are entitled to fortnightly visits to any private physician to check their viral load and CD4 counts (a gauge of the strength of the immune system), to determine how well they are doing on prescribed medication.

"Over and above these benefits, staff and family members have access to an HIV/AIDS helpline, where trained staff offer counselling and practical advice on all aspects of disease management, from identifying drug side effects and opportunistic infection symptoms, to coping with stigma, discrimination and disclosure. Family members are also provided with post-exposure prophylactic treatment in the event of accidental exposure," said De Clark.

Despite this costly intervention, De Clark is one of only three known HIV-positive Vodacom employees making use of the life-prolonging treatment benefits.

Having counselled many of his colleagues, he blames their reluctance to get tested on the "arrogance of management".

"While enough has been done, by the book, to encourage VCT and the promotion of the AIDS management programme, top-level executives still believe they are not susceptible to HIV infection. This is a mild form of discrimination that encourages the stigma, which leads to employees at all levels unnecessarily succumbing to HIV and, ultimately, AIDS-related illnesses," De Clark said.

He warned that unless senior staff became more involved by acknowledging that the virus affects all aspects of the corporate sector, even elaborate programmes, such as Vodacom's, would have no effect.

Coupled with the financial losses due to AID-related staff sick leave, and an eventually diminished workforce, HIV/AIDS could have a devastating impact not only on business, but also on South Africa's economy.

De Clark's sentiments are not uniquely South African; they are shared by the World Economic Forum (WEF) in their 2003-04 report, 'Business and HIV/AIDS: Who me?', which covers 103 economies and provides the first global survey of business leaders' perceptions of the impact of HIV/AIDS and their responses to the pandemic.

Jointly undertaken by UNAIDS and the Harvard School of Public Health, the WEF study found that few companies had an HIV policy, most discriminated against those who were HIV positive, and believed their policies and responses were satisfactory.

According to the research, less than 6 percent of companies provided ARV drugs to their employees, and only 15 percent had a policy that did not compel employees to disclose their HIV status.

While some HIV-positive professionals may be hesitant to take advantage of free treatment programmes, their semi-skilled labour counterparts remain locked in battle with employers over the provision of basic workplace care.

### Derrick's battle

Derrick Khathi, a 26-year-old HIV-positive textile machine operator at Cotton King, a factory in the coastal province of KwaZulu-Natal, says he is "appalled" at the lack of basic healthcare and AIDS education available to the estimated 300 labourers at the factory.

"When I was diagnosed towards the end of 2003, all I had was the tiny company surgery where I spent a great deal of time, as I was constantly ill. It was obvious to many, including management, what was wrong with me, but it was left up to me and the factory nurse, who referred me to one of the public hospitals for testing," Khathi told PlusNews.

He says the high level of discrimination in the factory prevents other workers from getting tested, "even when the symptoms are visible".

"There is very little action from the management to educate workers about the disease," he explains. "There is one poster in this huge factory that doesn't do much to encourage staff to find out about their HIV status. But I sometimes am approached by sickly workers for advice, because most of them know about me being HIV-positive, and my active role in the clothing and textiles worker's union HIV/AIDS programme."

Khathi comments that if factory owners made treatment programmes available, workers would be more willing to get tested, and attitudes and misconceptions about HIV and AIDS would change.

Doctor Feroza Munsoor, who heads the HIV/AIDS Project of the South African Clothing and Textiles Workers Union (SACTWU), says business and all organisations can do a lot more in education and treatment by developing partnerships with government.

"Synergies need to be formed between government and organisations like SACTWU that compliment the health department's HIV/AIDS treatment plan, so that our workers don't become a burden to the government," Munsoor said.

Noting the lack of readily available treatment at factories, she suggests that government provide SACTWU with antiretrovirals for its members, as the union already has a comprehensive education programme and is willing to help roll out drugs to members.

"If government can do that, SACTWU can provide quality care to our members, and not be rushed by huge target figures [for providing treatment]."

For now, Munsoor hopes that SACTWU's education campaign, which also uses live theatre performances to encourage testing, will be sufficient until the union is able to provide the necessary HIV/AIDS treatment.

She says if her campaign can assist in educating just one worker per day about HIV and AIDS, then it will have been successful.

### [Resource:

- "ILO Report with Estimates on HIV/AIDS and Global Trends in the World of Work", International Labour Organization, 2004 - [http://www.ilo.org/public/english/protection/trav/aids/publ/global\\_est/](http://www.ilo.org/public/english/protection/trav/aids/publ/global_est/)

## SOUTH AFRICA: Monitoring access to free ARVs



18,500 South Africans are currently receiving ARV treatment.  
Credit: PlusNews

A South African non-profit organisation has initiated a nationwide network to monitor access to free antiretroviral (ARV) treatment.

The project, called the 'Treatment Monitor', collects data from a wide range of organisations throughout the country, which will be used to lobby government, detect shortfalls in research and develop best practices.

The Health Systems Trust (HST) began keeping track of access to ARVs and care early this year, and functions as a clearinghouse for treatment information. The Trust saw the need to launch the project because "there is no single monitoring framework available that provides a national picture" of South Africans' access to treatment, said HST senior researcher Rob Stewart.

"Access to information is a major hurdle a number of institutions have to overcome, and the government is certainly one of them," Stewart told PlusNews, adding that some government departments held back information that should be in the public domain.

The Treatment Monitor is aimed at helping to identify loopholes in the current health system and build consensus among the participating institutions.

Groups providing information to the Treatment Monitor include the Treatment Action Campaign (TAC),

AIDS Law Project, KZN Monitoring Forum, Medecins Sans Frontieres, South African HIV Clinicians Society, South African universities, government departments and parastatals, such as Eskom, and private sector corporations, including Anglo-American and Daimler Chrysler.

"We try to pull the different pieces together and create an environment where information can be shared," said Stewart.

Another goal of the Treatment Monitor initiative is to identify gaps in research. According to Stewart, research has not been done in a number of areas, such as service delivery models, the role of community health workers and traditional healers in screening and supporting drug adherence, financing of the national ARV programme and its sustainability, and making structural changes to the health system required for a successful rollout of ARVs.

Although HST will only be disseminating the first observations of the Treatment Monitor next year, Stewart could identify some core weaknesses of the South African government's health policy.

According to the latest numbers from the Joint Civil Society Monitoring Forum, 18,500 South Africans are currently receiving ARV treatment - just a third of the government's target of having 53,000 people on treatment by March 2005. "We have a long way to go," said Stewart.

## ZAMBIA: Second-class women left behind in access queue



Public health services are accessed more by women than men only when they are free.  
Credit: IRIN

Zambia's rollout of anti-retroviral therapy (ART) is one of the largest in Africa, but it is missing a vital chunk of the population - HIV-positive women.

According to Central Board of Health figures, of the 1,483 people who enrolled for ART in January 2004, only 537 were women. In spite of a higher HIV prevalence rate among women, men

accessed more than 70 percent of ART, health minister Brian Chituwo told PlusNews.

Gender imbalance was even more pronounced in rural areas, he pointed out, where women were often not in formal employment or in control of household budgets, and therefore could not afford the government's antiretroviral (ARV) drugs, even at the subsidised price of US \$8 a month.

"Public health services are accessed more by women than men only when they are free," said HIV-positive activist Winston Zulu. "Most Zambian women are disempowered [and] disadvantaged - it's part of the general societal picture."

At a recent meeting of Zambia's Network of People Living with AIDS on the problems of ART access, clinical officer Karana Mutibila commented that when household budgets are tight, men generally ensured they received treatment first.

"Many families cannot afford to have more than one person on ARVs because of the financial implications, so if there is one person that should go on the drugs, it is usually the man because, as the perceived head of household, he is less dispensable," Mutibila told PlusNews.

Saraphina Nakazwe said even though she was the family breadwinner, her husband controls household expenditure. He "literally grabs the day's takings and apportions how it is spent. There is money for food for the children, and what is left is for drink, but not for my medication". Her husband refuses to take an HIV test and claims her HIV-positive status was not a "family" problem but hers alone.

