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Stepping back from the edge

The pursuit of antiretroviral therapy
in Botswana, South Africa and Uganda

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Cover photos

Preparing blood samples for various tests related to antiretroviral therapy at the Botswana HIV Reference Laboratory in Gaborone, Botswana.

Photographer: Jon Heusa

Children attending a day care centre in Gaborone, Botswana.

Photographer: The African Comprehensive HIV/AIDS Partnership (ACHAP)

Treatment Action Campaign (TAC) activists' march, Cape Town, South Africa, March 2003.

Photographer: TAC volunteer

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This document was prepared under the direction of the UNAIDS Intercountry Team for Eastern and Southern Africa, in Pretoria, South Africa (responsible staff member, Catherine Sozi). The document was written by Sue Armstrong at the request of UNAIDS.

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The Botswana Harvard AIDS Institute Partnership, HIV Reference Laboratory
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In South Africa:

TAC (Treatment Action Campaign)
The AIDS Law Project
The Community Health Media Trust
COSATU (Congress of South African Trade Unions)
GARPP (Generic Antiretroviral Procurement Project)

In Uganda:

NGEN+ (The National Guidance and Empowerment Network of People Living with HIV/AIDS)
NACWOLA (National Community for Women Living with AIDS in Uganda)
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The Masaka Regional Referral Hospital
The Joint Clinical Research Centre
Medical Access
The Ministry of Health

Uganda AIDS Commission
UNICEF
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Acronyms

| | |
|---------|--|
| ACHAP | African Comprehensive HIV/AIDS Partnership |
| AHF | AIDS Healthcare Foundation |
| AIC | AIDS Information Centre |
| AIDS | Acquired immunodeficiency syndrome |
| AIDSETI | AIDS Empowerment and Treatment International |
| ALP | AIDS Law Project |
| ANC | African National Congress |
| ART | Antiretroviral therapy |
| ARV | Antiretroviral |
| AZT | Zidovudine |
| BONEPWA | Botswana Network of People Living with HIV/AIDS |
| CBO | Community-based organization |
| COCEPWA | Coping Centre for People Living with HIV/AIDS |
| COSATU | Congress of South African Trade Unions |
| DAI | Drug Access Initiative |
| GARPP | Generic Antiretroviral Procurement Project |
| HAART | Highly Active Antiretroviral Therapy |
| HIV | Human immunodeficiency virus |
| JCRC | Joint Clinical Research Centre |
| JMS | Joint Medical Stores |
| MAP | Multi-country HIV/AIDS Program for Africa (World Bank) |
| MHC | Masaka Health Centre |
| MSF | <i>Médecins Sans Frontières</i> |
| MTCT | Mother-to-child-transmission |
| NACWOLA | National Community of Women Living with HIV/AIDS in Uganda |
| NGEN+ | The National Guidance and Empowerment Network of People Living with HIV/AIDS in Uganda |
| NGO | Nongovernmental organization |
| PHATAM | Pan-African HIV/AIDS Treatment Action Movement |
| PMA | Pharmaceutical Manufacturers' Association of South Africa |
| PMTCT | Prevention of mother-to-child transmission |
| SADC | Southern African Development Community |
| STI | Sexually transmitted infection |
| TAC | Treatment Action Campaign |
| TASO | The AIDS Support Organization (Uganda) |
| TB | Tuberculosis |
| TRIPS | Agreement on Trade-Related Aspects of Intellectual Property Rights |
| UBC | Uganda Business Coalition |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNGASS | United Nations General Assembly Special Session |
| VCT | Voluntary counselling and testing |
| WHO | World Health Organization |
| WTO | World Trade Organization |

Foreword

The history of the global AIDS movement has been one of overturning conventional wisdom—refusing to accept that ‘it can’t be done’ and taking the bold steps necessary to combat the unprecedented threat of AIDS.

Today, one of the pre-eminent barriers to an effective global AIDS response is the gulf that separates the rich and poor worlds in terms of access to life-prolonging HIV treatment. There are still those who say ‘it can’t be done’—but it must be done. It is morally, ethically, politically and even economically unsustainable for the majority of the world’s people living with HIV to have no access to the treatments that can save their lives.

In 2003, UNAIDS (the Joint United Nations Programme on HIV/AIDS) is boosting its efforts to secure universal and equal access to antiretroviral treatment, with one of its nine cosponsoring organizations—the World Health Organization—taking a leading role. The campaign has adopted the goal of having 3 million people on treatment by 2005 as a first step.

This document spells out what it will take to achieve universal access to HIV treatment: vision, activism and risk-taking.

The examples in this Best Practice document are drawn from Botswana, South Africa and Uganda. They show communities and valiant individuals in action, overcoming the barrier of grossly inadequate resources to become models of effective activism. The challenges remain enormous: poor health infrastructures, inadequate hospital facilities, shortages of professional staff, and little expertise in treating HIV/AIDS. But with global will, combined with national and community action, the ‘impossible’ is being put within reach.

Equitable access to HIV treatment is one of the great moral challenges of our times. Alongside its essential counterpart—universal access to HIV-prevention efforts—it holds the key to halting the AIDS pandemic.

Let this document be a source of inspiration and energy—and let it be a practical tool for meeting the HIV treatment challenge.



Dr Peter Piot
Executive Director
Joint United Nations Programme on HIV/AIDS (UNAIDS)

Introduction

In August 2002, Zoliswa Magwentshu's family was called by the hospital in Cape Town, South Africa, where Zoliswa was being treated for tuberculosis and pneumonia. The family was told to come and take Zoliswa home; she was not responding to treatment and there was no more the hospital could do for her. "I couldn't walk; I was mentally confused, and I thought I was dying," she recalls. "I even made my last wish." But a friend told Zoliswa about antiretrovirals and helped her to register with the only provider of the drugs in Cape Town—a clinic run by *Médecins Sans Frontières* in her township of Khayelitsha. "On 21 August 2002, I started on antiretrovirals," she says with a big smile, as though the date will be etched on her mind forever. "After a week, my appetite was back. Everything was just subsiding—the pneumonia, the TB. I got stronger and stronger every day. Before, my life was shattered. But these drugs have given me hope. I know now I will live and watch my children grow up."

"We are angry. Our people are dying. We can no longer accept millions of needless AIDS deaths simply because we are poor Africans. We know antiretroviral treatment is feasible in our countries and we are launching a movement to demand antiretroviral treatment that won't take 'no' for an answer."

—Milly Katana¹

When Herriet Kopi, a young woman living in Botswana, was diagnosed with HIV in 2001, she knew very little about HIV/AIDS. Until then, she had accepted the traditional explanation for her chronic, distressing health problems: that she had been bewitched. Her skin rashes were so bad she hid her arms and legs under long clothes, and she was paralysed down one side. Herriet managed to enrol in the Masa antiretroviral programme being piloted in Botswana at that time, but her family were told that the chances of successful treatment were slim; Herriet's CD4 count was zero, which meant that her immune system was almost totally destroyed. She battled with severe side-effects before her doctor found the right combination of drugs. But, today, Herriet is clear-skinned and pretty again—a young woman with remarkable energy and sense of purpose as she goes about her work as a community liaison officer at the antiretroviral clinic in Gaborone.

Antiretrovirals have saved the life and rescued the future of Ruranga Rubaramira, too. A Major in the Ugandan Army, he was a long-term survivor of HIV, having been infected in the mid-1980s and suffered few ill-effects for nearly a decade. But, in 1997, the Major's health suddenly began to fail. The virus became active again and his CD4 count began to drop dramatically. He believed he did not have long to live, and he too fretted about the children he would leave behind.



Buddies at the Coping Centre for People Living with HIV/AIDS (COCEPWA), Gaborone, Botswana. Photographers: Anneke Zuyderduin and Pieter Jan Visser

¹ Milly Katana of the Health Rights Action Group, Uganda, is a founding member of the Pan-African HIV/AIDS Treatment Access Movement (PHATAM), launched in August 2002 at the World Summit for Sustainable Development, Johannesburg, South Africa. This quote comes from PHATAM's press release at the launch.

But, with the help of friends, Major Rubaramira was able to obtain antiretroviral treatment, and he is so confident of his own future that he and his wife decided to have more children.

Zoliswa, Herriet and the Major are among the fortunate ones. The vast majority of people living with HIV/AIDS in sub-Saharan Africa do not have access to antiretrovirals. The region is home to 71% of the global total of HIV-positive people—about 29.4 million²—yet only around 50,000 were taking the drugs at the end of 2002³. That is the equivalent of the population of a couple of villages in this whole vast continent. In fact, many people living with HIV/AIDS in Africa do not even have access to treatment for common opportunistic infections or for pain, and around 2.5 million have died annually over the last two years from AIDS-related illnesses⁴.

People in the developing world face myriad barriers to treatment with antiretrovirals. The drugs are expensive and, in many cases, protected by patents that keep the prices high. Although the prices of drugs are coming down fast and dramatically as a result of competition from generics⁵, campaigning by activists, discount prices offered by the pharmaceutical companies and other promising new developments including price brokering, a year's antiretroviral therapy still costs more than many families earn in a year. The health infrastructure in many places is poor, with run-down buildings, inadequate laboratory facilities, and chronic shortages of staff and professional skills, not to mention expertise in treating HIV/AIDS. Compounding these structural barriers is a chronic lack of political will at the national and international levels to tackle HIV/AIDS with the urgency, energy and resources necessary to bring this epidemic under control.

“Antiretroviral therapy is not only an ethical imperative, it will also strengthen prevention efforts, increase uptake of voluntary counselling and testing, reduce the incidence of opportunistic infections, and reduce the burden of HIV/AIDS—including the number of orphans—on families, communities and economies”⁶.

The effect of antiretrovirals on individual lives is often near-miraculous. However, it should be emphasized that these drugs are not a cure for HIV/AIDS, nor are they some kind of magic bullet. There is no single medical solution to this extremely complex epidemic. Antiretrovirals are just one part of an integrated package of interventions that include prevention, care and support activities, all of which complement and reinforce each other (see box overleaf). People living with HIV/AIDS still need treatment for opportunistic infections from time to time; they still need psychosocial support in coping with an incurable illness with serious implications for behaviour and lifestyle; and there is still a pressing need to prevent infection in those who are clear of the virus.

However, antiretrovirals are an extremely important component of the package: in the developed world, they have taken the sting out of HIV/AIDS so that it is no longer perceived

² *AIDS Epidemic Update, December 2002*, UNAIDS.

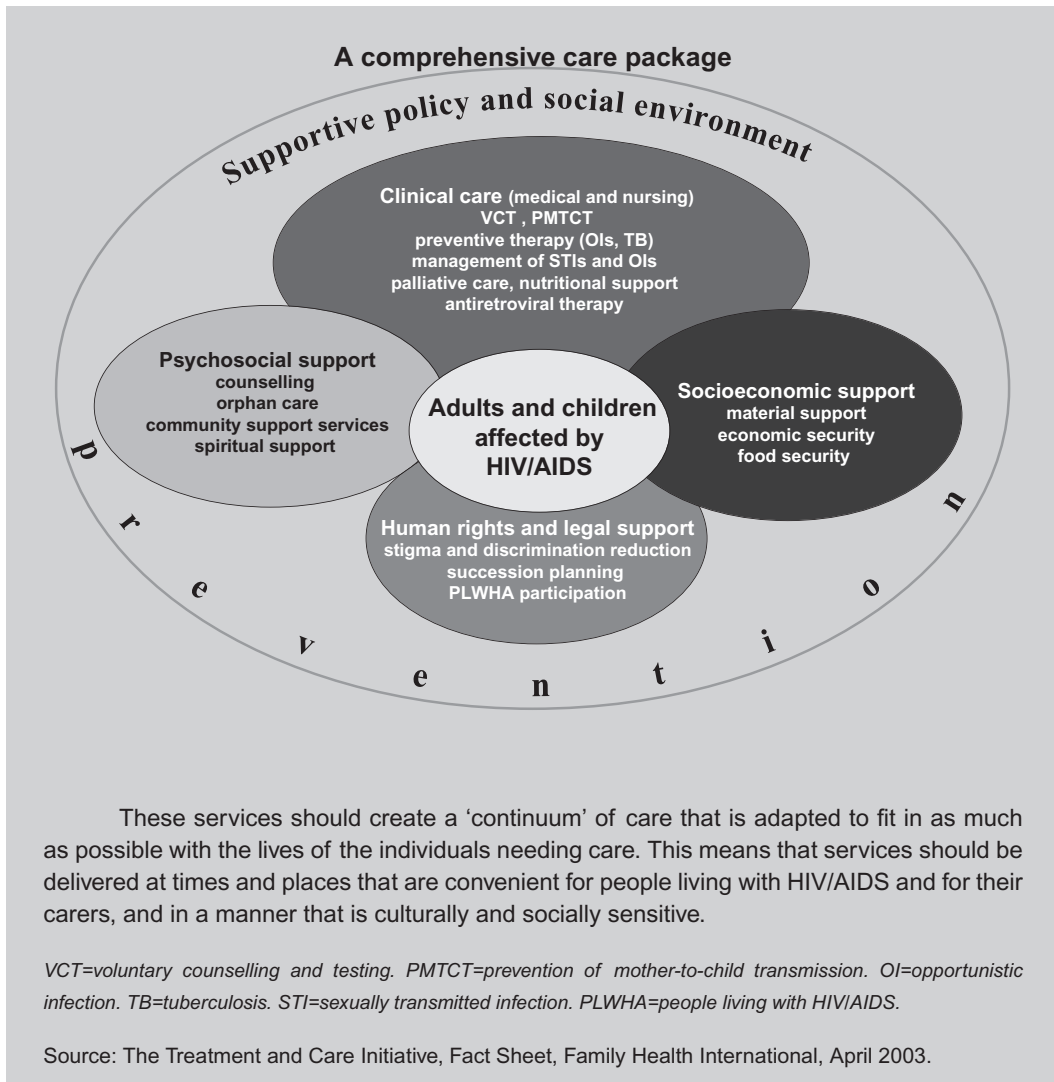
³ Source: WHO/UNAIDS (2002) *A Commitment to Action for Expanded Access to HIV/AIDS Treatment* International HIV Treatment Access Coalition.

⁴ *AIDS Epidemic Update, December 2002*, UNAIDS.

⁵ A generic is a drug sold under the official medical name of the basic active ingredient. In the case of antiretrovirals, it is usually a cheaper copy of a brand-name drug developed by a research-based pharmaceutical company.

⁶ Press release at the launch of the Pan-African HIV/AIDS Treatment Access Movement (PHATAM), August 2002, at the World Summit for Sustainable Development, Johannesburg, South Africa.

as an automatic death sentence, but a manageable chronic illness, much like diabetes or hypertension. Generally speaking, people with HIV/AIDS are able to stay in the mainstream of life, contributing to society and the economy, and remaining in good health most of the time. It is morally unacceptable that our brothers and sisters in the developing world, where the epidemic is at its worst, should be denied access to these life-saving drugs.



Over the last few years, many resolutions have been passed, bold targets set, and pledges of financial assistance made by rich countries to the poor (see box on Milestones on page 13). Key among these are the Declaration of Commitment on HIV/AIDS; the Millennium Development Goals; General Comment 14 of the Committee on Economic, Social and Cultural Rights; and the Commission on Human Rights resolutions on the right to the highest attainable standard of health and access to medication⁷. Regionally, through the Abuja and Maseru Declarations, for example, governments and the international community have committed themselves to improving access to treatment and care for people living with HIV/AIDS by, among other things, increasing the budgetary allocation to the health sector. The Global Health Sector Strategy for HIV/AIDS, endorsed by the 2003 World Health Assembly, provides a framework for scaling up activities, including care and treatment. At the international HIV/AIDS

⁷ *HIV/AIDS and Human Rights, International Guidelines, Revised Guideline 6: Access to Prevention, Treatment, Care and Support*, UNAIDS, 2002.

conference in Barcelona in July 2002, the World Health Organization (WHO)⁸, supported by UNAIDS, set a target for 3 million people to be on antiretroviral drugs by 2005.

But the truth is that, over two decades after AIDS was first known to exist, many people in positions of power and influence see HIV as an old enemy that they have learned to live with. Once they leave the public platform, all sense of urgency evaporates. It's back to business as usual. Progress in translating the worthy rhetoric from conferences and summit meetings into effective action is painfully slow, and every day of delay costs lives.

What are antiretrovirals and how do they work?

HIV is a virus that attacks the immune system—the body's defence system against infection and illness. HIV mainly infects cells in the immune system called CD4 cells, gradually destroying them and causing the number of CD4 cells in the body to drop, so that the immune system is weakened. HIV is what is known as a retrovirus; thus, the drugs used to control HIV infection are called antiretrovirals—or ARVs, for short. These drugs, which are used in combination to maximize their effectiveness, reduce the level of HIV in the body, so that the immune system is allowed to recover partially and further damage is slowed or prevented. While treatment with antiretrovirals can greatly improve the health and extend the life expectancy of people living with HIV/AIDS by several years, these drugs are not a cure. If a patient stops treatment, or if the virus develops resistance to the drugs, the infection resumes its natural course.

There are three main types of antiretrovirals, each of which targets a different part of the virus's multiplication cycle:

- Nucleoside reverse transcriptase inhibitors (NRTIs);
- Protease inhibitors (PIs); and
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs).

This report looks at what is being done to challenge the snail's pace of progress on access to antiretrovirals in three very different African countries—Botswana, South Africa and Uganda. It describes *who* is taking the initiative at grass-roots level and *how*. Those involved face a daunting task. “Nowhere in the world is there a programme of this magnitude, so there are no really comparable situations for us to learn from,” says Segolame Ramotlhwa, a pharma-

Coverage of antiretroviral therapy (ART) for adults in developing countries, by region, December 2002

| Region | Number of people on ART | Estimated need | Coverage |
|-------------------------------|-------------------------|----------------|----------|
| Sub-Saharan Africa | 50,000 | 4,100,000 | 1% |
| Asia | 43,000 | 1,000,000 | 4% |
| North Africa & Middle East | 3,000 | 9,000 | 30% |
| Eastern Europe & Central Asia | 7,000 | 80,000 | 9% |
| Latin America & Caribbean | 196,000 | 370,000 | 53% |
| All regions | 300,000 | 5,500,000 | 5% |

(Source: WHO/HIV/2002.24, www.who.int).

