

# Under the PATAM tree

Pan African Treatment Access Movement newsletter

Issue No. 3

December 2004

## Anchoring the Movement

by Njogu Morgan

Dear Reader,

Welcome to this issue of "Under the PATAM Tree," newsletter for the Pan African Treatment Access Movement (PATAM). In this edition you will find a broad range of articles on activities within the movement against obstacles to HIV/AIDS treatment. The articles all highlight different aspects of the struggle.

The first article by Ms. Siana Musine deals with the powerful theme of disclosure, self-acceptance and unequivocal decision to act. It's a profoundly inspiring story of the sometimes difficult but life affirming transformation from despair to living positively with HIV.

A number of articles explore systemic and governance obstacles to access to medicines and good healthcare. These articles tell us that the road towards universal access will be extremely uneven. For instance, while prices for

HIV/AIDS medicines have fallen dramatically in the last few years with the introduction of greater generic competition, the price barrier might rear its ugly head once again if efforts to enshrine patent protections in bilateral and regional free trade agreements are successful. We also know that prices for post first line regimens are still exorbitantly expensive.

Another illustration of this unevenness will be the extent to which the political environment may advance or retreat in favour of access to medicines. Despite some fairly reasonable policies on paper such as an AIDS levy, the governance environment in Zimbabwe is increasingly destroying that country's ability to respond meaningfully to the HIV/AIDS epidemic. The shrinking space for open expression such as draconian laws against media and restrictions on the activities that civil society may or

may not engage is diametrically opposite to a disease whose successful resolution demands a climate of openness. Similarly, macroeconomic mismanagement means that though Zimbabwe has a generic industry and blazed the trail in waiving patent rights for medicines, the industry cannot produce in mass quantities since currency weakness constraints its ability to purchase inputs beyond its borders.

Many in the movement have always said that the most difficult challenge in access to medicines that we will encounter, will occur after treatment roll-out. The articles in this volume suggest it is so. The lesson then is that in our efforts towards universal access to treatment to never take any victories for granted nor should we assume despite all suggestive signals, that the road ahead is even. So we must always be vigilant. This is why our efforts towards transformation into a more operationally efficient and strategically astute movement are so important. The next few months will see us working to produce a discussion document for adoption of an Africa-wide intervention plan to increase access to treatment for people living with HIV/AIDS and a framework to implement, monitor, evaluate and adjust these plans if necessary. Everyone's participation and input is vital. This is your movement. Make it work better – work better to save lives.

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# “A PLWA has a right to dignity, to be respected and protected.”

by Ms. Siana Abraham Musine

“Hello. I am Siana Abraham from Kenya. I’ve come to give you my life testimony on how I’ve lived positively with HIV. I was tested in the year 1998. When I received the results I was shocked. In fact, I didn’t know what to do. It hit me and I thought immediately I was going to die. Bit by bit my life was being chipped away. I lost weight dramatically and then there was the stress of mortality – living each day looking down the barrel of the gun. You cannot be normal, you have HIV and that’s it. I wanted to clinch to normality but my mind, my body, my soul could not allow me.

An illness of this magnitude scared so many people. I lost most of my friends, but I was blessed to have the support of my family members and close friends. With all the opportunistic infections, every doctor I saw poured me a mixture of confusion and well, there was probably nothing they could do because ARVs (antiretroviral drugs) were not yet in Kenya. Then I asked myself, why me? Brothers and sisters, HIV robs you of the blissful ignorance that led you to believe that tomorrow lasts forever. But it has also shown me the importance of living in the present. Tomorrow is a near present bonus.

I got academically involved in my illness through an international humanitarian organisation, Médecins Sans Frontières (MSF). The HIV/AIDS awareness campaign that MSF was conducting in the Kibera slums of Nairobi where im from, gave me a positive attitude to go and seek treatment.” Now I’m on my ARV treatment and I have to adhere to it and am doing well. I just have a message to all the PLWAs in the world: being HIV positive is not the end of the world, it’s not about giving up. It’s about living life and making a future in this so that you still can do the things you enjoy.

A wise chap once said, “A man does not stop drinking water just because his son drowned in the river.” Contracting the virus that causes AIDS is not the end of life. It is the beginning of a new life experience. So people with HIV and AIDS should bless themselves and take this challenge. We should be a tower of strength to those infected and affected. We cannot spend the rest of our lives regretting ourselves. If we become bitter and vindictive, then our bitterness will only help to erode our health and by the end of the day, there may be no light at the end of the tunnel.

Nobody knows what he will do in a terrible situation until first in it. You are a true picture of this world. You are a role model. I urge you to give a human face and voice to the epidemic back in your own countries. We PLWAs do not need pity, we do not need mercy. We want acceptance, integration and involvement in all aspects of society and life. We do not accept societal stigma directed toward us – we are human just like everybody else.

