# MISSING THE TARGET

*A report on HIV/AIDS treatment access from the frontlines*

**International Treatment Preparedness Coalition (ITPC)**

*28 November 2005*

**The International Treatment Preparedness Coalition (ITPC)**
was born at the International Treatment Preparedness Summit that took place in Cape Town, South Africa in March 2003. That meeting brought together for the first time community-based treatment activists and educators from over 60 countries. Since the Summit, ITPC has grown to include over 600 activists from around the world and has emerged as a leading civil society coalition on treatment preparedness and access issues.
See appendix at the end of this report for more information.

Note: This is an except version focusing on South Africa.
For the complete report please visit www.tac.org.za

**AIDS Law Project**
101 St George's Mall, 7th Floor
CAPE TOWN
T + 27 21 422 1490
F + 27 21 422 1551
www.alp.org.za

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## Report Research Team

### DOMINICAN REPUBLIC

Eugene Schiff, Agua Buena Human Rights Association
Paloma Piña, MD
Michelle Galeas, MD

### INDIA

K. K. Abraham, President of Indian Network for People living with HIV/AIDS (INP+)
Dr. Venkatesan Chakrapani, INP+
Daisy David, INP+
Aasha Elango, INP+
Murali Shunmugam, Social Welfare Association for Men (SWAM)
Dr. Joe Thomas, FXB International

*With assistance from:*

National AIDS Control Organization (NACO)
Dr. SY Quraishi, director general, NACO
Dr. Indrani Dasgupta, office of the WHO Representative to India
FXB International
State and district level networks of INP+
Social Welfare Association for Men (SWAM)

### KENYA

James Kamau, Kenya Treatment Access Movement (KETAM)
Dr. Bactrin Killingo, Meru Hospice and KETAM
Elizabeth Owiti, Healthpartners, Kenya

### NIGERIA

Olayide Akanni, Journalists Against AIDS Nigeria
Bede Eziefule, Centre for the Right to Health
Tobias Luppe, Médecins Sans Frontières

### RUSSIA

Shona Schonning, Community of People Living with HIV/AIDS

*With Assistance from:*

Irina Diabaldt, Community of People Living with HIV/AIDS
Daniel Novichkov, Community of People Living with HIV/AIDS
Dmitry Samiolov, Community of People Living with HIV/AIDS
Timur Islamov, Doverie (Trust)
Ilya Kondtatiav, Positive Initiative
Slava Tsunik, Kovchek Antispid

### SOUTH AFRICA

Fatima Hassan, AIDS Law Project

PROJECT COORDINATION
Chris Collins
Gregg Gonsalves
Maureen Baehr

EDITING ASSISTANCE
Jeff Hoover
MEDIA COORDINATION
Kay Marshall
DESIGN
Lei Chou

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## CONTACT INFORMATION

**Dominican Republic**
Eugene Schiff Eugene.schiff@gmail.com

**India**
K. K. Abraham inpplus@eth.net or inpplus@vsnl.com
Joe Thomas joe_thomas123@yahoo.com.au

**Kenya**
Elizabeth Owiti lizawiti2002@yahoo.com

**Nigeria**
Olayide Akanni olayide@nigeria-aids.org

**Russia**
Shona Schonning s_schonning@positivenet.ru

**South Africa**
Fatima Hassan hassanf@law.wits.ac.za

**Project coordination**
Chris Collins ChrisCSF@aol.com
Gregg Gonsalves gregggonsalves@earthlink.net

**International Treatment Preparedness Coalition (ITPC)**
SG-ITPC@yahoogroups.com

## Executive Summary

The campaign for global AIDS treatment delivery has reached a defining moment. The first years of programme scale up demonstrated that AIDS treatment can be delivered effectively, even in the poorest settings. But "3 by 5", an initiative by the World Health Organization (WHO) to treat three million people by the end of 2005, is coming to an end—and it has fallen at least one million men, women and children short of the target. This leaves at least four million people who urgently need antiretroviral drugs today in order to have any hope of survival. Although progress has been made over the past few years, we cannot call this success.

G8 leaders have pledged a new goal of coming as close as possible to universal AIDS treatment access by 2010. This will be a hollow promise unless governments and international agencies learn the lessons of the early years of treatment delivery and dedicate increased resources, capably address barriers, collaborate more effectively, and hold themselves accountable for steady, measurable progress.

The "3 by 5" initiative failed to treat even 50% of people in need of antiretroviral treatment (ART). If the organisations responsible for carrying out this programme are to accomplish an even greater goal in five years' time, it will take courageous new leadership from all parties to confront the monumental task ahead. The status quo will not get us there.

Will the international community rise to this challenge? The fate of millions of people around the world hangs in the answer to that question.

The International Treatment Preparedness Coalition (ITPC) is a global alliance of over 600 treatment activists that includes people living with HIV/AIDS (PLWHA) and their advocates. The ITPC AIDS Treatment Report is the first systematic assessment of treatment scale up based on the research of people living in communities in six countries where the epidemic has hit the hardest—the Dominican Republic, India, Kenya, Nigeria, Russia and South Africa. The report is based on their experiences and first-hand knowledge of the situation on the ground. Each country used a case study methodology, which emphasizes interviews with carefully selected key informants.

Clearly, much more work needs to be done to understand the complexity of this challenge. But what we found tells an important story—of individuals exhibiting dedication and courage while caught in desperate situations; and of institutions often struggling to transition, be efficient, and throw off bureaucratic obstacles that stand in the way.

The ITPC AIDS Treatment Report is a prescription for the future. As ART has started to roll out in these six countries, the ITPC research teams have identified barriers that could imperil efforts to make treatment more widely available. The teams have also made concrete recommendations for governments and international institutions.

These recommendations must be taken up with urgency if the goal of universal access by 2010 is to be achieved.

Major roadblocks to success include the following:

- inadequate leadership at the national level that fails to dedicate sufficient resources or mobilize governments;
- a global system that does not collaborate speedily and efficiently to address bottlenecks;
- inadequate and uncertain funding levels for programs and financing mechanisms such as the Global Fund to Fight AIDS, TB and Malaria (GFATM)—a situation that keeps countries guessing about the sustainability of services and the meaning of pledges like "universal access";
- bureaucratic delays that prevent urgently needed resources from reaching treatment programs;
- procurement and logistics challenges that demand more comprehensive and effective technical assistance; and
- pervasive stigma against people living with HIV/AIDS that requires moral leadership from national and global communities.

**Need for improved leadership at the national level**

In every country surveyed there were concerns about inadequate leadership at the national level and the subsequent failure to dedicate sufficient resources or mobilize governments. We heard about the necessity for a well-functioning national AIDS programme that can provide this leadership, implement a comprehensive national AIDS plan, and compel international and domestic organizations to abide by that plan. Sadly, the state of national AIDS programmes in these six countries did not make the grade. Scale up of treatment will not happen unless countries fulfill their responsibilities to those living within their borders—and national governments must be the primary engine for increasing access to care.

In addition, in just about every country we saw a failure to link TB and HIV programming effectively, missing opportunities to diagnose and treat these interconnected diseases and establish coordinated systems of the health care.

We also found that each country has a different constellation of challenges and potential solutions.

- In the **Dominican Republic** bureaucratic delays and power struggles between agencies delayed implementation of a Global Fund grant for months. Many of those initial problems have now been overcome, but

delivery of ARVs is still hampered by lack of political leadership; stigma and discrimination; supply problems with ARVs, treatments for opportunistic infections, and CD4 tests; and continued lack of coordination between programs.

- In **India** treatment remains unavailable for the vast majority of the millions of people living with HIV. Although the government has signaled increasing commitment to ART delivery, the national AIDS program has failed to act on several critical issues and national treatment guidelines are under-enforced and have several significant gaps. Many people seeking care are forced to travel long distances, and shortfalls in funding and human resources threaten efforts to expand the response.
- In **Kenya** treatment services are being scaled up through new funding from the Global Fund, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), and other programs. Yet people in need of care and service providers from around the country are confronting significant obstacles that include widespread stigma and discrimination against PLWHA and women, misinformation, lack of treatment literacy, and insufficient resources to meet basic nutrition needs or afford travel to health clinics for care.
- In **Nigeria** the government has set new and ambitious targets for treatment delivery, but services remain concentrated in a few "cluster zones" while people in rural areas struggle to get care. Lack of adequate funding and human resources complicate treatment expansion. The high costs of CD4 and viral load tests put these diagnostic tools out of reach of most people in treatment. Stigma and a lack of treatment literacy programs both undermine scale up efforts.
- In **Russia** efforts are underway to significantly scale up ART delivery in response to a fast-growing epidemic concentrated among injection drug users (IDUs). Yet multiple bureaucratic obstacles stand in the way, including a faulty drug procurement system, lack of collaboration among providers, absence of a national treatment protocol, a Global Fund Country Coordinating Mechanism (CCM) that is widely described as ineffective, and lack of leadership from government agencies. Widespread discrimination against IDUs inhibits scale up at an even more fundamental level.
- In **South Africa** activists and providers have forged ahead with treatment delivery even as the national government continues to drag its feet and fails to combat misinformation and pseudo-science. Multilateral agencies have been largely invisible and the CCM is widely criticized. Many practical problems inhibit scale up as well, including a severe shortfall in nurses and other providers, limited access to HIV testing, and inadequate availability of drugs.