⁸ WHO is the lead UNAIDS cosponsoring agency responsible for HIV care and treatment.

cist with the management team developing the antiretroviral programme in Botswana, where around 35% of the adult population is HIV-positive. Furthermore, says his colleague Dr Ernest Darkoh, who is operations manager of the programme, “one of our biggest challenges is that everyone who turns up on our doorstep is very, very sick.” Patients often require treatment for failing livers or kidneys, blood transfusions, intravenous drips, a hospital bed, and intensive care by health professionals before they are ready for antiretroviral therapy.

The purpose of the report is to offer insights and draw lessons from first-hand experience that may help and encourage others working towards better access to antiretrovirals. It is intended for all those with an interest in the issue, from policy- and decision-makers with the power to create a favourable environment for antiretroviral treatment, to those working on the front line in health services, NGOs and AIDS service organizations, as well as those living personally with the virus, whose role in the battle for wider access is so vital.

Milestones in the history of antiretroviral treatment

- 1987 (March) Zidovudine (AZT), the first ARV drug, becomes available.
- 1996 Highly Active Antiretroviral Therapy, or HAART, which uses a cocktail of antiretroviral drugs, is introduced.
- 1997 (November) Launch of UNAIDS’ Drug Access Initiative, designed to develop innovative, effective models to improve access to medicines to treat HIV and opportunistic infections in developing countries.
- 1999 (December) Using the prize money received from winning the Nobel Peace Prize *Médecins Sans Frontières* launches a campaign for Access to Essential Medicines for neglected diseases, including HIV/AIDS.
- 2000 (May) Launch of the Accelerating Access Initiative (AAI) —a partnership between five UN organizations and six pharmaceutical companies⁹ to address the lack of affordability for HIV medicines and to increase access to HIV/AIDS care and treatment in developing countries.
- 2000 (September) the World Bank launches the Multi-Country HIV/AIDS Program for Africa (MAP) to make funds available rapidly and flexibly to assist countries in scaling up their HIV/AIDS-related activities.
- 2001 (January) The African Comprehensive HIV/AIDS Partnership (ACHAP) between the Government of Botswana, the Merck Company Foundation, and the Bill & Melinda Gates Foundation starts with the development and implementation of a comprehensive HIV/AIDS strategy in Botswana, which includes large-scale access to antiretroviral treatment in the public health sector.
- 2001 (April) African leaders at the summit of the Organization of African Unity (OAU) in Abuja, Nigeria endorse the need for greater efforts to fight HIV/AIDS on the continent, and committed their leadership to the cause. In the Abuja Declaration on HIV AIDS, Tuberculosis and Other Related Infectious Diseases, African governments committed themselves to a target of allocating at least 15% of their annual budgets to the improvement of the health sector, and to making available the necessary resources for the improvement of the comprehensive multisectoral response to the HIV/AIDS epidemic.

—>

⁹ Partners in the Accelerating Access Initiative (AAI) are: UNAIDS, UNFPA, UNICEF, WHO, the World Bank, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, Merck & Co., Roche and Abbott.

- 2001 (April) The UN Commission on Human Rights adopted a resolution recognizing for the first time that access to drugs in the context of epidemics such as HIV/AIDS is “a fundamental element of achieving progressively the full realization of the right of everyone to enjoyment of the highest attainable standard of health”.
- 2001 (June) Declaration of Commitment on HIV/AIDS adopted unanimously by the UN General Assembly Special Session (UNGASS) on HIV/AIDS. Access to antiretroviral drugs specifically recognized by the world’s governments as an essential element in the response to the epidemic.
- 2001 (July) The Global Fund to Fight AIDS, Tuberculosis and Malaria is set up. An initiative strongly supported by the UN Secretary-General, Kofi Annan, the Fund is an independent, public-private partnership designed to attract, manage and disburse new resources to fight the global crises represented by these three diseases.
The Fund provides funding for comprehensive AIDS programmes, including ARVs.
- 2001 (November) The Doha Declaration on TRIPS¹⁰ and Public Health is adopted by members of the World Trade Organization, reconfirming the right of national governments to override patents, if necessary, in order to promote access to medicines by all.
- 2002 (April) WHO includes 12 antiretrovirals on its Model List of Essential Drugs, which is used by countries to develop essential drugs lists appropriate to their own needs.
- 2002 (July) At the World AIDS Conference, Barcelona, WHO announces a commitment to the goal of having 3 million people on ARV therapy in low- and middle-income countries by the year 2005.
- 2003 (July) Maseru Declaration adopted by Heads of State at a Southern African Development Community (SADC) Summit on HIV/AIDS, held in Maseru, Lesotho, reaffirms the commitment of governments of the region to combating the epidemic as a matter of urgency through multisectoral action. Priority areas include access to testing, care and treatment, and the mobilization of funds.
- 2003 (August) Decision on implementation of paragraph 6 of the Doha Declaration on the TRIPS Agreement and Public Health, the one remaining piece of unfinished business on intellectual property and health that was left over from the WTO Ministerial Conference in Doha in November 2001. WTO member governments broke their deadlock over intellectual property protection and public health. They agreed on legal changes that will make it easier for poorer countries to import cheaper generics made under compulsory licensing if they are unable

¹⁰ Agreement on Trade—Related Aspects of Intellectual Property Rights—an agreement supervised by the World Trade Organization (WTO).

Botswana: a vision struggling for realization

Botswana has one of the highest recorded HIV prevalence levels in the world, estimated at 35.4% in pregnant women attending antenatal clinics (National AIDS Coordinating Agency 2002). This is the figure used as an indication of the adult (15–49-year-olds) seroprevalence among its 1.7 million people. On average, around 85 people become HIV-infected every day¹¹. One in eight babies is born HIV-positive and 66,000 children have been orphaned by the epidemic.

“We are threatened with extinction. People are dying in chillingly high numbers. It is a crisis of the first magnitude,” said Festus Mogae, Botswana’s President. Shocked not only by the death toll and the very high infection rates showing up in sentinel surveys, but also by the expert predictions that, within 10 years, the average household income would fall by 8%, pushing more than half of Botswana’s people below the poverty line, and that the economy as a whole would be progressively crushed under the burden of sickness and death, the President has vowed to do everything necessary to bring the epidemic under control.

“My message to those who are on therapy is: commit to your therapy; marry it and remember that divorce is not an option. You have the privilege of re-living your life; give it your best shot and plan well for your new-found future.”

—Patson Mazonde¹²

In 2000, the Cabinet declared AIDS a national emergency, allowing HIV/AIDS funding to be considered at any time and not tied to the annual budget. Considerable extra resources were put into HIV/AIDS-prevention-and-care activities and, in July 2000, the programme to prevent mother-to-child-transmission of HIV, which had been piloted in Gaborone and Francistown, was scaled up across the nation. The President subsequently declared his intention of making antiretroviral drugs available to every HIV-infected person who needed them, in due course. Thus, in 2001, Botswana became the first country in southern Africa with a national programme offering the total package of comprehensive care through the public health system, which includes the provision not only of drugs for opportunistic infections, but also treatment with antiretrovirals. In 1997, a presidential task force had set out long-term development goals for the country that envisioned an AIDS-free generation by 2016. Clearly, access to antiretrovirals was necessary in order to make this bold vision a reality.

¹¹ Botswana Country Brief, updated February 2002, UNAIDS.

¹² Patson Mazonde is Director of Health Services in the Ministry of Health of Botswana. This quote comes from the Masa newsletter, October 2002.

The Masa antiretroviral programme

The Masa ('new dawn') antiretroviral programme was set up in 2001 with technical and financial assistance from the African Comprehensive HIV/AIDS Partnership (ACHAP)¹³. A team representing a wide range of expertise was put together and commissioned to develop detailed implementation plans and ultimately launch the programme. Its members include public health specialists, professional management consultants, medical and nursing personnel, pharmacists, social workers, IT specialists, educationalists, administrators, and public relations people. Because of Botswana's small population and scarcity of professional skills, key professionals were recruited from abroad, but their brief is to pass on their skills in the course of their work to build up local capacity. Most are 'embedded' within Botswana's health services rather than operating out of an 'ivory tower'. And, in order to prevent the programme from getting bogged down in government bureaucracy, the team as a whole has been given a good deal of responsibility and decision-making power.

Taking stock

They started by commissioning a comprehensive study of the situation in Botswana, intended to:

- estimate the potential demand for antiretrovirals—i.e., how many of Botswana's 300,000 or so HIV-positive people were at a stage where they could benefit from such treatment;
- Assess the country's situation in terms of funds and human and physical resources to provide the treatment, and to identify the main gaps; and
- make recommendations on how to set up the treatment programme.

The study took two months and entailed multi-disciplinary teams fanning out across the country to talk to interested parties at all levels of government and society, including, of course, people living with HIV/AIDS and dedicated organizations.

At that time, says Dr Donald De Korte, project leader of ACHAP, "we did not have a good idea of how and where capacity needed to be built in order to improve AIDS care".

Estimating the demand for antiretroviral treatment meant deciding at what point in the progress of HIV infection it would be most appropriate to initiate therapy. After exhaustive research and deliberation, the team decided that an HIV-infected person with a CD4 count below 200 and/or with symptoms of AIDS should be considered eligible for treatment. They calculated that this would be about 110,000 of the total 300,000 people currently believed to be living with the virus. However, no more than a fraction of this number would be expected to come forward for treatment in the short term, since heavy stigma means people are reluctant to be tested for HIV and only a small proportion are aware of their infection.

The Masa programme was launched initially at four test sites across the country—Gaborone, Francistown, Serowe and Maun—where there are sizeable concentrations of people.

¹³ ACHAP was set up jointly by the Bill & Melinda Gates Foundation and the Merck Foundation.

Staffing the programme

One of the biggest gaps identified by the study was in the area of skilled personnel to provide the treatment. Throughout Botswana, the health services were operating with shortages of staff, and there was practically no expertise in treating HIV/AIDS. So a big recruitment drive, both inside and outside the country, was initiated to bring on board not just extra doctors, nurses and pharmacists, but also new types of counsellors to help patients with adherence to their drug regimens.

Health personnel at all levels needed specialized training in providing antiretroviral treatment and, in developing a training programme, the Masa team turned to the Harvard AIDS Institute, which was already conducting clinical research in Botswana and helping the Ministry of Health upgrade its laboratory services. Together, they developed the Kitso AIDS training course. The training programme consists of 12 basic lectures covering everything from virology and immunology, to drug interactions and the side-effects of antiretrovirals. Trainers are free to add their own specialist information to the basic course. Trainees take an exam at the end, and the doctors among them are certified by the Ministry of Health to prescribe antiretrovirals (which no doctor can do without specialized training).

By mid-2003, over 700 people country-wide and at all levels of the health services had completed the Kitso AIDS course. It has become the standard training package, used also to train private practitioners and health personnel employed by the big mining houses that run their own hospitals.

A second training programme, supported by ACHAP, is the 'preceptorship' programme in which HIV experts from renowned international institutions work in the clinics with staff, mentoring them and giving additional lectures. Professor Freers, who joined the Masa programme from the medical faculty at Makerere University in Uganda, says, "When the doctors under supervision have presented so many cases, including a number of problem cases (patients needing to change therapy, for example) we sign them off. It's just like in medical school." Clinical preceptors are usually AIDS experts from overseas who go to work in Botswana for anything from three months to two years. The impact of the programme is impossible to quantify but is likely to be enormous, says Dr De Korte, because people who come for a while make friends, develop bonds with the places where they work, and when they go home they often keep up the links. They can give advice and guidance on difficult cases to their former colleagues by e-mail, if necessary.



Preparing blood samples for various tests related to ARV therapy at the Botswana-Harvard HIV Reference Laboratory in Gaborone
Photographer: Jon Heusa

Choosing the drugs

A major consideration in setting up the programme was which drugs to choose from those available on the market. Since the country's health-care workers had no experience in antiretroviral treatment, a committee in the Ministry of Health was given the task of finding combinations that had been shown to be effective elsewhere. They chose 10 brand-name antiretrovirals to put on the Essential Drugs List¹⁴, offering a fairly wide range of combinations and flexibility in prescribing. "Our concern was to maximize the number of options a patient had for treatment, at the same time as making the drug regimen as easy as possible to adhere to," explained Segolame Ramotlhwa, the pharmacist on the Masa team. So they looked for drugs that were as simple to take as possible and the side-effects of which were well documented and predictable.

Another major concern was minimizing the risk of drug resistance, and this also affected the choice of drugs, as well as the guidelines drawn up for their use.

"The issue of resistance is raised frequently during the training of doctors," said Mr Ramotlhwa. They are taught how best to prescribe to avoid problems with resistance, a first principle being to keep as many options as possible open for the future. Thus, there is a rule that when a patient develops resistance to the first-line treatment, the doctor must seek advice from a specialist on what combination of drugs to try next.

Antiretrovirals are treated in much the same way as narcotics. They are kept under lock and key, and removing them from safe storage requires the signature of two people. Every tablet has to be accounted for, from the Central Medical Stores to the user. Thus, whenever tablets leave the store or the hospital pharmacy, a record is made of who took them and when.

A commitment for life: adherence to treatment and the role of the pharmacist

Olusola Oyenuga and Urhie Emo Boyle are pharmacists recruited from Nigeria to work at the Segkoma Memorial Hospital in Serowe. They do two-monthly shifts at the antiretroviral clinic where they take key responsibility for adherence counselling and dispense the drugs. Compliance with treatment is something that all pharmacists are taught to raise with their customers. However adherence is altogether more serious: "It's 'compliance-plus'," says Mr Boyle. "We are not in a hurry to give out the drugs. This is for life and we must be sure people understand the risks and implications of resistance and are ready to make that commitment."

In the initial counselling session, the pharmacist finds out how much the patient knows about their condition. He also finds out about their personal circumstances—the family set-up; to whom, if anyone, they have disclosed their HIV status; where they live and how far they must travel to the clinic; and details of their social and economic background. In Serowe, the antiretroviral programme has developed a checklist of issues to cover in adherence counselling. When patients are given their first supply of drugs, they are also given a sheet of paper marked up with days of the week and times of day, and they are asked to record when they take their pills. They bring the record to the clinic to show the adherence counsellor, and he or she can then correct any mistakes in the pattern of pill-taking. Patients are also given a sheet of paper describing the common side-effects they might expect with each drug and are asked to make a note of what they experience.

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¹⁴ Essential drugs are medicines that satisfy the priority health-care needs of the population. Those included on the Essential Drugs List of a country are intended to be available in the public health services at all times in adequate amounts, in the appropriate dosage forms, of assured quality, and at prices the individual and community can afford.

Problems with adherence may be psychological, social or logistical, say the counsellors. Many people have difficulty finding the time and money for regular visits to the hospital for tests, and to the clinic for monitoring and collecting their drugs. Some of their patients travel 260 kms or more for treatment in Serowe, says Mr Oyenuga. Some people have not disclosed their HIV-positive status widely within the family and are afraid of being found out when they take their drugs. A few suffer early side-effects they find hard to bear. And some struggle to abide by the counsellor's advice to give up smoking, drinking, or taking any other kind of drugs that may react with the antiretrovirals or otherwise undermine the effectiveness of treatment. In Botswana, many people consult traditional healers and this can pose a dilemma for those on antiretrovirals if the healers do not support adherence.

Though not compulsory, the counsellors do encourage people to have an 'adherence partner' or buddy—someone to share the responsibility and remind the patient to take their drugs on time; to encourage them when they are perhaps feeling too sick or demoralized to bother; to collect their repeat prescriptions, if need be; and to alert the health services in an emergency.

Like the infectious diseases clinic in Gaborone, the clinic in Serowe is overwhelmed with work. The counsellors regularly see 20, and sometimes many more, patients in a day. "You must take time to listen, and you must be a good listener," says Olusola Oyenuga. "When you discover that someone isn't taking their drugs properly, or has even been sharing them with someone else," adds Urhie Boyle, "it is very important not to show exasperation or anger, or you will deter them from telling the truth about their behaviour and the difficulties they are having. You must work with the reality of people's situations."

"It's exhausting work and you can get burnt out," comments Mr Oyenuga. "You have to make sure you take your breaks regularly."

Keeping records

When the Masa programme began, doctors, nurses, pharmacists and counsellors were keeping their patient records in handwritten files—a system that was inefficient, open to abuse, and generated unwieldy piles of paper. IT specialists on the Masa team have therefore developed a computer-based patient management system that has been set up in the treatment centres.

The challenge for the IT specialists was to create a system that enabled the programme to track patients, to see what drugs they were given and when, and to monitor adherence and health parameters. In the computer-based system they have developed, each patient is given an identity number, and their contact details are recorded. Thus, if someone goes to another treatment site and tries to register, they will immediately be identified as being already in the system. All the drugs prescribed to a patient are recorded, along with the dates when they should return for a re-supply. If the patient does not return on the correct date, it is immediately apparent in their notes.

The record has four categories of users: doctors, pharmacists, laboratory staff, and programme administrators. Each has a different type of access to the records, with each being able to enter data relevant to their own area of concern, but able only to read data entered by others. Thus, a pharmacist can enter data about drugs dispensed, but can only read what doctors have written. And doctors can read what drugs the pharmacists have dispensed, but can only enter data about consultation with the patient. Only those with the right to enter data in a report can make changes to that part of the report, and the computer will record the identity of the person making changes and the date and time those changes were made. And no one can delete

a whole file. “This way, we’ve built accountability into the system,” says Aziz Haidari, one of the three IT specialists who developed it.

The system helps the pharmacist with stock management, too. All drugs dispensed are recorded in the patients’ records and, at the end of the day, the pharmacist can call them up as a total figure. To guide the pharmacist in ordering supplies, the daily total can be subtracted from whatever was in stock to give a figure for what is left.

The package underwent a process of continuous field testing and refinement over a period of about nine months, and is now being delivered to the centres. However, health-care personnel need training in using the electronic system, and the IT people have been holding intensive, week-long workshops. Each trainee is given a hard-copy manual with the basics of computing as well as an instruction manual for the patient management programme itself. Staff can also get help on-line from the IT specialists at Masa headquarters.

Botswana is breaking new ground, learning to deal with an epidemic that is one of the worst in the world and with distinctive features, so there are many questions needing answers. Will the drugs behave the same way in the people of Botswana as they do elsewhere, and will the side-effects be the same? Do genetic, or even behavioural, variations in people make a difference? Research is a core part of the antiretroviral programme, and the computer-based system, with its powerful capacity to gather data, serves the purposes of research also. It can organize data according to gender, age groups, or topic—pulling out, for example, all the data pertaining to CD4 counts or viral load. And it will also assist in the monitoring of drug resistance and adherence: the computer can call up data showing how many patients have failed to return for re-supply of their drugs on the correct date, and by how many days they are late. “We haven’t been able to anticipate all the uses to which people might want to put the data,” said Aziz Haidari, but the system has a good deal of flexibility and his team is ready to provide a programme to access whatever data researchers might be looking for.

