

Care, treatment and support for people living with **HIV/AIDS**

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The Declaration of Commitment (from the United Nations General Assembly Special Session on HIV/AIDS) is a historic landmark in the fight against HIV/AIDS. For the first time, treatment and care, including access to antiretroviral drugs, were specifically recognized by all the world's governments as an essential element of the response to the global HIV/AIDS pandemic.

Comprehensive care for people living with HIV/AIDS involves a number of important features, in addition to increased provision of antiretrovirals. These features include, but are not limited to, the following:

- available, accessible voluntary counselling and testing (VCT) services;
- prevention and treatment of tuberculosis and other infections;
- prevention and treatment of HIV-related illnesses;
- palliative care;
- prevention and treatment of sexually transmitted infections (STIs);
- prevention of further HIV transmission, through existing technologies (e.g. male and female condoms, clean needles and syringes), and using future technologies (e.g., vaccines and microbicides) as well as behavioural change);
- family planning;
- good nutrition;
- social, spiritual, psychological and peer support;
- respect for human rights; and
- reducing the stigma associated with HIV/AIDS.

A central element of a comprehensive HIV/AIDS care strategy is the wholesale integration of prevention and treatment planning and interventions. Prevention and treatment can no longer be seen as unrelated strategies.

Research is needed to anchor an effective overall response to HIV/AIDS. Rigorous analyses of basic, clinical, epidemiological and sociobehavioural research results must be used to guide the implementation of prevention, treatment and care programming.

Despite significant achievements in the past two years, the vast majority of the over 38 million people living with the virus in low- and middle-income countries at the end of 2001 remained severely deprived of even basic medications for treating HIV-related illnesses and for relieving pain.

Several factors contribute to this. Firstly, HIV diagnostic tests (as part of broader voluntary counselling and testing services) are not universally available and the majority of people living with HIV/AIDS remain unaware of their HIV status. Secondly, despite recent reductions in the price of antiretroviral drugs, the lowest prices currently on offer still greatly exceed the annual per capita health expenditures of most low- and middle-income

countries. Thirdly, health systems in such countries are ill-equipped to deliver effective treatment of HIV/AIDS and its associated illnesses. Finally, in places where these services are available, fear and stigma associated with HIV/AIDS and the abuse of human rights of people living with the virus contribute to the ongoing reluctance among many people to come forward for testing and treatment.

Declaration of Commitment

By 2003, ensure that national strategies, supported by regional and international strategies, are developed [...] to strengthen health-care systems and address factors affecting the provision of HIV-related drugs, including antiretroviral drugs, inter alia, affordability and pricing, including differential pricing, and technical and health-care system capacity [...] (paragraph 55).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

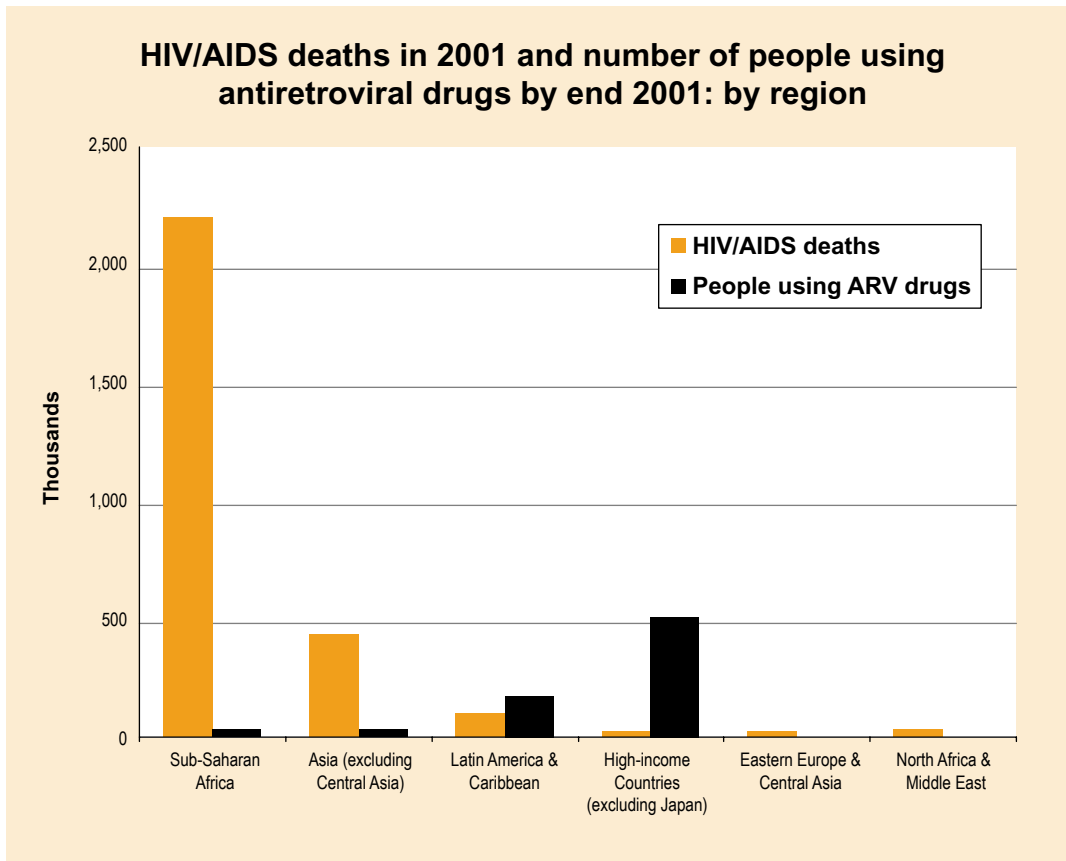
Treatment for all? A beginning

Improving access to antiretroviral drugs is a global priority. More drugs will catalyse better health-care delivery systems. Better health-care delivery systems will promote greater capacity to deliver affordable medical technology.

When the current number of HIV/AIDS-attributable deaths is contrasted with the numbers of people using antiretroviral drugs in different regions around the world, the current global inequity in treatment is glaring (see Figure 32). However, at the same time, it illustrates the dramatic impact of extended treatment access on the lives of some people living with HIV/AIDS.