Apart from a lack of cash, both for the battery of tests that precedes treatment and the US \$8 a month for ARVs, women are also disempowered by a culture that frowns on discussing sex-related issues. Sometimes they are simply too shy to seek treatment for what is likely to be a sexually contracted disease, said Chituwo.

On top of this, women are often daunted by the bureaucracy surrounding delivery, Mutibila explained. "There are official documents to sign and many women cannot read or write, so they feel intimidated. Some health workers speak the local languages so badly that they end up confusing the people about the process." While men demand explanations or clarifications, some women are reticent, he noted.

The lack of treatment literacy and preparedness has been a problem area in Zambia's rollout. Malita Himaanje, who until recently lived in Gwembe, a rural outpost in western Zambia, said in her villages women were given very little information about treatment. Mwila added that if her daughter had not told her about ARVs and brought her into town, she would probably have died last year.

"At one time the information we were receiving was that it was only available to men; then the information was that it was for prostitutes with STDs [sexually transmitted diseases]. Up until I left Gwembe early this year, there was very little information that ARVs were for all."

Himaanje suspects that the health officer in the area deliberately discouraged women from accessing ARVs because supplies were limited. "They do that for all drugs, whether its chloroquine or antibiotics, they try to give men first - I know the way these [guys] operate."

According to the Zambia Demographic Health Survey of 2002, the HIV prevalence rate among adults aged between 15 and 49 was about 16 percent. The level of HIV infection was higher among women (18 percent) than men (13 percent), and the urban population was more affected (25-35 percent) than the rural population (8-16 percent).

Under the World Health Organisation's '3 by 5' initiative, Zambia has set itself the target of having 100,000 people on treatment by the end of 2005. At present [December 2004] 13,555 people are receiving ART.

The Deputy Resident Representative of the UN Children's Fund, Tomoko Nishimoto, wants the ministry of health to make it policy that at least 50 percent of the allocation for treatment be spent on women, "and for people in absolute poverty, who cannot even afford transport to collect free ARVs".

Chituwo acknowledges the problem. "We need to have the women who are not pregnant or not lactating on the programme; we need to get rid of cultural or social taboos that discourage women from discussing their sexuality or reproductive health - this is the only way women are going to be empowered to seek treatment."

## 4. Treatment

### AFRICA: A short history of antiretrovirals



From failed cancer drug to multi-billion dollar industry.

Once upon a time there was a failed anti-cancer drug called zidovudine, which had been rejected because it was so toxic and had such unpleasant side effects. Twenty years later, under the name AZT, it became the vanguard of medicines in the fight against the human immunodeficiency virus (HIV).

AZT was seen as a breakthrough - the first medication that seemed to attack the virus itself. It was thus the first real hope for people infected with HIV, which until then had almost certainly led to death.

In 1986 a clinical trial on patients in eight American cities was stopped after four months because AZT seemed to have such dramatic effects on the virus. The next year AZT (Retrovir) became available commercially as the first antiretroviral to be registered by the US Food and Drug Administration (FDA).

Unfortunately, follow-up research was not so optimistic. Clinical trials in Europe found no long-term benefit from using AZT, especially if patients started taking the drug before they showed signs of AIDS. And, worryingly, healthy patients taking AZT seemed to die faster than their sicker counterparts.

What was not appreciated then was that taking only one antiretroviral at a time - monotherapy - has only a short-term benefit, because the virus mutates so rapidly that drug-resistant strains swiftly become dominant.

Until 1991 AZT was the only - and very expensive - hope available for people sick with AIDS. In that year another antiretroviral, ddl (didanosine, Videx), created specifically for patients who had become resistant to AZT, was registered. By this time the World Health Organisation estimated that 10 million people were infected with the HI virus worldwide, of whom a million were in the United States.

In 1992 ddC (zalcitabine, Hivid), was approved for use in the US, followed by d4T (Zerit) in 1994 and 3TC (Epivir, lamivudine) in 1995.

All these drugs are classified as nucleoside reverse transcriptase inhibitors (NRTIs), which resemble the chemical building blocks - nucleosides - used by reverse transcriptase, a key enzyme required by the HI virus for intracellular replication. NRTIs have a chemical twist, which ensures that, once taken up by the enzyme, the NRTI molecules terminate the building of the viral DNA chain, stalling virus production.

The problem is that HIV can show cross-resistance to different drugs in the same group. So, for example, a patient treated with AZT monotherapy is likely to quickly show some resistance to other NRTIs but because they are all slightly different, dual therapy using two drugs in the same class is still more effective and sustainable than monotherapy. This was demonstrated in 1997 when the FDA registered Combivir, a combination drug containing both AZT and 3TC. In this case resistance to one drug appeared to counter resistance to the other.

1996 brought registration of nevirapine (Viramune, NVP), the first in a new class of antiretrovirals: non-nucleoside transcriptase inhibitors (NNRTI), a group of drugs that stops the duplication of viral DNA by directly disabling the reverse transcriptase enzyme itself.

The development of NNRTIs was a breakthrough because they worked against viruses that had become resistant to NRTIs, and researchers quickly found that dual therapy - using two drugs simultaneously - was most effective when the drugs were from two different groups. Other NNRTIs, such as delarviridine (Rescriptor, DLV) and efavirenz (Sustiva, EFV) followed in 1997 and 1998.

NNRTIs were overshadowed by the arrival of a third class of drugs - protease inhibitors (PIs). These work at a later stage of the HIV life cycle by interfering with the protease enzyme, the other key enzyme required by the HI virus for intracellular replication.

First off the blocks with FDA registration were saquinavir (Fortovase, SQV, Invirase) in 1995, followed by ritonavir (Norvir, RTV) and indinavir (Crixivan, IDV) in 1996, nelfinavir (Viracept, NFV) in 1997 and amprenavir (Agenerase, APV) in 1999.

With three groups of anti-HIV drugs available, HAART - highly active antiretroviral therapy, using multiple drugs - began to evolve, and antiretrovirals became known as Lazarus drugs because they appeared to resurrect patients from near death.

The latest class of antiretrovirals to be developed are fusion inhibitors, which prevent the HI virus from infecting human cells by blocking the viral proteins used to dock into cell membranes. To date there is only one FDA-registered fusion inhibitor - enfuvirtide (Fuzeon, T-20), registered in March 2003. Fuzeon has to be administered by injection, is expensive and has many side effects but, because it is the first of a totally different class of drugs, it offers another chance to patients who have become resistant to other treatment regimes.



## AFRICA: Local manufacture - competition key to cheaper ARVs



Developing countries have had the right to produce generic drugs to fight health crises since 2001.  
Credit: IRIN

The high-tech compression machine at Aspen Pharmacare's new facility in Port Elizabeth, South Africa, spits out Nevirapine tablets at a rate of 150,000 an hour. Pharmacists clad in surgical masks and hairnets fiddle with controls and

take regular samples to ensure the tablets are consistent in size and hardness, but mostly there is little for them to do but stand back and watch.

Across the road, Aspen's older facility struggles to produce the same quantity of tablets in a day. This is only the third batch of antiretroviral (ARV) drugs to come out of the new facility, but eventually all ARV drugs made by Aspen will be manufactured here. Over the next 18 months the company will almost double its capacity.

"We can manufacture the full requirements of the continent," said Aspen's senior executive for strategic trade development, Stavros Nicolaou. "But we're not going to get 100 percent of that business."

As the only company currently manufacturing anti-AIDS drugs in South Africa, and one of the few countries on the continent with the size and capacity to sustain local ARV production, it seems likely that Aspen is set to seize a significant portion of "that business".

Procuring affordable supplies of ARVs is central to the increasingly pressing question of how cash-strapped African governments will sustain their HIV/AIDS treatment programmes. But there is no consensus on whether manufacturing the drugs locally is the answer.