A state-of-the-art laboratory

Until recently, there was no AIDS laboratory in Botswana and all samples were sent to South Africa for analysis. In December 2001, a newly-built, state-of-the-art HIV reference laboratory opened at the Princess Marina Hospital in the capital Gaborone. It was funded by the Botswana Government, Bristol-Myers Squibb and ACHAP but is operated with technical

assistance from the Botswana-Harvard AIDS Institute Partnership. A much smaller, but equally modern, laboratory has also been set up in Francistown, the site of one of the earliest treatment centres, with assistance from the US Centers for Disease Control and Prevention (CDC). Together, the two laboratories handle all the CD4 and viral load work



Testing at the Botswana-Harvard HIV Reference Laboratory in Gaborone
Photographer: Jon Heusa

for the Masa programme, with samples being transported by courier service by road or by air from the outlying sites.

By September 2003, the Botswana-Harvard HIV Reference Laboratory in Gaborone had 18 technicians—mostly local science graduates trained on the job over a period of four-to-six months. The laboratory handles around 400 samples a day, says the director, Dr Trevor Peter. But the antiretroviral programme is expanding fast, and there is a pressing need for more technicians to keep up with the growing demand.

Walking round the bright new laboratories, with their grumbling machines, flashing computer screens and printers ceaselessly churning out data, Dr Peter comments that people often blanch at the capital cost of equipment. But hi-tech machines usually pay for themselves in a matter of months; the real expense, he says, is the supply of reagents. Negotiations with the suppliers have therefore been part of the regular work of the laboratory, and they have managed to bring down the cost of many of the tests by up to 80% since the programme started, largely through agreements with the pharmaceutical companies.

On the front line

The corridors of the infectious diseases clinic at Princess Marina Hospital in Gaborone are lined with people. Every chair is taken, and more people are leaning against the wall or squatting on the floor. A handful of children are playing about everyone's feet. White-coated nurses and doctors bustle among the waiting patients, and disappear into consulting rooms, closing doors on the low hum of voices and the hacking coughs. Everyone pulls in their feet and presses closer to the wall as a hospital trolley is wheeled in, the patient covered with a blanket so that only her braided hair and a stick-thin arm attached to a drip are visible outside the bedclothes. The woman's young son and daughter stand by her in the queue for the doctor.

Like so many of the patients on antiretrovirals, this woman has come for treatment at a very late stage of the disease. Though individuals are eligible for treatment when their CD4 count drops below 200, most do not know they are HIV-positive until they are very sick. Records show that the average CD4 count on registering with the programme is about 57, but for some patients it is zero.

“When you show up with one week of life left in your body and you need heroic efforts to bring you back, there is no opportunity to plan your care,” comments Dr Ernest Darkoh. “The analogy I like to draw is of driving through a thick mist, when objects only show up when you are nearly upon them and have little time to take evasive action.” This situation was not anticipated by the programme planners, and the health-care personnel on the front line are struggling to cope. The original assumption was that people would have four-to-five visits to the clinic per year for review and monitoring, but the very sick patients registering with the clinics today need to be seen four-to-five times just in the first few weeks of treatment. Nevertheless, despite the enormous pressure on services, the programme had already enrolled 14,307 patients by the end of October 2003, 9,228 of whom were on antiretroviral treatment.

The great majority of patients on the programme are referred by hospitals and clinics. However, increasing numbers of patients are coming from voluntary counselling and testing (VCT) centres. Those who test HIV-positive are sent for screening of their CD4 count and viral load, and those meeting the criteria for treatment are referred to the infectious diseases clinic. Some patients who turn up at the government clinic to join the national antiretroviral programme have been receiving treatment in the private sector but can no longer afford to do so.

Upon enrolment, a detailed medical history is taken and patients undergo a range of routine tests, such as liver and kidney function, X-ray, and haemoglobin tests. Then they are seen by an adherence counsellor. No patient is given drugs on the first appointment; the clinic team must be satisfied that he or she understands what is involved and is ready and able to make the life-long commitment to treatment before drugs are prescribed.

People with HIV/AIDS are not like other patients; they are already stressed by their condition, and you have to be very sensitive in handling them. You have to give them time to express themselves, and you have to listen properly. Building trust is very important so that they feel they can be open and speak to you truthfully about problems they are having with treatment, with compliance and with side-effects.

—Francinah Lethapa, nurse, Infectious Diseases Clinic,
Segkoma Memorial Hospital, Serowe

“There are national guidelines for treatment,” says Professor Freers. “Unless there are contra-indications, a patient gets the first-line drugs. And, normally, people do very well on these.” Most patients are ‘drug naive’, which means this is their first exposure to antiretrovirals. But a few who come from the private sector have been on and off drugs, through no fault of the private practitioner, but because the patient was not always able to pay, said Professor Freers. When a person is sick and needs drugs, he or she may sell the house or the car in order to pay for treatment. Then, when they are feeling better, they think they can manage through good diet and nutrition, so they stop the treatment. “But,” says Professor Freers, “such patients are a very small minority.”

Patients are expected to return for monitoring of their CD4 count and viral load fortnightly for the first month, then monthly for the next three months and, finally, every three months. But if they experience bad side-effects, they are advised to return to the clinic immediately. All laboratory tests other than CD4 and viral load must be done at the patients’ local clinic or hospital, and patients are expected to bring the results with them when they visit the antiretroviral clinic. This aspect of the programme is not ‘user-friendly’, especially for patients living in remote areas. But most appear to have found ways of coping.

Patients are only given a month’s supply of drugs at a time. This gives the dispensing pharmacists an opportunity to keep tabs on patients and to drive home the messages about adherence. However, says Professor Freers, there has to be flexibility in the dispensing policy. “If you are emphasizing adherence, you cannot afford to withhold drugs unnecessarily.” If people cannot come for their drugs themselves, the clinics will allow them to be collected by a trustworthy proxy. Botswana’s population is highly mobile, and the clinics will give more than a month’s supply to people who have to travel away from home, if need be.

A view from the front line

Dr Ndwapi Ndwapi is director of the infectious diseases clinic in Gaborone. His team is dedicated to the antiretroviral clinic, and it does not work in rotation with the general hospital, as do health staff in some centres. He believes this is important, because people need to become very familiar with the procedures in order to be efficient. In addition, there is a huge need to build up experience in HIV/AIDS treatment in Botswana.

Dr Ndwapi did his medical training in the US and studied HIV/AIDS as an elective subject. He developed expertise in treating HIV/AIDS, but says that almost nothing could have prepared him for the conditions he found in Botswana. Whereas only about 0.5% of the cases he dealt with in the US were HIV-related, in Botswana over 75% of patients in hospital wards are suffering from AIDS. "The sheer volume of AIDS-related sickness here is an emotional and psychological burden for doctors and other health staff," he says.

An issue that seriously concerns him at present is follow-up, which he does not believe was given adequate consideration when the programme was designed. "Follow-up is a brand-new concept in terms of health care," says Dr Ndwapi. He explains that if he treats someone with diabetes or hypertension and they fail to turn up for review appointments because they are feeling better, it does not matter unduly; they are not a health risk to the public. But, with HIV/AIDS patients, there is a public health imperative that they be followed up and their adherence monitored for life. "You can write off a whole range of medications if you don't get follow-up right."

This is an enormous challenge for Africa, he believes. Even in California, where people are well educated, highly literate about treatment, and accessible by phone and e-mail, compliance over the long term is very poor. How much more difficult will it be to ensure good compliance here, where communications are so much less developed, he asks. His records show that compliance so far is actually very good, but Dr Ndwapi believes this might be because many of those on antiretrovirals now were once at death's door; they view their improvement as a near miracle, so their commitment is strong. But the same may not be true for those who have not personally experienced just how bad AIDS can be.

Botswana's 'Family Welfare Educators' and home-based-care nurses have the primary responsibility for follow-up, but they are greatly over-stretched. Meanwhile, there are many outside the health services, such as NGOs and support groups for people living with HIV/AIDS, who could be called upon to assist with this work, believes Dr Ndwapi. More effort needs to be made to empower such people and draw them into the antiretroviral programme at all levels.

A limited role for people living with HIV/AIDS

Helen Mhone took an HIV test in 1992 out of mild curiosity. She had heard the messages about getting tested and was sitting at home bored, so she went to visit her local voluntary counselling and testing (VCT) centre. She never dreamed she could be infected and was terribly shocked by the results. Helen veered between anger and denial, and slid finally into suicidal depression. "I thought of throwing myself into the dam outside Gaborone, and I even imagined the soldiers pulling my body out of the water," she says. "There was very little support for people who were infected at that time and the stigma was very bad."

It was three years before she was able to disclose her status, even to her own family, who she feared would reject her. Attending a conference in Cape Town for people living with HIV was the turning point. Helen was asked to speak at the conference and says, "My presentation went very well, and I felt so good for the first time since my diagnosis. You know, when you have HIV, you often feel useless."

Coming out was the beginning of Helen's activism. Thereafter, she took every opportunity to challenge the stigma and to point out that HIV-positive people were like everyone else; it could happen to anyone, and was not a sin. But she then came to realize that there was no support for people living with HIV/AIDS. They needed a place where they could meet, cry together, and share experiences of living with the virus, she says. So, working informally from a room in her own home, she started a support group, which she called the Coping Centre for People Living with HIV/AIDS (COCEPWA). Helen had realized that not everyone with HIV was sick and going to the clinics for care, and that what was needed for these people was 'wellness' centres where they could learn to live positively with the virus.

"Ask any HIV-positive person and they will tell you there is no better support than to talk to another HIV-positive person, who experiences the same as they do. We care from the heart! There is no substitute for that feeling of being understood..."¹⁵

Today, COCEPWA has branches in all the main urban centres. Its principal purpose is to provide supportive counselling to members and their families, and people are generally referred from the voluntary counselling and testing centre, the clinics and the hospitals. Everyone who joins COCEPWA is offered training at workshops. The first objective is to ensure that HIV-positive people are knowledgeable about HIV/AIDS and about antiretrovirals. But COCEPWA also offers instruction in public speaking as part of the fight against stigma, and training for 'treatment buddies'.

The buddy programme started as a result of what Helen and her colleagues observed with tuberculosis treatment among their members. People had all kinds of problems adhering to the drug regimen: the pills tasted nasty, they were difficult to swallow, and people felt ill if they took them on an empty stomach, for example. Helen anticipated similar problems with antiretrovirals and recognized the need to prepare for the day when treatment would be widely available. So COCEPWA started the buddy programme, whereby everyone on treatment is

teamed up with someone specially trained to support them. Many of their members have not been able to disclose their seropositive status to their spouses and partners, which makes it especially difficult for them to stick to their drug regimen, explains Helen. Buddies encourage their 'clients' to disclose to their families, and help them do so, if appropriate.

Buddies attend a four-day workshop. The first two days cover the basics of HIV/AIDS, and the remaining two days are devoted to the principles and practices of buddying. A buddy may well experience the sickness and death of a client, explains Helen. This is a harrowing experience, which may also raise fears in the buddy about what the future might hold for him



COCEPWA buddies showing off their T-shirts and certificates after a training course. Photographers: Anneke Zuyderduin and Pieter Jan Visser

¹⁵ Visser A, Mhone H, *Needs Assessment Report: People Living with HIV/AIDS in Botswana*, COCEPWA, 2001.

or herself. This is dealt with in the training, and the extent of the buddy's role is defined carefully. Buddies are advised, for example, to keep socializing to a minimum, and never to go out drinking with their clients. They are also told that they are not supposed to be counselors, nurses, or legal advisers to the client, so the training teaches them to identify the services available within the community and how to access them. Buddies must take care not to become overburdened with responsibilities for their clients. They meet regularly in support groups to share their experiences.

Helen herself can testify to the value of the buddy system. She has been on antiretrovirals for a number of years, buying them with the help of a sponsor and going to a private doctor before the drugs were available in the public health system. She takes a total of 13 tablets a day at different times—some with food and some without, some with water and some with fruit juice. Her viral load and CD4 count are monitored every three months (or more frequently if she is not feeling well) and she keeps a record of these readings on a small card in her handbag. Helen's husband and children are very supportive of her treatment, reminding her to take her pills and preparing food or drink for her, when necessary. But her buddy is an invaluable part of the support team. (She calls Helen regularly to find out how she is, and when she feels that Helen is working too hard she cautions her to take more rest. She also talks to Helen's husband and helps him in his supporting role.)

Despite the widely recognized value of treatment partners, the Masa programme has given only limited support to COCEPWA's buddy training programme. The role of people living with HIV/AIDS in the treatment programme, as a whole, is tenuous and ill-defined, and a source of great frustration to them and their support organizations. In the harsh climate of stigma and fear in Botswana, they have had a difficult time building their networks and finding their feet, and now they feel their lack of power acutely. However, explain David Ngele and Herriet Kopi of BONEPWA (Botswana Network of People Living with HIV/AIDS), because Botswana is one of the economic success stories of Africa, it is considered by donors to be a low priority for funds. The support groups struggle just to keep going, let alone find the money to train themselves in order to play a more meaningful role in the treatment programme.

We really appreciate how our government has set up and changed the health services, and made them accessible to everyone. But now we want greater involvement as patients.

—Herriet Kopi and David Ngele,
Botswana Network of People Living with HIV/AIDS

Herriet is a community liaison officer with the infectious diseases clinic in Gaborone. She started as a volunteer but the Harvard Partnership managed to find her a part-time salary. Having observed the relationships between patients and health staff and the pressure everyone is under, she feels that many more HIV-positive people should be working in the treatment programme. They are needed to help vulnerable patients deal with a system that makes many (especially those from small villages) feel intimidated and afraid to admit the difficulties they are having with adherence. For example, says Herriet, a mother given antiretrovirals to prevent the transmission of HIV to her baby may agree with her counsellor that she will feed her child with infant formula to avoid the risks of infection through breastmilk, but when she gets home she is unable to withstand the pressure from her relatives to breastfeed. Yet she may be unable to discuss this honestly with a professional health worker. "We have experienced the problems the patients are going through, and we're the best people to help them," says Herriet.

Good nutrition is essential for people living with HIV/AIDS, and patients on anti-retrovirals or tuberculosis treatment particularly are eligible for supplementary ‘food baskets’ provided by the government if they cannot afford to feed themselves adequately. However, social workers are overstretched and often it is only those who know how to work the system who benefit, while those who rely heavily on social workers to make sure they get what they are entitled to are overlooked, explain Herriet and David. “We see these gaps and we are ready to fill them if we are given funds. We would also know who is most needy in our communities. But the network is not being used,” says Herriet.

Antiretroviral treatment for children: a special challenge

Reaching children who might benefit from antiretroviral treatment presents special challenges. Nobody knows how many children there are in Botswana with HIV, because there is no routine screening of children, and they are totally dependent on adults to identify their need for treatment and take them to the clinic.

As of mid-2003, there were about 500 children registered with the infectious diseases clinic in Gaborone alone, and most of them had been referred from the general hospital or the PMTCT¹⁶ clinic. All HIV-positive children below the age of 12 months and those with symptoms of AIDS are eligible for antiretrovirals. In addition, tests are done on those who have no symptoms, to assess the state of their immune systems and to establish whether or not they would benefit from antiretroviral treatment.

Treating children has been made easier in recent years by the provision of paediatric formulations of antiretrovirals in syrup form. However, a major challenge is ensuring adherence. Many children are orphans and it is difficult to find a relative or guardian who will make the commitment to see that the child takes the drugs and is brought to the clinic regularly, says Dr Philip Mwala, director of the infectious diseases clinic in Serowe. He tells the story of one child—a small orphaned boy whose guardian had been supervising his treatment very reliably. Then the guardian died, leaving the child with other relatives who had not been party to his treatment plan and did not understand what was required. When the child seemed to get better, his relatives did not see the need to bring him to the clinic, and he dropped out of treatment.

Another difficult issue is knowing when to involve the child directly in his or her own treatment. There are no national guidelines; it is a matter of judgement, says Dr Haruna Baba Jibril, who heads the paediatric section of the infectious diseases clinic in Gaborone. Relatives are often reluctant to tell children of their HIV-positive status because of the problems such knowledge can cause in their daily lives. But it is clear, says Dr Jibril, that some children feel cheated if they find out about their situation by mistake—as was the case with one of his patients (a nine-year-old girl) who realized from watching television that the drugs she was taking were for HIV/AIDS. She was very upset with her parents.

The challenge ahead: scaling up

The four sites chosen for the launch of the Masa programme were intended to demonstrate what was possible, to challenge fears and prejudices about antiretrovirals by showing what they can do for a person with HIV/AIDS, and to gain experience in running treatment programmes. The programme has subsequently been rolled out to two additional sites, and a further seven sites will be offering treatment by the end of 2003.

¹⁶ PMTCT stands for ‘prevention of mother-to-child transmission’. This programme was started on a pilot basis in April 1999 by the Botswana Government in partnership with UNICEF, WHO and bilaterals (Harvard and CDC). National roll-out began in July 2001 and was completed in November 2001.

The biggest challenge in expanding the programme remains the shortage of trained staff. But reaching people in villages beyond the tarred roads and airstrips presents formidable challenges too. A lesson learned from experience so far, says Mr Ramotlhwa, is that programmes should not be put on hold until everything is in place and conditions are ideal before introducing antiretrovirals. Doctors and nurses are already spending much of their time caring for people living with HIV/AIDS, since the majority of cases they see in the hospitals and clinics are HIV-related. They need training, first and foremost, to handle antiretrovirals in their normal work situations, and then they need space in which to develop a programme.

But Dr Ernest Darkoh warns that there can be a lot of pain on the path to success, since new programmes must be created within an existing system of health care. It is a question of breaking the mould, and challenging existing relationships and procedures, which is inherently stressful.

South Africa: forcing action and preparing the ground

More than 4.7 million South Africans are infected with HIV, and the virus continues to spread and to kill at terrifying speed. Around 1700 people, including 165 babies, were newly infected with the virus and 600 died of AIDS¹⁷. That is well over 200,000 AIDS deaths in a year.