In high-income countries where combination antiretroviral treatment became widely available from 1996 onwards, AIDS-related mortality dropped sharply for two or three years and has since plateaued. The past two years have seen significant achievements in the availability and use of antiretroviral and other essential drugs in some low- and middle-income countries. Improvement in mortality and morbidity trends due to availability of antiretrovirals is particularly notable in Brazil and should become visible during the next few years in other countries in Latin America, the Caribbean and Asia.

Figure 32



Source: WHO/UNAIDS, 2002

Drug prices plummet

Following the introduction of combination therapies in 1996, conventional wisdom held that these treatments would, for the foreseeable future, remain financially and logistically beyond the reach of most HIV-positive people living in low- and middle-income countries.

In order to contest this conventional wisdom, in 1998, UNAIDS and WHO set up a Drug Access Initiative comprised of pilot projects in Côte d'Ivoire and Uganda and, later, in Chile and Viet Nam. This initiative examined constraints—technical, administrative and financial—to the use of antiretroviral therapy in resource-poor environments. The projects

involved small numbers of people (e.g., 1600 in Uganda), but yielded important lessons about evidence-based treatment guidelines, patient compliance, stock management and referral systems. These insights have been invaluable in helping expand AIDS-related care, treatment and support, now that prices are being significantly reduced.

In 2000, broad application of differential pricing for AIDS drugs, based on country need and ability to pay, meant that prices offered to low- and middle-income countries fell dramatically. At the beginning of 2000, the price of combination antiretroviral drugs to treat one patient for one year was typically between

Progress in treatment access

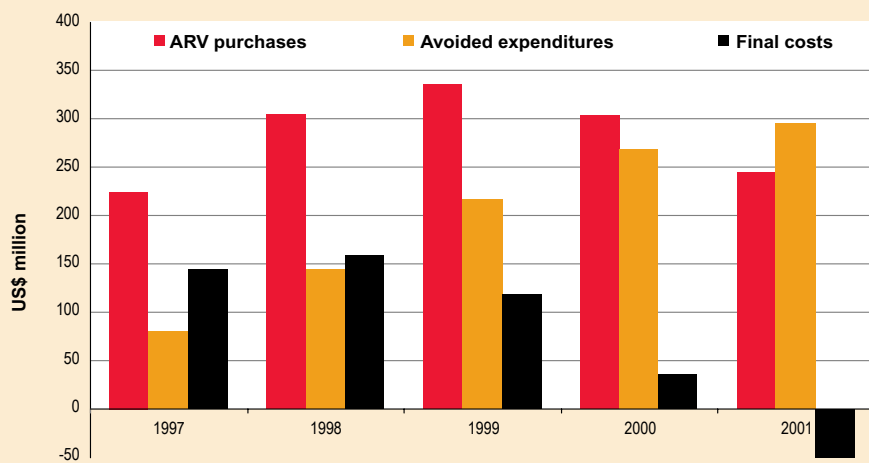
Latin America and the Caribbean have become leaders in providing antiretroviral treatment to people living with HIV/AIDS. Of 24 countries in the region surveyed in 2001, 11 have policies, regulations or laws that guarantee access to antiretroviral therapy.

Brazil has shown a long-standing commitment to providing universal antiretroviral access for its population. But in many other countries of the region, thanks to the bold advocacy efforts of a range of nongovernmental organizations and people living with HIV/AIDS, an increasingly strong commitment to provide access to antiretrovirals has emerged. At the end of 2001, approximately 170 000 people across the region were receiving ARV treatment, including 105 000 in Brazil, where prevention efforts are complemented with an extensive treatment and care programme that guarantees state-funded ARV therapy for those living with HIV/AIDS. By reducing HIV/AIDS-related morbidity, Brazil's treatment and care programme is estimated to have avoided 234 000 hospitalizations in 1996–2000.

By 2002, the public sectors in Argentina, Costa Rica, Cuba and Uruguay were also providing free and universal access to ARV treatment. However, there are still large disparities in the quality and scope of different countries' ARV programmes. There are also recent reports of drug supply shortages in Argentina, due to the current political and economic crisis in the country.

Countries such as Honduras and Panama are now also providing treatment access. At the request of the Caribbean Heads of Government, Caribbean countries (led by CARICOM, within the framework of the Pan-Caribbean Partnership) are developing a common regional strategy to accelerate and broaden access to treatment and care for those living with HIV/AIDS. Countries such as St Kitts and Nevis, Barbados and Grenada have begun implementing new national programmes to enhance care and treatment.

Cost of antiretroviral drug purchases, avoided expenditures and final costs to the Ministry of Health Brazil: 1997-2001*