*I recently learned a visualisation technique: I visualise that the virus is a parasite that needs me to survive. By killing me, it will be committing suicide – and the virus doesn’t want to do that. Thank you.”*

A PLWA has a right to dignity, to be respected and protected. I believe that because of this conference, we will walk positively, speak positively, talk positively, breathe positively, and to crown it all – live positively. This combined with constructive action will surely work for us all. We cannot live in the past and dwell in the memories. The present is the only thing that counts now. Our objective should be to live positively. Let us live the years ahead of us actively, cheerfully and not indulge ourselves in pity or complaint.

This is the testimony from Ms. Siana Abraham Musine on her experience living openly with HIV/AIDS. The testimony was delivered at a treatment literacy and advocacy workshop held in South Africa. See other pages on this workshop. Siana is active in the Kenya Organisation of People Living with HIV/AIDS (KOPLWA). She can be reached on [abraamsiana@yahoo.com](mailto:abraamsiana@yahoo.com).

## PATAM builds further momentum at treatment literacy workshop

by Dara Cooper

From 2-8 October 2004, over 90 civil society practitioners from Africa participated in a treatment literacy and advocacy workshop in Bronkhorstspuit, Mpumalanga, South Africa. The workshop that was hosted by the Treatment Action Campaign (TAC) and financially supported by Brot für die Welt was primarily aimed at increasing knowledge on the science of the HI Virus, medical knowledge of antiretroviral therapy and the political factors that impede or facilitate access to HIV/AIDS treatment.

*“If the government is beating the drum and everyone is dancing, who is going to speak for the people?”*  
— workshop participant

For seven information-packed October days and nights, approximately 90 delegates from countries all over Africa gathered to learn about HI virology as well as treatment and advocacy impediments. With unwavering diligence, comrades learned, exchanged (everything from information to chocolate) and committed to supporting each other in the struggle against HIV and transforming Africa’s health care sectors. Upon the workshop’s commencement, delegates fervently called for an in-depth analysis and advocacy agenda for treatment campaigns. “Some people want to make an omelet but don’t want to crack the shell of the egg!”

In a captivating monologue, Ibrahim Umoru, a participant from

Nigeria, eloquently pleaded with all to engage in a meaningful dialogue that would extend beyond the surface of typical advocacy discussions and agendas. “Let’s be real,” Ibrahim continued, “what are some of the things we have avoided discussing? What *are* the side effects and negative impacts of ARV’s? Let’s be real, everyone.”

And the workshop embarked upon just that. Traveling through a seven-day journey through a vast array of scientific, nutrition, economic, and medical discourse, the participants of the workshop tirelessly indulged in extensive dialogue, critiques and advocacy challenges often times late into the night.

One recurring theme within many of the discussions was the importance of monitoring

governments as participants criticized the absence of checks and balance systems within many African countries.

“If the government is beating the drum and everyone is dancing,” probed one workshop participant during a voluntary evening discussion on social mobilization and Zimbabwe, “who is going to speak for the people?”

Some delegates remained leery of monitoring their governments for various reasons ranging from faith in their governments’ effectiveness to believing dissent will ultimately result in being classified with opposition parties or in some cases – incarceration. Towards the conclusion of the workshop, however, delegates collectively agreed upon the importance of creating a powerful Africa wide body to monitor and assist national HIV/AIDS treatment programmes.

Throughout the week long discussions, it was apparent that the diversity of experience from the level of community activism to availability of HIV/AIDS treatments at country level was quite disparate. Some representatives came from countries that offer free antiretroviral therapy (ART), while others from country programmes that require some payment and even from countries that had yet to

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## PATAM builds further momentum at treatment literacy workshop continued

begin providing treatment in the public sector. In another stark contrast, the widespread availability of condoms is such that in some countries they are often used as balloons or toys while the condoms in other countries remained of such poor quality they are damaged with very little effort, yet still other areas have very little (or no) condoms available at all (although it is estimated that men in sub-Saharan Africa have access to an average of only three condoms per year, and females—virtually none). Lastly, civil society advocacy for access to treatment was equally as divergent. The general picture that emerged from country presentations was that there is increasing collaboration and coalition-building for access to

treatment across the continent. The impact and coordination only varies in degree.

Despite all of the varying factors and degrees of difference, comrades were passionately committed to embarking upon a collective agenda. A call for an organized continent-wide movement was roaringly present. And the final day of the workshop resulted in 46 ambitious resolutions under six categories: Urgent Access to Medicines, Treatment Literacy Advocacy, Community Mobilization to Increase Access to ARV's, Pan-African Solidarity and Accountability, International and National Funding Priorities, and Drug Research and Access.