### National pride

Developing countries have had the right to produce generic drugs to fight health crises since 2001, but most African countries lack the infrastructure or market size to support such enterprises. Although the prices of ARVs have plunged with the introduction of generics, the vast majority are still manufactured elsewhere.

"Every little country wants to manufacture ARVs," said South African coordinator for the World Health Organisation's (WHO) Drug Action Programme, Martin Auton. "A lot of it's national pride - but you have to make sure it's economically viable, and not just producing for the sake of producing."

To be economically viable, smaller countries need to be able to market their drugs beyond their own borders but, before another country will consider

buying them, they want an assurance of quality. At the moment, South Africa is the only country on the continent with a trusted regulatory body, like the Medicines Control Council, that can give that assurance.

In the absence of local regulatory authorities, WHO has stepped in to provide a stringent quality assessment of its own, and passing WHO's prequalification scheme is now a requirement for countries seeking funding for local drug manufacture from the Geneva-based Global Fund.

WHO is also developing an assessment to help countries determine whether a local drug-making venture is likely to succeed financially. Auton suspects that few of the smaller countries would make the grade unless they formed alliances that could guarantee them sizeable markets. WHO is in the process of researching this option.

The real key to keeping drug prices down, though, said Auton, was to create competition in the marketplace, and that might mean a combination of locally manufactured and imported drugs would be the best solution for government-sponsored ARV programmes. Using multiple suppliers would also help guarantee an uninterrupted supply of the life-prolonging medicines.

"You don't want to be dependent on one supplier, who then holds you ransom down the line," he explained.

"If it's a question of saving lives, you can't just rely on local production," agreed Jonathan Berger of the AIDS Law Project in South Africa. "Given that there aren't enough local producers, they have to compete with importers."

South Africa's health department has yet to announce which companies will supply ARV drugs for its national treatment programme, but chief director of pharmaceutical planning and policy, Dr Humphrey Zokufa, confirmed that the tender would be divided between several suppliers.

At the same time, he made no secret of the government's preference for local manufacturers and its long-term goal of reversing South Africa's reliance on importing drugs, particularly ARVs.

"If we're importing ARVs, and the manufacturer is experiencing an increased demand in their country, they'll be looking at supplying their local populations before us," Zokufa said.

That Aspen will win several of the bids in the tender was virtually assured even before its purchase in March of Fine Chemicals, a Cape Town-based facility that manufactures raw materials for pharmaceuticals. Currently, Aspen still imports the active ingredients of ARV drugs, but the plan is eventually to manufacture

those ingredients at Fine Chemicals to secure their supply and further reduce the end cost of the drugs.

## How much profit?

Dr Marta Darder, coordinator of the Medecins Sans Frontieres Access to Essential Medicines Campaign in South Africa, was wary of government's dependence on the private sector to supply its treatment programme. She would prefer a situation like that in Thailand and Brazil, where government-owned facilities are successfully supplying those countries' treatment programmes with affordable ARVs.

"It's fine to make a profit; it's about what is the margin of profit," Darder said. She was satisfied that Aspen was supplying the public sector with ARV drugs on a "cost-recovery" basis but, at more than three times the subsidised rate, regarded the cost of their drugs to the private sector as prohibitively high.

"Generic companies are just like other companies," Auton pointed out. "They get the maximum price they can charge."

Until recently, Aspen was the only company in South Africa in possession of "voluntary licenses" to make generic versions of ARV drugs developed by drug multinationals Bristol-Myers Squibb, GlaxoSmithKline and Boehringer Ingelheim. But, following a complaint lodged by the Treatment Action Campaign, and several other groups and individuals, that Glaxo and Boehringer were charging excessively high prices, the Competition Commission required the companies to release licenses to other local companies.

According to Andy Gray, a senior lecturer with the department of therapeutics and medicines management at the Nelson R Mandela School of Medicine, there were a number of good quality plants in South Africa that could move into ARV production with the right technology. Gray said he knew of at least two that were looking into the possibility, but noted that if the goal was to keep prices down by encouraging competition, more could be done by the government to provide such companies with financial incentives.

Nicolaou insisted that Aspen was happy to compete with other suppliers and that it took its "socio-economic responsibility to the continent" seriously.

Besides the "humanitarian aspect," he said, providing ARVs as cheaply as possible was about securing future markets for the company.

"If economies collapse due to the HIV/AIDS epidemic, then governments can't buy your products," he explained.

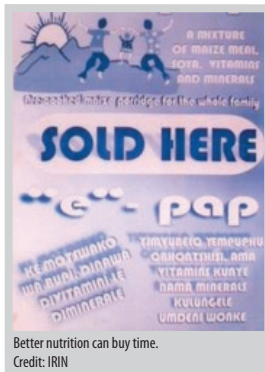
After a two-year wait, Aspen completed registration of its six adult and two paediatric ARV products with the Medicines Control Council in September and, according to Nicolaou's estimates, was already supplying about 60 percent of the local public sector demand and about a third of the total number of South Africans on ARVs.

So far they are only supplying a local market, but their licensing agreements allow them to export the drugs throughout sub-Saharan Africa. Since winning a contract from the Clinton Foundation in October to supply several other African countries, Aspen has been in the process of getting a WHO assessment and, with a view to supplying drugs to programmes in the region funded by the US President's Emergency Plan for AIDS Relief, the company recently invited the Federal Drug Administration to inspect its gleaming new facility.

The British regulatory authority, the Medicines and Healthcare products Regulatory Agency, will visit the plant in January.

As long as the outlook for sub-Saharan Africa's HIV/AIDS epidemic remains gloomy, a bright future for Aspen Pharmacare seems assured.

## AFRICA: "Positive living" eclipsed by ARV drive



In sub-Saharan Africa, the region hardest hit by the HIV/AIDS pandemic, the thrust to bring antiretroviral (ARV) drugs to the 3.8 million people who need them has tended to overshadow all other treatment efforts.

The reality on the ground is that only five percent of those who qualify for the life-prolonging medicines are so far receiving them.

The World Health Organisation is pushing to increase access with its "3 by 5" initiative, which aims to have three million people in developing countries on ARVs by the end of 2005. But putting millions of people on lifelong drug regimens in countries with under-resourced health systems presents enormous logistical hurdles that will take time to overcome.

The question, in the meantime, is how to slow down the alarming loss of life that is robbing children of their parents, communities of their spirit and economies of their skilled workforce. In other words, how can governments buy their HIV-positive citizens time until they can make the drugs more widely available? The answer may be as simple as good nutrition.

But in sub-Saharan Africa nutrition is no simple matter. Here people who contract the HI virus spiral towards death much more quickly than their western counterparts, not primarily because they lack access to ARV drugs, but because they often lack even basic foods in sufficient quantity. The HI virus reduces the body's ability to absorb nutrients, making good nutrition especially important to people living with the disease, and particularly devastating to those who cannot afford it.

"The problem of food, in so many southern African countries, is desperately acute," Stephen Lewis, the UN's special envoy on HIV/AIDS in Africa, pointed out recently. "I'm not merely talking nutrition; I'm talking survival. Enough food not to be starving and perpetually hungry, so hungry it robs your immune system of its ability to fight the virus."

The World Food Programme has expanded its focus on disaster and famine relief to include providing nutritional support to HIV/AIDS programmes in eight African countries. In general, though, the issue of food security is still not attracting anything like the international attention and resources that ARVs has.

In South Africa, in particular, the issue of nutrition has been marginalised by a damaging debate that has tended to frame it as an alternative to ARV drugs.

Statements by the health minister, suggesting that eating immune-boosting foods, like garlic and olive oil, can delay the need for ARV drugs, have been perceived as a tactic to divert attention from the slow place of the government's ARV rollout.

In fact, say many nutritionists, she was on the right track, although she could be accused of bad marketing.

In the early days of the epidemic, when South African David Patient was diagnosed as HIV positive, doctors told him there was nothing they could do. Patient began watching his diet - avoiding sugar and fast foods, eating more fresh fruits and vegetables and taking multivitamin tablets - because, he says: "It was the only thing I could do to empower myself".