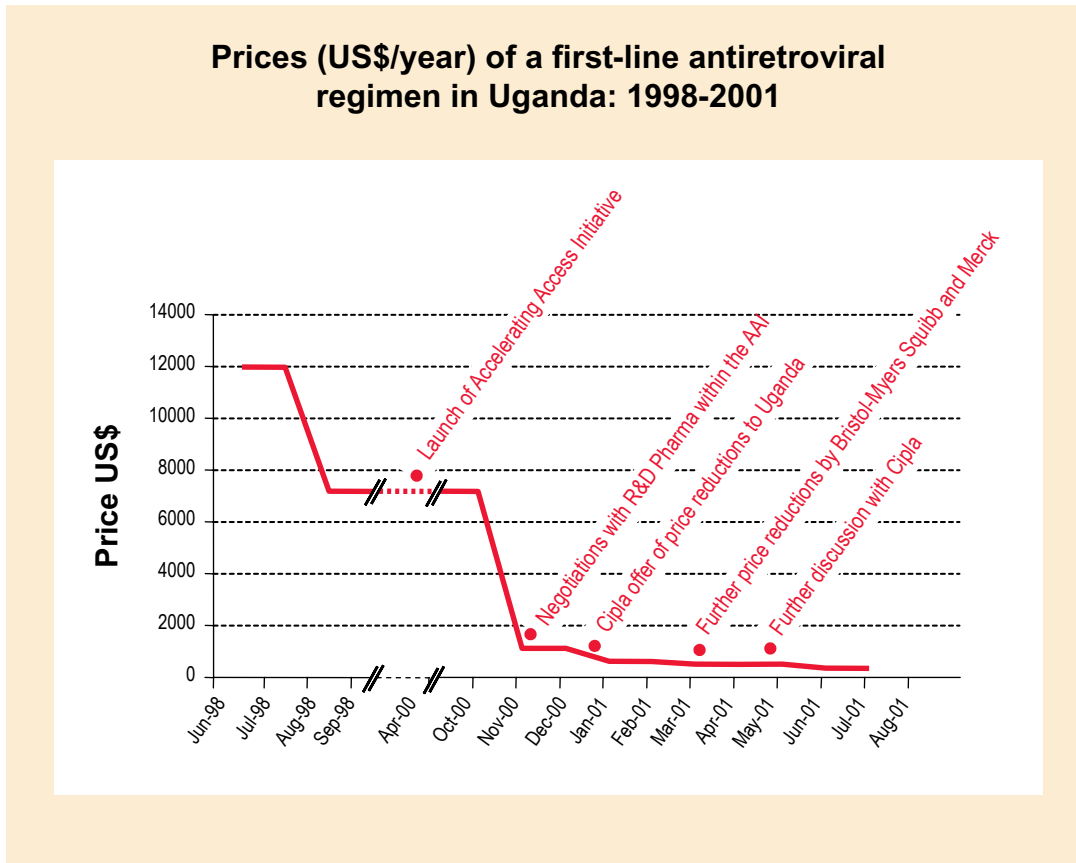


* Estimated data

Figure 33

Source: Ministry of Health Brazil, 2001

Figure 34



Source: WHO/UNAIDS, 2002

US\$10 000 and US\$12 000 almost everywhere. By the end of 2000, prices of US\$500 to US\$800 were being negotiated by low- and middle-income countries for therapies based on patented and generic drugs. By December 2001, certain generic combinations were on offer for as low as US\$350 per person per year.

Price reductions of this magnitude have, of themselves, a significant impact on the accessibility of therapy. Analysis conducted by McKinsey and Company on increasing access to antiretrovirals in Uganda has underlined the extent to which drug costs seriously limit the country's capacity to boost treatment provision. At an annual charge of around

US\$2400, about 5000 people could be reached. When the annual cost of drugs per person fell to US\$600, about 50 000 people could be reached.

For middle-income countries with relatively low HIV prevalence, the price reductions bring the cost of providing universal access to antiretrovirals down to proportions of gross domestic product similar to those of the world's high-income countries. Reduced prices would lower expenditures in Chile, Morocco and Romania to less than 1% of gross domestic product for example. These countries already have health infrastructures with the capacity to deliver the drugs. However, in low-income countries with

high AIDS prevalence, a much higher proportion of economic output would be required to provide antiretrovirals to those in need.

The reductions achieved during 2001 in the prices of antiretroviral treatments for low- and middle-income countries were the result of a convergence of forces. Activist organizations and people living with HIV/AIDS throughout the world have been instrumental in placing treatment-access issues at the top of the agenda. Other important factors influencing large-scale price reductions have included dialogue between national governments, international organizations and large pharmaceutical

manufacturers; competition from generic drug manufacturers; and legal and diplomatic action at national and international levels.

A number of nongovernmental organizations, including OXFAM and *Médecins Sans Frontières*, have prioritized advocacy efforts to secure price reductions for antiretrovirals to improve treatment access in low- and middle-income countries. In addition, the International HIV/AIDS Alliance, a nongovernmental organization based in the United Kingdom, has produced practical resources to assist community-based organizations in improving access to HIV/AIDS treatment.

Accelerating access

An important element of international efforts to secure price reductions for antiretroviral drugs has been the establishment of an international framework—a public/private partnership on accelerating access. This partnership was initiated in 2000 between the UN (UNICEF, UNFPA, WHO, the World Bank and the UNAIDS Secretariat) and five major pharmaceutical companies with products, research and development portfolios in HIV/AIDS (Boehringer Ingelheim GmbH, Bristol-Myers Squibb, GlaxoSmithKline, Merck & Co., Inc. and F. Hoffmann-La-Roche Ltd), with Abbott Laboratories Ltd joining later. The purpose of the partnership is to increase access to HIV/AIDS care, treatment and support. Negotiations have proceeded along two tracks: firstly, dialogue with the pharmaceutical industry to make high-quality drugs (including generics) more affordable in low- and middle-income countries; and, secondly, technical collaboration with countries to expand their capacity to deliver care, treatment and support.

The UNAIDS Contact Group on Accelerating Access to HIV/AIDS Care and Support reports to the UNAIDS Programme Coordination Board. It provides an important forum for exchanging information and sharing country and regional experiences. This group includes governments of donor and low- and middle-income countries, civil society representatives, the private sector and various multilateral organizations.

In May 2000, agreement on a set of fundamental principles to guide collaboration helped pave the way for preferential pricing agreements that governments would negotiate individually. Additional impetus for action came in May 2001, when the UN Secretary-General met with representatives of the major pharmaceutical companies to make the case for moving ahead on differential pricing. As all of these pieces fell into place, the situation began to improve rapidly.

Following breakthroughs on the principle of preferential pricing for AIDS drugs in low- and middle-income countries, attention has turned to securing procurement agreements between countries (or groups of countries) and drug manufacturers.

Meanwhile, generic drug manufacturers in low- and middle-income countries (notably Brazil, India and Thailand) are producing their own versions of certain antiretrovirals and offering them in their domestic and, in some cases, overseas markets. ‘South-to-South’ cooperation on drug access is increasing. In April 2001, India and South Africa signed a declaration of intent to cooperate in a variety of health fields, including technology transfer and importation of inexpensive HIV/AIDS-related drugs. Thailand, which has considerable experience both in generics production and community care, has signed a similar agreement with Ghana. In late 2001, Indian generics manufacturer, Cipla Ltd, agreed to supply the Nigerian Health Ministry with a three-drug antiretroviral therapy at US\$350 per patient per year. Under the US\$4 million pilot programme, about 10 000 adults and 5000 children are to be treated in selected hospitals throughout the country. People undergoing treatment will pay US\$120 per year and the government will cover the remaining cost.

Progress at country level

As of March 2002, 36 of 78 countries who have expressed an interest in collaborating with UNAIDS on access to care and treatment (see ‘Accelerating access’ box) have completed, or are in the advanced stages of developing, national care and treatment plans, with technical assistance from the UN. Eighteen of these countries—Barbados, Benin, Burkina Faso, Burundi, Cameroon, Chile, Republic of the Congo, Côte d’Ivoire, Gabon, Honduras, Jamaica, Mali, Morocco, Romania, Rwanda, Senegal, Trinidad and Tobago, and Uganda—have reached agreement with manufacturers on significantly reduced drug prices. Individual companies have reported reaching agreements

with four additional countries—Botswana, Chad, the Democratic Republic of the Congo and Malawi. The funding mechanisms employed range from direct government subsidies to patients (in Chile, Côte d’Ivoire, Gabon, Mali, Romania, Senegal, and Trinidad and Tobago), to the purely out-of-pocket-purchasing arrangement in Uganda.