It is estimated that, of the more than 4.7 million HIV-positive people in South Africa, between 400,000 and 500,000 have reached the stage where they should be on antiretroviral treatment to save their lives¹⁸. Although antiretrovirals have been used in the public health system for the prevention of mother-to-child transmission, for people who have been sexually assaulted and as post-exposure prophylaxis for health-care workers nationally within the last two years, these drugs have not been available for the majority of HIV-positive South Africans for treatment purposes. On 8 August 2003, the South African Government announced that plans were under way to include antiretroviral treatment as part of the enhanced programme on HIV/AIDS for all its citizens. This momentous decision has been received globally as a major step in the right direction.

“One of the key messages of TAC is that, as a person living with HIV, you have to take prime responsibility. You have to know as much as the doctor; you have to follow the politics; you have to be involved. I think that’s the key to TAC activism.”

—Sipho Mtathi, Treatment Action Campaign (TAC) national coordinator

By the end of 2002, a total of about 30,000 people were estimated to be on antiretroviral treatment, delivered mostly through private medical aid schemes (which cover about 20% of the population), or workplace programmes run by some of the larger companies. A handful of people receive treatment through research projects, or through the clinic that was set up by the international NGO, *Médecins Sans Frontières*, in Khayelitsha, Cape Town, to demonstrate the feasibility of delivering antiretrovirals in a poor environment with only basic facilities. And some people, desperate to save the lives of themselves or their loved ones but with no prospect of treatment from any of these sources, catch the bus every month to neighbouring countries such as Lesotho, Swaziland, Mozambique or Namibia where imported generics are available.

This is the environment in which the Treatment Action Campaign (TAC) was founded in December 1998.

The Treatment Action Campaign

It all started with a protest on the steps of St George’s Cathedral in Cape Town by a group of 15 people—some living with HIV and all personally affected by the virus. They were calling on the government to develop a treatment plan for people with HIV/AIDS, who were dying in great numbers for lack of medication.

¹⁷ *HIV Antenatal Survey*, Department of Health, South Africa, 2002.

¹⁸ *Summary report of the Joint Health and Treasury Task Team Charged with Examining Treatment Options to Supplement Comprehensive Care for HIV/AIDS in the Public Health Sector*, South African Government, 1 August 2003.

Days earlier, on 30 November 1998, they had buried Simon Nkoli, the first black South African man to come out openly as gay, who had become a prominent and inspirational gay rights and AIDS activist. Simon's death was a wake-up call to the AIDS community, says Zackie Achmat, a founding member and now chair of TAC. Simon had recently given an interview to a newspaper, in which he urged people living with HIV/AIDS to picket the Department of Health until it provided the treatment that would stop the dying. Until then, explains Achmat, people in South Africa had known almost nothing of the revolution in treatment going on in the West. Antiretrovirals were considered so unaffordable by developing countries that no one gave them much thought. Indeed, treatment issues in general were not high on the agenda of AIDS activists, who were more preoccupied with prevention and human rights issues. Simon's interview was "a cry of desperation", says Achmat, and his dying so young and so unnecessarily was a powerful stimulus to action.



TAC logo from TAC's media archives

The protest in Cape Town resulted in hundreds of signatures of support being collected, and TAC was officially launched on International Human Rights Day, 10 December 1998. Registered as a charity, the Campaign is an alliance of civil society organizations and individuals who share its vision and support its objectives. Headed by a small core of staff operating out of offices in six of the nine provinces of South Africa (Western Cape, Eastern Cape, Gauteng, KwaZulu/Natal, Limpopo and Mpumalanga), it has tens of thousands of volunteer members in 110 branches throughout the country. In 2001, TAC held its first congress, at which an Executive Committee was elected with representation from all the organizations with which it works. To avoid being compromised, they have passed a resolution not to take money from pharmaceutical companies or from the government, and today TAC is a powerful and independent force in South African politics.

TAC's objectives

TAC's objectives are:

- to educate and promote understanding in all communities of development in HIV/AIDS treatment and care;
- to ensure access to affordable and good-quality treatment for people with HIV/AIDS;
- to prevent new infections; and
- to improve the affordability and quality of health care for all.

Although its relationship with the South African Government is volatile and often stormy, TAC tries hard to avoid confrontation, realizing that it is almost always counterproductive. "Let me state very clearly that this is a government that many of us fought for. And much of what it has done is not only laudable but necessary to redress the imbalances of the past—racism, the social inequalities, the poverty. The social damage wrought by apartheid is going to take a very, very long time to undo, and this government, I believe, so far has done a really good job," says Zackie Achmat. "But irrespective of what government is in power, in order to

ensure that HIV is prevented, in order to ensure that people with HIV are treated properly and have access to a good public health-care system, and in order to ensure that people stay *alive*, you have to work with government.”

A broad alliance

TAC forms alliances and partnerships at different times with all kinds of people and organizations with which it has common cause. Its key partners include the following:

- **COSATU** (The Congress of South African Trade Unions), is the biggest labour federation on the African continent, with a membership of around 1.8 million people. It was launched in 1984 by the mass democratic movement set up to fight the apartheid government, and remains in a formal alliance with the African National Congress (ANC), which is the ruling party in South Africa today, and the South African Communist Party (SACP).

In 1998, a resolution was passed at the COSATU congress to campaign for treatment in the public health services. “It was clear to the labour movement at that time that its lowest paid members were dying because they couldn’t afford medicines,” says Theodora Steel, Campaigns Coordinator at COSATU. “We saw TAC as a natural ally in a campaign for treatment. We passed a formal resolution at our congress to assist and build TAC.”

Today, all labour unions in the federation have HIV/AIDS coordinators, and issues of treatment are addressed in every workshop and other suitable forums.

- **The AIDS Law Project (ALP)** was set up in 1993. Initially, the bulk of their work was addressing issues of confidentiality, and discrimination. But, as the epidemic matures, sickness-related issues such as entitlement to funeral and death benefits, medical negligence, and insurance are becoming important too.

ALP was a co-founder of TAC. Simon Nkoli’s death made it very clear that the legal framework was not in place to protect people with AIDS, explains Jonathan Berger, a researcher with the project, and it shifted the focus of ALP towards access to treatment. For example, there is no statutory requirement that medical aid schemes offer full cover to people living with HIV/AIDS, without discrimination. And, as yet, antiretrovirals are still excluded from the statutory minimum package of care. So much of ALP’s work is in challenging the practices of the medical aid companies.

ALP has provided legal advice and opinion for all TAC’s campaigns and, in 2002, a dedicated Law and Treatment Unit was set up within ALP for the purpose of identifying opportunities for action in national as well as international law. “If the law as it stands doesn’t give us options for action in a case, we ask what we need to make the law responsive,” says Jonathan Berger. They push for review and reform, and lobby ministers of justice and social affairs, where necessary. The Treatment Unit is looking at how they can bring drug prices down, as well as trying to influence the broader health framework by advocating such things as treatment literacy.

Partnership with lawyers is essential in campaigns to gain access to treatment, says Fatima Hassan, an attorney with ALP. But how easily they can help depends on three key factors: the basic constitution of the country; the independence of the judiciary; and the strength of the rule of law and of civil society. South Africa’s constitution

has created an ‘enabling’ legal environment. It lays down very specific rights and these also confer obligations on government. ALP therefore takes a human rights approach to treatment issues, which means making people aware of the fact that health services are not a privilege but a right, and that the government has obligations to provide treatment services of a certain standard.

In the apartheid era when people’s voices could be silenced by the State, one of the few ways to be heard was to make an affidavit that had to go into the court records. The ALP has continued to use this strategy to advantage. Its lawyers make a point of not fighting legal cases in a rarefied atmosphere of hypotheses and legal jargon, but humanizing cases by using the voices and testimonies of real people. These are then heard in court and enter the court records. They have a powerful effect not just on the public when they are reported in the media, but on judges sitting in the cases, comments Jonathan Berger.



Zackie Achmat with Nelson Mandela at a MSF clinic providing antiretrovirals in Khayelitsha, CapeTown, South Africa, December 2002
Photographer: TAC volunteer

“Any decent activist in any field has to know the laws of their country, because if you know the rules, if you know the laws, you can take your battle so much further. But you must use the law as part of social mobilization. There’s no point in having a court judgement that you can’t enforce. It’s no use government adopting a policy if no one knows about it. But a mobilized society that knows how to use the law is an incredibly powerful force.”

—Zackie Achmat,
founding member and chair of TAC

- **The Community Health Media Trust** works out of busy offices next door to TAC in Cape Town. It was set up in 1998 as a non-profit company by Zackie Achmat and Jack Lewis, who runs a mass media company called Idol Pictures. “TV overcomes the barriers of illiteracy,” says Lewis. “And images have the power to stay with you more than any other medium.” He and Achmat had been discussing the power of television to educate people, and regretting the fact that it has not been used more widely and imaginatively in the fight against HIV/AIDS.

Most television programming that addresses the topic sets out to give basic information and prevention messages to the public as a whole. They felt there was a need also to make programmes that speak directly to HIV-positive people as a constituency, and that have an activist slant. The Trust was set up for that purpose, and it makes programmes, under the series title ‘Beat It’, that deal with issues of direct concern to people with the virus, such as their constitutional rights, the quality of services, and access to treatment. The aim is to give people living with HIV/AIDS a voice of their own and “a line out of their isolation,” says Lewis.

Two series of 'Beat It' went out on commercial television in 1999 and 2000, and, in 2001, the tapes were edited to produce a series of 11 videos for training purposes. The Trust has developed facilitators' notes so that the videos can be used by trainers who do not have specialized knowledge of HIV/AIDS. And to make it easy to find the topics the trainer wants to focus on, each lesson is on a separate cassette. The videos have been sold widely across South Africa, and there are demands to translate the series into a number of other African languages.

Core 'Beat It' messages are the importance of good nutrition and seeking early treatment for opportunistic infections in order to protect the immune system, says Lewis. The next series will be based on studio discussions in which people living with HIV/AIDS will tell their own stories to illustrate particular issues. Experts will be invited to comment on the personal stories and to put the issues in a broader context, he explains. The studio audience will be largely HIV-positive people and their partners and families, and the kinds of topics that will be discussed include:

- the value to clinics of having educated and informed patients;
- sexual relationships among the first generation of children who have grown up with the virus; and
- rape and post-exposure preventive treatment.

The Trust is exploring ways of delivering the programmes to clinics across the country via satellite TV.

- **Médecins Sans Frontières (MSF)**. In May 2001, MSF started an antiretroviral treatment programme in Khayelitsha, a poor township in Cape Town. It uses generic drugs from Brazil and works out of a dedicated clinic in cooperation with three local hospitals. MSF works closely with TAC and has been able to demonstrate, not just to South Africa, but to the world, that it is possible to deliver antiretroviral treatment in poor communities where health facilities are basic.
- **Volunteers** are the backbone of TAC. They come from all race groups, all ages, and all walks of life, and it is they who keep the campaign alive at community level. Many, but not all, are HIV-positive and they hear about TAC from the media or friends. New members are referred to their nearest branch, where they are given orientation in HIV/AIDS, and told about the campaign and how it works before joining the effort to mobilize the community. They are assigned to different committees or different tasks, depending on their skills. Members speak in churches, schools and community groups. They visit clinics to talk to the waiting patients and assist the nurses and counsellors, where possible. They attend parliament when HIV/AIDS is on the agenda to listen to debates and report back to their branches. They go to court to give testimony or observe proceedings when legal battles are being fought. And they turn out in their thousands for protest or solidarity marches.

One of the main tasks of the volunteers, however, is to sort out any problems that patients may be having with treatment. If medicines for an opportunistic infection are not available, they will go with the patient to the clinic and meet with the sister in charge or the superintendent to find out what the problem is and what they can do to help. The visits are not confrontational: TAC has considerable experience in working

the system and the aim is simply to ensure that the patient gets what he or she needs as quickly as possible.

Branch coordinators are responsible for supporting the volunteers and representing them in the organization. Coordinators, who are usually given a stipend to help cover their out-of-pocket expenses, meet every week at their provincial offices to discuss how their branches are doing, what problems they have, and what help they need.

“TAC is only what it is because of its volunteers; there are thousands of them, and they mustn’t ever feel marginal to this campaign.”

—Rukia Cornelius, TAC

Recently, TAC introduced a programme to offer their volunteers reading and writing workshops. The idea is to help them express themselves fluently in English, so that they can get their messages across more easily and increase their effectiveness as activists. Many volunteers are women with dependents whom they struggle to support, and TAC is hoping in due course to offer computer literacy workshops, too, aimed at empowering them with skills that are broadly useful. “TAC is only what it is because of its volunteers; there are thousands of them, and they mustn’t ever feel marginal to this campaign,” says Rukia Cornelius, who works at TAC’s office in Cape Town.

Milestones in the Treatment Action Campaign

In its four-and-a-half years of existence, TAC has waged a number of important campaigns in the national as well as international arena. These include:

The campaign for the prevention of mother-to-child-transmission (PMTCT) of HIV. When TAC was set up, the South African Government was opposed to the use of antiretroviral drugs for the prevention of mother-to-child transmission of HIV. The Minister of Health was, at the time, raising questions about the toxicity of the drugs, and whether they could be administered safely in a country such as South Africa. Meanwhile, tens of thousands of babies who could have been saved from infection were being born each year with the virus. The situation was urgent, and TAC took up the case. It gathered extensive evidence of the effectiveness and safety of AZT and nevirapine—either of which can be used for PMTCT—and laid this before the government. But only when TAC threatened court action did the government commit to a pilot programme in 11 sites around the country.

The pilot programme was ostensibly to answer the government’s continuing doubts about antiretrovirals. However, it was poorly conceived and implemented: all sites were in urban areas, for example, and offered no insights into how to deliver such services to rural communities. So TAC sought meetings with the government to try to improve the situation. At the same time, pressure started to come from health institutions: doctors were upset that they were unable to offer their patients badly-needed treatment that was available in the pilot sites. The crisis came to a head when a young woman who was enrolled in a pilot programme went into labour unexpectedly, far from home. The hospital to which she was taken could not give her nevirapine because it was not a registered site, and did not have access to the drug anyway. The incident prompted TAC to start litigation on the grounds that the government was preventing health personnel from carrying out their professional duty of care to patients, and that it was in violation of the constitutional rights of patients to treatment.

The first judgement of the case was in 2001 and the government was ordered to provide antiretrovirals where medically indicated. The government appealed, but lost the appeal in April 2002 and was ordered to roll out the PMTCT programme nationally. So the government took its case to the Constitutional Court, and again lost in July 2002. The provincial health services are therefore obliged to supply antiretroviral drugs for PMTCT. Those that drag their heels are threatened with a ‘contempt of court’ action by TAC, and this has been effective.

The nationwide provision of a PMTCT programme with the use of nevirapine, however, continues to be an issue. On 30 July 2003, the Medicines Control Council of South Africa gave reasons for why it could not continue to approve the use of nevirapine as a single agent in reducing the risk of mother-to-child transmission of HIV, citing the findings from the HIVNET 012 Ugandan study’s inability to validate its use for this purpose. Dialogue with researchers and the manufacturer, Boehringer Ingelheim GmbH, continues as they work towards an understanding.

The Christopher Moraka Defiance Campaign. Christopher Moraka, one of TAC’s earliest and most active supporters, died in July 2000 of systemic thrush, an overwhelming fungal infection that makes it painful even to swallow. Fluconazole, made by the pharmaceutical company Pfizer, could have eased his suffering and prolonged his life. But it was too expensive to be provided in the public health services. Christopher Moraka was one of many HIV-positive people who died for want of fluconazole in South Africa, and when TAC discovered that a generic version of the drug was available from Thailand at one-twentieth the price of fluconazole, they determined to challenge Pfizer and the South African Government. Zackie Achmat travelled to Thailand and brought back 30,000 capsules of the generic, biozole, in defiance of South Africa’s patent laws. He was charged with smuggling, but the case attracted so much negative publicity that the government later dropped charges. Pfizer tried to limit the damage to its image by reaching a deal with the government to provide fluconazole free of charge for two years to public health facilities. But the company put strict limits on the use of the drug, which meant it was still beyond the reach of many AIDS patients who needed it. So TAC has continued to import biozole from Thailand to meet as much of the demand as it can, and to keep the pressure on Pfizer to drop its prices in the market place.

“We believe that the drug companies are a very important part of the solution to access, not just to AIDS drugs, but to all essential medicines for people. But we have several problems with them. The first problem is obviously the current intellectual property regime. TAC’s official position is that we support intellectual property protection. That’s not the problem. It is how that intellectual property protection is used excessively to profiteer: that’s the problem for us.”

—Zackie Achmat

The Campaign against the Pharmaceutical Manufacturers Association (PMA). The Medicines Act of 1997 gives the South African Government powers to bypass patent rules and issue compulsory licences for drugs when there is a clear public health need. Such drugs can then be bought on the open market and from the cheapest source. This is perfectly consistent with the rules of the World Trade Organization, but, seeing a threat to its profits, the pharmaceutical industry took the South African Government to court in March 2001 to try to prevent it from passing the Act into law. TAC campaigned vigorously in support of the Act and the government’s case, stimulating intense media coverage of the debate at home and abroad. In the face of opposition from the PMA, which brought the case, the judge awarded TAC the status



of ‘friend of the court’. This would have allowed it to deliver personal testimonies from people living with HIV/AIDS who had been denied treatment because the drugs were unaffordable. But recognizing the damage to its image and reputation, the PMA eventually dropped the case, and the company had to pay everyone’s legal costs.

This was the second battle TAC had to fight in defence of the 1997 Medicines Act and the right to obtain drugs as cheaply as possible. In 1998, the US Government, under pressure from the immensely powerful pharmaceutical industry, had put South Africa on a ‘watch list’ of countries that could face economic sanctions for threatening its interests. The former President of the USA, Bill Clinton, has been instrumental in negotiating prices from generic companies down to a more accessible US\$0.38 per day.

TAC poster for the Global Day of Action, 5 March 2001, from TAC’s media archives

“We believe the drug companies are misusing the enormous power they have to try to force countries, whole countries, to adopt programmes that are against the health interests of their people. This is an important battle that I don’t think we’ve seen the end of.”

—Zackie Achmat

The Pan-African HIV/AIDS Treatment Action Movement (PHATAM). On 25 August 2002, at the World Summit on Sustainable Development in Johannesburg, the Treatment Action Campaign went international. Together with activists and organizations from 20 other countries across Africa, TAC launched PHATAM (see Annex).