Twenty-two years later, Patient recently started taking ARVs because he wanted to lower his viral load enough to safely father a child. In his view, the successful promotion of good nutrition will mean changing the perception of AIDS as an automatic death sentence.

"For 20 years we've been telling people AIDS kills, and now we're saying, 'you can live with this disease', so we need to remarket it," he told PlusNews. "We need to educate the population about wellness, so people realise that their health is in their hands."

In the last five years, Patient said, nutrition has become increasingly "mainstream". Positive living campaigns have helped spread awareness and the "either or" debate has evolved into widespread recognition that nutrition is essential, both as a means of postponing the time when ARV treatment becomes necessary, and in terms of the body's ability to handle the powerful drugs.

The key issue now is one of affordability. With poverty deepening across much of Africa, most people living with HIV do not have the resources to support a healthy diet. In Southern Africa they fill up on starchy maize-based staples that have been largely stripped of their nutrient content as a result of food processing.

A more sustainable solution to food insecurity may come in the form of nutritional supplements that can be cheaply produced and easily distributed.

Industrial chemist Basil Kransdorff developed one such product three years ago at the request of Community AIDS Response, a Johannesburg-based NGO that provides home-based care to severely ill AIDS patients. The product, called ePap, is a powdery mixture of pre-cooked maize meal, soya and a host of vitamins and minerals that can be mixed with cold or lukewarm water or milk to create a filling porridge or shake.

According to Kransdorff, one portion of ePap has 29

times the nutritional value of refined maize meal and is nutritionally equivalent to eating a five-course meal. Without fanfare, largely through word of mouth, ePap has developed into something of an international phenomenon. Distributed mainly by NGOs and community projects, 2 million portions of ePap a month are now consumed in 17 countries across the continent.

Kransdorff believes he may have hit upon "an African solution to an African problem" - an affordable intervention that can empower people with HIV to continue living productive lives, while governments develop the capacity needed to manage large-scale ARV rollouts.

#### [Resources:

- "Living well with HIV/AIDS - A manual on nutritional care and support for people living with HIV/AIDS", - [http://www.fao.org/documents/show\\_cdr.asp?url\\_file=/DOCREP/005/Y4168E/Y4168E00.HTM](http://www.fao.org/documents/show_cdr.asp?url_file=/DOCREP/005/Y4168E/Y4168E00.HTM)  
- ProNut-HIV - an electronic forum on Nutrition and HIV/AIDS - <http://www.pronutrition.org/discgroups-hiv.php>

"My belief is that with good nutrition we can turn the HIV pandemic into one very similar to diabetes, where you can live with the problem and manage it with good nutrition and medicines," Kransdorff said. "Parents can carry on living, working and caring for their children."

## AFRICA: MSF calls for child-friendly ARVs



A mother receives information about ARV dosing for her child.  
Credit: IRIN

Seven months ago, Nomlindelo Nkoninga began giving her four-year-old son a combination of drugs to stem the progress of HIV. But only last month did he weigh enough to take the anti-retroviral (ARVs) medication as three separate

tablets, instead of the syrups commonly prescribed for young children.

"It's easier now because some syrups need refrigeration and I don't have a refrigerator," said Nkoninga, 24, who lives in South Africa's rural Eastern Cape province.

In recent years, many countries in sub-Saharan Africa have begun to distribute government-funded ARVs to some of the estimated 4.4 million people in need of the drugs. Yet, despite advances made in AIDS treatment for adults, it remains complicated and expensive to establish the correct doses of ARVs for children, who are smaller and constantly growing.

"A majority of people are not treating children, because they are scared of computing the doses," said Dr Eric Goemaere, head of Medecins Sans Frontieres (MSF) in South Africa.

MSF, which has launched a public campaign around this issue, claims that children with AIDS are needlessly dying because medicines have not been

simplified for widespread dispersal. The medical humanitarian agency alleges that because most children with HIV/AIDS live in the developing world, there is little commercial interest in creating and marketing child-friendly treatments, and children are given small portions of adult doses.

"With kids, you have to individualise, and each one gets their own doses, their own regimens," said Dr Hermann Reuter, project coordinator of MSF's treatment programme at Lusikisiki in the Eastern Cape, where children make up eight percent of ARV users.

Although treatment for HIV is constantly evolving, generic ARVs for adults typically consist of three drugs in a "fixed-dose combination" in one pill. Most adults on ARVs therefore take standard doses of drugs in one or two pills twice a day.

The most common combination of drugs for first-time ARV users is "D4T," (or Stavudine, trade name Zerit) made by BristolMeyersSquibb, "3CT," (or Lamivudine, trade name Epivir) made by GlaxoSmithKline, and "NVP," (or Nevirapine, trade name TK), made by Boehringer Ingelheim/Roxane.

But treatment for children is not so simple. Pharmaceutical companies have not yet developed fixed-dose combination treatments in dosages appropriate for them, and physicians must often portion out a cocktail of three separate adult-dose medicines in different combinations as the child grows.

To determine correct paediatric doses most effec-

tively, caregivers should ideally use the three drugs according to the surface area of the child - a number obtained by a complicated formula of multiplying the child's weight by its length, dividing by 3,600, and then taking the square root of that figure.

This kind of calculation is often impossible in the developing world. "We don't have calculators at the clinics and no one can work out square roots in their heads," said Reuter. "It's just not practical. If you're doing this in clinics, you have to simplify."

Simplification means setting dose standards - including combinations of syrups and crushed or broken pills - by the weight of the child. This sometimes results in overdosing HIV-positive children and increased side effects, Reuter explained, but overdosing is generally preferred to underdosing, which can gradually lead to resistance to the medication.

"As soon as there's not enough drugs in the body, the virus starts to multiply," Reuter said. "As soon as it multiplies, there's a chance for it to develop resistance and if there's resistance, the ARVs won't work any more."

Paediatric formulations are also more expensive than adult treatments. MSF noted that while the most popular fixed-dose combination pill (D4T, 3TC, and NVP) are available for adults at about US \$200 a year, treating a 14-kg patient with three separate drugs costs roughly \$1,300 a year.

"We need to make paediatric treatment nurse-friendly at a primary care level," said Goemaere. "We need to make it so that treating children becomes as simple as treating adults - close to home, in their own health centres, in their own environment, in their own language."

## SOUTH AFRICA: HIV-positive and pregnant - weighing the risk



AIDS councillors hear varied reasons from women as to why they want to conceive.  
Credit: IRIN

As anti-AIDS drugs become available to more South Africans, a growing number of HIV-positive women are choosing to become pregnant in spite of their status.

Although it is generally accepted that all women have the right to bear children, society finds it harder to accept when women living with the virus exercise that choice.

Admittedly there are risks involved. In the absence of intervention, an estimated 15 to 30 percent of mothers with HIV will transmit the infection to their baby by the time it is born, according to the World Health Organisation. A single dose of Nevirapine, given to mother and baby, halves the chances of infection during labour, when the risk of transmission is highest.

"Initially people assumed that if someone knew their HIV-positive status, then pregnancy was a 'no-no'. But the reality is that most of these people are young women in their prime, who want to have babies," Dr

Pumla Lupondwana, a research doctor at Chris Hani Baragwanath hospital in Johannesburg, told PlusNews.

Lupondwana is conducting a study on resistance to Nevirapine at the perinatal HIV research unit based at the hospital. She estimated that about a third of the 250 women participating in the trial had made a conscious decision to fall pregnant. In fact, an increasing number of women were second-time mothers who had been diagnosed HIV-positive during their first pregnancy.

"They've been exposed to Nevirapine, and they know all the risks involved," she said.

The reason for having a baby varies. According to Lupondwana, some may want a child they can leave behind as "some form of legacy or reminder". For some women, a new partner might insist on having a baby, with the woman too afraid to disclose her status. But pressure from the community, and fear of stigma and discrimination were other reasons, she explained.