Over the first few months of operation, there was already a marked increase in treatment access in countries where plans were beginning to be implemented. In the first 11 countries, as of December 2001, some 22 000 people had gained access to antiretroviral therapy, representing a seven-fold rise in the number of patients treated. Although these numbers are small, amounting to only a fraction of those in need of antiretroviral therapy, they nevertheless represent an achievement, given the fact that virtually no one in these countries had previously received treatment. Since the end of 2001, the numbers have continued to grow.

The quest for a ‘new deal’

It is important to ensure that further research and development of new and improved HIV therapies are not compromised by price reductions on existing drugs. In the absence of a cure and a vaccine, and in view of the serious risk of resistance to existing antiretroviral drugs, innovation is critical. Historically, the protection of intellectual property through patenting has ensured that profits are made by the pharmaceutical industry in return for ongoing investments in research and development. However, although patent protection has benefited shareholders and society in high-income countries, it has not worked for the poorer countries, where approximately 95% of the world’s population with HIV/AIDS lives.

In 2001, UNAIDS called for a ‘new deal’ with industry to ensure that new forms of HIV treatment are made available as rapidly to people living with HIV/AIDS in low- and middle-income countries as to those in high-income countries. Multiple approaches are needed, including the following:

- a system of tiered pricing, dependent on the relative incomes of countries;
- competition between suppliers to reduce prices;
- regional procurement to secure price reductions through large-volume purchases;
- licensing agreements between patent-holding companies and manufacturers in low- and middle-income countries;

- reinforcement of health safeguards in trade agreements, such as compulsory licensing to manufacture-patented medicines where HIV/AIDS constitutes a national emergency; and
- new private- and public-funding mechanisms to help pay for treatment for the poorest countries of the world.

At the same time as these approaches are applied to extending access to treatment in low- and middle-income countries, high-income countries need to continue to support the intellectual property protections and financing systems that allow for investment to be recouped for research and development by the pharmaceutical industry.

TRIPS clarified at Doha

The Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) has been the subject of a great deal of debate regarding its impact on public health, in general, and its impact on access to medications, in particular. The World Trade Organization Ministerial Conference in Doha, Qatar, however, achieved a broad international consensus that TRIPS must be part of wider national and international action to address serious public health problems, including the AIDS epidemic, in low- and middle-income countries. In November 2001, all 142 World Trade Organization Member States endorsed the Doha Declaration on the TRIPS Agreement and Public Health. This document stresses that TRIPS “can and should be interpreted and implemented in a manner supportive of WTO members’ right to protect public health and, in particular, to promote access to medicines for all”.

While acknowledging the importance of intellectual property protection for the innovation of new medicines and technologies, the Doha Declaration provided a blanket extension of 10 years (from 2006 to 2016) for countries classified as ‘least developed’, to comply with the patent requirements of the Agreement in the pharmaceutical sector.

The Doha Declaration states explicitly that “public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency” for which governments can issue a compulsory licence authorizing, under certain conditions, the use of patented products.

Financing mechanisms

Price reductions for antiretrovirals notwithstanding, difficult decisions are required by national governments to allocate scarce resources to boost HIV/AIDS treatment access. A number of new sources of financing have emerged to support low- and middle-income countries in the purchase of antiretrovirals.

The Global Fund to Fight AIDS, Tuberculosis and Malaria reviewed its first round of funding applications in April 2002, and announced its first disbursements. Resources in the Fund available for the year 2002 amount to some US\$800 million, and the Fund has made the financing of treatment access one of its core activities (see ‘Meeting the need’ chapter).

The World Bank’s Multi-Country HIV/AIDS Prevention and Control Program (MAP) for Africa has approved a package of loans and grants for several Caribbean countries and has agreed that parts of these loans may be assigned to the purchase of antiretroviral drugs. Barbados is the first country that has met the required criteria and drawn on these funds to finance antiretroviral access. The second phase of MAP will more directly address treatment access.

Private industry initiatives

A number of initiatives have been set up by individual pharmaceutical companies to help improve the response of low- and middle-income countries to the HIV/AIDS epidemic. These include Abbott’s Tanzanian Drug Access Initiative, Bristol-Myers Squibb’s ‘Secure the Future’ project, Boehringer Ingelheim’s offer to provide nevirapine free of charge for use in preventing mother-to-child transmission of HIV, and projects initiated by GlaxoSmithKline, Hoffmann-la-Roche and Merck & Co.

Public/private partnerships are also aiming to achieve results. The Botswana Comprehensive HIV/AIDS Partnership (a joint effort of the Government of Botswana, the Merck Company Foundation and the Bill and Melinda Gates Foundation) has made significant strides towards improved care and treatment in Botswana. Cash contributions total US\$100 million over 5 years, and Merck is supplying free of charge to the Government of Botswana any antiretrovirals it produces.

Medicines for opportunistic infections and pain

HIV/AIDS care requires a variety of essential medicines, in addition to antiretrovirals. If available, these effective and relatively inexpensive drugs can prevent or treat many of the common HIV-related diseases that are responsible for the main burden of illness and death in high-prevalence countries.

So far, agreements between countries and individual pharmaceutical companies, under the Accelerating Access Initiative, cover only eight drugs—all antiretrovirals. Even where cheaper alternatives exist, many of those trying to procure drugs have access neither to comparative prices nor to the identity of manufacturers who can supply these drugs. To address this problem, a partnership of *Médecins Sans Frontières*, UNICEF, WHO and the UNAIDS Secretariat has issued biannual reports since 2000, on sources and prices of drugs. The reports, based on surveys of over 200 pharmaceutical manufacturers in 40 countries worldwide, provide market information on the best prices available to help procurement agencies make informed decisions on where to buy drugs.

The pharmaceutical company Pfizer has donated its anti-fungal Diflucan (fluconazole)

for low-income AIDS patients in South Africa suffering from cryptococcal meningitis and esophageal candidiasis—two opportunistic infections commonly associated with AIDS. Through a partnership with the South African Ministry of Health, 6000 patients had been treated with fluconazole in all nine provinces by September 2001. In late 2001, Pfizer began expanding its Diflucan Partnership Programme, which also includes a package of physician training for secondary- and tertiary-care hospitals in the treatment of AIDS-related opportunistic infections, beyond South Africa, and the company has declared its commitment to work towards ensuring access to fluconazole in all least-developed countries.