Crucial to the success of all TAC’s campaigns is that activists be well informed so that they can speak with authority and counter opposition arguments. This became very clear during the campaign for PMTCT, when TAC needed to answer the government’s claims that AZT and nevirapine were toxic. TAC therefore makes a point of ensuring that its campaign leaders are kept up-to-date both on the science of HIV/AIDS and the drugs needed to treat it, and on the trade, economic and political issues surrounding AIDS.

Building trust is also crucial, says Achmat. “We try, as far as possible, never to exaggerate—whether it’s statistics, or the effect of illness, or the benefit of drugs. For us, the rule is: always give the facts, and base them on the best scientific evidence available, not a personal opinion. That’s very important to us. And it’s enabled us to create very good relationships with specialists of all sorts—doctors, pathologists, economists. They trust us because they know we don’t misuse the facts they give us, and that we take a serious interest in their work.”

The treatment literacy programme

One of TAC's fundamental aims is to empower the general public with knowledge about HIV/AIDS and how to treat it—and, most especially, to make HIV-positive individuals informed and confident consumers of the health services. The cornerstone of the campaign is therefore the treatment literacy programme, which includes workshops in the community.

“Trying to shift the minds of people living with HIV, who are normally passive recipients of whatever the professionals decide, to being people who participate in the debates and say: ‘no, we won’t accept this,’ and ‘we want that,’ is a real challenge. I think that’s the uniqueness of TAC’s approach compared to the many other organizations that are working on HIV/AIDS issues,” says Siphon Mtathi, the programme’s national coordinator. “What we are trying to say with all the materials we’ve produced and throughout our training is: HIV changes everything about the way we’ve done things before. As a person living with HIV/AIDS, you have to take prime responsibility for yourself. You often have to know more than the medical professionals.”

“I think the most important thing that we’ve done is to challenge the paternalism of the public health system.... The official who knows best... AIDS presents public health with an enormous opportunity to educate people about chronic illnesses, about infectious diseases, and to create movements in which patients are agents, in the best sense of the word, making sure that they stay healthy, and that they don’t misuse medicines.”

—Zackie Achmat

The primary participants in the treatment literacy workshops are TAC’s volunteers, all of whom need to be well informed in order to be effective activists, and some of whom become community education officers in their branches. But the programme also runs courses for the carers of people living with HIV/AIDS, for pupils in schools, and for health workers. Medical and nursing students learn very little about HIV to prepare them for dealing with it in hospitals and clinics, says Mtathi, and there is a demand from nurses, especially, who are often in charge of the clinics, for treatment literacy workshops. “We’re currently producing a treatment manual for health-care workers, which we’re going to use for training throughout the country.”

Workshops vary according to the audience, but the most intensive run for four days. They cover the basics of HIV transmission and prevention and then focus on key issues such as mother-to-child-transmission, diagnosis and treatment of opportunistic infections, and everything about antiretrovirals. Facilitators make an assessment of what trainees already know, and they take questions from the floor as a starting point for discussion. “People have a lot to contribute, and if you allow them space to talk, you can learn new ways to approach things. I think drawing from people’s own experience can be very valuable,” says Mtathi. The workshops use role play and lots of other activities that encourage active participation. “During a course, we may get people to design the virus, actually make a model of what they think the virus looks like, for example. Those practical ways of getting people to deal with the issues are very effective, and people feel they are part of the process. So the treatment literacy programme is not just about the issues, it’s also about methodology, and participation is very important.”

‘HIV-POSITIVE’: TAC T-shirts make a bold statement

Within a fortnight of TAC being launched, a young mother, Gugu Dlamini, was stoned to death in a township in KwaZulu-Natal soon after disclosing that she was HIV-positive at an AIDS awareness gathering. The tragedy was a terrible blow for the campaign against stigma, and TAC organized a march through Gugu’s township to protest her killing and show solidarity with all infected people.

The marchers all wore a T-shirt specially designed for the occasion, with a photograph of Gugu on the back and the words, ‘HIV-POSITIVE’ across the front.

“We wrote a letter to the Minister of Health, who was from KwaZulu-Natal, asking her to come,” says Achmat. “Our idea was to get the entire ANC membership in that area, all the health-care workers, the churches, and as many people from the community as we could mobilize. We said, let’s all wear this T-shirt, walk through the township and create a sense of openness.”



Zackie Achmat and Nelson Mandela with supporters at an event to celebrate the MSF antiretroviral programme in Cape Town, South Africa, December 2002. Photo: TAC.

The Minister did not respond but many others did, and the T-shirt caused quite a stir. What exactly did those bold words, ‘HIV-positive’ mean? That all the marchers were carrying the virus? Or that all the marchers, whether infected or not, felt positive towards those who were? Onlookers were left to ponder the meaning and their own reactions.

The idea for the T-shirt was prompted by the story of Christian the Tenth, King of Denmark, during the Nazi occupation of his country. He urged all his countrymen to wear the Star of David in solidarity with Jews who were forced to wear it by

the Nazis as a mark of identity, explains Achmat. “We understood from that story that the best way to create openness around HIV is not to force the disclosure of people living with the virus, but for everyone to wear something that says HIV-positive.”

At the time of the march, TAC had no members in KwaZulu-Natal. “Today, we have 30 branches there and we don’t have enough T-shirts to go around,” says Achmat. “Everyone is prepared to wear them. That doesn’t mean there’s no stigma. There is stigma. And there is still fear—too much of it. But the situation’s much better than in many other countries.

“The T-shirt is an assertion. It’s in your face and it makes you think. It says we have a crisis. But there’s nothing wrong with having HIV. It’s an illness, a virus; let’s deal with it rationally.”

One of the most important moments in his long life as an activist, says Achmat, was when Nelson Mandela wore the T-shirt during a visit to Khayelitsha. “For me, that means another million people will be prepared to wear it,” he says.

An expanding role

Now that the government has committed itself to the development of a National Treatment Plan that will include antiretrovirals (which has been the focus of TAC’s main campaigning effort thus far) the organization’s role is likely to shift to monitoring how the

plan is being implemented and keeping the pressure on to ensure equitable delivery of drugs, says Rukia Cornelius of the Cape Town office. Already, its role is expanding beyond pure campaigning as the organization finds itself increasingly used as a resource by health institutions, individuals and others seeking advice and help with treatment issues.

In August 2002, TAC started the Resource Project, whose aim is to pull together the wealth of information on antiretrovirals ‘hidden’ in scientific journals and academic institutions and to translate this into a form that is accessible to the general public. “Most people are illiterate as far as drugs are concerned, and it’s not enough for us to tell them ‘you have a right to treatment’. We have to explain why, what’s available and how it works,” says Cornelius, who is in charge of the Resource Project. TAC has already created a series of posters on individual drugs for use in the treatment literacy workshops. And it has started a library of newspaper cuttings and other information materials that are available to the general public.

Over its short life, TAC has watched many of its members die for want of medicines, and everyone has become acutely aware of the fact that a wealth of campaigning experience dies with them. Leaders such as Zackie Achmat have, until recently, been refusing to take antiretrovirals in solidarity with all those infected and whose lives are on the line because of the failure of the government to provide treatment through the public health services¹⁹. Achmat’s friends and colleagues in TAC have watched his battle with illness with foreboding. Recognizing the need for him and others who have led the campaign so far to pass on their skills to others and to distribute the burden, TAC has recently developed a leadership training programme. Aimed at TAC volunteers and others with a proven record of activism, the programme will impart skills of investigation, critical reading and literature review. And it will cover topics that range across African and world history and politics, as well as the struggle for social justice and human rights.

***“One thing we make sure is that every TAC activist understands is that HIV is a political issue. It’s not a party political issue; it should never be a party political issue because all parties should strive to reach consensus about this. But it’s a deeply political issue in the sense that it’s about how men relate to women; how parents relate to their children; how multinational corporations relate to poor countries markets and consumers; and how governments allocate resources.*”**

“And because HIV is going to be with us for another generation or more, we as activists need to understand the politics of HIV, as well as the social and economic context that we’re operating in globally and locally.”

—Zackie Achmat

Antiretroviral treatment for activists

The regular loss of friends and comrades in the campaign has prompted another new initiative—an antiretroviral treatment programme that TAC began working on in February 2003. Under the programme, TAC will register as a provider of medicines and will supply generics to those who need them through a network of doctors and health facilities that agree to work according to a strict protocol being laid down by TAC. They will register as a non-

¹⁹ At its Congress in August 2003, TAC members and volunteers moved a resolution to appeal to their chairman Zackie Achmat to resume taking antiretrovirals to boost his ailing health. He accepted the appeal in view of the fact that the Medicines Control Council has now registered generic antiretrovirals for use in South Africa.

profit company and will appoint a pharmacist to act as director with a 14-member board and a secretariat made up of TAC activists. “So the company will be controlled by TAC members, not the leadership,” says Eduard Grebe, coordinator of the programme.

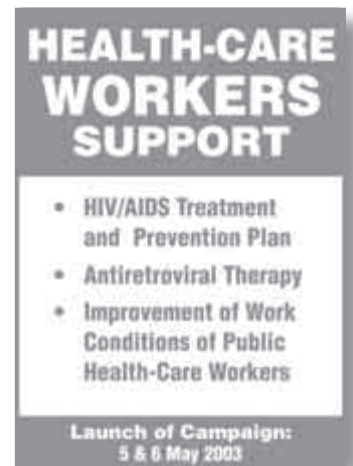
To provide generics legally, TAC has to obtain licences from the Medicines Control Council. It is a lengthy process designed primarily to ensure that the drugs being brought in are safe, effective and of good quality, and that their use will meet ethical and professional standards. TAC will not be bringing in the generics itself but obtaining them from the Generic Antiretrovirals Procurement Project (GARPP), a non-profit company set up in November 2002 by existing treatment programmes and other interested parties, including TAC, to supply their drug needs. The programme will develop a database of all activists and other volunteers requiring treatment, but the costs and complexity of administering the programme mean that it will have to start small and expand gradually.

To be eligible for treatment, a person living with HIV/AIDS has to have a CD4 count of less than 200, and to show that they will be able to comply with treatment. They will also be asked to contribute towards the cost of their treatment, if possible, since this is not a charitable enterprise but a solidarity programme, explains Grebe. Initially, TAC will offer treatment to activists within its own ranks who fit the criteria and, for each activist treated, one person in the community unrelated to the organization will also be offered treatment. The intention is to expand the programme as funds permit, and eventually to offer treatment to anyone who is in need of antiretrovirals and cannot access them elsewhere.

Besides the pressing need to save lives, the programme is intended to show what can be achieved with existing conditions. TAC does not deny any of the government’s concerns about the inadequacies of the infrastructure, and of staff capacity to run programmes, nor does it deny the need for training and for addressing people’s nutritional needs, says Grebe. “But we don’t see these as reasons to shy away from treatment. Rather, we see them as reasons to invest more in making treatment possible.”

The programme will be infringing patent rules and will therefore put TAC in conflict with the government as well as the pharmaceutical industry. But, once they are up and running, they would welcome being sued by the PMA, says Grebe. Because the industry would be challenging the treatment of people with names and faces and voices for whom this would be a life-or-death issue, it would be a public relations coup for the campaign. In addition, TAC would be able to argue that the big brand-name drug companies would not be losing money since the generics were going to people who would not have been able to afford the brand-name drugs anyway. Because of the legal implications, TAC has worked closely with the AIDS Law Project in developing the programme.

Confrontation with the government is regrettable, admits Grebe, because, in the end, the activists and government need each other in order to ensure access to treatment.



TAC poster calling on health-care workers to support the campaign for ARV treatment in public health-care settings, May 2003 (from TAC’s media archives).

Zoliswa Magwentshu: getting it right

“When I first started on antiretrovirals, I was worried about the side-effects that they were talking about. I was put on a combination that included efavirenz, and that’s the drug they say mainly affects the brain. They said you might have hallucinations and vivid dreams, and I was worried about that.

“For the first six months, I took the drugs with no side-effects. But, during the seventh month, I had terrible nightmares. That’s when I became concerned: one of my kids, the 17-year-old, said to me, ‘Mama, have you ever killed someone?’ When I asked, ‘Why do you ask me that?’, she said, ‘It’s because you are always scared at night, you don’t sleep, you always cry’. I became concerned about these terrible nightmares, so I went to the doctor. The doctor changed the efavirenz to nevirapine, which I’m now on and, oh, I recommend these antiretrovirals! Before I started, my CD4 count was only 83. But, after six months, it was 438, and the viral load was undetectable!”

How easy does Magwentshu find it to take her drugs and to comply with the regimen? “The combination is in one pill—you take one in the morning and one in the evening. Easy! And I don’t see any difficulty with compliance, although at first I was forgetful. I used to forget whether I had taken my pill because I was still in that stage of confusion. But there’s a pillbox that they give you, and it has all the days of the week written on it, so that you can remind yourself. And they give you a chart sheet to just tick whenever you’ve taken the pill.

“Also, for everyone who is on treatment at the *Médecins Sans Frontières* clinic, there must be a treatment assistant—the one who witnesses when you have taken your drug. Because there are times when you forget, and this compliance, adherence, is very important. If you don’t adhere, the HIV may become resistant to the treatment.”

“For me, my brother was always there, at first, when I was too sick to take it properly. But now he sees that I’m always taking the treatment before he can remind me! So now, at last, he’s relaxing.”

Uganda: risking all for treatment

“In a battle, I would look at a guy, appreciate the situation and know what to do. But this time I didn’t know what to do, and that was the worst thing. Confronting the enemy in battle it is clear: it’s him or me. But not with this enemy.”

—Major Ruranga Rubaramira

Uganda is, in many ways, a source of hope to a continent ravaged by AIDS. Having been at the epicentre of the pandemic from the late 1980s to the mid-1990s, it has recorded steadily declining rates of infection over recent years so that, today, about 6.2% of the adult population is believed to be carrying the virus²⁰. However, the average masks huge variations (the infection rate ranges from 2% to 25% in different areas and population groups) and HIV/AIDS continues to be a massive problem for Uganda²¹. Virtually no family has escaped the tragedy of extended illness, untimely death and orphaned children.



Children attending a day care centre in Gaborone, Botswana.
Photographer: Prathima Naidoo

Between one and two million of Uganda’s 22 million people are thought to be HIV-infected²². Of these, between 100,000 and 220,000 are in need of antiretroviral treatment²³. But those who are on antiretrovirals have to pay for them themselves. Although the government has stated its intention to provide the drugs via the public health services, it faces formidable challenges in doing so. The cheapest combination of antiretrovirals available at the moment costs about US\$42 a month per person for the drugs alone, and the total amount spent by the government per person *per year* on health care is just US\$4. At present, Uganda’s health services reach less than half the population, and only 57% of health workers are professionally qualified (with most of them in hospitals in the urban areas). There are 125 voluntary counselling and testing (UCT) sites countrywide, however six provinces have none.

The lack of human resources is the biggest constraint on access to treatment, says Dr Elizabeth Madraa of the STD/AIDS unit at the Ministry of Health, and there is a massive shortage of counsellors, in particular. Many are nurses and midwives for whom counselling is an added burden in their overly-busy working lives. Moreover, counselling for treatment is very different from the counselling for psychosocial support in which most have been trained, and there is a need for reorientation and upgrading of their skills, says Dr Madraa. “This is very

²⁰ *Access to Antiretroviral Drugs in Uganda: A Country Case Study*. Dorothy Ochola (unpublished).

²¹ Presentation by Dr Akol Zainab, on the Uganda National VCT Policy, at a UNAIDS retreat, 8-10 May 2003, Uganda.

²² *Access to Antiretroviral Therapy in Uganda*, Oxfam, June 2002.

²³ Antiretroviral Therapy Policy for Uganda, Ministry of Health, 2003.

important. We must avoid the misuse of antiretrovirals at all costs or we could do more harm than good.”

In 1998, Uganda was one of four countries selected by UNAIDS to take part in its Drug Access Initiative (DAI)²⁴, whose purpose was, among other things, to prove to the world that antiretroviral treatment could be delivered in countries with such limited resources. The initiative set out to develop innovative and effective models to improve access to HIV/AIDS drugs. Health workers were trained in workshops across the country, and a critical core of physicians with skills to provide antiretroviral treatment was created. By the time the programme was handed over to the Ministry of Health in 2000, there were five accredited treatment centres and more than 900 patients on antiretrovirals. The DAI taught valuable lessons, and the Government of Uganda has now developed a policy and guidelines for the use and management of antiretroviral treatment. All interested parties (including people living with the virus, nongovernmental organizations and the business community) have a voice in key decisions and policy-making through the Partnership Forum of the Uganda AIDS Commission. The country proposals to the Global Fund have been approved, and funds from the World Bank’s Multi-country HIV/AIDS Program for Africa (MAP), specifically for the provision of antiretrovirals, are already in the country. The MAP funds should cover the treatment of 6,000 patients for one year, and the Ministry is working out the criteria for eligibility, and who will get the drugs completely free, who will be subsidized and who will be asked to pay for their medicines themselves.

Meanwhile, the dying continues at a shocking rate: more 15–49-year-old Ugandans die from AIDS than from any other cause, and HIV-positive people and their families are doing everything in their power to pay for antiretroviral treatment for themselves.

Where there’s a will there’s a way

Nearly half the population of Uganda lives below the poverty line, and the average worker in Kampala takes home a pay of about US\$50–150 a month. Yet, between 5,000 and 10,000 people are taking antiretrovirals that they pay for themselves. Perhaps half obtain them from one of the 25 treatment centres that have been accredited by the government to date. But the other half get them from other sources. Some go to private physicians. Some get treatment through workplace health schemes run by a few big companies. People who travel bring them back in their briefcases from abroad. And some desperate people buy them over the counter at pharmacies without prescription or medical supervision.

As the following stories illustrate, many people living with HIV/AIDS in Uganda face agonizing choices between keeping themselves alive with expensive drugs and paying the household bills from day to day.