HIV-positive Theodora's (last name withheld) third child will be one year old this month. Theodora was diagnosed during her second pregnancy and received Nevirapine, but the baby died a week later from meningitis.

In April last year she conceived again, after she had



become resistant to Nevirapine during her second pregnancy. "I had wanted to wait a bit longer, but I really wanted this baby - there was this hole inside me after the first one died. I knew this was my last chance," she said.

In a study presented at the 2004 International AIDS Conference in Bangkok, Thailand, South African virologist Dr Lynn Morris showed that although there was high resistance to Nevirapine six weeks after a woman had taken a single dose, this dropped to 14 percent after six months.

Resistance to Nevirapine decreases the drug's effectiveness and makes it difficult to treat the baby if it is born HIV-positive.

After consulting with her doctor and undergoing CD4 count and viral load tests (which measure the strength of the immune system and the amount of HIV in the blood), Theodora had a safe pregnancy and her baby was born HIV-negative.

"I ate more fruit and vegetables, and did all the things you should be doing anyway when you are pregnant and negative. But for the whole nine months I was being eaten up with worry, thinking about all the risks."

Most HIV-positive pregnancies are usually trouble-free, unless the mother is at an advanced stage of the disease and has a compromised immune system, Lupondwana said.

Of concern to Lupondwana and her colleagues, however, is the fact that most of the women are practising unsafe sex, despite receiving extensive family planning advice.

"Some might have planned to have the babies, but most of these women are having unplanned pregnancies because they are not using any form of contraception, or their partners refuse to use condoms," she commented.

Sharon Ekambaram, an AIDS activist and former PMTCT coordinator of the lobby group, the Treatment Action Campaign, pointed out that the country's prevention of mother-to-child transmission of HIV (PMTCT) and antiretroviral (ARV) rollout programmes had failed to take this into account.

"These programmes are missing the point by not addressing the woman's inability to disclose to their spouse or partner and negotiate safer sex. These women are forced to hide the fact that they are on treatment, just to avoid disclosure," she said.

Theodora, for example, admitted that she was "alone in my HIV status". When she found out she was pregnant the first time, her partner told her not to take an HIV test. "I went behind his back and tested because I wanted to know for myself. I didn't tell him the result and he still doesn't know," she said.

There are many women in a similar position at her support group meetings. "Their men don't want them to use condoms, and they are too scared to tell them about having HIV, so they just keep quiet," Theodora said. "When some women did gather the courage to disclose, the men would say 'if we both have it, then it doesn't matter - we don't have to use condoms.'"

With a CD4 count of 131, Theodora is on a waiting list to receive free ARVs and has not decided whether she will disclose to her partner. They are both unemployed and survive on a government child support grant.

"I really don't understand why I'm on a waiting list because, with all the stress I'm having, it [CD4 count] can go even lower - I don't even want to think of [dying and] leaving my children now," she said.

The latest UNAIDS report on the global AIDS epidemic estimates that in South Africa the number of orphans is expected to increase from 2.2 million in 2003 to 3.1 million by 2010.

According to the latest numbers from the Joint Civil Society Monitoring Forum, an NGO coalition set up to monitor the ARV rollout, about 18,500 South Africans are accessing ARV treatment.

Nevertheless, as an increasing number of people receive treatment and start living longer, government would "have to stay on top of their PMTCT programme," Lupondwana warned.

"More and more HIV-positive women will want to have kids - this is still a new issue that hasn't been adequately dealt with in the public sector. Healthcare workers cannot afford to be "judgemental" by treating women living with the virus, who choose to have babies, "as if they are crazy", she added.

Lupondwana cautioned that becoming pregnant when HIV-positive still has its risks, as it could compromise the woman's immune system. "But, at the end of the day, it is their choice to make."

## 5. Interviews

### AFRICA: Interview with Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa



Stephen Lewis UN Special Envoy for HIV/AIDS in Africa.  
Credit: IRIN

Stephen Lewis is the UN Special Envoy for HIV/AIDS in Africa, and has been a key campaigner for urgent and robust international action to meet the challenge of the pandemic. He spoke to PlusNews about his optimism over the '3 by 5' initiative.

**QUESTION: After the problems seen in Arusha with the Global Fund's next round and donors' apparent reluctance to increase their funding, what guarantees of sustainability can mass antiretroviral (ARV) treatment have?**

**ANSWER:** My own feeling is that it will be impossible for the western world to turn off the financial tap once the treatment is underway. The treatment will be abridged by the amount of money available, but I think however many people are put into treatment, that treatment will be sustained. I do not foresee a situation where the resources will suddenly be cut off in the middle of the treatment.

I also feel confident that we're going to turn a significant financial corner in 2005; that there's something really important happening, which isn't fully understood yet, and that's that the United Kingdom is taking over the AIDS agenda. The UK has the chairpersonship of the G8 next year, and of the European Union. They've already said they're going to host the Global Fund meeting in September, and they've asked for a major meeting in March to bring together all the major players.

[Chancellor of the Exchequer] Gordon Brown is pursuing relentlessly [industrialised countries], moving them to the 0.7 percent of GDP target for ODA [Overseas Development Aid]. The way in which the United Kingdom is taking on this agenda finally gives leadership to what has been the most difficult problem on the planet: the leadership simply has not been there before.

So, I have a cautious optimism that we're about to see a significant jump in resources. And I'm one of those people who still believe that it is possible to achieve the WHO's [World Health Organisation] target of three million people in treatment by 2005. I genuinely believe it's still within reach, and that the momentum is picking up at country level. I don't want to pretend it's going to be easy, though - it's going to be very tough.

**Q: Are we urging poor countries to take on life-or-death commitments that are dependent on erratic outside funding?**

A: In a sense we are. Let's take Lesotho, for example: they want to have 28,000 people on treatment by 2005, and this is without question one of the poorest countries on the face of the earth; a country that lacks capacity and has one of the highest prevalence rates in the world. Nevertheless, the government is so determined to save its people that I feel nothing will stop them, and if Global Fund money suddenly dried up, they'd be on the hook, but I don't believe their treatment programme would fall apart - because every one of these countries understands they are in a life-or-death struggle. Personally, I don't believe they'll be faced by abandonment but, if that terrible prospect happened, they would somehow sustain treatment.

**Q: To what extent has the recent controversy around some generic companies withdrawing from the World Health Organisation's prequalification list threatened the survival of ARV programmes?**

A: I don't think it's threatened it one whit. I think what is important is to recognise that what the WHO was doing was being fiercely protective of quality assurance. I think the significant thing that's happened is not that the drugs were de-listed because they're of lesser quality, but because some of the bioequivalence work done by others was shoddy.

What I think is really important is the fact that two of [generic drug manufacturer] CIPLA's drugs have been reinstated after they were given appropriate bioequivalency studies. In early 2005 I think you'll see additional drugs reinstated and new drugs put on the list. The WHO's 3 by 5 programme and its prequalification process, and the support they've given for generics, are among the most dramatic and visionary interventions of any made by the UN since this began.

**Q: Isn't there a danger that the positive living aspect of HIV/AIDS treatment is being lost with all the focus on ART?**

A: There is inevitably the argument being put that prevention is being sidelined by this obsession with treatment, and that nutrition is being diminished somewhat, and that the various opportunistic infections are being inadequately attended to, and that the simple truth of positive living is being diminished because of the obsession

with ARVs - I understand that. But my own feeling is that once we get treatment significantly underway, everything else will be given its due.

It was inevitable, as you have 25 million people in Africa fighting for survival, that the treatment process would preoccupy us. But it will calm down and, as it does, the focus on positive living and nutrition - all these things - will reassert their place again. I don't really think they're being lost, but I think the debate and the loud discourse about treatment inevitably takes the centre of attention.

[Meanwhile] the health sector must benefit from what's happening, otherwise it makes no sense - it must include the building of capacity: they won't be able to sustain the treatment unless they have greater capacity. In many ways capacity is an even greater hurdle than the flow of resources. Treatment must not displace all the other priorities in the health system. We have to recognise ARVs are the centrepiece of the struggle at the moment, but the treatment of AIDS must be seen as a way to strengthen capacity and infrastructure.