Improved tuberculosis management must be linked to HIV treatment

Approximately one-third of people living with HIV worldwide are co-infected with *M. tuberculosis*, and 70% of them live in sub-Saharan Africa. Tuberculosis is also the leading cause of death among HIV-infected people, and HIV has been responsible for a global surge in the number of cases of active tuberculosis.

Treatment of active tuberculosis is as effective among those living with HIV as it is among HIV-negative people. However, in the absence of antiretroviral therapy, effective tuberculosis therapy has no long-term effect on HIV disease progression or mortality. It is crucial, therefore, that improved management and control of tuberculosis go hand in hand with increased provision of antiretrovirals and other HIV-related treatment. WHO's Pro-TEST Initiative aims to promote voluntary counselling and testing for HIV as a means of achieving a more coherent treatment, care and

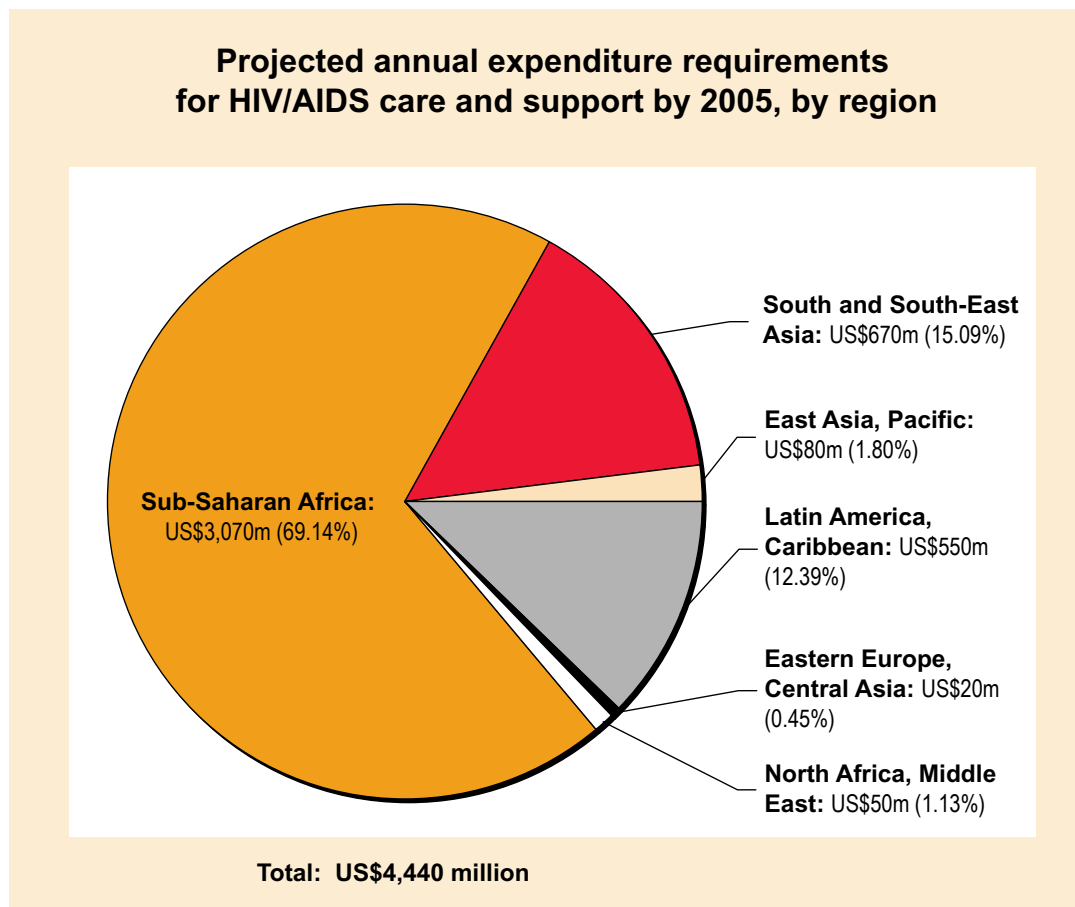
support strategy for HIV and tuberculosis in high-HIV-prevalence countries

Infrastructure must support treatment and clinical management

Drug prices are only one of many obstacles to boosting access to HIV/AIDS-related medicines. Effective treatment depends on general health services being able to procure, store, diagnose, select and administer the necessary drugs and to provide related treatment, care and diagnostic services to monitor health status and treatment response. Where health centres and district hospitals are available and accessible, diagnosis of the common infections and complications related to HIV/AIDS (e.g. tuberculosis, pneumonia, diarrhoea and candida infection of the mouth and throat) is usually possible, and these conditions can be treated or palliated with inexpensive, effective antibiotics and basic nursing procedures. However, many communities do not have access to such health-care facilities, and the most basic clinical management is not possible. Alternatives to conventional delivery systems need to be found—for example, the use of health services at the workplace to support delivery where local systems are weak (a development encouraged by ILO).

Two initiatives by WHO aim to improve the ability of low- and middle-income countries to ensure quality control of essential HIV/AIDS drugs and guide their use across a range of settings. The Access to Quality HIV/AIDS Drugs and Diagnostics project completed Phase I in March 2002 and published a list of 16 drugs, including 11 antiretrovirals and both generic and research-based pharmaceutical products, that have met WHO's

Figure 35



Source: Schwartlander B et al. (2001) Resource needs for HIV/AIDS, *Science*

recommended standards. All of these products meet standards for quality and compliance with Good Manufacturing Practices. A further 13 suppliers and 100 products are currently under review. WHO and UNICEF will use this list to advise countries on the procurement of HIV/AIDS-related medicines.

In addition to evaluating the quality of AIDS-related medicines, guidelines on minimum standards for laboratory monitoring of HIV drug treatment, guidelines for antiretroviral use, and training and quality-assessment programmes for health-care workers to ensure correct use of diagnostic tests have been developed by WHO. It is critical that HIV-treatment guidelines for low- and middle-

income countries be clear, concise and suitable for rapid implementation.