Connie

Connie Ojiambo, a tall, slender, dignified lady, sat over lunch at a retreat for people living with HIV/AIDS near Kampala and told her story. Nine of her brothers and sisters have died of AIDS and she is looking after four of their orphaned children, together with her own three children. She, too, is HIV-positive, and when she began to get sick and was unable to go to work, she found her salary as a teacher being stopped. Finally, she was asked to leave her

²⁴ The DAI was a partnership between the US Centers for Disease Control and Prevention (CDC), the French *Agence nationale de recherches sur le sida* (ANRS), UNAIDS and WHO.

job. Connie then joined the staff of NACWOLA (the National Community for Women Living with HIV/AIDS in Uganda), and was able to earn 250,000 shillings (about US\$126) a month. But there, too, she found herself struggling to cope with the job. She was losing weight fast, and says she was “almost gone” before, in desperation, she went to the Academic Alliance, a group of physicians active in research and offering antiretroviral treatment at Mulago Hospital. The Academic Alliance put her on antiretrovirals in August 2001. Connie had no time to look around for a sponsor; she was the sole supporter of the kids and desperate to survive for them, so she bought the drugs herself. They cost her 200,000 shillings a month (US\$101). On the 50,000 shillings (US\$25) she had left, she could no longer afford the things her children needed for school, and they had to stay at home. She could hardly afford to feed and clothe them. So, in August 2002, a year after starting treatment, she stopped, unable to justify the expense in the face of all the other family needs.

Connie began to decline fast and went back on to antiretrovirals again in December 2002. But she could only afford the drugs for one month before dropping out of treatment once more. Almost constant illness kept her away from her job at NACWOLA and she eventually lost that job too: she simply found that when she returned to work after a bout of sickness, her job was being done by someone else. Connie is still unable to afford to go back on treatment and her CD4 count has gone down to 25. So how does she survive now? “I survive by mistake. And goodwill—handouts from others,” she says. “I live a miserable life. I have no job and no income. I am an educated woman; I can speak out and make a lot of noise; how much worse must it be for someone who has no education?” she wonders.

But now she is tired of speaking out in the media, of writing to the government and going to see ministers to try to get her dues (she is still owed salary and severance pay from her job as a teacher). Nothing seems to make an impact, she says. “I’ve decided to keep quiet. I think I must just go to my room and die silently.”

Is Connie not encouraged by what she has heard from the Ministry of Health about extending access to antiretrovirals through the public service, and their commitment to making the drugs available even to those who cannot pay? “Maybe I will not be alive when it happens,” she answers. “We have been hearing such things for years. So many meetings like this. Policies, policies, policies. But when will they be implemented?”

Gideon

Gideon Byamugisha is well known in Uganda as the first and only priest to disclose publicly, in 1992, that he was HIV-positive. Today, he works for World Vision in Kampala, but his original ambition, before HIV/AIDS overturned his life, was to be a professor of theology. In 1991, he was about to begin a PhD at Cardiff University in Wales, sponsored by the Church Missionary Society, when his wife was suddenly taken ill and died in hospital within the week, leaving him with a baby daughter. Gideon did not know for several months that the hospital had found his wife to be infected with HIV, and it took him a few more months to gather the courage to be tested himself.

How long did it take, after his diagnosis, to decide to disclose his status? “About 20 minutes,” he says. “I thought, this is something too terrible to keep to myself.” The first person he told was his sister-in-law, the person who had brought him the terrible news about his wife. He told the principal at the theological college at which he was teaching and his students, as well as his own brothers and sisters. “The circle continued to expand,” he says. But it was in 1995, at

an international AIDS conference in Kampala, that he gave his first very public testimony. His disclosure brought a frenzy of media attention.

That year, Gideon had joined the Church of Uganda diocese of Namirembe as health secretary, responsible for running an AIDS programme for 520 congregations in 55 parishes. His Bishop, Samuel Balagadde Sekkade, had promoted him to Canon in recognition of his courage for speaking out, and has been a constant source of support throughout. It was he who appealed for help when Gideon had a crisis in 1998. “My story is miraculous!” says Gideon. “That time I was very sick and I nearly died. I had lost 20 kilos. My CD4 count was below 200. Bishop Samuel and his wife Ellen wrote to the AIDS Control Programme Manager, Elizabeth Madraa, and said: ‘we are soon losing a young man who’s been leading the way in breaking the silence and challenging stigma.’” Elizabeth Madraa shared the Bishop’s letter with a number of friends, who showed it to others, and gradually the circle of concern grew until they had raised the money for Gideon to start on antiretroviral treatment. Today, this group of concerned individuals, which spreads as far as the USA and the UK, has formalized into a charity, the Friends of Canon Gideon Foundation. The Foundation not only funds his treatment, but has promised, if he should die, to keep up his work in fighting stigma, caring for children orphaned by AIDS and seeking out and helping fellow HIV-positive priests who are living in secrecy, fear and shame.

Before he started on antiretrovirals, Gideon had been in and out of hospital with pneumonia, tuberculosis, fevers, and infected sinuses that left him deaf in one ear. He responded quickly to the drugs and began to regain his lost weight, but he soon began to suffer bad side-effects. He vomited and felt constantly nauseous. His stomach was swollen and he felt dizzy. His prescription was changed, and he has felt well ever since, except for an often overwhelming weariness. But this, he believes, could just as easily be overwork as the effect of the drugs.

Gideon takes a total of five pills a day—some at lunchtime and some at night. The critical thing for adherence, he says, is openness. “Then other people remind you, and you have no problem taking your pills in public, if necessary.” He is monitored every three months and has seen his CD4 count creep up above 700 and his viral load become undetectable.

In 1995, Gideon got married again, to an HIV-positive woman whose husband had died of AIDS. His wife is not yet in need of antiretrovirals and, in 2002, she gave birth to a daughter, whose last name, Rukundo, means ‘love’ in Rukiga. Having a child was a momentous decision, reached after extensive counselling about the implications and risks involved. “In Africa, you don’t tell a woman she will never have children,” says Gideon. “I saw it was eating her up.” His wife had watched the progress of the PMTCT programme in Uganda and done her own extensive research into the use of nevirapine to protect the babies of HIV-positive mothers from infection. So they decided to try for a child—a sibling for the daughter of his first marriage, who is now a teenager.

But Gideon’s happiness at the turnaround in his own fortunes as a result of anti-retroviral treatment is tempered by sadness that “what is happening to me isn’t happening to others”. The constant appeals he gets from people he does not have the money to help are one of his biggest sources of stress, he says. He and a number of other people living with HIV/AIDS are trying to set up a treatment fund, through his Foundation, for AIDS activists—people they feel are fighting stigma and being open about their HIV status at the expense of their own health. “We see them giving so much, and then wasting away,” he says.

They have elected a board for the new fund, drawn up guidelines on how it should work, and signed a memorandum of understanding with Nsambya Hospital as the service

provider for antiretrovirals. But Gideon struggles to find time in his busy schedule for the work it needs to get the initiative off the ground. Fundraising is particularly challenging in the case of antiretrovirals: people are understandably anxious about giving to something that demands such enormous, long-term commitment, and where failure to carry on giving will have such serious implications.

Deciding on the selection criteria presents problems, too, says Gideon. “Who do you take on and who do you leave out, given the level of need?” Do you stipulate certain values for CD4 and viral load? Many people cannot afford these tests, yet they know from all the signs that they have AIDS. Do you stipulate that they must be able to pay 20% of the costs of their treatment? People are unlikely to admit, even to themselves, that they cannot meet these costs. And how, exactly, do you define an activist and decide who is most worthy of treatment? “That is very, very difficult,” says Gideon. “Isn’t someone who puts on dramas in their local village to try to raise awareness as deserving as someone who speaks out on national television,” he asks. These are all questions he and his colleagues in the initiative still have to work out. Meanwhile, a few people have already found sponsorship for their treatment from the Friends of Canon Gideon Foundation. One of them is Rebecca Nakabazzi.

Rebecca

Rebecca Nakabazzi lives with her mother, some of her brothers and sisters, and lots of children, including her own son Julius, 11 years old. There are 13 of them sharing a home—a bungalow set among banana trees down a bumpy dirt road on the edge of Kampala. A young woman looking thin and frail, but with a radiant smile, Rebecca walks with difficulty into the room. She is recovering from malaria and has also been taking medication for tuberculosis, which has caused numbness in her lower legs.

Rebecca’s husband died of AIDS in 1992 after many months of illness, including TB and creeping paralysis. She nursed him throughout and did not realize it was AIDS because she had believed his vehement denials at the suggestion that it could be. But when her son got sick with TB and she and he both tested positive for HIV, she felt terribly betrayed. “I lost hope, I thought I would die in a few months,” she says simply. She was subjected to terrible discrimination and stigma in the village, where her husband had been one of the first to die of AIDS. In 1995, she joined NACWOLA, and soon became part of the drama group set up to fight the stigma. She has fought fiercely, and says that stigma has definitely subsided in her village. Now, every family has lost someone to the epidemic, she says, and they come to her for advice. “I’m so strong ever since I went public.”

She has been trained at the Philly Lutaaya Initiative²⁵ to bear testimony in public, and says being open has helped her enormously in her determination not to succumb to the virus, as so many of her family and friends from the village and NACWOLA have done.

In 2001, Rebecca became terribly ill and was bed-ridden. Eventually, tuberculosis was diagnosed at Mildmay Clinic, a specialist referral centre in Kampala for people with HIV/AIDS. Her family persuaded the doctors to put her on antiretrovirals. They were reluctant at first, believing she was too mentally unstable to comply with the treatment. But her

²⁵ Philly Lutaaya was a musician, and the first well-known Ugandan to go public about his HIV infection in 1989. He died on 15 December the same year. The Philly Lutaaya Initiative was set up specifically to help HIV-positive people to disclose their status, and to train them to speak publicly about their infection to help combat stigma.

mother, brothers and sisters were adamant. They had already lost four in the family, including an 11-year-old girl, and could take no more dying. They were desperate to save Rebecca.

But Rebecca's first bout of treatment was not a success. After three months, she was still very ill and consulted a private doctor, who found her to be anaemic and transfused her with two bottles of blood. She was also found to have active TB again, and was given intravenous medicine. "I was so thin you would wonder where to put the needle," she says. Her CD4 count was still zero, as it had been at the start of treatment. Her prescription was changed and she began to improve. After three months, her CD4 count was 29, and three months later it had risen to 211. But she still finds herself succumbing to opportunistic infections, including TB, from time to time.

Paying for her drugs is a real struggle. A woman from the UK who heard of Rebecca through Canon Gideon and was touched by the Memory Book she has compiled for her son Julius, now helps to support her with donations whenever she can. Rebecca is deeply grateful, but she still lives with chronic uncertainty as the bills keep coming. She slips out of the room to fetch her latest receipt from the Mildmay pharmacy. It is for 376,950 Ugandan shillings (US\$190). In addition to the drugs, she has to pay 10,000 shillings (US\$5) for each consultation and 50,000 shillings (US\$25) for a CD4 count. Travel to and from the clinic costs her 3,000 shillings (US\$1.50). And then there is Julius. He is not on antiretrovirals and she cannot bear to check his CD4 count, she says, "because I don't have money to buy drugs for him". But he does get sick from time to time and then she must pay for the medicines to treat him quickly.

At present, the large family survives on the wages of Rebecca's brother who is a driver and her sister who is a teacher, with contributions from two other married sisters who live elsewhere. The World Food Programme (WFP) has recently started distributing food to people living with HIV/AIDS through the Mildmay Centre, and this could be another welcome source of support for Rebecca and her family.

Major Rubaramira

Major Ruranga Rubaramira is the founder and national coordinator of NGEN+ (National Guidance and Empowerment Network of People Living with HIV/AIDS in Uganda). He discovered he was HIV-positive in 1989. A close friend who worked for an AIDS project had talked to him often about the virus, but he had been dismissive. "I asked her, 'does this thing kill faster than a bullet?' I'd been fighting in the jungle and had been shot at and I was still alive, so I wasn't worried about AIDS."

But when the Major read the materials his friend had given him, he began to think. "I realized everything I read was pointing at me, and that I could indeed be infected." So he and his friend went together to the Uganda Virus Research Institute at Entebbe to be tested. "In those days, there was no counselling," he says. When they went back for the results some weeks later, the Major was wearing his full military uniform, including a gun at the hip, and the nurse was rather intimidated. He smiles at the memory. But the news she gave him was devastating. "That was the moment I realized I'm a mortal man. HIV was even more powerful than a bullet. I was speechless."

For about three months after his diagnosis, he was paralyzed with the sense of helplessness. "I was scared—but not for myself, for my family. I'd been away fighting in the jungle for five years and my children were looking forward to a more normal life. And now I was going

to die. That was so painful.” He found himself weighing up his life, the investment he had made in it, his family, his mother, and he thought, “What a waste!”

The Major gradually became curious to know more about HIV/AIDS and to do something about it. He went to TASO (The AIDS Support Organization) to train as a counsellor, and he learned there that he did not have to accept the prospect of imminent death. He never hid his status from anyone—not at TASO, not in the Army, where he told his commanding officer. After working with TASO for a while, together with friends and colleagues, he founded the AIDS Information Centre, to give out more focused information on HIV/AIDS. He attended training workshops at Mildmay, too, and then began to take information and prevention messages back to the UPDF (Uganda People’s Defence Force), moving back into barracks to help with the medical services there.

Major Rubaramira started NGEN+ in 1994. In 1992, he had attended his first conference of people living with HIV/AIDS, in Amsterdam, and it had been a turning point in his life. “It was life-affirming. I realized that counselling is not enough. Sharing with others who have the same problems as you is what’s needed. Sharing is actually the best medication,” he says. He felt there was a need for a pressure group of people living with HIV/AIDS to campaign for treatment. Uganda has undoubtedly made a success of openness, and this is very important, he says. “But we need to go further and start looking at treatment as a mandatory thing if we are to avoid continuing to spread the virus.” It is a public health imperative, believes the Major. “We can’t talk about a breakthrough in this epidemic without treatment for all.”

The Major himself started on antiretrovirals in 1997, when his health began suddenly to decline after nearly a decade of living with the virus. He had done a good deal of reading and was aware of the range of drugs and the side-effects, but there was very little choice in Uganda at the time so he went on what was available. It did not agree with him. He developed kidney stones and started to pass blood in his urine, which greatly alarmed him. His doctor found him another combination and, over the past five years, he has had four changes of regimen. When he started on the drugs in 1997, the cost of a month’s supply was about 1.7 million Ugandan shillings (about US\$855), he says. It was way beyond his means, but because he was a well-known activist and a personal friend of President Museveni, the President supported his treatment. The Major is now on 13 pills a day, and does not find it a burden in the least. It is a question of mental attitude, he says. “I would be prepared to take 100 pills every day if that was what was needed, because I know what the alternative is.”

AIDSETI: Lifelines from across the world

AIDS Empowerment and Treatment International (AIDSETI) was set up in 1999 as a solidarity organization by people living with HIV/AIDS in the developed and developing world. Its purpose is to help HIV-positive people in developing countries to get access to antiretroviral treatment. AIDSETI's first step was to create a 13-member board to develop a plan of operation.

AIDSETI-Uganda has its own management board, with subcommittees that are responsible for recruiting patients and for screening them medically. Treatment is managed by one of the accredited centres in Uganda (mainly the JCRC and Mildmay), but the patients' drugs are collected by their partners and friends in the USA and sent out to Uganda. Some money is also paid into personal treatment funds at the centre to cover the costs of their laboratory tests.

At present, about 12 patients are benefiting from the scheme. AIDSETI offers them an invaluable lifeline, but not yet complete peace of mind. There are breaks in the supply line from time to time, and it is difficult for the doctor attending the patient to change the drug combination.

The service providers

By early 2003, a total of 25 treatment centres countrywide had been accredited by the Ministry of Health. For accreditation, a centre has to satisfy inspectors that there are health-care personnel available with clinical expertise in managing HIV/AIDS and counsellors for psychosocial support and follow-up. In addition, there have to be adequate laboratory services, efficient storage and dispensing systems for drugs, and a proven record of managing opportunistic infections. Accreditation is reviewed periodically. Though they all adhere to the same basic standards of service, the treatment programmes have different characteristics and ways of operating. This section will describe just three of them.

The Joint Clinical Research Centre (JCRC)

The JCRC was set up in 1991 as a joint project of the Ministry of Defence, the Ministry of Health, and Makerere University medical school for the principal purpose of studying HIV/AIDS. Despite its connections with government, the JCRC is an autonomous company and, today, it offers laboratory services and treatment to private patients as well as carrying out research. At its centre in Kampala, there is a 16-bed in-patient ward.

One of the Centre's first research projects demonstrated that an antiretroviral drug, AZT, could achieve equally good results at much lower doses than were being recommended by the manufacturer and prescribed by doctors. But, as its work with antiretrovirals became public knowledge, people living with HIV/AIDS began turning up at the Centre to ask for help. "It was our duty to start treating them," says Peter Mugenyi, JCRC's director. "We are doctors; it was our moral obligation."

The JCRC was the first centre in Uganda to offer antiretroviral treatment, in 1996. But the cost of the drugs meant it could treat only a tiny number of patients at first, so the Centre led the battle to reduce prices in Uganda. In defiance of the government's patent laws, it started importing generics from India and Brazil in 2001. "Patients were dying in our hands," explains Dr Mugenyi. "When you know they can be saved, you can't just sit there and do nothing. And

if we had tried to do it legally, it would have taken forever.” People living with HIV/AIDS were prepared to demonstrate at the airport to embarrass the government, if the importation of the drugs was blocked. But it was not necessary. So many government officers have personal experience of HIV/AIDS that they have no desire to obstruct access to drugs, explains Dr Mugenyi, and the only real problem is red tape. “The bureaucracy inherent to developing countries is a big constraint.”

Many a time, in order to get a shipment of drugs released from the airport, he has had to spend hours on the telephone to the customs department or leap into his car to visit the head of the National Drug Authority—the agency responsible for registering medicines and issuing special licences, when necessary. “You cannot afford to have a break in the supply line of drugs and to interrupt treatment,” he emphasizes, because this leads to resistance. “It’s very important that the potency of the first-line regimen is maintained as long as possible, because the second- and third-line regimens are very much more expensive and patients can’t afford them.”

So far, the big pharmaceutical companies have not taken the JCRC or the government to court over infringement of patents, and competition from generics has had a dramatic effect on their prices. Some big companies offered to match the prices JCRC was paying for generics, says Dr Mugenyi, and he then managed to get the generics company to reduce its prices in response. As a result of the price reductions, the number of patients treated at JCRC rose by 200% within a year—from about 962 in 2000 to over 3000 in 2001.