**Q: What do you think are the key components of a successful government rollout of ART?**

A: Number one: there must be a voluntary testing and counselling culture developed in the country - testing must become central to the response and very careful and sophisticated counselling techniques must be developed and honoured and implemented. Number two, I think, is the constant and steady and reliable flow of drugs - those drugs must never be interrupted. Overall, it would be preferable to have the fixed-dose combination generic as the first line of response. It may be that the brand-name products will one day come up with a fixed-dose combination of their own but, at the moment, we need a continuous flow of the fixed-dose combination drugs.

Number three: we need the facilities and the capacity to sustain the treatment, and that means an adequate number of health professionals, which means an emergency training intervention - you don't always need a doctor or even a nurse, but you do need people who are carefully trained in the minimum requirements.

We can't continue to lose health professionals from these high-prevalence countries - western countries have to come up with an agreement whereby we won't be poaching health workers from these countries; they have to be paid an adequate salary and given benefits, so that they'll be induced to stay in their countries.

The fourth component is to make sure that you have a network of community health workers, who can follow the people who have AIDS back into their communities and make sure the regimens are adhered to, and that resistance or side effects are dealt with - the most recent UNAIDS report showed that 90 percent of the care is being done at a community level. I'm probably missing many things, but for me those four points are key.

There's another ingredient people don't talk about enough, and that's food; I'm not merely talking nutrition; I'm talking survival - enough food not to be starving and perpetually hungry; so hungry it robs your immune system of its ability to fight the virus. The problem of food in so many of the southern African countries is desperately acute.

Again, you have a UN agency which is showing an astonishing resolve and response, and that's the WFP [World Food Programme]. What they're doing at a country level - you just have to see it to believe it. They've completely enlarged their focus, so they're not only responding to natural disasters, they're responding to the human predicament of AIDS.

**Q: Beyond the rhetoric, are people living with AIDS really considered an asset in the response to HIV and AIDS, rather than the source of the problem?**

A: I think the rhetoric is largely illusory - I don't trust the rhetoric. When I travel I don't see it being translated into genuine respect for people living with AIDS, and recognition of what they can contribute. A lot of it is extremely pro-forma and offensive, and it's used as a way of fobbing off the issue. I think it varies from country to country but, in most cases I've encountered, the government considers the people living with AIDS, who are leading the fight against prevention, as more of a nuisance than real contributors.

They just simply don't get enough of a hearing, because it's not yet understood that they can contribute because they are the experts - they know everything about the virus. They should be meeting with ministries of health on a daily basis and talking to all the other sectors, including education and agriculture, and they should be demonstrating to governments - whether it's through the workplace or community programmes - how you overcome stigma. They should be integrated completely into public policy at every level and in every sector, and they are not.

I never see due respect for the very knowledgeable and important community of people living with AIDS. I'm constantly reminding communities and governments that it's not just respect that's needed, it's also a recognition that you can't afford to lose this body of knowledge.

## AFRICA: Interview with Dr Jim Kim, director of WHO's HIV/AIDS department



Dr Jim Kim, Director HIV/AIDS Department, WHO.

In 2003 the World Health Organisation (WHO) joined UNAIDS and the Global Fund to Fight AIDS, Tuberculosis and Malaria to declare the lack of access to antiretroviral (ARV) drugs a global health emergency. In response, WHO and its partners launched the 'Treat 3 Million by 2005' (3 by 5) initiative. PlusNews spoke to Dr Jim Kim, director of WHO's HIV/AIDS department.

**QUESTION: After the problems seen in Arusha with the Fund's next round and donors' apparent reluctance to increase their funding, what guarantees of sustainability can mass antiretroviral therapy (ART) have? Are we urging poor countries to take on life-or-death commitments that are dependent on erratic**

**outside funding?**

**ANSWER:** Around the world, entire communities face social collapse because of the AIDS pandemic. The drive to provide treatment comes from affected countries and their leaders. WHO is working with ministries of health to provide technical assistance to help scale up treatment.

Because treatment is for life, long-term funding is essential to ensure that an entire generation will not be lost to HIV/AIDS. Current resources are the result of extraordinary advocacy efforts by communities living with HIV, activists, NGOs, faith-based organisations, leadership from heads of state and multilateral organisations.

There was nothing automatic about getting the funding we have, and there will be nothing automatic about sustaining it but, in my view, this is simply the task we are faced with if we are serious about tackling the worst pandemic mankind has faced for hundreds of years. Those of us who have the means to mobilise at a community, national and international level must do so to ensure appropriate resources.

The Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria has been a remarkable instrument in galvanising global treatment and prevention of HIV/AIDS. Three years ago, the Global Fund was an idea: since then it has raised US \$3 billion - two-thirds of which is dedicated to HIV/AIDS - and are successful in rolling that money out into effective prevention and treatment programmes.

The United States President's Emergency Programme for AIDS Relief (PEPFAR) has committed \$15 billion to AIDS relief globally and is also moving quickly. National governments have also increased funding for treatment - the British government recently doubled its international AIDS budget. New commitments from the World Bank, as well as the private sector and non-governmental, faith-based and community organisations, have also emerged.

Six million people living with AIDS need ART now, and this number is growing. The '3 by 5' target aims to mobilise the world to treat half of those in need - three million by the end of 2005. Continued long-term national and international support is essential to continue to move towards reaching the target. We simply must recommit ourselves to doing whatever it takes to meet the challenges ahead.

**Q: To what extent has the recent controversy around generic companies withdrawing from the World Health Organisation's prequalification list threatened the survival of antiretroviral programmes?**

**A:** What we are talking about here is short-term pain for long-term gain; it is about improving the overall quality of medicines for all poor people, not just those living with HIV. As drugs are relisted over the next few months, in the medium to long term I think we will all conclude that the prequalification process will have had a positive affect on scaling up treatment.

The Prequalification project, set up in 2001, is a service provided by WHO to facilitate access to medicines that meet unified standards of quality, safety and efficacy for HIV/AIDS, malaria and tuberculosis.

Prequalification was originally intended to give United Nations procurement agencies, such as UNICEF, the choice of a range of quality medicines. Countries most in need of life-saving ARV and other drugs often do not have the regulatory capacity to ensure the safety and quality of medicines from different suppliers around the world. With time, the growing list of medicines that have been found to meet the set requirements has come to be seen as a useful tool for anyone purchasing medicines in bulk, including countries and other organisations.

Companies wishing to have a product prequalified voluntarily submit a dossier to WHO, to allow qualified assessment teams to evaluate its quality, safety and efficacy. The manufacturer must also open its manufacturing sites to an inspection, comprised of regulatory experts from among 28 of the world's leading national regula-

tory agencies, including experts from Europe, Canada and Australia.

Ranbaxy Laboratories Limited informed WHO in November that it was voluntarily withdrawing all its antiretrovirals (product dossiers under assessment and all prequalified products) from WHO prequalification. This action was taken after the company found discrepancies in the documentation relating to proof of the products' bio-equivalence with originator medicines.

The company has already presented WHO with a plan indicating proposed dates for the submission of new study reports for these products - the first study is expected to be completed by December 2004. Rather than threatening the survival of antiretroviral programmes, this withdrawal seeks to ensure the improvement of medicines.

[Information on the practical implications of the withdrawal of the above-mentioned products from the list of prequalified products for treatment programmes can be accessed on the WHO prequalification project web site, where the list of alternative products prequalified by WHO may also be found.

[\[http://mednet3.who.int/prequal/\]](http://mednet3.who.int/prequal/)

**Q: Isn't there a danger that the "positive living" aspect of HIV/AIDS treatment - better nutrition, for example - is being lost with all the focus on ART?**

A: WHO supports positive living - good nutrition, exercise, etc. - but none of those things alone have ever been shown to halt the progression of HIV disease. The only intervention that has ever been shown to have a proven impact on mortality is ARV therapy. However, there is no question that good nutrition, exercise and many other aspects of healthy life can have beneficial effects for everyone, especially those living with HIV and AIDS.