The widespread provision of antiretroviral therapy in communities most affected by the epidemic would radically change the AIDS-care landscape by greatly reducing the need to treat opportunistic infections, and the amount of time spent on provision of care in homes and hospitals. The need to build and improve infrastructure to support antiretroviral treatment becomes even more urgent, given the prospect of rising demand for such treatment. In addition to trained staff, basic facilities should be available to monitor potential drug toxicity and to measure the efficacy of antiretroviral treatment. Although drug prices have

fallen, most tests routinely used in relation to antiretrovirals are expensive and not widely available. Viral load tests (to measure viremia, or the amount of HIV in the blood) cost an average of US\$100, excluding equipment and laboratory facilities. The least expensive flow cytometers to monitor CD4+ cell counts (white blood cells that play a crucial role in the functioning of the immune system) cost between US\$75 000 and US\$100 000, and this does not include the funds needed to hire and train technical staff, maintain or repair equipment, or sample shipment and storage.

In the early stages of enhanced provision of antiretroviral and other HIV-related treatment, most low- and middle-income countries will need to rely on cheaper prognostic measures, such as total lymphocyte counts and standard measures of liver and kidney function.

Research is urgently required for the development and implementation of inexpensive, locally-appropriate technologies to improve the capacity to effectively monitor antiretroviral and other HIV-related treatment in low- and middle-income countries.

The considerable costs of boosting HIV care and support are outlined in Figure 35. These do not include the costs of infrastructure required for delivery of effective HIV treatment.

The challenges of adherence, resistance and toxicity

A frequently-cited concern regarding widespread provision of antiretrovirals in both high-income and low- and middle-income countries is the ability of health systems to ensure patient adherence to complex antiretroviral regimens—in other words, to make

sure that patients take all of their medications, as prescribed.

Adherence is a serious issue in all countries, because of the potential emergence of drug-resistant HIV. In the United States of America, a national survey revealed that 14% of cases of newly acquired HIV were highly resistant to at least one HIV drug, and 5.5% highly resisted two or more drugs. In 1995–1998, the corresponding figures were 3.5% and 0.4%.

To help address these concerns, a Global HIV Drug Resistance Monitoring Project was recently established by WHO and the International AIDS Society to monitor regional drug resistance patterns in parallel with the boosting of antiretroviral treatment programmes.

Adherence is also a critical factor in the failure or success of antiretrovirals in reducing HIV viremia to undetectable levels. A study in the United States of America, for example, has shown that successful virologic suppression through the use of combination antiretroviral therapy was highly associated with 95% adherence (i.e., persons taking their medication as prescribed by their doctors over 95% of the time), and that failure to suppress viremia increased dramatically as adherence decreased. The same study revealed that, among the modifiable variables associated with failure, two were significant: active depression and substance abuse, including that of alcohol. Depression and substance abuse have been shown to be significant predictors of poor adherence in a number of studies in high-income countries. These results underline the need for ongoing psychosocial support before and during treatment.

Practical issues related to the antiretroviral treatment regimens themselves, including the

number of doses per day, the number of pills per dose, and dietary restrictions, also contribute to people's ability to adhere. Recently, however, progress has been made towards developing easier-to-manage, less complicated treatment regimens.

An informed observer in Uganda notes the complicated and extremely human set of problems that caused 15–20% of patients receiving antiretroviral therapy to drop out of treatment in 2001: “Too many additional financial burdens, failure to sustain high-income earnings, depreciation of the local currency, donor fatigue of relatives and friends, unpredictability of foreign sources. Beyond these financial aspects of sustainability, compliance is still a major concern: very sick patients can't cope with antiretroviral complexity, improvement reduces the drive to take pills, and too many family advisers on overall care tend to favour alternative therapies”.

None of these problems is inherently unsolvable, as has been seen in a number of small-scale projects. A well-known project in the Haitian

highlands, based at the Clinique Bon Sauveur and connected with Harvard University, has reported good ongoing responses to antiretroviral treatment, with patients being able to return to work and to care for their children. And *Médecins Sans Frontières*, in nine small-scale antiretroviral treatment projects in Africa, Asia and Latin America, has also found that effective treatment is feasible.

Short- and long-term toxicities have emerged in high-income countries as a further complicating factor in the delivery of HIV treatment. While short-term side effects, such as diarrhoea, nausea, fatigue and rash, can be managed with relatively close monitoring of patient response to treatment, longer-term toxicities may require complex monitoring technologies and other treatment interventions. Chief among these potential long-term complications of antiretroviral treatment are imbalances in blood lipids, liver and kidney function, and diabetes. The potential toxicities of antiretroviral treatment further underscore the need for well-developed health-care infrastructures.

Need for a continuum of care and support

Treatment in the form of drugs is an essential tool in the response to the morbidity and mortality caused by HIV/AIDS. However, it is not the only one. To be able to cope successfully with HIV/AIDS, people living with the virus must have access to a wide range of treatment, care and support options provided across a continuum. This continuum of care should cover individuals' evolving needs as their condition develops and progresses through the various stages of HIV infection.

As depicted in Figure 36, care should be accessible at several points along the continuum—from VCT services, health services (primary, secondary and tertiary health care) and social services, to community-based support and home care. Formal health-care services may refer clients to community-based care organizations, which, in turn, may refer clients to health-care services, when necessary. Within a catchment area, an effective referral system between VCT services, basic hospitals and

Declaration of Commitment

By 2005, develop, and make significant progress in implementing, comprehensive care strategies to: strengthen family and community-based care, including that provided by the informal sector, and health-care systems to provide and monitor treatment to people living with HIV/AIDS, including infected children, and to support individuals, households, families and communities affected by HIV/AIDS [...] (paragraph 56).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