## Need for a better functioning global system

All implementation is local, but the international community has to do better at identifying and quickly addressing impediments to the flow of resources and delivery of services. Each of the component parts of the multilateral system has strengths that are needed in AIDS treatment scale up, but UNAIDS, WHO, GFATM, and PEPFAR need to work in more efficient partnership both within countries and in Geneva. Countries need additional assistance from the international community in several areas, from logistical problems (like drug procurement) to long-term challenges (like reducing stigma).

What gets measured gets done. A much more systematic approach to setting goals, measuring progress, and assessing and addressing barriers is needed.

- **Rich countries** need to stay true to their word and provide increased and sustained support for the Global Fund and other AIDS treatment programmes. The G8 countries cannot defensibly set a goal of universal access and then under-finance the response by billions of dollars.
- **African countries** need to live up to their commitment as part of the 2001 Abuja Declaration to devote 15% of their budgets to addressing health priorities, including HIV/AIDS.
- **UNAIDS, WHO, the Global Fund, and PEPFAR and other bilaterals** must keep the world's vision focused on treatment scale up. The operational plan for universal access now under development should emphasize improved collaboration among agencies and include defined country-specific strategies, with hard timelines and milestones, and clear assignments of responsibility for specific tasks. Incremental targets for treatment delivery to children and marginalized populations are needed, as are action plans for delivery of second- and third-line regimens. In the next six months we want to see concrete evidence of a more collaborative system that more effectively meets the diverse needs of countries.
- The **International Monetary Fund** and the **World Bank** need to end macroeconomic policies that unnecessarily constrain public spending so that countries heavily affected by AIDS can train and hire more doctors, nurses and teachers.

If the international community succeeds in treating the vast majority of people with HIV/AIDS who need it, we will have indeed changed the world. The delivery of anti-retroviral therapy will only be possible with a revolution in global public health, which makes primary care available to those who have never had it before. This will pave the way for the treatment of countless other diseases that are now left untreated and unaddressed in most communities around the planet. The goal is before us. We should seize this moment in history together.

## Introduction and Overarching Recommendations

The "3 by 5" initiative challenged the world to provide treatment for three million people living with HIV in less developed countries by the end of 2005. Even though this goal was always only a partial one—six million people are in urgent clinical need of antiretroviral treatment (ART) now—it still proved impossible to achieve. Developments toward this goal over the past few years have demonstrated that AIDS treatment delivery can work, even in the poorest settings, yet delivering it is much more difficult and complicated than "3 by 5" campaigners originally anticipated. Hundreds of thousands of lives have been saved, but millions of other HIV-positive individuals have not benefited.

Now the campaign for global AIDS treatment delivery has reached a defining moment. Governments and non-profit service providers are grappling with implementation challenges. The Global Fund to Fight AIDS, TB and Malaria (GFATM) is struggling to raise necessary resources. Dr. Kevin DeCock is replacing Dr. Jim Yong Kim as head of the HIV/AIDS office at the World Health Organization (WHO). As the "3 by 5" assessments are being prepared, will the governments and multilateral agencies involved in AIDS treatment delivery learn from challenges that have been encountered, systematically address barriers, and hold themselves and their partners accountable for steady, measurable progress?

The movement for access to treatment is irreversible—and will continue to be driven by people living with HIV/AIDS (PLWHA) and their advocates. The commitment of the rest of the international community is less certain, however. The priorities outlined and decisions made over the next few years by all involved in the global HIV/AIDS response will directly affect the lives and livelihoods of millions of people in every part of the world. Goals mean nothing unless the will and resources to achieve them are in continuous supply at all levels, from multilateral entities to each and every individual affected by the virus.

This report from the International Treatment Preparedness Coalition (ITPC) is a prescription for the future. It examines treatment scale up efforts in six less developed countries, identifying barriers to wider delivery and making recommendations for governments, the United Nations, and other multilateral institutions. The report documents systems in transition that need to continue to learn and change if the catastrophe of tens of millions of deaths from AIDS is to be averted.

The first years of treatment scale up revealed barriers to wider access to antiretroviral treatment (ART), many of which are discussed in detail in this report. If left unattended, these barriers will undermine the new G8 goal (announced in July 2005) of "universal treatment access", just as they caused "3 by 5" to come up short. None of the challenges are easy, but they all have solutions. One solution is improved leadership at the national level. Another is a better functioning global

system that efficiently assists countries in recognizing and tackling problems. This report identifies several specific areas where many countries need additional assistance, including: management of expanded programmes, drug procurement, provision of treatment literacy education, anti-stigma efforts, promotion of adherence, and human capacity development.

ITPC is a leading civil society coalition of treatment activists. A year prior to the "3 by 5" deadline, its members agreed that AIDS treatment scale up needed a performance appraisal. We set out to do a systematic analysis of the barriers to scale up from the perspective of advocates not wedded to the fortunes of any particular agency or organization. Six countries (Dominican Republic, India, Kenya, Nigeria, Russia, and South Africa) were selected by ITPC to be the focus of this report, based on the number of people in need of treatment and the availability of ITPC members to commit substantial time to research and writing. A research team was assembled in each of the six countries and the teams all developed research plans. A case study interview template was developed for use and adaptation in each country.

From June through September 2005, country teams completed between 12 and 20 interviews with representatives of governments, multilateral agencies, provider organizations, advocates, and PLWHA. (Kenya was an exception: in that country, 113 people completed a questionnaire compiled by report organizers.) Most people and organizations we contacted were happy to participate, although some did not respond.

Analysis of the results is presented in the individual country case studies in this report. Each country used a case study methodology, which emphasizes interviews with carefully selected key informants. Although each country followed a standard outline, the six country reports are distinct both in findings and in presentation, and writing styles vary depending on researchers' approach and background. While each team focuses on the specific issues that most affect HIV/AIDS treatment access in their country, many common themes nonetheless emerge. Most center on urgent policy issues as discussed by policymakers, providers, and advocates. The Kenya case study is based on the personal experiences of over 100 PLWHA and their service providers. Taken together, these six case studies provide a rich picture of the state of AIDS treatment access as seen from the frontlines.

**What we found — country level results**

Respondents in each country stressed the need for a well-functioning national AIDS programme that can provide leadership, implement a comprehensive national AIDS plan, and compel international and domestic organizations to collaborate within the plan's broad outlines. Sadly, the national AIDS programmes—and by association, the national governments—in these countries did not make the grade. Scale up of treatment cannot happen efficiently and consistently unless national governments

become the primary engines for increasing access to care within their borders. We found many common barriers in the countries surveyed, including those related to procurement and logistics, bureaucratic delays, stigma, and lack of sufficient leadership and coordination. In addition, in just about every country we saw a failure to link TB and HIV programming effectively, thus missing opportunities to diagnose and treat these interconnected diseases and establish coordinated systems of health care.

**In six months, we want to see the governments of these six countries address the issues raised in this report and to greatly scale up their own investment and engagement in access to treatment. We also want key government officials to meet with PLWHA groups and their advocates as part of a greatly enhanced effort to move forward together on treatment access. This has been impossible to date in many of these six countries, and is a symptom of the disregard those governments have for PLWHA. Such attitudes must be changed so that governments and those on ART now or in the future can work collaboratively to ensure that treatment is scaled up effectively. In addition, African countries need to live up to their commitment as part of the Abuja Declaration to commit 15% of their budgets to addressing health priorities, including HIV/AIDS.**

**What we found — the major multilaterals and bilaterals**

Most multilateral entities, such as WHO and the Joint UN Programme on HIV/AIDS (UNAIDS), have strengths that are needed in AIDS treatment scale up—but these agencies are not yet collaborating effectively. A 2005 analysis produced by some of these agencies themselves, in collaboration with international donors, concluded that the international response is "unevenly coordinated".[1] Reports from the six countries in this document frustratingly reinforce that conclusion. Better coordination means many things, from strategic planning among agencies in Geneva to closer communication on the ground to maximize effective use of resources.