Comprehensive programmes that integrate treatment and prevention, as well as the promotion of 'positive living', are essential. As access to treatment and prevention is increased within countries, health systems and infrastructures will be strengthened, which will have wide-reaching effects on improving public health services for everyone.

As more people are brought onto treatment, People living with HIV/AIDS visiting health centres for their treatment checkups will have increased opportunities to consult with a health professional about their overall health. A focus on ART does not mean the neglect of other, essential areas of care for [people living with HIV/AIDS] PLWHA - rather, it enhances these other areas.

**Q: What do you think are the key components of a successful government rollout of ART?**

A: The most important component is strong political will and commitment to implementing a comprehensive approach to HIV that involves accelerating both treatment and prevention. Leaders have the responsibility to stand up to AIDS and take the fight forward. We have already seen great progress in terms of leadership: we now have nearly \$ 20 billion pledged for integrated AIDS prevention and care, and more and more countries are committing to scaling up treatment and care.

Partnerships and collaboration at country and international level between all stakeholders - national authorities, UN agencies, multilateral agencies, foundations, non-governmental, faith-based and community organisations, the private sector, labour unions and representatives of the community of people living with HIV/AIDS - are absolutely essential for successful rollout. Everybody has a role to play and all stakeholders need to work together, coordinating in line with the 'three ones' principals initiated by UNAIDS for one agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners; one national AIDS coordinating authority, with a broad-based multi-sector mandate; and one agreed country-level monitoring and evaluation system.

WHO works closely with ministries of health and others partners in-country, to design national HIV/AIDS plans and to identify existing gaps. Prevention and treatment needs differ from region to region, as well as country to country. The kind of assistance Belarus needs might be quite different from the needs of Swaziland or the Philippines. But what countries are consistently asking for is technical assistance to turn funding into national AIDS plans, and to turn plans into real programmes for people living with and affected by HIV/AIDS. WHO is working with countries to provide this technical assistance, but much more collaboration is needed.

**Q: Beyond the rhetoric, are people living with HIV and AIDS really considered an asset in the response to HIV and AIDS, rather than the source of the problem?**

A: HIV is non-discriminatory and can hit anyone at any time and in any walk of life. Conversely, PLWHA are absolutely central to the fight against HIV/AIDS and, from the beginning, it has been AIDS activists who have pushed society towards deeper dialogue and swifter action in fighting AIDS.



PLWHA live in the communities with the most need of prevention, treatment and care, and are best equipped to advocate for change. Never before have a group of people affected by a disease stood up so loudly and effectively to fight it. As ambassadors, PLWHA involved in the fight against HIV/AIDS can help defeat the epidemic like no one else.

WHO is involving PLWHA at every level of the drive to reach the '3 by 5' target. In November 2004, WHO awarded a \$1.5 million contract to the Tides Foundation-Collaborative Fund, a global consortium of people living with HIV/AIDS, and treatment activists, to help prepare PLWHA for ART. In implementing the million-dollar grant, the Tides Foundation-Collaborative Fund is supporting more than 30 networks of PLWHA around the world in treatment preparedness activities, including treatment literacy projects and civil society advocacy initiatives.

The future of health belongs as much in the hands of those affected as those who care for them. People living with HIV/AIDS must be involved in all aspects of HIV/AIDS programmes and at all levels of decision-making and activity.

## SOUTH AFRICA: Interview with treatment campaigner, Zackie Achmat



Credit: TAC

South Africa's Treatment Action Campaign (TAC) leader Zackie Achmat has been a powerful global voice in the struggle for HIV-positive people to access free antiretroviral drugs.

**QUESTION: After the problems seen in Arusha with the Fund's next round and donors' apparent reluctance to increase their funding, what guarantees of sustainability can mass antiretroviral (ARV) treatment have?**

**ANSWER:** What we would like to see, in the long term, for HIV funding sustainability is countries committing at an international level. We'd like to see conditional debt cancellation based on spending on health, social security - which includes food security - and education. And that, taken together with the lifting of unfair trade subsidies, particularly agricultural ones in the developed world, would allow

developing countries greater access to the markets of developed countries. So, raising our own funds through taxation will be critical for sustainability.

The Global Fund is also critical, because we're dealing with an emergency and, in the short term at least, the bulk of HIV funding and treatment needs to go through the Global Fund.

**Q: Are we urging poor countries to take on life-or-death commitments that are dependent on erratic outside funding?**

A: The sad thing is that poor countries are not leading the demand because, just as none of us argue that human security is not a national or a local issue ... it should also be an international burden. For example, the war on terror is funded on an international level, and no one questions that we should all find the funding to deal with it, but when it comes to healthcare or development, the poorest countries, especially, are left to their own devices.

If you take a country like Malawi or Mozambique - they don't have the funds to finance an ARV treatment programme, and where they don't have the funds, it's an international responsibility. The steps taken by [British Prime Minister] Tony Blair and [Chancellor of the Exchequer] Gordon Brown to increase their overseas development aid to 0.7 percent of ... GDP over five years are very positive. At the moment, in the United States for example, overseas development aid amounts to less than 0.05 percent of GDP.

**Q: To what extent has the recent controversy around some generic companies withdrawing from the World Health Organisation's (WHO) prequalification list threatened the survival of ARV programmes?**

A: In the long term, I don't think it threatens the survival. The way, unfortunately, that some generic companies did their documentation for bioequivalence was a mistake, and helped undermine the confidence in generics. But I think there's a broader question, at the moment, about making all generic companies take responsibility for their mistakes.

From our point of view, the WHO's pre-qualification process is a good one, particularly for countries that don't have the mechanisms to regulate themselves. We need the WHO to bring brand-name and generic companies together to make commitments to encourage competition, and to encourage as many companies as possible to enter the market and, therefore, keep prices down. What we need in the longer term, if we're going to get 3 to 5 million people on treatment, is to encourage competition for price reduction and sustainability to ensure supply.

**Q: Isn't there a danger that the positive living aspect of HIV/AIDS treatment is being lost with all the focus on antiretroviral therapy (ART)?**

A: The problem is, there's not enough proper focus on ART and how it could be integrated with other aspects of treatment and prevention. Providing ARV treatment presents opportunities, which are not only important for positive living but for prevention, because our prevention efforts so far have been pretty much a shotgun approach.

But with the scaling-up of treatment, WHO in particular has a role to play in seeing that national programmes encourage HIV-positive people to play a role in prevention. So if you come and collect your ARVs you get your condoms, and in that way we combine our prevention and treatment programmes.

The problem is, if you take South Africa, for example, it's not helpful when you get people saying we first have to solve poverty and nutrition before we can treat people - it should never be either nutrition or ARVs. The epidemic presents an enormous opportunity to talk about the economic future of women and marginalised young men, and we need to see prevention, treatment and development as part of the same continuum, as social justice issues. As activists we've always said you can't, for instance, talk about ARV treatment without talking about health sector reforms. The difficulty is when you have agencies coming from a conservative background, pushing a certain agenda, it makes it hard to push social justice aspects.

**Q: What do you think are the key components of a successful government rollout of ART?**

A: Political leadership, sustainable funding and, most importantly, community mobilisation for treatment preparedness. Also, a national human resource plan to strengthen the whole health sector, and to integrate sexual and reproductive health, [and] include prevention of HIV. There obviously also has to be a positive living aspect at a primary healthcare level. And it goes without saying that programmes for treatment of opportunistic illnesses, like TB and malaria, must be part of [the] programme. It's an enormous opportunity to strengthen the public healthcare sector and to make health everyone's human right.

**Q: Beyond the rhetoric, are people living with AIDS really considered an asset in the response to HIV and AIDS, rather than the source of the problem?**

A: Two things I think are a problem - one is that there's not sufficient understanding: the most critical agents of prevention should be people living with HIV; they're an enormous human resource to communities, but also at a governmental level. Unfortunately, governments and agencies, and even the private sector, hope to utilise HIV-positive people as faces and as tokens, rather than as active, critical participants.