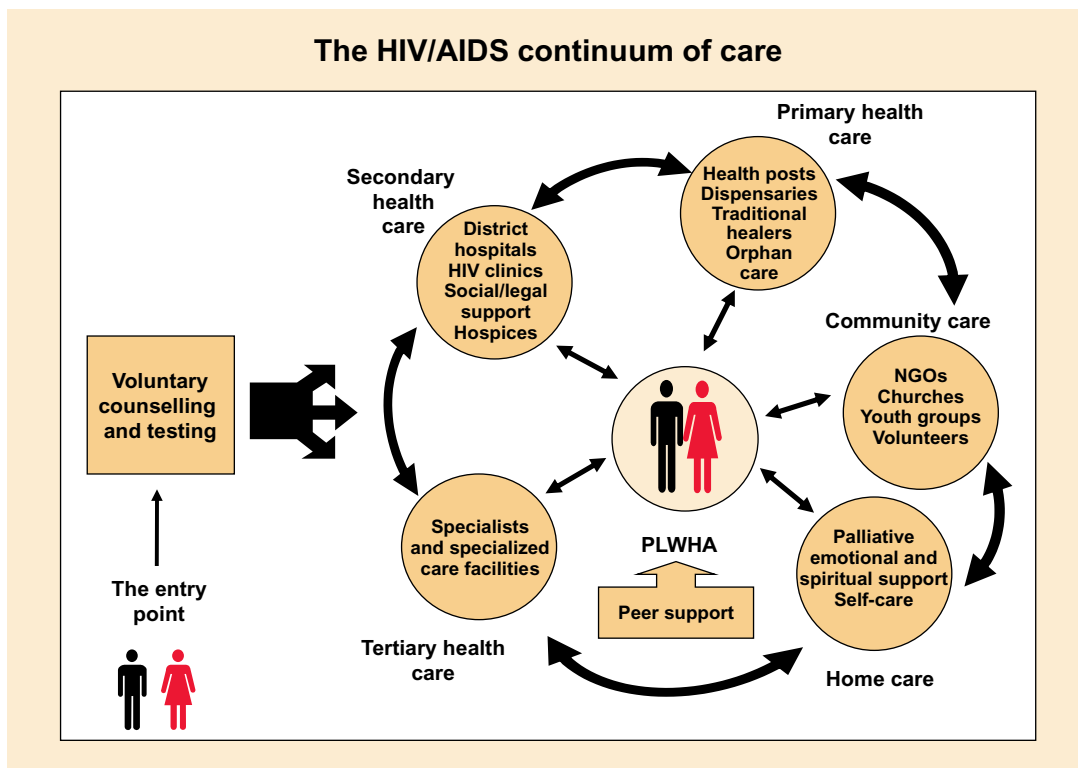
health centres, and home-care services should be developed in the form of partnerships between organizations and institutions.

Home and community care

An essential part of the response to the epidemic has been, and continues to be, home-

and community-based care. Community care and support groups have sprung up almost everywhere the epidemic has appeared—from the richest to some of the poorest of countries—and have shown amazing creativity and tenacity in providing comfort and hope to persons living with, or affected by, HIV/AIDS.

Figure 36



Source: WHO/UNAIDS (2000) *Key Elements in HIV/AIDS Care and Support*. Draft working document

Support to home and community caregivers

Support is needed for families carrying the burden of care, to prevent them from unraveling and to enable caregivers to perform other critical tasks apart from that of providing care. Depending on available resources and on the prevalence of AIDS in any given country, such support may feed into existing social security nets, or it may call for the creation of new funding mechanisms (see ‘Meeting the need’ chapter). But some countries have few social safety nets beyond those provided by family resources, which severely hampers their capacity to absorb any new funding that might become available.

In cases where responsibility for services is being decentralized to community level, administrative requirements regarding disbursement of funding to community-based organizations have frequently delayed implementation. A number of innovative financing methods are being used to overcome this problem. In Zimbabwe, for example, in order to speed up disbursement of funds and to ensure that they reach the intended beneficiaries, funds from the National AIDS Trust Fund are now disbursed to District AIDS Committees after the National AIDS Council has approved their plans. The funds are then channelled to Ward AIDS Committees’ bank accounts. All wards have opened accounts with commercial banks to which three members are signatories: the district/urban councillor, the traditional chief and the local school principal. All three signatories are in positions of authority, entrusted with making sure that resources for the National AIDS Trust Fund reach the appropriate people.

Greater support to nongovernmental organizations and community-based organizations

that provide community-based care is critical if home and community care is to become a truly significant part of the continuum of care. Approaches such as that of Ecuador’s Programme for AIDS Initiatives (*Programa de Iniciativas Frente al SIDA*) prove invaluable in building the capacity of community projects and nongovernmental organizations. The Programme links and supports community HIV prevention and care programmes throughout the country. It also assists nongovernmental and community-based organizations already working with women and in local development (but with no experience in AIDS) to assess the AIDS-related needs of their communities, and to begin, or take over, AIDS-related work. For example, it has helped a leading reproductive health nongovernmental organization in Ecuador to include prevention of sexually transmitted infections and HIV in its clinics’ educational programmes and family planning counselling. Other organizations have been helped to improve their fundraising or administrative capacity—often a weak point with community-based organizations.

An important lesson learnt over the past decade is that national HIV/AIDS responses cannot reach the necessary scale, maintain quality, or provide sufficient flexibility by acting solely through centrally-operated programmes. However, when national programmes work in partnership with nongovernmental and community-based organizations, a great deal can be accomplished. An example of such collaboration is the Continuum of Care Project in India’s Manipur State. Its cooperative approach links nongovernmental and community-based organizations (including World Vision, Sneha Bhavan, Manipur Network of Positive People, and the Kripa Society) to gov-

ernment health services, and permits many people (particularly those who are hard to reach) to access services they might otherwise be unaware of or shun.

Working with traditional healers and pharmacists

Since many people do not seek health care from formal health-care systems, it is important to find ways of integrating alternative health care more positively into the continuum of care. In Africa, it is estimated that about 80% of people rely on traditional medi-

A frequently-used strategy has been to train a core group of traditional healers, who are then supported in their efforts to educate communities or train their peers.

Many people in low- and middle-income countries visit their pharmacist when symptoms of opportunistic infections first appear. But pharmacists' qualifications and training can vary widely. In Cambodia, it is known that many HIV-positive people go directly to pharmacies for drugs. Around four-out-of-five Cambodians live in rural areas—far from the two Phnom Penh hospitals that offer HIV/AIDS treatment for the nation's AIDS

Traditional and modern health practitioners: together against AIDS

In Uganda, two nongovernmental organizations, the Ministry of Health and the National AIDS Commission have been working since the early 1990s in an initiative called Traditional and Modern Health Practitioners Together against AIDS. It trains traditional healers with a curriculum that covers not only sexually transmitted infections and AIDS, but also cultural beliefs and practices, counselling, leadership, sexuality, gender and legal issues. The initiative has been expanded to six rural districts of Uganda. An evaluation in 1997–1998 showed that 60% of trained traditional healers reported distributing condoms (compared to 9% of untrained traditional healers). Other benefits included initiation of record-keeping, initiation of patient-support groups and improved collaboration with biomedical health practitioners.

cine for their health-care needs, both in urban and rural settings. Many public health experts conclude that it makes sense to build collaboration between the formal health systems and traditional healers. In both Africa and Asia, such collaborative projects have been successfully designed, planned, implemented and evaluated.