**UNAIDS, WHO, GFATM, and PEPFAR and other bilaterals must do a better job of working collaboratively to identify and quickly address impediments to flow of resources and delivery of services. These agencies are now working on a plan to "operationalize" universal access. This plan should include defined country-specific strategies and goals with hard timelines and milestones, as well as clear assignments of responsibility for specific tasks.**

- **GFATM** is playing an essential role in AIDS treatment scale up, providing vital resources and using its funding to drive needed reforms at the country level. By focusing on the three major pandemic diseases in developing countries and by allowing investment in health care capacity, GFATM aids efforts to rehabilitate health sector capacity that has been undermined by decades of structural adjustment, under-financing, and privatization. From its inception, GFATM has placed high priority on good fiscal management, accountability for results, and sustainable country ownership. These are

laudable goals that, unfortunately, have proved difficult to meet in many countries. This report documents numerous cases of delays or even outright barriers to the flow of GFATM resources to those in need. Among the reasons for substandard flows are in-country financial mismanagement, problems with a principal grant recipient, and dysfunction at CCMs. As one study found, GFATM requirements often reveal longstanding tensions between partners at the country level that need to be addressed to promote sustainability of service delivery.[2]

Substantially increased funding is urgently needed to sustain and expand GFATM grantmaking. Without increased resource commitments, the G8-declared goal of universal access is a hollow promise. Where country-level impediments limit the planned scope and reach of grants, GFATM, UNAIDS, WHO, PEPFAR, and other funders have a responsibility to work together closely to address problems and ensure that the money reaches its planned recipients, including those providing treatment. GFATM needs to ensure that countries have reliable access to high quality technical assistance, improve structures for monitoring implementation, and play a stronger role in pushing CCMs to function properly.

**Substantially increased and sustained funding for GFATM is a top priority in AIDS treatment delivery. In six months we want to see more resources not only pledged but disbursed to GFATM, and more examples of the multilateral system working collaboratively to accelerate delivery of grants and supporting implementation of AIDS treatment programmes.**

Note: GFATM disbursements are ongoing so numbers used in this report may not always coincide with most recent GFATM numbers. The GFATM website is updated daily and provides information on disbursement amounts http://www.theglobalfund.org.

- **WHO** deserves a great deal of credit for setting the "3 by 5" target, and for struggling to re-organize its bureaucracy to better serve scale up efforts. Jim Yong Kim, outgoing head of the AIDS programme, should be congratulated for his willingness to identify countries that are lagging, as well as those that are succeeding, in their scale up efforts. Other notable strengths of WHO's efforts include publication of ARV guidelines in resource-poor settings; establishment of the WHO Prequalification project; technical assistance to GFATM; and provision of training modules and training resources on ART delivery. But it is cause for concern that most of the people contacted for the report did not know what WHO does in their country.

  As the chief technical agency on global AIDS treatment, WHO needs to be a more visible leader on specific implementation challenges that are encountered

in countries, be more of an advocate at the country level, and work more closely with civil society. WHO also needs to set more detailed treatment goals that include specific targets for children and marginalized populations, such as IDUs, women, migrants, commercial sex workers, and men who have sex with men (MSM). The agency should create targets for delivery of second- and third-line regimens based in part on observed resistance trends and prevalence of side effects. The agency should take the lead in responding to anticipated drug resistance. Information to guide providers in addressing resistance should be more widely available.

**In six months we want to see detailed action plans for treatment scale up for all of the countries that have told WHO they want to be part of "3 by 5." These plans must have timelines, deadlines, and milestones for countries and for WHO itself. Countries and WHO should then be held accountable for meeting these goals.**

- **UNAIDS** has been an outspoken advocate for the rights of women, sex workers, gay and bisexual men and other marginalized groups even while some countries persecuted these groups and other UN organizations failed to champion their needs. UNAIDS is the global communicator on AIDS, a technical assistance provider, repository of information, and preeminent convener. The agency has spearheaded efforts to bring greater harmonization to planning and monitoring at the national level. While this report documents UNAIDS' good work in several areas, many of the people interviewed want to see more advocacy and other tangible efforts from the agency in support of AIDS treatment scale up at both the global and country levels.

  No voice should be louder than UNAIDS in championing the principle of universal access to treatment within each and every country of the world. As the coordinating body of the multilateral system, UNAIDS needs to be increasingly answerable for accelerated, coordinated treatment scale up at the country level. Where funding is held up, or management or other deficits stand in the way, UNAIDS should ensure that resources from somewhere in the UN system are devoted to fix the problem.

  **In six months we want to see UNAIDS' visibility in countries greatly improved. We also want to see more concrete examples of UNAIDS acting as a problem solver, resolving barriers to treatment scale up in countries by bringing the resources of the entire UN system to bear on these obstacles.**

- **PEPFAR** has initiated HIV/AIDS assistance efforts in 15 countries over the past two years. Many report interviewees praised PEPFAR for quickly setting up treatment programmes with measurable goals and for operating in a determined and efficient manner. However, the programme has attracted

considerable criticism at the same time. A 2004 assessment of PEPFAR from the U.S. General Accounting Office identified "coordination difficulties among both U.S. and non-U.S. entities" as a major challenge.[3]

This report corroborates that shortfall with examples of PEPFAR creating separate systems of care and failing to coordinate with others. PEPFAR is saving lives today; the question is whether it is building sustainable systems that will survive for the long term. More immediately, there are grave concerns around PEPFAR-imposed policy prescriptions, including disallowing grantees from providing counseling on abortion; requiring grantees to adopt a policy specifically opposing sex work; promoting abstinence-only prevention approaches; and forbidding the use of PEPFAR funds to purchase medicines that are not approved by the U.S. Food and Drug Administration. These policies undermine efforts to reach women at elevated risk, implement evidence-based prevention programmes, and utilize quality generic and fixed-dose combination drugs.

The U.S. Congress must increase funding for PEPFAR and repeal destructive policies. Investment in PEPFAR is also no substitute for the U.S. government's responsibility to fully support GFATM financially and programmatically. PEPFAR programme managers should work more closely with country partners and nurture local investment in scale up.

**In six months, we want to see PEPFAR delivering treatment to thousands more and pointing to specific examples of how it is building sustainable health care systems in its 15 target countries. PEPFAR also needs to coordinate its medicines portfolio with country-owned national treatment protocols, procurement, and supply chain management systems. PEPFAR needs to focus much more intensely on creating capacity in-country and supporting country ownership of HIV/AIDS programming. We want specific and independently verifiable evidence that PEPFAR is seeking to fully integrate its activities on the ground with other partners.**

- While the shortage of health care workers in developing countries has many reasons, some of the blame must lie with the **International Monetary Fund (IMF)** and the **World Bank**. Often, loan agreements with these institutions directly or implicitly mandate national macroeconomic policies that restrain public sector spending and lead to cutbacks in basic government services, including health care. We agree with ActionAid's recommendations that "finance ministries or treasury departments need to take concrete steps on the Executive Board of the IMF to stop loan conditions that call for 'tight' monetary policies that constrain public spending at unnecessarily low levels […] in order to allow the 'fiscal space' necessary to hire the many more doctors, nurses and teachers necessary for fighting HIV/AIDS effectively."[4]

In August 2004 ITPC wrote a letter with signatories from over 35 countries to the managing director of the IMF and the president of the World Bank on this matter. The reply from both organizations was an unsatisfactory defense of current policy and indicates an ongoing lack of understanding of their loan provisions' potentially devastating effects. These international financial institutions need to be confronted directly and vigorously by advocates and governments around the world, and urged to reform their policies and procedures.

ITPC is committed to pursuing the recommendations in this report and has developed a set of principles and a plan of action that follows.

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[1] UNAIDS. Global Task Team on improving AIDS coordination among multilateral agencies and international donors. Geneva, 14 June 2005.

[2] Brugha, R, et al. Global Fund tracking study: a cross-country comparative analysis, 2 August 2005.

[3] General Accounting Office. US AIDS Coordinator addressing some key challenges to expanding treatment, but others remain. Government Printing Office, Washington, DC. July 2004.

[4] ActionAID. Square Pegs, Round Holes, Why You Can't Fight HIV/AIDS with Monetarism. An issue briefing by Rick Rowden, ActionAid International USA, that outlines ways in which the IMF is obstructing progress in fighting HIV/AIDS. ActionAid International USA. March 2005.

## Principles and Follow-Through Plan

ITPC and the report's authors have developed a set of principles and a plan of action designed to move forward on the report's findings and recommendations. In this plan we look at the past in order to learn how to do better in the future. The immediate goal is to use existing and future resources to ensure that three million people are on life-saving ART as soon as possible.

If, as the optimists say, the goal of getting three million people on treatment is reached by spring of 2006, we will celebrate the success and reset the goal for the rest of 2006. Each goal met sets the baseline for the next goal.

### Principles

### 1. What gets measured gets done

If the mission of getting treatment to millions of people was run like many businesses, specific goals would be defined and agencies and their managers would be responsible for having specific plans to reach these targets. Although AIDS treatment scale up is not a business, the effort could benefit from a much more pragmatic approach to accomplishing goals. To date, there are only broad targets established by WHO and by some of the countries that have expressed interest in participating in the "3 by 5" initiative. Far more detailed and rigorous international and country-level planning is needed to in the future. Milestones and deadlines need to be reached and honored—shifting milestones forward in time is not a solution for success, but instead represents a recipe for perpetuating failure.

### 2. Continuing global and multilateral commitment are essential

UNAIDS, WHO, GFATM, and bilaterals like PEPFAR must continue to provide funding, apply pressure, and keep the world's vision focused on the importance of treatment scale up. They must implement organizational changes to increase effectiveness and decrease redundancy. Excuses about "the nature of the UN" or "the national politics of the United States" cannot be used to avoid the requirements for better coordination and greater accountability.