Although the majority of JCRC patients pay for their treatment, a sizeable number access ARVs through clinical trials that are taking place at the centre, where the treatment is given free of charge. One such study currently ongoing is the Developing Antiretroviral Therapy in Africa study (DART), which commenced in January 2003. This study, which, among other things, is looking at options for simplifying treatment and patient monitoring, using scientific evaluation, is being implemented in Uganda at JCRC and the Uganda Virus Research Institute-Entebbe in collaboration with TASO. The target is to have 2000 patients at these two sites over a period of one year and follow them up over a period of five years. Although the drugs and monitoring are provided free for the duration of the study, the Ministry of Health has given a letter of commitment to the effect that, should ARVs be within the public sector by then, the study participants will be given priority access.

“The three things most important to an antiretroviral treatment programme are compliance, compliance and compliance,” says the JCRC director. “The bottom line is that, no matter how sophisticated your infrastructure, you are not going to succeed with antiretroviral treatment unless you ensure compliance.” At JCRC, this message is hammered home by well-trained counsellors, as well as by the doctors and pharmacists. But most of the Centre’s patients are highly motivated and don’t need reminding: they have been pulled back from the edge and know the value of the drugs.

“I see this [the evidence of resistance to drugs in developing countries] as a warning to pharmaceutical companies and international aid organizations. In developing countries, black-market antiretrovirals are becoming the biggest source of antiretrovirals, and these drugs are going to be increasingly used by the community outside of medical institutions. In Kampala, the Joint Clinical Research Centre is the biggest formal user of antiretrovirals, and it sees not even a half of the users of antiretrovirals in Kampala. Therefore, the best way forward is not to try to prevent people from using the drugs [but] to make the drugs affordable, widely available and demystified, so that they can be dispensed to patients under medical supervision.”

—Peter Mugenyi²⁶

Jajja’s Home

In September 1998, the London-based AIDS charity, Mildmay International, opened the Mildmay Centre in Kampala as an AIDS referral centre to which severely ill patients with symptoms that were difficult to manage could be sent by other institutions and programmes for help. It is a centre of excellence in AIDS palliative care—particularly the management of pain, which it offers on an outpatient basis. In 1999, Mildmay provided antiretroviral treatment for those who could afford to pay. Jajja’s Home, a Mildmay International project that shares the same hillside site as the Mildmay Centre just outside Kampala, looks after the children and adolescents living with HIV/AIDS.



Nurse and care assistants at Jajja’s Home, caring for children with HIV/AIDS. Photographer: Sue Bonner

Jajja means ‘*grandma*’ in Luganda, and it was the name chosen for the special programme, which was developed by staff at Mildmay after it became apparent that children’s needs were not being met fully in the mainstream treatment programme.

Jajja’s Home is a day-care centre for children with HIV/AIDS who are severely disadvantaged. Many are orphaned and living in families that struggle with the extra burden. They are often sick, lonely, neglected and suffering from unresolved grief. Besides giving the children medical treatment and the individual care and attention they so badly need, the purpose of

Jajja’s Home is to offer respite and help to their carers, and children are only admitted to the programme on condition that their carers are prepared to work in partnership with the centre. They are involved in a care plan for the child, and are invited to attend carers’ workshops held

²⁶ Bass E, “Interview with Uganda’s Peter Mugenyi: No Second-best in AIDS Care,” *American Foundation for AIDS Research*, January 2001.

at Jajja's Home. In addition, there is individual counselling to help them work through a host of personal issues, such as feelings of resentment, neglect of the children, fear of infection, and coping with abject poverty.

The home is divided into three units: Kwagala (*'love'*), which caters for 0–5-year-olds; Mirembe (*'peace'*) for 6–12-year-olds; and Suubi (*'hope'*) for 13–17-year-olds. It has room for up to 85 children who are collected daily from homes within a 25-kilometre radius of Kampala. At Jajja's Home, they are cherished in bright, child-friendly surroundings. Much attention is paid to diet, and they are given a nutritious breakfast as soon as they arrive. The children's health is checked every morning as a matter of course and ailments treated promptly. A small number are on antiretroviral treatment under the supervision of the Mildmay Centre.

Unlike the rest of their health care, antiretroviral treatment for children is not free, so they must find someone who will pay for them, explains Jennifer Nabukenya, one of the doctors who work at Jajja's Home. When a sponsor comes forward, a child is selected for treatment according to strict clinical criteria. Then the child's carer is invited to see the doctor, who discusses in detail what is involved with antiretroviral treatment, including the need for consistency and regular timing in taking the drugs, and the need for good nutrition. The doctor then does a detailed assessment of the home situation to see whether there is the stability and commitment to the child that are essential to successful treatment.

The vital importance of a supportive home environment means that "the most neglected of our children can't go on antiretrovirals," says Dr Ruth Sims, director of Jajja's Home. "The more neglected the child, the less suitable they are for antiretroviral treatment. That's the sad reality." It is very hard for the health team at the children's home to make such choices, but Dr Sims says she has to fall back on her faith in palliative care, because that they can all have.

Every child at Jajja's Home has a file labelled 'care plan', which notes all the issues regarding the child's health and how they are to be handled. This will include everything that the members of staff, who work closely together as a team, need to know about the child's antiretroviral treatment. Once treatment is properly established, children on antiretrovirals are monitored about every three months. But this can raise difficult issues for the clinical team, says Dr Nabukenya. Ideally, they would like to do all kinds of tests to check for signs of treatment failure. But Dr Nabukenya knows the families are generally very poor, and the tests are expensive. So she is anxious to keep the costs down. Also, she is aware that making big demands on the family budget for one child risks breeding resentment, because it means hardship for the rest of the family.

Treating children with antiretrovirals raises many other issues as well, says Dr Nabukenya. It is hard to be sure that they are getting their drugs, and the staff at Jajja's Home are taught to look out for clues as to how well a child is complying. Sometimes, when they come to the doctor's clinic, she finds more pills in a child's bag than there should be at that point in the month. So she asks the nurses and care assistants on the team to visit the home, and to explore the possibility of drawing others, perhaps even neighbours or family friends, into the circle of care.

Knowing when and how to involve a child in his or her own treatment is a real challenge, says Dr Nabukenya. In the baby unit, this is not a problem. Little children do not need to know, and most are already taking a host of pills every day for other health problems so they would not notice anything remarkable. But, with adolescents, it is a very big issue. Sometimes, the guardians or carers say they do not want the child to be told by the medical staff and,



Fun and physiotherapy at Jajja's Home.
Photographer: Sue Bonner

when the child is under 18, and therefore still a minor, the staff must respect the guardian's wishes. "But sometimes a child will ask you, 'Am I on antiretrovirals?' or 'Have I got HIV?', and that's very hard," says Dr Nabukenya. She sometimes feels she is colluding with a conspiracy of silence, or betraying the trust of the child. This is something that the staff members of Jajja's Home have discussed a great deal in their weekly interdisciplinary meetings, and Dr Ruth Sims is busy developing guidelines. "But, at present, it's a matter of judgement and it's stressful," says Dr Nabukenya.

A child tells her story

Miriam is 13 years old, a lanky little girl in a brown velour top. She slides into a chair on the opposite side of the table, drops her chin onto her folded arms and stares impassively, waiting for questions. She is an orphan, and she and her two brothers and sisters have been taken into her aunt's family, where they live along with many cousins. She has been taking antiretrovirals for nearly two years now, and was very sick—unable to walk—before she started this treatment. Her brothers and sisters do not know that she has HIV, or that she is taking antiretrovirals; it is a secret between her and her aunty, who she says is very kind and whom she loves. She says of her siblings, "They know I'm sick but they don't know I'm taking those drugs. I'm not supposed to tell everybody". Did the nurses and doctors talk to her before she started taking antiretrovirals? Yes, she says, they told her that she must not miss her pills or she will have problems. And they told her she would have to take them forever. She felt dizzy, at first, but she understood that this feeling would pass and it has. Now she feels fine. Miriam takes her pills twice a day, and she remembers by herself.

The voice of experience: treating children with HIV/AIDS

Dr Ruth Sims started working at Mildmay as matron of the original hospice in London, and rose through the ranks to become group chief executive—a post she held for 15 years. In Uganda, she started the special children's unit at Mildmay, Kampala, which eventually became Jajja's Home.

Dr Sims has extensive experience of working with children and their families or guardians in the context of HIV/AIDS. She developed the workshops that Mildmay International runs, at which HIV-positive mothers and fathers learn how to disclose their status to their children. And, at Jajja's Home, she is developing guidelines for her staff on how to communicate with incurably-ill children who may not know their status.

The first principle, says Dr Sims, is always to be honest with a child. This does not mean that one has to give a direct answer to questions, but one should not lie. It is her view that, by the age of 12, children should know their status. But disclosing to children—whether it is they themselves who are infected or one of their parents—is a process not an event, she emphasizes. It is important to explore where children are coming from when they ask questions, and not to make assumptions about what those questions mean. Children should be given as much or as little information at a time as they can cope with and should be given support as they come to terms with it. A counsellor or carer should learn to recognize when children are traumatized by the knowledge, and how to help them.

In a team working with children, it is important to train everyone in communication skills, rather than just one person who is appointed to be the 'counsellor'. A child may choose to talk to a cleaner or a driver with whom they may feel comfortable rather than one specially designated adult, explains Dr Sims. At Jajja's Home, everyone is trained in communicating with children, but the staff members are told that if they get out of their depth with a child's questions they can always come to her for help. The lesson here, says Dr Sims, is that "you give a child as many choices as possible in who to speak to. They get so few choices, generally".

But it is never the duty or prerogative of the health worker to disclose to children their status, unless, perhaps, they are orphans with no one else in the world, stresses Dr Sims. If children ask a direct question of the doctor or nurse, such as, "Why am I taking these pills?", the health worker should turn the question round, and ask children what they think, suggesting that they talk to their carer. The health worker should then explore the issue of disclosure with the carer. One of the things you tell a carer who is reluctant to get into a discussion, says Dr Sims, is that the child is asking questions because he or she is feeling uncertain "and all human beings find uncertainty intolerable". But when a child does not want to talk about the subject any longer, this must be respected. "We must never break down someone's coping mechanism, even if it's denial," says Dr Sims. "We're not about looking at death and dying; we're about getting on with living!"



Tea-time at a day care centre in Gaborone, Botswana.
Photographer: Prathima Naidoo

‘Uganda Cares’

The Uganda Business Coalition (UBC) on HIV/AIDS is an organization set up to help the business community develop its response to the epidemic. In 2000, some members of the coalition met up with people from the US-based AIDS Healthcare Foundation (AHF) and discussed their idea of setting up an antiretroviral treatment programme that would be a model of such care in very poor communities. A regional AIDS conference in Kampala in 2001 gave the two organizations the opportunity to share the idea with President Museveni, who offered the full cooperation of the Ministry of Health in getting the idea off the ground.

‘Uganda Cares’ was launched in February 2002 as a partnership between the UBC, the AHF²⁷, and the Uganda Ministry of Health at the national level, and with a number of community-based organizations and interested parties as its partners at the local level. The treatment programme was set up in Masaka, 120kms south-west of Kampala, where the first AIDS cases in Uganda were reported in 1981. It was given space in the Masaka Regional Referral Hospital and the first few months were spent renovating a row of dilapidated rooms in the grounds of the main hospital to serve as a clinic. At the same time, intensive consultations were going on with all the partners on what the treatment criteria should be (see box), and how the programme should be run.

‘Uganda Cares’ treatment criteria

- patients should be resident in Masaka District
- patients should be ambulatory
- patients should come from a stable social network or family
- patients should be ‘antiretroviral-naïve’—that is, they should have no previous history of taking antiretrovirals
- patients should have a CD4 count of 200 or less, in the case of adults, or a CD4 count below 25% of the normal range for their age, in the case of children
- patients should not be suffering from a major opportunistic infection
- patients must have a known address
- patients must be willing to comply with treatment schedules and follow-up procedures
- patients must be referred through TASO, Kitovu Mobile, the VCT Unit, or AIDchild (a home for children with HIV/AIDS in Masaka)

Local partners of ‘Uganda Cares’ include the hospital itself, the Masaka District Administration, the Medical Research Council (UK), TASO, Kitovu Mobile Home-Care Services, and the AIDS Information Centre, which provides voluntary counselling and testing. The Masaka Healthcare Centre (MHC), which is the name of the clinic set up by Uganda Cares, serves a very poor, rural population and its patients are treated free of charge. The clinic, which operates two days a week on an outpatient basis, is staffed by a medical director, Dr Bernard Okongo, and a case manager, Sister Hope Katete, who is a nurse. They saw their first patient on 15 February 2002 and, as of September 2003, they had about 100 patients on their books.

²⁷ The AIDS Healthcare Foundation is the parent body of Global Immunity, which is also involved in ‘Uganda Cares’.

Insisting that the patients be referred by TASO, Kitovu Mobile or the AIC is important for a number of reasons, explains Dr Okongo. It ensures that they are automatically part of a network that knows who they are, where they live and in what sort of circumstances. The community-based organizations (CBOs) are responsible for all follow-up activities of the treatment programme, so people need to be registered with them. “Also, many times patients have psychosocial problems, and then they don’t take their medications well. CBOs can help patients with these problems.”

The key focus of the programme is adherence to treatment, says Dr Okongo. “Everything else is secondary.” Patients are given some information about antiretrovirals by the organizations that refer them, but this is not their area of expertise and most adherence counselling is done at the clinic. One or two patients who are already on the treatment programme have been asked to talk to new patients before they see the doctor or nurse. “They tell them about their own experiences with antiretrovirals, about how they take them, and the side-effects and things,” says Dr Okongo. “And, after that, we evaluate what they have learned.”

In their sessions with patients, the doctor and the case manager try to learn as much as they can about the person’s pill-taking habits so that they can drive home the importance of taking them at the same time every day. “It is very crucial that the blood concentration of the drug remain constant. If it fluctuates, it can give a window of opportunity for the virus to develop resistance. So we emphasize that every time,” explains Dr Okongo. “When a patient comes, we always ask, ‘What time do you take the drug?’ We ask casually and we compare with the notes we wrote down last time to check that they have got the message.” If a patient does not have a wrist watch, the doctor urges them to get one. “It’s a small investment (you can get a watch for about US\$0.50), and we remind them the clinic is paying US\$70 a month for their drugs.” The clinic data suggest that the programme is achieving adherence levels of more than 90%.

In the early days of treatment, patients are monitored weekly, then fortnightly, and then monthly if they are clinically stable and responding to treatment. Blood samples are sent by road to laboratories in Kampala because the facilities at Masaka Regional Hospital are very run-down at present. Drug supplies must be collected from Kampala also, and are mostly bought from Medical Access (Uganda) Ltd (see box on page 57). The Masaka Healthcare Centre uses only brand-name drugs, at present, at a cost of about US\$800 per patient per year. Though their treatment is free, patients are asked to make a small contribution—typically 2,000 shillings (about US\$1). “This money we keep separately to help them buy sugar, to take tea when they come here, or to help someone who may have come far and have transport problems,” explains Dr Okongo.

The clinic staff members build close relationships with their patients and know much of what goes on in their daily lives. Over the months, it has become clear that getting back on their feet involves more than just regaining their health. Many have dropped out of work when they became ill, and they struggle to find jobs and to get back into the social swing. Uganda Cares is looking at what it might do to help people find a livelihood again.

After the first 18 months of operation, Dr Okongo is enthusiastic about what ‘Uganda Cares’, has achieved in this very poor rural area, which still has the highest rates of HIV infection in the country. The secret has been in building on what already exists and forming cooperative partnerships with everyone working for people living with HIV/AIDS in the area. “This is a model that can work very well in Uganda. It is replicable because everywhere in the country we have organizations such as TASO, the AIC, and church-based organizations that

are helping people living with HIV/AIDS,” he says. They are currently making plans to start a similar programme in Soroti, in the north-eastern part of Uganda.

Treatment gives a boost to prevention

In January 2001, the voluntary counselling and testing (VCT) unit at Masaka Regional Hospital closed its doors. The service had become inefficient, and records showed that there was very little interest among local people to know their HIV status. Only 297 clients had come for HIV testing in the previous year. But, in 2002, the VCT services were rehabilitated (counsellors were trained, laboratory facilities improved), and the unit started operating again from the same premises as ‘Uganda Cares’, just as the treatment programme began. Attendance at the unit soared. By February 2003, a total of 5,060 clients had received VCT—a 17-fold increase on 2000.

VCT is one of the cornerstones of prevention, especially in areas where the infection rate is high. It represents an acknowledgement of one’s personal vulnerability, and is often a first step towards taking responsibility for protecting oneself and others. Until the treatment centre opened, people felt there was little they could do if they were infected, explains Dr Nathan Kenya-Mugisha, medical superintendent at Masaka Regional Hospital. “Now that antiretroviral therapy is available, people have a reason to know their status”²⁸.

Slow steps towards a brighter future

Experience in the 25 centres accredited thus far has resulted in many invaluable lessons being learned about what is needed for effective delivery of antiretroviral treatment. Based on this experience, the Ministry of Health has mapped out an expansion programme, together with implementation plans, says Dr Madraa.

The plan is to provide treatment in the regional hospitals, initially, then the district hospitals and then the health centres. But the challenges faced in bringing it to fruition are enormous, and the slow pace of delivery causes frustration and often despair in those who are in need of treatment now. At a retreat for people living with HIV/AIDS, held in Kampala in May 2003, Dr Elizabeth Namagala of the Ministry of Health presented the government’s draft antiretroviral policy for comment. Its ultimate aim is to provide AIDS drugs in the public health system for all who cannot afford to pay for their own treatment. But Dr Namagala pointed out that Uganda is currently unable to meet the costs of the most basic medicines required by the health services, such as simple painkillers and antibiotics, costed at about US\$3.5 per person per year.

Providing antiretroviral treatment will cost about US\$519 per person for one year, the government has calculated. “We are just costing for the cheapest regimen,” said Dr Namagala. “Antiretrovirals are very expensive. But they are necessary; everyone knows you can’t put a cost on the value of life.” In the immediate term, the government is looking to the Global Fund to Fight Aids, Tuberculosis and Malaria and the World Bank’s Multi-country HIV/AIDS Program for Africa for the financial assistance it needs. Meanwhile, Ugandans living with HIV must continue their own desperate search for antiretroviral treatment and the money to pay for it themselves.

²⁸ Mpiima S et al. ‘Increased demand for VCT services driven by introduction of HAART in Masaka District, Uganda’, poster presentation to the Second IAS Conference on HIV Pathogenesis and Treatment, Paris, France, 13-17 July 2003.