Collaboration with traditional healers can also help dispel the many myths that prevail in some low- and middle-income countries about the causes of HIV/AIDS, as well as countering spurious claims about 'miracle AIDS cures'.

patients—and few can afford to visit a private clinic. In contrast, there are thousands of pharmacies in rural towns and villages. (Phnom Penh itself has about 300.) Knowing this, the international non-profit organization, PATH, has been working with the Cambodian Government, the national pharmacy association and local nongovernmental organizations to teach pharmacists about sexually transmitted infection identification, as well as treatment, counselling and dispensing. A pilot programme has also been created whereby pharmacists can provide patients

Declaration of Commitment

By 2003, ensure that national strategies are developed in order to provide psychosocial care for individuals, families and communities affected by HIV/AIDS (paragraph 57).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

with coupons directing them to a health-care facility at a specific time and place, thus establishing a direct link to the formal medical system.

Psychosocial support: critical in the continuum of care

Counselling, spiritual support, support in disclosing one's seropositive status and for engaging in safer sex or abstinence, medication adherence, end-of-life and bereavement support, and practical economic assistance are all part of psychological support for those living with or affected by HIV/AIDS. Mitigating the devastating impact of AIDS on people's personal lives, their social interactions and income have, in the past, been sufficient reason for providing such support. Yet psychosocial support is also crucial to the success of medical treatment—an issue of increasing

importance as more and more HIV-positive people gain access to antiretrovirals.

The greater involvement of people living with HIV/AIDS (GIPA) is critical in the provision of psychosocial care, and such involvement should be an integral part of care and support programmes. HIV-positive peer support programmes have demonstrated success around the globe, with little cost to health-care systems, in providing psychosocial care to help those living with HIV/AIDS. In South-East Asia and in many other areas, there is considerable evidence of the psychological benefits of self-help clubs for HIV-infected and -affected people. Such clubs (and other support groups) can also be very useful in providing or advocating social and economic support such as vocational training, small projects, and funds for personal health insurance. The AIDS Support Organisation of

Showing the way

Among the many innovative home-based care projects is that of Hua Rin, a Buddhist temple located near Chiang Mai, Thailand, which houses a group of 35 women living with HIV/AIDS. Phra Athikarn Thanawat Technopanyo, the temple's abbot, founded the support-group project in 1993 in order to educate villagers about HIV/AIDS through Dharma teachings, as well as to decrease the stigmatization of the families affected. Known as the Prasarnjai Group, the women arrange various projects that, for example, help grandparents care for their orphaned grandchildren, or provide small-scale jobs for widows and infected women. Meanwhile, the monks disseminate HIV/AIDS knowledge and information throughout the community, promote income-generating activities and tend to people's physical and spiritual needs.

Uganda (TASO) has become a world leader in this area. Its AIDS Challenge Youth Club is a peer AIDS prevention and care project that provides counselling and other support services to people living with HIV/AIDS.

Improved nutrition

The inclusion of nutrition as a core part of any HIV-care package is essential. The current focus on increasing access to antiretroviral drugs in low- and middle-income countries should not obscure the fact that, for much of the world's population living with HIV, the need for food remains an overwhelming priority.

Nutrition and AIDS operate in tandem, both at the individual and the societal level. Nutritional deficits make people with HIV more susceptible to disease and infections of all sorts. And malnutrition is one of the major clinical manifestations of HIV infection.

At the household level, HIV/AIDS and food security are closely linked: a HIV-affected household increasingly risks food insecurity and malnutrition via declines in work, income and time available for care of younger children, together with increased expenses for

health care. Food insecurity may, in turn, further increase both the risk of being exposed to HIV and a household's vulnerability to its increasing impact as the disease progresses.

Nutrition is also linked to treatment. As access to antiretrovirals improves, clean water supplies and adequate food must be made available as part of an overall treatment, care and support package.

TASO has been distributing food to clients for 10 years as part of an overall community outreach response in Uganda. Food assistance has proven to be a powerful means of attracting clients to other HIV services, including voluntary counselling and testing. In addition, this form of assistance has proven to greatly facilitate nutritional counselling and education for TASO clients throughout Uganda. And the World Food Program is using food aid to provide an incentive for children to stay in school; building on the success of its take-home rations and school-based feeding projects for girls, it is implementing a similar strategy for orphaned children. Already, the agency manages projects for these children in Cambodia, Kenya, Uganda and Zambia.

Enhancing treatment, care and support: the way forward

There is growing recognition at the highest levels of political and economic power that ensuring a stable, secure future for the world requires a massive boosting of interventions aimed at improving the health of the poor worldwide. Significant efforts have been made to assess what is required, how it must be done, and how much it will cost.

This groundswell of political and economic opinion converges with the increasing determination among decision-makers and communities alike to make decisive inroads against the epidemic by paying equal attention to HIV prevention and HIV care.

Many of the constraints in place that prevent improved health systems and improved access

to HIV care in the world's poorest countries can be overcome with additional funding. Such constraints include the currently low levels of expenditures on health by low- and middle-income countries, limited numbers of qualified health personnel, weak infrastructures, limited drug supplies, etc. Additional finances are crucial to ensuring the success of HIV/AIDS treatment, care and support programmes throughout the world.

As increased resources become available to enhance HIV/AIDS treatment, care and support, expenditure will need to be closely linked to evidence of good governance, including respect for the rights of people living with HIV/AIDS. Corruption, poor rule of law and armed conflict are among the greatest barriers to ensuring that resources reach those in need.

The ongoing development of treatment, care and support plans of action by the coordinating bodies of individual countries, collaboration across regions, and the efforts of international governmental and nongovernmental organizations are helping to improve the response to HIV/AIDS. The continuing AIDS-related death toll is a constant reminder of the urgency of the task—a task that requires simultaneous action in technical guidance, political support, resource mobilization, infrastructure-building, and human capacity development.

Above all, the unswerving commitment of people living with HIV/AIDS and their supporters is ensuring that the worldwide demands for access to effective treatment, care and support will not go unanswered. 