### 3. Some barriers can benefit from shared solutions

Many of the issues discussed in the report's individual case studies cut across all countries. Some are reflections of the deep-seated prejudice of people towards each other, but many are organizational or logistical, such as drug procurement and distribution. The mechanical issues, at least, are fixable in the short term—and in our recommendations we call for the best minds of the world to work at fixing them. For instance, stock-outs of drugs should not be happening in any programme,

yet we see several programmes around the world at risk of running out of medicines for the thousands of PLWHA on ART in these countries. UNAIDS, WHO, GFATM, and bilaterals must collectively monitor these barriers and assign task teams to address them in an expeditious manner.

**4. All implementation is local**

In-country implementation is the make or break for reaching treatment delivery goals. In each of these countries there is a large gap between the number of people needing treatment and the number of people receiving it. A tailored set of solutions is required because there is a different constellation of barriers in each country. Greater focus and investment need to be given by both governments and on-the-ground multilaterals to honestly assess the problems with treatment delivery in countries and to develop local strategies for resolving them—instead of seeking solutions from generalized guidance provided by technical agencies and others from afar.

**5. Treatment access is not only drug access**

The ultimate unit of success for treatment delivery is the number of PLWHA retaining decent health and prospering. The country reports document that poverty, lack of access to food, very long travel time to clinics, and discrimination against marginalized groups all remain important barriers, even when ART is available. Consequently, each country report includes recommendations for addressing those issues. It is clear that some of the problems with delivery of treatment are part of the larger problems of human development in less developed countries. However, treatment advocates' work would seem even more overwhelming if HIV/AIDS were simply folded in among these broader problems.

The push for access to AIDS treatment thus should be seen as a wedge to mobilize communities and other stakeholders around these broader issues while always maintaining a focus on achieving the goal of universal access by 2010. Expanded delivery of evidence-based HIV prevention interventions should also be a top priority. Treatment scale up provides many opportunities—at testing sites, in clinical settings, and elsewhere— to increase the reach of HIV prevention and awareness initiatives.

### *ITPC Action Plan for 2006*

ITPC has created a follow-through plan and timeline for taking action on the report findings. Members of the coalition will place top priority on the actions and objectives listed below.

**First quarter 2006**

- Meet with senior representatives of each major multilateral, bilateral, and other funders included in this report to review findings and develop specific and measurable goals, timelines, and action points
- Meet with senior representatives of country governments
- Meet with national AIDS organizations in each of the report's six target countries to review findings and develop specific country-level implementation plans
- Define specific target number goals (by quarter for 2006-2007) for people on treatment for each of the six countries
- Work with major players (global and country-level) to develop an integrated process for counting the number of people on treatment

**Second quarter 2006**

- Issue update bulletin on treatment access progress against the plan
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Develop Level Two Report process to ensure in-depth follow-up in the six countries
- Identify six additional countries to begin Level One Report analysis

**Third quarter 2006**

- Issue update bulletin on treatment access progress against the plan
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Provide report update and forum to discuss results and actions among global players at International AIDS Conference or another venue

**Fourth quarter 2006**

- Issue AIDS Treatment Access Report II, including update on the six initial countries, first level analysis on six more countries, and overall global progress report
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Develop and share top-level plan for 2007


By Fatima Hassan,
AIDS Law Project

*"Without Greater Vigour"*

Since 1998, the Treatment Action Campaign (TAC) and its allies have led a lengthy public campaign for access to ART through the public health sector. Eventually, on 8 August 2003, the Cabinet made a commitment to provide ART treatment, and two months later the government published the Operational Plan on Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (the Operational Plan).

By the beginning of 2004, several of the nine provinces in South Africa had started implementing the Operational Plan. At that time, fewer than 5,000 people were on ART in the public sector in the whole country. By the end of 2004, all nine provinces had fully commenced with implementation.[1] Nearly one year later, according to the National Department of Health (NDoH), there were 192 public health facilities providing HIV/AIDS-related services, including ART.[2]

The estimated total number of people who need treatment in South Africa is between 500,000[3] and 700,000. Preliminary unconfirmed actuarial estimates indicate that only about 18% of all those in need of treatment in the public sector are accessing it.[4] Given the need, patient numbers in the public sector are significantly lower than what the demand actually requires. A more aggressive approach to scaling up is needed to avoid falling further behind as the AIDS epidemic matures.[5]

## How the research was conducted

- 15 confidential interviews with representatives of public, not for profit and private sector providers and organisations (Staff from the National Department of Health and the HIV/AIDS Directorate did not respond to repeated interview requests)
- Review of key policy documents

## Major barriers to treatment delivery:

- Lack of effective national political leadership
- Denialism and pseudo-science
- Shortage of human resources, especially nurses
- Inadequate access to VCT
- Inadequate drug supplies and formulations
- Lack of integration of TB, HIV and PMTCT programmes
- Inadequate donor co-ordination and concerns about sustainability of funding
- Dysfunctional GFATM CCM
- Invisibility of multilateral agencies
- Inadequate response from the private sector

# SOUTH AFRICA

By August 2005, the total number of people on treatment in both the public and private sector stood at about 150,000: some 70,000 people were accessing ART in the public sector, with an additional 70,000–80,000 receiving it in the private sector.[6] Several reports of good outcomes are available.

The majority of the approximately 70,000 patients (both adults and children) receiving public sector care are concentrated in three provinces (Gauteng, Western Cape, and KwaZulu Natal). Most of the patients are women and about 10% are children. Paediatricians and children's rights activists are particularly concerned that very few children are accessing treatment. They estimate that at least 50,000 children need ART now, but that currently only about 10,000 are receiving it. The total public sector figure also hides huge inter- and intra-provincial disparities in patient numbers. It is also worrying that very few men are accessing treatment in the public sector.

Several donors partially or fully fund patients accessing ART in the public sector and contribute towards the costs of staff or medical equipment. For example, many provinces have entered into partnerships with donors such as Médecins Sans Frontières, Absolute Return for Kids, One2One Kids, Catholic Relief Services, the South African Medical Association, and PEPFAR. Without this support, the public sector patient figures would be even lower.[7]

The private sector figures include treatment provided by NGOs (community treatment programmes funded by internal and external donors),[8] workplace treatment programmes (funded by employers), medical insurance and aid schemes to which the employer and employee contributes)[9,10] and the unfunded private sector (self-paying patients).

While the total public and private numbers of patients on treatment are a step forward, the public sector numbers indicate that treatment is far off for many adults and children who need it urgently. In many cases where patients have received treatment, it has arrived too late. This means that many PLWHA are suffering needlessly and that we will continue to witness the premature deaths of thousands of people.

Therefore, unless the pace of implementation is substantially improved, thousands of people who are in need of treatment will either suffer or die prematurely.

Against this backdrop, the South African government has come under severe criticism from local advocacy and trade union organisations. In particular, most recently, Zwelinzima Vavi, the secretary general of COSATU, the country's largest trade union federation, publicly stated that President Mbeki and his health minister, Manto Tshabalala-Msimang, had betrayed "our people and our struggle" because of the lack of government leadership on HIV. As noted in this case study, people interviewed for this report unanimously agreed with Vavi and some expressed even stronger rebukes. President Mbeki, in his State of National Address on 11 February

2005 said that the national government would respond to the AIDS epidemic with "great vigour." The sentiment of all participants was that the programme is not being led "with great vigour ."

**Background**

From July through October 2005, a total of 15 confidential interviews were conducted among individuals representing public, not for profit and private sector organisations and providers. Regrettably, the NDoH and, in particular, the head of the HIV/AIDS directorate, did not respond to repeated telephone and e-mail requests for an interview. The NDoH's views are, therefore, not included in this report.

**Limitations**

Many of the respondents were unfamiliar with the TB programme, and therefore were not in a position to comment on the TB section of the interview (section 3). This is because they had not heard of the TB programme, felt that they had insufficient knowledge or information about it, or believed that the TB programme and response to the TB/HIV epidemic was inadequate and lacking. Due to the paucity of responses on the national TB programme, the summary below contains limited information about TB.[11] This is in itself telling.

**Key barriers**

Participants identified the following barriers, which they felt were affecting the speedy implementation of the Operational Plan. They are not ranked in any order of importance. However, the first two barriers listed below were the most frequently identified. These barriers are dealt with in detail in the recommendations section.