Medical Access (Uganda) Ltd: Streamlining drug supplies

Medical Access (Uganda) Ltd was set up as a non-profit company in 1998 to procure and distribute drugs as part of the UNAIDS Drug Access Initiative. It was supported by some of the big pharmaceutical companies²⁹ who were keen to get their drugs on the market as cheaply as possible by avoiding the middlemen. Also, says Denis Tugume, administrative officer for Medical Access, the companies were concerned about misuse of drugs in developing countries without good infrastructure and efficient systems for handling them. And they were anxious, too, that drug supplies and distribution be handled independently of politicians.

The plan was to set up as lean an operation as possible. Medical Access has just three staff members, headed by the general manager who is, as the law requires, a pharmacist. The company contracts out the storage and stock control of the drugs to an existing company, Joint Medical Stores (JMS), which also gives the small team office space.

Security is a major consideration, and the antiretrovirals are kept in a special safe in JMS's stock room. Stocktaking is done regularly, and no one is ever allowed to undertake this task alone. JMS has a store pharmacist with a stores officer working under him, one of whom has the key to the antiretroviral safe. When a staff member from Medical Access wants to go to the antiretroviral store, they have to apply for the key and go with someone else. So the whereabouts of the key and who is in possession of it is always known, and that person is responsible for the stock at that point. Another safeguard, says Denis Tugume, is that very few people are authorized to go to the store. It is a very simple system with no red tape. In addition, treatment centres have to submit their stock cards, and anything that has left the central store has to be accounted for by a prescription.

For the first three years, the pharmaceutical companies paid the operating costs of Medical Access, so drugs were sold on to the customers at cost price. But, since the end of the pilot phase, the pharmaceutical companies have been gradually withdrawing their support, so Medical Access has had to start putting a mark-up on its prices. However, it is also looking for donor support.

One of the biggest headaches in trying to balance the books, says Mr Tugume, is the instability of the Uganda shilling. Medical Access operates on credit of 30-120 days, and sometimes the exchange rate drops between the arrival of the drugs and paying for them, in which case the company loses out. Fluctuations in the exchange rate cause problems for their customers also, as they too are on credit. But they are particularly painful for the individual patient who never knows exactly what he or she will have to pay each month.

When Medical Access started its business, it was supplying about 90% of the market for antiretrovirals, says Mr Tugume. But, because of its relationship with the big pharmaceutical companies, it stocks only patent medicines, and its share of the market has dropped to about 75% since the arrival of generics.

²⁹ Glaxo-Wellcome, Bristol-Myers Squibb, Roche Products, and Merck Sharpe and Dohme.

The lessons of experience

This section of the report is intended to highlight lessons and observations from the field that have broad relevance, and that lend themselves to being adopted elsewhere.

■ **Antiretrovirals are neither a cure for AIDS nor a magic bullet. They must be part of a comprehensive package of care, support and prevention.**

Antiretroviral drugs are essential for protecting the health and prolonging the lives of people with HIV/AIDS, but they are not enough on their own. Antiretroviral treatment must always be part of a comprehensive package of care that emphasizes, among a range of issues, the importance of a healthy diet, and that offers treatment for opportunistic infections, counselling, support and family planning, as well as addressing issues of prevention.

As demonstrated in Botswana and Uganda, antiretroviral treatment programmes should work in close partnership with other services that provide VCT and home-based care, as well as with organizations offering counselling and support to people living with HIV.

■ **Most important to the success of an antiretroviral programme is adherence to the treatment.**

If the concentration of antiretrovirals in a patient's blood is allowed to drop, it weakens the suppression of the virus and gives it an opportunity to develop resistance. This is bad news for the patient, since it might necessitate changing to another, probably more expensive, drug combination. Furthermore, there is only a limited number of treatment options available. It is bad news for public health also, since drug-resistant viruses in circulation undermine the effectiveness of antiretroviral treatment for everyone. Strict adherence to the drug regimen is therefore one of the most important aspects of antiretroviral treatment, and it should be emphasized in every interaction between patients and health-care workers.

The support of family, friends and others outside the health team is also very important, and this report provides a number of good suggestions for ensuring adherence. As in Botswana, patients can be encouraged to have a 'treatment buddy' or 'treatment partner' to support them in taking their medicine. And, in the case of children, other people (including family members or even friends and neighbours) can be drawn into the treatment 'circle' if the child's primary caregiver is having difficulty carrying the full responsibility for drug-taking. This is the course of action taken by Jajja's Home in Uganda.

■ **Stigma is a powerful obstacle to adherence.**

People who are unable to be open about their HIV-positive status have particular difficulty in taking their drugs because of the need for secrecy. The personal testimonies in this report make it clear how important it is for the patient to have the support of family members, and even friends and work colleagues, in sticking to the regimen. Therefore, fighting stigma on the broad front, and encouraging and assisting individuals to be open (at the very least with their families) is always an important part of treatment.

■ **Disclosing their HIV-positive status to children is a process not an event.**

At some point, children on antiretroviral treatment need to become involved in their own treatment, and this means being aware of their HIV-positive status. Children should be

given the information in a manner they can understand and at a pace they can cope with. And they should be supported as they come to terms with the knowledge. Prime responsibility for disclosing to a child lies with the parent or guardian, and health workers should be guided by this primary caregiver in what they say to a child about his or her HIV status or treatment. They may, in fact, be asked by the caregiver for help and support in disclosing to the child. The case study of Jajja's Home in Uganda demonstrates the need for health staff working with children to be trained to recognize when a child is traumatized by the knowledge of his or her seropositive status, and how to help the child to cope.

■ **The advantages of 'treatment literacy', both for the patient and the health services, are enormous.**

Patients who are knowledgeable about HIV/AIDS medications (including antiretrovirals), and know when and how they should be used, are in a strong position when they need medical help. They know what to ask for, and can discuss their treatment on an equal footing with the doctors and nurses. Furthermore, they can make demands if they feel they are not getting what they need from the health services. For health-care providers, having well-informed patients who take responsibility for themselves greatly facilitates their work. Such patients know what is involved in treatment, what to expect of it, and the importance of adherence. 'Treatment literacy' should become a regular component of information, education and communication activities relating to HIV/AIDS. It is the cornerstone of the Treatment Action Campaign in South Africa.

■ **Time taken to prepare the ground for a new treatment programme is never time wasted.**

Treatment programmes do not develop in a vacuum, and changing the status quo is a sensitive business, since there is always the risk of causing resentment. Therefore, time taken to do the groundwork for a new programme is time well spent, as the example from Botswana demonstrates clearly. Everyone with an interest in the programme or who is likely to be affected by it (either as 'consumers', providers, or local government administrators, for example) should be consulted in advance, and their views taken into consideration in the planning and development of the programme.

■ **People living with HIV/AIDS have a vital role to play in treatment programmes, but they need to be empowered to do so.**

People living with HIV/AIDS understand each other's situations better than anyone and are often best placed to counsel and advise one other. A person having difficulty adhering to their treatment regimen, for example, may find it easier to admit failure to someone with personal experience of such problems than to the doctor, nurse or adherence counsellor at the clinic. Besides providing support, people living with HIV/AIDS can play an important role in follow-up, treatment literacy and campaigning. They should be recognized as a valuable asset to any treatment programmes and given the funds and training necessary for them to play their part.

■ **Antiretroviral treatment programmes should network and build on what exists rather than setting up new structures.**

In two decades of coping with HIV, all kinds of organizations have grown up in response to the epidemic. Many have something to offer a treatment programme in the way of experience, skills, services and/or facilities. Particularly in settings where resources are scarce,

it makes sense to make the most of what is already available. But, in addition to being cost-effective, building on what already exists helps to ‘root’ a programme and to encourage a wide sense of involvement and ownership. It is also important for sustainability. Both Uganda and Botswana have found this to be an important principle.

Treatment programmes should look for, and take advantage of, expertise and technical help from wherever it might be available, including the UN agencies (e.g. UNAIDS, WHO, UNICEF and UNDP) and foreign organizations working in the country.

■ **Training should include hands-on experience as well as basic instruction during workshops.**

The ‘preceptorship’ programme in Botswana, in which newly trained staff work for a period under the supervision of AIDS experts in the clinics, offers a good model for practical training. Moreover, the value of such a programme is likely to go way beyond the passing on of skills. Visiting AIDS experts often develop strong bonds with the places in which they work and the people they train, and continue giving guidance and support by e-mail or telephone even when they return to their own countries.

■ **Good teamwork is essential to the success of a treatment programme and should be nurtured.**

Because successful treatment with antiretrovirals depends on a continuum of care from the doctor’s surgery to the patient’s home, it is important that all those professionally involved (including doctors, nurses, pharmacists, laboratory personnel, counsellors, social workers, nutritionists and home-care staff) work together as a team. Building and nurturing team spirit requires effort, and the example of Jajja’s Home and the Mildmay Centre in Uganda show the importance of setting aside regular time for multidisciplinary meetings at which staff discuss their work, share their experiences and support each other.

■ **Competition in the drugs market is essential in bringing down prices.**

Experience from Uganda and South Africa shows clearly that the more freedom a treatment programme has to shop around for drugs, the more competitive are the prices it is offered by the pharmaceutical companies. Governments should therefore look to market forces rather than altruism to make life-saving treatment affordable for their people. They should take advantage of all the options given to them under World Trade Organization rules to liberate the market in drugs. This means, in particular, passing the necessary legislation to allow for the manufacture and/or importation of generics, and for the purchase of brand-name drugs from the cheapest sources.

■ **Computers for keeping clinical records should be geared up to gather data for research purposes, too.**

Antiretroviral programmes in Africa are breaking new ground and there are many questions that need answering. These should be taken into consideration in designing computerized systems for keeping clinical records so that the relevant data can be gathered at the same time for monitoring and evaluation purposes and accessed easily by researchers.

■ **It is vital that treatment campaigners be knowledgeable about the issues, not just skilled in political activism.**

An important lesson learned from TAC in South Africa is that treatment campaigners need to be able to speak with authority and hold their own debates with all the key players (e.g. drug manufacturers, medical professionals, scientists, economists, lawyers and government officials). They therefore need to be up to date with the science and economics of HIV/AIDS as well as the politics. It is also important for campaigners to base their case on the best scientific evidence available, rather than on personal opinion, and never to exaggerate facts. This ensures the credibility of the campaign and encourages respect and cooperation from specialists who are not afraid that their information will be misused.

■ **Lawyers are essential partners in treatment campaigns.**

As the case study from South Africa shows, the law has a major part to play in terms of access to drugs, creating either an enabling or an obstructive environment for treatment programmes. Treatment campaigners need to work with lawyers to identify opportunities for action in both national and international law, and to push for reform, where necessary, to make the law more responsive to their needs. In addition, 'legal literacy' needs to be part and parcel of social mobilization, since making the most of the opportunities offered by the law depends on activists at all levels of the campaign being well-informed.

Conclusion

Antiretrovirals are the only hope for countries hard hit by HIV/AIDS of stepping back from the edge. Access to HIV/AIDS-related treatment is also fundamental to realizing the right to health. There are now a large number of antiretroviral treatment programmes in the developing world that have demonstrated conclusively that, given the political will, these drugs can be used safely and effectively in settings where the health infrastructure is poor and resources for health-care are scarce. The *WHO Guidelines for Scaling up Antiretroviral Therapy in Resource-Poor Settings—A Public Health Approach* provide guidance on the use of standardized regimens and simplified monitoring. The examples from Africa, where the pandemic is at its worst and the challenging conditions in which treatment programmes operate, should persuade the doubters that there are no good practical reasons for not setting up antiretroviral treatment programmes wherever in the world they are needed. Indeed, failure to do so is likely to result in the very thing the doubters most fear: treatment chaos and the development of widespread resistance to antiretrovirals.

As Dr Peter Mugenyi of the Joint Clinical Research Centre in Uganda points out, there is a fast-growing black market in antiretrovirals to supply the needs of the hundreds of thousands of people living with HIV/AIDS who are desperate to survive but have no hope of getting on a bona fide treatment programme. More than half of those on antiretroviral drugs in Uganda are taking them without proper medical supervision or follow-up. What is happening in Uganda is surely happening in other countries where people with HIV/AIDS are dying for want of antiretroviral treatment. Desperate people cannot wait while their governments and the international community prevaricate. They and their families will do whatever it takes to get drugs, and there are many people who are prepared to cut corners to meet their needs. In Kampala, for example, it is easy to find a pharmacy that will sell the drugs over the counter without a prescription.

Thus, in addition to the humanitarian imperative, there are pressing public health reasons for making antiretrovirals widely available through the mainstream health services. In all three countries visited for this report, the same key message was delivered: countries should not wait until everything necessary is in place before making the commitment to provide treatment in the public health service. They should start with what already exists and meet the challenges as they arise.

But in order to do so, countries must mobilize the necessary resources — estimated at US\$10 billion by 2005 and US\$15 billion by 2007. In addition, mechanisms must be found to ensure that the money does not get caught in a bottleneck at government level — as it so often does at present — but that it trickles down to the grassroots and delivers real, practical assistance to people living with the virus.

New ventures such as the World Bank's Multi-country AIDS Program for Africa and the Global Fund to fight AIDS, Tuberculosis and Malaria have great potential to channel additional resources effectively to the countries most affected by HIV/AIDS.

The vision of the Botswana Government for an AIDS-free Botswana by 2016, the activism of the Treatment Action Campaign in South Africa, and the risks that people living with HIV/AIDS and their families will take in Uganda (all to ensure that their right to treatment is respected) are examples of what is being done and what is possible.

Useful reading and resources

UNAIDS/OHCHR (2002) *HIV/AIDS and Human Rights, International Guidelines, Revised Guideline 6; Access to Prevention, Treatment, Care and Support*. Available electronically from: www.unaids.org.

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International HIV Treatment Access Coalition (ITAC)

ITAC is a coalition of partner organizations including people living with HIV/AIDS and their advocates, NGOs, governments, foundations, the private sector, academic and research institutions and international organizations. (See www.itacoalition.org.)

The Global Fund to Fight AIDS, Tuberculosis and Malaria

Established in 2001, the Global Fund is an independent, public-private partnership working to attract significant new resources to fight AIDS, tuberculosis and malaria, and to innovatively manage and disburse such funds to effective prevention and treatment programmes in countries with greatest need. (See www.theglobalfund.org.)

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Annex: The Pan-African HIV/AIDS Treatment Action Movement (PHATAM)

“We are angry. Our people are dying. Without treatment, the 28 million people living with HIV/AIDS on our continent today will die predictable and avoidable deaths over the next decade. This constitutes a crime against humanity.”

These are the words with which activists and organizations from 21 countries across Africa launched the Pan-African HIV/AIDS Treatment Action Movement (PHATAM) on 25 August 2002 at the Earth Summit in Johannesburg. Their declaration goes on to say that “access to antiretroviral therapy is not only an ethical imperative but will also strengthen prevention efforts, increasing the uptake of voluntary counselling and testing, reduce the incidence of opportunistic infections, and reduce the burden of HIV/AIDS (including the number of orphans) on families, communities and economies.”

PHATAM makes a whole series of demands, addressed specifically at national governments, as well as at donor countries, multilateral institutions³⁰, the pharmaceutical industry, and the private sector. Among other things, it demands that:

National governments

- create and implement clear, legally-binding HIV/AIDS policies and plans that include antiretroviral treatment as part of a comprehensive continuum of care for people living with HIV/AIDS;
- fulfil commitments made at the Abuja Summit to dedicate at least 15% of their annual budgets to improving health; and
- intensify treatment education and promote treatment literacy for people living with HIV/AIDS, communities and health workers.

Donor countries

- fulfil their existing commitments to give at least US\$10 billion annually to the Global Fund and other HIV/AIDS-related financing mechanisms; and
- implement the Doha Declaration in good faith to ensure that countries with insufficient manufacturing capacity have the right to import quality generics in the most efficient manner.

Multilateral institutions

- develop a strategic plan including specific targets and timelines to achieve the goal of providing antiretroviral treatment for at least 3 million people by 2005;
- provide technical assistance to African countries to develop and implement sound treatment programmes; and

³⁰ The institutions identified include WHO, WTO, UNAIDS, UNICEF, and the Global Fund to Fight AIDS, Tuberculosis and Malaria.

- develop international ethical guidelines for clinical trials that guarantee life-long treatment free of charge to all trial participants.

The pharmaceutical industry

- unconditionally reduce prices of drugs, diagnostics and monitoring tools;
- immediately stop blocking the production and importation of generic drugs by developing countries; and
- provide free treatment for life for all participants in clinical trials and abide by international ethical standards.

The private sector

- implement comprehensive workplace policies, including the provision of antiretroviral therapy for all workers; and
- ensure that private medical insurance policies provide appropriate care and treatment for people living with HIV/AIDS.

In launching their movement, PHATAM members committed themselves to doing their part in meeting the goals of antiretroviral treatment for all who need it by mobilizing and educating their societies, and keeping their governments and the international community on their toes.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together nine UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its nine cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

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The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV/AIDS, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the HIV/AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact-alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the HIV/AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

Find out more about the Best Practice Collection and other UNAIDS publications from www.unaids.org. Readers are encouraged to send their comments and suggestions to the UNAIDS Secretariat in care of the Best Practice Manager, UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland.

Stepping back from the edge

The pursuit of antiretroviral therapy in Botswana, South Africa and Uganda

Out of the 40 million people estimated to be living with the human immunodeficiency virus (HIV) around the world in 2003, about 70% are from the sub-Saharan African region. AIDS killed approximately 2.3 million people in the region in 2003. With so many already infected with HIV, this staggering annual death toll is expected to climb considerably in the coming years. The only chance to mitigate this rise in AIDS mortality is a massive expansion in the delivery of antiretroviral treatment.

Several countries in the region are investing in efforts to provide antiretroviral and other AIDS-related medicines to people in need, usually with considerable assistance from bilateral and multilateral donors. However, the coverage of these initiatives remains extremely low, with only about 50,000 people on treatment by the end of 2002.

This report looks at what is being done to challenge the snail's pace of progress on access to antiretroviral medicines in three very different African countries—Botswana, South Africa and Uganda. It describes *who* is driving these initiatives at grass-roots level and *how*. It offers insights and draws on lessons from firsthand experiences that can help those already working towards better access to antiretrovirals, and encourages others to embark on similar initiatives. It is intended for all those with an interest in this issue—from policy- and decision-makers with the power to create a favourable environment for antiretroviral treatment, to those working on the front line in health services, NGOs and AIDS service organizations, as well as those living with HIV, whose role in the battle for wider access is so vital.



Joint United Nations Programme on HIV/AIDS

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