On the other hand, we, as people living with HIV, must never assume a holiness and be self-righteous about our status. In TAC, for example, my colleagues who don't have HIV work 10 times as hard as those of us who do. They have an equal right to contribute on an equal basis.

## ZAMBIA: Interview with Minister of Health Dr Brian Chituwo



Minister of Health Dr Brian Chituwo.  
Credit: IRIN

Zambia has one of Africa's largest HIV/AIDS treatment programmes, reaching almost 14,000 people, and is projected to expand to 100,000 by the end of 2005. PlusNews spoke to Minister of Health Dr Brian Chituwo about the treatment challenge.

**QUESTION: After the problems seen in Arusha with the Fund's next round and donors' apparent reluctance to increase their funding, what guarantees of sustainability can mass antiretroviral (ARV) treatment have?**

**ANSWER:** The question of ART [antiretroviral therapy] sustainability is on the government's agenda. We were of the view that we did not have the reassurance of the sustainability of this programme and, therefore, what Zambia did last year was introduce a medical levy into our tax revenue system in order to support the ART programme with readily available funds, should donors decide to withdraw for one reason or another.

It is an amount of money which is nowhere equal to, in the short term, the funding that we have been promised by the Global Fund. We have been urged to target 100,000 people with ARVs by the end of 2005, as part of the [World Health Organisation] WHO's "3 by 5" [three million people in the developing world on treatment by 2005] initiative. Prior to this initiative, in 2002, we allocated [US] \$3 million of our own resources to purchase ARVs, targeting 10,000 people.

This was following a decision we made that Zambia's socioeconomic development would almost come to a halt if we did not make ART available in our public health institutions. By September of this year [2004], after an initial very sluggish start, we had nearly 14,000 patients on ARVs - certainly, we have embraced the 3 by 5 initiative. We have an estimated 1.1 million people living with HIV/AIDS in Zambia, out of whom 140,000 require ARVs.

We have additional funding from PEPFAR [US President's Emergency Plan for AIDS Relief] and an additional grant from the World Bank, and with this funding we should be able to cover the 100,000. Our serious handicap, however, is the human resource shortage in the health system - that, believe you me, is a headache.

So, we are scratching our heads to find out how best can we scale up, and we've embarked on a training programme [for health workers]. Of course, we're also mobilising communities to participate in this programme. Given any opportunity, I have reminded the Zambian people that the fact that the government and its partners are providing therapy should not negate the important issue of prevention - so this message is being repeated again and again, especially for the youth.

**Q: Are we urging poor countries to take on life-or-death commitments that are dependent on erratic outside funding?**

**A:** Nobody is urging Zambia to take on the commitment, because we foresaw the catastrophe and the need to make as widely accessible as possible life-saving ARVs. The next thing was to urge our cooperating partners to see what we've done, and come on board and assist us. We can only urge PEPFAR and the Global Fund that they have to assist us in this life-long commitment.

**Q: To what extent has the recent controversy around some generic companies withdrawing from the World Health Organisation's prequalification list threatened the survival of ARV programmes?**

**A:** If that threat is real, it is definitely a source of worry for developing countries like Zambia, who cannot afford the brand-name drugs. We sincerely hope that, whatever difficulties or differences there were, these should be resolved in the shortest possible time.

**Q: Isn't there a danger that the positive living aspect of HIV/AIDS treatment is being lost with all the focus on ART?**

**A:** In a way, I must say 'yes', because one can see such a dramatic improvement in patients who are on their deathbeds, and within a short space of time after being on ART, they're able to walk; they're able to look after their children. That in itself, indeed, has endangered the positive living philosophy. It has helped us too, in that people now wish to know their status. Because of this dramatic improvement in quality of life, more and more people are being encouraged to undergo voluntary counselling and testing. Living positively, therefore, is in my view complimenting ARVs. We believe there's a role to play in advocating for positive living prior to people becoming

very ill, because then one can put off for quite some time the need to start ARVs.

**Q: What do you think are the key components of a successful government rollout of ART?**

A: For us, we feel we have been fairly successful so far in that, as a government, we took the lead. We said, 'No one can do this for us, we must do it ourselves'. We also recognised that government alone cannot succeed. So we brought on board faith-based organisations, who provide nearly 30 percent of the health care in our rural areas. Of course, we support them very seriously - we give them monthly grants, pay for their staff and provide the drugs. In addition, we involved churches in advocacy campaigns promoting messages of prevention and encouraging home-based care.

We also brought on board civil society - and Zambia depends on our mines, so we brought them on board as well - and then there is an army of NGOs. So what I'm saying, in a nutshell, is that in our planning on issues of implementation, all those things are discussed and reviewed together with these partner organisations.

I must state that one of the keys is that we have a National AIDS Council, which is a corporate body mandated to coordinate and monitor all activities to do with HIV and AIDS. It is overseen by the Cabinet Committee of Ministers. The Council works on strategic plans for the whole country: through their technical committee they undertake research, they promote advocacy, they mobilise the communities and monitor this army of NGOs. We just provide the political leadership and really push them, and I think so far we've been able to do what we have because of the Council, but there's a lot of work to be done.

**Q: Beyond the rhetoric, are people living with AIDS really considered an asset in the response to HIV and AIDS, rather than the source of the problem?**

A: I think in many countries, as in Zambia, there are networks of people living with AIDS. Initially there was a misunderstanding that government should only look after the people who registered with those institutions. Our view is broader than that - as far as we're concerned, any Zambian citizen who has undergone voluntary counselling and testing is a person living with HIV and, ultimately, AIDS.

So our constituency is broader than organizations that call themselves people living with AIDS. These people are represented on the National AIDS Council, so they have a voice. Secondly, we are utilising them, in that they are living testimony to the fact that AIDS has got a human face, it's not just numbers; they're being utilised in our hospitals and communities as counsellors. So, as far as we're concerned, people living with AIDS are not a problem, they are, indeed, part of the solution.

## 6. Resources

The WHO 3 by 5 Initiative

<http://www.who.int/3by5/en/>

The Global Fund to Fight HIV/AIDS Tuberculosis and Malaria

<http://www.theglobalfund.org/en/>

The President's Emergency Plan for AIDS Relief

[http://www.usaid.gov/our\\_work/global\\_health/aids/pepfarfact.html](http://www.usaid.gov/our_work/global_health/aids/pepfarfact.html)

World Bank AIDS site

[http://www1.worldbank.org/hiv\\_aids/](http://www1.worldbank.org/hiv_aids/)

Pan-African Treatment Access Movement

<http://www.patam.org>

WHO Prequalification Project

<http://mednet3.who.int/prequal/>

Eldis Resource on ARVs

<http://www.eldis.org/hivaids/ARVindex.htm>

## Contact PlusNews

### IRIN - Southern Africa - Johannesburg

3rd Floor, Sandton City Office Towers, Rivonia Road, Sandton 2146

P.O. Box 1617, Parklands, 2121, Republic Of South Africa

Tel: +27 11 895 1900

Fax: (Admin) +27 11 784 6223

Email Address: [Irin-Sa@Irin.org.za](mailto:Irin-Sa@Irin.org.za)

### IRIN - West Africa - Dakar

Sur La Vdn - Villa N° 9368 Sacré-Coeur 3,

Bp: 45792 Dakar-Fann, Senegal, Code Postale 12523

Tel: +221 867 27 30

Fax: +221 867 25 85

Email Address: [Irin-Wa@IRINnews.org](mailto:Irin-Wa@IRINnews.org)

### IRIN Liaison Office - Geneva

Office A827, OCHA/ESB/IRIN,

Palais Des Nations, 8-14 Avenue De La Paix, Ch-1211

Geneva 10, Switzerland

Tel: +41 22 917 1135

Fax: +41 22 917 0067

Email Address: [Joanne@IRINnews.org](mailto:Joanne@IRINnews.org)