- Lack of effective national political leadership coupled with denialism and a flirtation with pseudo-science
- Operational issues, including:
  - Shortage of human resources, in particular nurses
  - Inadequate access to VCT
  - Inadequate drug supplies and formulations
  - Lack of integration of TB, HIV and PMTCT programmes
- Inadequate donor coordination, including concerns about the sustainability of donor-funded programmes
- Ineffective functioning of GFATM's Country Coordinating Mechanism (CCM)
- Invisibility of multilateral agencies
- Inadequate response from the private sector

# SOUTH AFRICA

## What is needed now?

- Create  a true national AIDS program
- Train nurses and other health care workers to provide treatment consistent with international standards, and develop programmes to retain them once trained
- Greatly expanded access to voluntary counseling and testing services
- Develop a new, more effective CCM—or initiate a new process for soliciting and overseeing the implementation of GFATM grants
- Establish true civil society representation on the CCM
- Demand fewer restrictions and more collaboration from PEPFAR
- Assure the ability to use generics through PEPFAR-funded programs
- Increased visibility and leadership from UNAIDS and WHO
- Expanded involvement from civil society in treatment expansion

## Recommendations

The following recommendations emerged from the interviews.

**1. Launch an international campaign to hold government accountable.**

> *The major obstacles are political—so we need a political solution—and we need to address the silence.*
> *—Staff member from leading legal research and advocacy group*

Most participants felt that the political impasse created by the president and the health minister is hampering the country's overall ability to effectively respond to the epidemic. Many participants felt that a strategic international campaign should be directed at the South African government to hold the health minister accountable and/or remove her from office on the basis that she is showing no leadership and continues to undermine the international, regional and local struggle against HIV/AIDS.

South Africa needs to get to the point where the AIDS programme has its own momentum and it is willingly implemented. It should not require ongoing vigilance from civil society. No one is championing the programme. More groups and people should be less complacent and less reliant on TAC and the ALP to do the dirty work.

The following specific concerns on leadership were identified:

- First, the health minister refuses to act in a transparent and open manner, thus limiting access to information about the HIV/AIDS programme. It was felt that multilaterals should be more critical and vocal about the lack of leadership of the AIDS programme and the deep levels of mistrust and secrecy that characterize the minister's actions. As one participant observed, "There is no programme driver."
- Second, ambiguous messages issued by the health minister about ARVs have led to confusion among many PLWHA. For example, many respondents held the minister responsible for creating a false dichotomy between nutrition and HIV/AIDS. They argued that this is because, in addition to issuing ambiguous statements about nutrition and ARVs, she has refused to act against false claims by persons who are associated with AIDS denialists and with the minister herself. Most participants felt that international organisations and agencies should consider the minister's inaction to be not only scandalous, but deadly—and to directly confront her and the government as part of an effort to cease discouraging patients from taking ART. The interviews noted that in some parts of the country, the health minister's open opposition to ART has prompted many patients to hold off on seeking treatment until a very late stage in their infection, thus endangering their lives and creating additional burdens on the health care system.[12]
- Third, the minister's attempt to centralise key decision making powers (such as accreditation of treatment sites) makes politically weaker provinces dependent on the national department for leadership and support. Most participants felt that the minister simply has too much power. Again, this is an issue of leadership.

Almost all respondents questioned the effectiveness of the National AIDS Programme (NAP). Most stated that in their view the programme is inefficient, non-existent and even "an embarrassment ." For example, paediatric treatment guidelines were only publicly available in October 2005, nearly two years after the Operational Plan was adopted. The government's National HIV /AIDS Strategic Plan expires at the end of 2005, but a plan for 2006 and beyond is not yet available.

**Positive comments**

The Khomanani programme (government communications component of the AIDS programme, which includes TV, print, radio advertisements and information materials) was considered by one participant to be a worthwhile component of the NAP. In addition, at the provincial government level, progress seems to be made in fostering a better working relationship with the NDoH. Aside from this, there were no other positive comments about the NAP.

**What should the NAP do?**

> *People are afraid to do anything or to say anything. National and provincial should be honest about what they need help with and do so regularly. They have created this tension between nutrition and ARVs, which is just ridiculous. They should be accountable and report to the country about treatment, participate in the programme, encourage testing and CD4 tests—or else why would people volunteer to get tested?*
>
> *— Staff member from nonprofit treatment funder*

Given that most participants agreed that for all intents and purposes there is no existing NAP, it is useful to list what they identified as the crucial components of an effective NAP:

- Lead, coordinate and deliver on the Operational Plan by assisting weaker provinces and ensuring that monitoring and evaluation is regularly carried out
- Ensure that the programme is not exclusively hospital-based.
- Monitor and improve policies, guidelines and systems that will ensure that the health and well-being of poor people are promoted and protected as mandated in the Constitution
- Act in a transparent manner, provide access to information, include civil society in deliberations, provide leadership, act with a sense of speed and increase the pace of rollout
- Appoint suitable people with the right skills to run the programme.
- Issue unambiguous messages
- Publicize outcomes

**2. Expand human resources**

> *We have large numbers (truckloads) of patients who need help, but not enough qualified staff to measure their blood pressure, take their medical history and check for OIs and TB, which is a huge problem in this area. We just need to train them to listen to a patient's chest. We have very few staff and they are unskilled. We have in our province the highest prevalence of MDR-TB in the world— 80%. What do we do?*
>
> *— Non-profit treatment provider*

Many participants identified inadequate human resources as a major barrier to scaling up treatment. According to them, the pace of implementation is being hampered by a lack of trained doctors, nurses, pharmacists and other health care

providers. Therefore, attracting, retaining and training health care workers is critical. The ongoing crisis in human resources is a result of poor working conditions, low salaries, lack of incentives, and the international poaching of health workers. Without a reasonable, flexible human resources plan that addresses short, medium and long term needs, the Operational Plan will continue to be undermined.

In particular, most participants regarded nurses as the backbone to scaling up treatment in South Africa, especially in primary health care settings. In addition, participants believed that nurses must be trained to administer ART with appropriate doctor supervision. Incentives to attract, retain and professionally develop nurses are also urgently needed. This requires the intervention of multilateral agencies to ensure that foreign governments and the private sector do not poach nurses who are needed in the public sector.

One interviewee argued that given the prevalence of HIV among health care workers, government, trade unions and international agencies have to embark on a national campaign to assist nurses who are living with HIV to access VCT, early diagnosis and timely access to treatment. That respondent suggested that if such an effort were not undertaken and made successful, the health care system would collapse in the next few years because of the direct burden of HIV/AIDS on health care workers.

**3. Expand VCT access**

Many participants felt that the current model of VCT was not working. In order to scale up more speedily, they felt that a new VCT model was necessary—one where counseling and testing is available routinely, more widely and before treatment becomes necessary. This would allow health care workers to better manage patients during the initial stage of infection and provide them with treatment at an appropriate time. Some participants suggested introducing the routine offer of testing at all health points, mass counseling, and self-testing. Others felt that a new model could include the aggressive marketing of testing at all public places, including schools, universities, shopping centres, places of worship, TB clinics, PMTCT clinics, general health wards and clinics, workplaces and places of recreation and leisure.

Some recommended that CD4 testing should be routinely available with VCT, a development that would assist health care workers with patient tracking and management, reduce unnecessary waiting lists and lengthy delays in treatment commencement, and in many cases limit loss related to patients' failure to follow up. In terms of the Operational Plan, a CD4 test result is a prerequisite for commencing treatment. Participants therefore suggested that it would make practical sense to couple CD4 testing with VCT.

In addition, many participants suggested that children should be tested much earlier after birth. They felt that it is vital that PCR testing is available at all health facilities

to diagnose children early enough and avoid losing them later in the system. As with adults, early testing assists with patient tracking and management.

**The role of multilaterals**

Varied responses were received from participants regarding the role of UNAIDS, WHO, GFATM and PEPFAR. Responses differed according to the proximity of the participant to the relevant organisation. Some bias in responses is therefore evident and should be acknowledged.

GFATM

There are two key issues in regard to GFATM. The first concerns GFATM itself, and the second is the appropriateness of the South African National AIDS Council (SANAC) as the CCM. Most participants agreed that the role of GFATM is mainly to be a financing mechanism. Some felt that GFATM operates as a willing listener and acts from the "ground up"—that it respects local priorities, is transparent and flexible, and provides incentives for meeting targets. Others argued that it is inefficient, bureaucratic, and has not met its mandate. Some could not comment on GFATM given that they had no dealings with it or felt that GFATM had "no impact on [their] work." Some participants considered GFATM's accounting requirements too rigid. Questions were also raised about who the key contact person for GFATM is in South Africa and to what extent GFATM has attempted to truly identify local needs and fund smaller community based organisations.

> *SANAC is invisible. It is not meeting, it is not transparent, it is not working. Who is heading it now?*
>
> *— Staff member from nonprofit treatment provider*

Many participants contended that SANAC is not a fit CCM and is instead undermining and hampering grant applications. Given the political complexities in South Africa, respondents suggested that either GFATM should allow direct applications or actively insist on a new CCM that is not under the control of the NDoH. One participant suggested that GFATM should invest resources in training and for the appointment of a full time secretary.[13] An external evaluation of SANAC was also suggested. Given that Provincial AIDS Councils are all represented on SANAC, one of the recommendations was that more resources should be spent on strengthening weaker councils to ensure that their representation at SANAC is more meaningful.[14]

In October 2005, it was learned that South Africa's Round 5 proposal to GFATM had been rejected, a development that most observers attributed to the failure of SANAC to function as a proper CCM. This means that an important organisation like Soul City has been deprived of funding from GFATM. South Africa's proposals to all three of the most recent GFATM rounds have now been rejected, primarily

due to the substandard performance of SANAC and the health minister's lack of leadership. These rejections have deprived the country of as much as 2 billion rand ($297 million) in funding for HIV, TB and malaria. As such, GFATM has referred the issue of future funding for the Lovelife prevention program (they were successful in Round 1) back to SANAC, which has been asked to revise the original Round 5 proposal and resubmit it. The GFATM board decision requires that the revised request also address the issue of an effective governance structure and CCM oversight. The problem is there has been absolutely no CCM oversight of any of the grants to date. This is despite the fact that over the last two years repeated requests have been made to SANAC for better reporting on the status of grant applications, the amount of money received by GFATM beneficiaries, and how funds have been spent.[15]

While some participants recommended bypassing SANAC and submitting applications directly to GFATM, two respondents warned against that step because they felt that a single and central coordination body is necessary so that country applications are based on a country's real, overall needs. Allowing direct applications to GFATM would lead, they said, to a situation in which only strongly written proposals were accepted, regardless of overall impact. Most participants felt that GFATM should follow PEPFAR's lead and award smaller, more targeted grants to key community organisations. They noted that as things stand now, reliance on the CCM to prepare and submit country applications means that GFATM money mainly benefits larger community organisations to the detriment of smaller ones.

Other recommendations for GFATM include the following:

- Improve GFATM's local profile so that people in South Africa are aware of its role, its funding successes and limitations, etc.
- Provide easily available access to information about where, how, and when to apply, including details of the main GFATM contact people in the country
- Ensure that GFATM has enough money to continue to fund the 128 countries that it is currently supporting (i.e. ensure sustainability)
- Fund smaller treatment projects—but not through the current CCM
- Address the current failings of the CCM, including its ongoing exclusion of effective civil society participation in decision-making processes regarding grant applications
- Replace the current CCM in its entirety with a new one that is more consultative
- Coordinate regularly with other treatment providers in the country

## PEPFAR

> *So far PEPFAR funds the "big fish"—but it needs to target smaller groups. PEPFAR is unclear about what it is NOT doing. It has major resources but it is politically tip toeing with the South African government.*
> *— Staff member from nonprofit treatment funder*

PEPFAR has been a lightning rod for controversy since it first began operating in South Africa in 2004. It is undeniably providing substantial assistance in the HIV/AIDS area, but its methods remain questionable.

Most participants regard PEPFAR as a parallel funding mechanism that is inappropriately taking resources away from GFATM. One participant disagreed and argued that PEPFAR is investing huge resources and providing intensive technical assistance for treatment purposes. While several participants recognised that some elements of PEPFAR are providing necessary and useful support for public sector treatment efforts that are as yet unfunded, others criticized PEPFAR administrators for taking credit for treating patients who are not receiving PEPFAR-funded care. There is also some concern about how national PEPFAR patient numbers are calculated.

Mainly, though, participants were worried about the conditions attached by PEPFAR regarding the procurement of drugs as well as the Bush administration's policies regarding condom use, termination of pregnancy and contraception—all of which have implications for reproductive health rights and access to appropriate prevention programmes.

Some participants contended that PEPFAR is part of a broader political agenda of the U.S. government to boost his credibility in the face of anti-Bush sentiments—i.e., to make him appear human. It was recognized, however, that PEPFAR may be creating a solid foundation to improve access to treatment for many people and that it could become a critically important program if certain political and ideological barriers were removed. Having said this, several respondents argued that PEPFAR very often does not meet local needs and is contributing to turf wars within provinces because PEPFAR does not allow two different organisations to work at the same site. One of the main concerns about PEPFAR is that it "simply does its own thing" (in Western Cape, for example) without due regard for what is happening at a national or provincial level.

According to the US health attaché, not for profit providers must meet two conditions in order to receive PEPFAR funds: they must only use U.S. Food and Drug Administration (FDA) approved drugs, and they must sign a declaration that the organization will not promote sex work. However, PEPFAR-funded programmes and partners indicated that the only condition that is strictly applied and observed is the one requiring that ARVs be approved by the FDA.

It should be noted that SA's own medicine regulatory system requires a drug to be approved or authorized by its Medicine's Control Council (MCC). In other words, drugs used by a provider funded by PEPFAR will require both FDA and MCC approval.

Ironically, at government facilities that are PEPFAR funded, PEPFAR cannot impose the FDA registration requirement because the SA government is only obliged to use drugs that are registered and approved by the SA MCC. The FDA requirement is therefore not imposed at government facilities. It is unclear if the SA government has been asked to sign the declaration on sex work.

Many participants argued that more patients could be treated if PEPFAR-funded ART projects were allowed to buy lower-cost generic drugs that have not been approved by the FDA; many of them, they point out, have been cleared for use by WHO and South Africa's MCC.

As noted above, many respondents were concerned about official PEPFAR prevention policies that place higher priority on abstinence and being faithful than on encouraging condom use. Some participants noted that because of such policies, organisations in the developing world that are dependent on U.S. money are no longer able to promote condoms directly. In Uganda, for example, this has resulted in a number of community organisations closing down. Most respondents were aware of PEPFAR and its international implications; few, however, were aware of the potential long-term implications of its programmes for prevention and treatment in South Africa.

A significant and positive aspect of PEPFAR reported by participants is its regular (every three months) monitoring and evaluation of site and programme implementation. PEPFAR was also commended for its efficiency and speed in paying laboratory and other bills. Many participants were also of the view that it is easier to apply for funding from PEPFAR than from GFATM.

The programmes funded by PEPFAR are concerned about how the government plans to "take over" (fully fund) patients that PEPFAR has begun treating, especially after PEPFAR funding ends (perhaps as soon as 2008). In other words, while in the short term patients are benefiting from PEPFAR, there are concerns as to whether sufficient attention and thought has been given to exit strategies in the medium and long terms.

Other recommendations for PEPFAR include the following:

- Drop the "global gag rule": money for treatment should be de-linked from prevention. Either PEPFAR should support prevention separately or simply drop its "anti-choice" conditions.
- Drop the rule that requires all PEPFAR-funded ARVs to be approved by the FDA. If poor countries have to get FDA approval to use generics, it

increases the costs of putting patients on treatment and takes more time for products to enter the market. Respondents noted that if more generics were used, many more patients could be put on treatment. Until this provision is dropped, treatment advocates should lobby the FDA to fast track the registration of generic ARVs

- PEPFAR should be clearer about what it does and does not fund, and how it will ensure sustainability
- Ensure that PEPFAR reporting requirements are not cumbersome at a project level. Participants felt that too much detail about programme activities was required too often
- Ensure easier application processes for small grants and fund smaller NGOs
- Stop political tiptoeing with the health minister and demand certain assurances from the government. (Still, it was suggested that PEPFAR is more sensitive to the political complexities than UNAIDS and WHO.)
- PEPFAR should be part of a centrally coordinated treatment programme in the country, and not be allowed to operate independently
- The programme should be more transparent in its leadership and decision-making processes regarding grant applications

UNAIDS

Most participants viewed UNAIDS as a facilitator yet at the same time they were unaware of its activities South Africa; it was thought to be "invisible" and had "no presence." According to local UNAIDS staff, this perception is due to a number of factors: for one thing, until recently the country coordinator was the only technical person employed in the South Africa office (at the end of 2004 a monitoring and evaluation officer was appointed, and in October 2005 a partnership officer was appointed).[16] Also, according to UNAIDS staff, much of its work supports the programmes developed and implemented by co-sponsors and thus is largely "behind the scenes ."[17]

This to some extent explains why participants felt that UNAIDS has been silent during crucial campaigns for treatment in the last few years. However, with respect to the Geneva offices, participants recognised and were supportive of the role that UNAIDS plays in providing annual analytical and epidemiological information, as well as its significant contribution in making information available, particularly on the global epidemic.

Other recommendations for UNAIDS include the following:

- Increase its profile and presence in South Africa and in each country where it operates by conducting awareness campaigns to let people know its roles and functions
- Increase or start consultation with key partners in South Africa[18]

- Act more forcefully as an advocate for PLWHA, which would include being willing to criticize government policy in South Africa
- Be more supportive of civil society and advocacy efforts in South Africa
- Talk more openly, directly and supportively about ART and the government's Operational Plan
- Influence strategy direction of GFATM and assist with raising money for it
- Scale up and increase pressure to support the treatment and care of children and adolescents in South Africa and elsewhere (working with UNICEF)

WHO — including "3 by 5" staff

There is no WHO office in South Africa or dedicated WHO staff person for the country; instead, the Southern African office is based in Zimbabwe. This may be part of the reason that of all the multilaterals surveyed, WHO received the worst assessment from participants. Most participants asked, "Who is the WHO?" in South Africa and questioned whether it plays any constructive role in the country. Save for its work on preparing and issuing international treatment guidelines and facilitating the WHO drug pre-qualification process, participants were hard pressed to comment positively about WHO.

One participant lamented that the organization has "lost its focus ." However, this is difficult to assess given that at the time of writing this report, the WHO did not have senior staff in the country. It is possible to imagine the government has not been welcoming of a WHO presence. Recently, UN Special Envoy to Africa Stephen Lewis said he had been banned from carrying out his duties in South Africa for the past year.[19]

It is therefore recommended that WHO and the South African government should work together to ensure that senior WHO staff are stationed in South Africa. Given the magnitude of the AIDS epidemic in the country, this is now extremely urgent. Other recommendations for WHO include the following:

- Like UNAIDS, WHO should increase its profile and presence in South Africa and the region
- Actively support the work of GFATM in South Africa and elsewhere
- Consider developing and issuing guidelines on health systems and human resources, as well as guidelines on using and improving existing health systems to provide essential health services. In addition, develop recommendations on addressing the human resource crisis in Africa: this could include scope of practice, retention strategies, incentives, training and professional development
- Engage in South Africa (not just the international community) on essential medicines

- The WHO pre-qualification programme should be more aggressive; for instance, it should put pressure on generic manufacturers to submit their products for inclusion in the review. While most participants believed that the WHO pre-qualification programme was a good concept, many felt that it is under-resourced and lacked a consistent plan of action
- Consult with local stakeholders and providers and be more inclusive of African health care workers

Civil society

Most participants felt that the health minister was excluding civil society from deliberations about the Operational Plan, with channels of information being deliberately closed and monitored. For this reason, many health care workers said they were afraid to speak out for fear of losing their jobs.

Many participants acknowledged the role that the Treatment Action Campaign (TAC) in particular has played in challenging the government's HIV/AIDS policies. Most argued that aside from TAC, AIDS Law Project and Médecins Sans Frontières, very few organisations have directly and consistently challenged the South African government. All of the participants were supportive of the newly established Joint Civil Society Monitoring Forum (JCSMF) and felt that it was doing work that should be done by the government.[20]

Some participants suggested that the current relationship between TAC and the health minister is too antagonistic, and that therefore solutions must be sought to reduce tensions. However, others felt that the confrontation posed by TAC is appropriate and timely. Some respondents recommended that TAC and other civil society organisations concentrate on treatment preparedness and literacy at community and clinic levels. In addition, several participants said that all members of civil society in South Africa (and not just TAC) should collectively address denialism and the lack of proper, rational leadership in the country.

Other recommendations for civil society include the following:

- Identify additional resources to carry out community mobilisation and treatment preparedness programmes
- Find a coordinated and less fragmented voice and be more critical about the existing political barriers that hinder ART scale up
- Create partnerships at different levels, especially with smaller community organizations
- Focus on good outcomes in treatment scale up, and not just on the negative outcomes
- Get more involved in addressing the operational issues of the national programme by improving clinic level advocacy, by helping the government move away from a hospital-based programme, and by ensuring that primary health facilities offer treatment

## ENDNOTES

[1] The 2005 budget shows an ongoing financial commitment by the government to address HIV/AIDS. With respect to resources set aside for the procurement of ARVs, more than 3.4 billion rand ($504 million) has been allocated for the period up to the end of 2007. But the award of the drug tender was only announced on 2 March 2005, some 13 months after the drug procurement process commenced and more than 16 months after the Operational Plan was adopted.

[2] These facilities are spread across all the 53 districts in the country and cover at least 62% of local municipalities.

[3] There are about 5.5 million people living with HIV/AIDS in South Africa. Of these, approximately 200,000 are children.

[4] Information compiled by the AIDS Law Project, September 2005.

[5] The Operational Plan set its first patient targets at 53,000 for the first year of its implementation. The target was then shifted twice: first by the health minister and then by the president in his 2004 State of Nation address. In her 2005 Budget Speech, the health minister refused to engage in any debate about patient tar gets and argued that the initial targets were estimates—and nothing more. She stated that patient targets are not important and that instead the debate should be about quality of care. See here Hassan F. Joint ALP/TAC Report issued in June 2005: "Let them eat cake" – A short assessment of provision of care and treatment 18 months after the adoption of the Operational Plan. Available at www.alp.org.za and www.tac.org.za.

[6] By the end of August 2005, the government estimated that at least 78,000 people had been initiated on ART in these facilities.

[7] Médicins Sans Frontières supports four public sector sites in the country; Absolute Return for Kids supports 17-19 sites in the Western Cape; One2One Kids through Kidz Positive supports two sites in the Western Cape, and PEPFAR supports 112 primary sites. Of these, about 30 are in the public sector and the rest are in the not for profit (private) sector or are public-private partnerships. Catholic Relief Services supports three sites in the Free State.

[8] Some of the community projects run by international donors and local donors, faith-based organisations or local communities include the South African Catholics Bishops Conference (which runs treatment projects at 20 sites with funding from PEPFAR and one site through non-PEPFAR funding); the TAC Treatment Project (which started in May 2003, is currently funding over 100 patients nationally); ACTS Mpumalanga (which started in 1996, is funded by Right to Care and PEPFAR and receives some money for operating costs from the NDoH); Ndlovu HAART programme (which started in 2001, and is the only community project in the country with its own HIV monitoring laboratory).

[9] Many private sector programmes are administered by disease management programmes (DMPs).

[10] Some of the larger companies that provide HIV/AIDS treatment for workers who cannot afford to belong to a medical scheme include: Eskom; Anglo American; Ford Motor; Daimler Chrysler; BP and Engen; Sasol; Tiger brands; Cape Town Municipality; Mtel; BMW; and Unilever.

[11] Zackie Achmat and Reid Roberts in Steering the Storm: TB and HIV in South Africa, a policy paper for the Treatment Action Campaign. Available at www.tac.org.za.

[12] Recently, the WHO Consultation on Nutrition and HIV/AIDS in Africa (co-hosted by the national department of health) confirmed that everyone requires good nutrition, including PLWHA. But the WHO Consultation Statement also noted that there is no scientific evidence to suggest that good nutrition alone can treat HIV. This is in accordance with official government policy as articulated in the nutrition chapter in the Operational Plan.

[13] The national budget has not allocated any money to SANAC since 2001-2002, despite the fact that international protocols such as UNAIDS's Three Ones Principles call for strengthening of national coordinating bodies accompanied by allocation of sufficient resources. The Three Ones Principles aim to ensure that national governments and their partners develop strong coordinating mechanisms, partnerships and funding mechanisms that would urgently respond to and reduce the impact of HIV and AIDS. SANAC's location within the health department in its first term actually undermined its authority to oversee and encourage HIV and AIDS activities in all government sectors. Strode and Grant (2004: 26) reported that SANAC has finally managed to move its secretariat out of the NDoH to offices outside of any government department. For SANAC's second term of office, a trust fund has been set up and all its finances will be managed by the trustees." The Trust was established in 2002. According to the auditor general, "inadequate progress was made in achieving the objective of the Trust" due to failure to submit budgets to the Board of Trustees as is required by SA law; not submitting monthly and quarterly reports on income and revenue; and lack of monitoring and involvement by the Trustees. The auditor general also found evidence of "fruitless and wasteful expenditure, to an amount of 571,114 rand."

[14] Similarly, it was suggested that the PLWHA, children and women sector in SANAC must be strengthened so that it operates effectively within and outside of SANAC.

[15] SANAC minutes of 17 March 2004; 19 June 2004; 7 October 2004.

[16] Because UNAIDS technically is not a UN agency but is instead a collective of 10 co-sponsors (other UN agencies) it regards itself as a "supporter" as opposed to an implementer. As such, its country level role is determined by the programme activities of the co-sponsors (e.g. WHO, UNICEF). At present, each country office (globally) including the South Africa office has been tasked with working on five core areas, identified as: supporting existing leadership for an effective national response; supporting partnerships between public/private and civil society actors; promoting and strengthening country management of strategic information; capacity building to track, monitor and evaluate the national response; and facilitating access to financial and technical resources.

[17] For example, UNAIDS has assisted in supporting the continued functioning of the AIDS Consortium, an umbrella body of AIDS service organizations in South Africa, after it almost closed down. It is supporting programmes currently being carried out by the South African National Defence Force with a view to replicating the

model with UN peacekeeping forces; it acts as the secretariat for the SA Donor coordinating forum which meets every two months and is made up of government, the UN and bilateral funding agencies; it assisted SANAC with putting together proposals to the GFATM; in 2005 it assisted Soul City to put together its GFATM proposal; and in 2004 it assisted provinces that had previously not applied to GFATM for funding to submit proposals to the CCM.

[18] This is now possible given that the UNAIDS office in South Africa has appointed a full time "partnership" officer.

[19] In his book Race against Time, Lewis singles out the South African government and President Thabo Mbeki for what he calls bewildering policies and a lackadaisical approach to treatment of millions of people living with HIV. According to Lewis, "Virtually every other nation in eastern and southern Africa is working harder at treatment than is South Africa with relatively fewer resources, and in most cases nowhere near the infrastructure or human capacity of South Africa." See LaFraniere, S. "U.N. Envoy Sharply Criticizes South Africa's AIDS Program." New York Times. 25 October 2005.

[20] The JCSMF is currently composed of the following civil society organisations: AIDS Law Project (ALP); Health Systems Trust (HST); Centre for Health Policy (CHP); Médecins Sans Frontières (MSF); Public Service Accountability Monitor (PSAM); Institute for Democracy in South Africa (IDASA); Open Democracy Advice Centre (ODAC); Anglo American; Southern African HIV Clinicians Society (SAHCS); UCT School of Public Health and Family Medicine; and Treatment Action Campaign (TAC). The JCSMF aims to assist with the monitoring and assessment of the implementation of the Operational Plan from a public health and human rights perspective. Its objective is to provide government and the public generally with an ongoing and accurate assessment of the programme's implementation, to act as an early warning system for problems, and to help communicate successes. To date, the JCSMF has met on five separate occasions and has accordingly issued five reports, which contain the findings of each meeting. These reports are publicly accessible.

# INTERNATIONAL TREATMENT PREPAREDNESS COALITION (ITPC)
## Fact Sheet

**What is the ITPC?**

The international Treatment Preparedness Coalition (ITPC) is a worldwide coalition of people living with HIV/AIDS and their advocates. The ITPC advocates for universal and free access to treatment for AIDS for all HIV+ people and greater input from HIV+ people in decisions that affect their lives. We work to achieve these goals at the local, regional and international level.

**History of the ITPC**

In 2002, a group of treatment activists from around the world identified the need for a stronger international response to address the need to provide HIV/AIDS t reatment to millions of people who require it around the world. In March 2003, one hundred and twenty five people with HIV/AIDS and their advocates from sixty-seven countries gathered in Cape Town, South Africa at the International Treatment Preparedness Summit to discuss strategies to establish and strengthen:

- Local and regional efforts to educate communities about treatment and mobilize them to demand access to these drugs and;
- local, regional and international efforts to secure the commitment and policy changes needed from governments, multilateral institutions and the private sector to expedite access to treatment for HIV/AIDS.

The ITPC grew out of this meeting as activists from around the world sought to join forces to advance these strategies.

**What Makes the ITPC Unique?**

ITPC is the only international coalition of people living with HIV/AIDS and their supporters solely devoted to advocacy on HIV/AIDS treatment access. It is a broad coalition of people from all affected regions comprised of people working in and for the community in their own countries and with strong expertise in HIV/AIDS treatment and related issues. As a community voice, it combines the knowledge of the grassroots with technical expertise, and has been successful in communicating the concerns of people living with HIV/AIDS who need treatment to governments, United Nations agencies, the large pharmaceutical manufacturers among other public and private bodies that influence the progress of the establishment, scale-up and sustainability of HIV/AIDS treatment programs.

## Collaborative Fund for HIV Treatment Preparedness

Currently, the ITPC has embarked on a partnership with the Tides Foundation, to form the Collaborative Fund for HIV Treatment Preparedness to directly fund local and regional treatment literacy and advocacy efforts. The Collaborative Fund has set up Community Review Panels in each region to locally define funding priorities and make funding decisions on specific projects. Treatment advocacy and literacy workshops have been held or are scheduled in every region and a grant-making program has been initiated to support local organizations' work on these topics. So far, the ITPC and Tides Foundation have raised over US $5 million for Collaborative Fund activities from various donors some of which include the World Health Organization (WHO), the Rockefeller Foundation, and the Open Society Institute.

## Other Activities & Accomplishments

- Solidarity Day in Support of Treatment Access in South Africa. In April 2003, ITPC members joined in demonstrations in their own countries to urge the South African government to sign and implement a national treatment and prevention plan that includes antiretroviral treatment for people living with HIV/AIDS.

- Solidarity Day in Support of Thai Drug Users Network. In June 2003 ITPC members joined in demonstrations in their own countries to protest the extra-judicial killing of Thai drug users and to press for HIV/AIDS treatment for Intravenous Drug Users.

- First meeting of people with HIV/AIDS with the Director General of WHO. In November 2003, a delegation of eight people with HIV/AIDS and their advocates from ITPC travelled to Geneva for the first meeting between a Director General of the WHO and people living with HIV/AIDS from around the world. The group discussed the WHO's 3X5 initiative to scale-up antiretroviral therapy to 3 million by 2005. The group also met with senior staff at UNAIDS and the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria to discuss access to treatment.

- Inclusion of active drug users in the WHO 3X5 initiative. In February 2004, ITPC members, supported by over two hundred people which included drug users, HIV-positive people and their advocates from around the globe, called on the Director General of the WHO to ensure the equal involvement of active drug users in the scale-up of antiretroviral therapy proposed by the WHO and take a leading role in recommending governments to make healthcare principles a priority over the law enforcement approach to illicit drug use.

- Inclusion of Methadone on the WHO's List of Essential Drugs and Medicines. In collaboration with harm reduction advocates across the world. ITPC members pushed for the inclusion of methadone on the WHO's list of essential drugs and medicines as a part of a comprehensive approach to HIV/AIDS care. Methadone was approved for inclusion on the list in March 2005. This issue was first raised in the ITPC meeting with the WHO Director General in November 2003.

- World Community Advisory Board Meetings with Brand-Name and Generic Pharmaceutical Companies. In February 2004, ITPC members met with Boehringer Ingelheim, Glaxo Smith Kline and Roche to discuss concerns about drug pricing and research practices. In particular, ITPC advocated for new policies by multinational companies on pricing for middle-income countries. In January 2005, ITPC members met with generic drug makers, Cipla, Ranbaxy, Hetero and Strides, to discuss quality control over generic manufacturing, paediatric formulations, second-line regimens and pricing policies.

- Solidarity Day with FrontAIDS in Russia. In December 2004, ITPC members sent faxes to protest to the police station in Kaliningrad Russia, where dozens of activists from FrontAIDS were being held after staging a demonstration to demand access to treatment and human rights for drug users. All activists were promptly released from custody.

- Advocacy for the revision of the antiretroviral procurement list in Moldova. In 2003, ITPC members in the Newly Independent States discovered that Moldova was procuring an expensive, sub-optimal antiretroviral regimen with its grant from the Global Fund. Through advocacy with the Global Fund, the WHO and others, ITPC was instrumental in rectifying this situation.

- Protest on Health Sector Spending Caps by the International Monetary Fund and the World Bank. In September 2003, ITPC members sent a letter to the Managing Director of the IMF and the President of the World Bank to urge them to modify macroeconomic policies that keep health sectors from growing to meet the needs of the AIDS epidemic.

**Governance & Structure of the ITPC**

The ITPC is a social movement, a coalition of individuals committed to treatment access, not a non-governmental organization or a network with a secretariat. This loose structure allows us to invest our energies and resources in our treatment advocacy and literacy work instead of having to sustain an organizational structure and move quickly to adapt and evolve to the changing realities of the epidemic. A Code of Governance for the ITPC is available at:
http://health.groups.yahoo.com/group/internationaltreatment preparedness

**International Steering Group, Regional Advisory Committees and Thematic Working Groups**

An International Steering Group (ISG) provides strategic guidance to the movement and deals with critical operational issues. The ISG is comprised of 30 treatment activists, 15 men and 15 women, from the following regions:

- Central & Western Africa;
- Eastern Africa;
- North Africa & the Middle East;
- Southern Africa;
- East Asia & the Pacific;
- South Asia;
- South East Asia;
- Caribbean;
- Central America;
- South America;
- The Baltic's & the Newly Independent States;
- Eastern Europe;
- Australia, New Zealand & Japan;
- Western Europe;
- The United States & Canada

Regional Advisory Committees (RACs) have been established to foster treatment literacy and advocacy efforts in their respective regions and identify issues to be addressed in the international setting.

**Funding**

The ITPC does not raise funds for day-to-day activities. Members donate their time voluntarily. Funds have been raised for certain projects initiated under the aegis of ITPC (e.g. meeting with generic antiretroviral drug manufacturers), but allied organizations act as the fiscal sponsor and provide financial management for these activities.

**Membership**

As of December, ITPC had over 600 members from over 100 countries. Membership is invited from all those individuals, people living with HIV/AIDS and their advocates, who are committed to fight for HIV/AIDS treatment access. Members are expected to participate and contribute to the best of their ability. While members are free to act under the name of the movement, they may only act in capabilities that enhance access to treatment, but may not act in formal capabilities such as fundraising without the approval of the International Steering Group. There is no fee or other requirements for membership in ITPC. The ITPC is a coalition of individuals, although members may be active participants or leaders in other local, regional or international networks, NGOs or other groups. Membership in the ITPC is initiated by joining the ITPC email group at http://health.groups.yahoo.com/group/internationaltreatmentpreparedness.