Yes, the shells of many eggs were indeed broken in this workshop, and this PATAM omelet is definitely in the making. And to borrow the cool, compelling style of Angelique Chiwetani's address on the last day... "viva, PATAM, viva!" This will be an omelet sure to be enjoyed by all, as members of this movement are sure to dance to the rhythm of its own collective, uncompromised, and powerful drum...

Further information on the workshop can be found at the PATAM website on [www.patam.org](http://www.patam.org)

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## Potholes, ditches, mud...and maybe some hope in assessing HIV/AIDS medicines in Ethiopia

by Mercy Otim

Abebe Kebede, like many other people living with HIV/AIDS around the world but like few others in Ethiopia, chose to use the life saving antiretroviral treatments (ARVs) after his body finally lost its ability to independently fight the HI virus. He spent a good amount of his lifelong savings on buying the medications. But like many other Ethiopians, this was not to last. He could only afford to

purchase the medicines for three months before he realized he was draining his family's resources and his family would soon have nothing further to live on. So he took the tragic but often too common decision, and stopped taking the medications. His condition is now worse than when he started.

Abebe's story might paint a grim picture on the HIV/AIDS situation in Ethiopia, but this is representative in the country and indeed across

Africa. A few people are aware of the life restoring potential of HIV/AIDS medicines but many more are dying due to ignorance and inadequate accessibility.

Although there are patches of awareness emerging within the country, a large part of the population remains ignorant. For instance, few pregnant women access the programme to prevent mother to child transmission of HIV available in some maternity clinics.

Elsa Egzabher, a social worker with the Jesuit Refugee Services' programme in Ethiopia says, "Many people here do not have economic empowerment to allow them access to the drugs, some are going without treatment while others are stopping because they do not have the resources to continue".

For a country where it is estimated that there are 1000 new HIV infections everyday, an estimated 3 million already infected, it is agonizing that only about 9,600 are on ARV treatment. And of that small number, only 400 of them access it for free. For the rest, the average cost of about 3,000-10,800 birr per year (about US\$ 375-1350 per year) is a major prohibitory factor.

These figures disturbingly reflect the limited access of ARV drugs and medical facilities in Ethiopia. Although generic ARVs are available, they are expensive and therefore not accessible to many Ethiopians.

Manufacturing the AIDS drugs locally would go a long way in reducing costs and easing the burden of those wishing to purchase them. However, lack of funding to kick start this process has been an impediment.

"The government has expressed interest to have the drugs manufactured locally, but the country lacks the necessary infrastructure and institutions to be able to effectively implement this," Says Elsa.

She says that even if this is done, the need to train medical personnel is still paramount as there is a shortage of qualified medical personnel to see the implementation of any treatment plans there might be. The World Health Organization's "3 by 5" plan to provide ARV drugs for 3 million people for free or at a nominal price by 2005, still seems like an illusive initiative for many in Ethiopia as there is uncertainty on what percentage of people living with HIV/AIDS (PLWAs) will be covered despite the guidelines and manuals being prepared for medical personnel and patients.

Another disturbing reality is the lack of support for HIV orphans. Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, was recently quoted as saying (after his trip in Ethiopia), "Frankly, unless the country devises an almost instantaneous strategic plan for orphans, backed by massive resources and focused intervention, Ethiopia will soon be reeling from the onslaught of

abandoned, rootless, bewildered and despairing kids of all ages. It will feel like a raging torrent of child trauma to which everyone responded too late. Tens of thousands of young lives will be lost and ruined."

Stephen Lewis could not have said it better and although it seems like the future is bleak, it is worth noting that efforts to scale up treatment do exist, though many times thwarted.

The Ethiopian government is working with civil society organisations to scale up ARV treatment primarily by boosting health system capacity. There are efforts for instance, to hire additional health workers, acquire various medical and laboratory equipments and form efficient referral systems in all health care centers. There might be some hope in the near future. But in the interim, while the government sets its house in order, collaborative buyers clubs or other association-based treatment models that are mushrooming in many countries on the continent might provide some relief.

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## Challenges facing civil society in HIV/AIDS intervention in Zimbabwe

by Tapiwanashe Kujinga

Zimbabwe sits at the epicentre of the HIV/AIDS epidemic in Southern Africa, with a seroprevalence rate of 33.7% of the adult population, and an estimated 2,3 million people are living with the virus. A total of 135 000 adults are thought to have died between January and August 2003 due to HIV/AIDS-related complications, and 36 000 cases of paediatric AIDS infections were recorded in the same period. According to the United Nation's 2004 Human Development Report, life expectancy in the country has plummeted from 55.3 years in 1990 to 33.9 years in 2004. This life expectancy figure is the second worst in Africa after Zambia at 32.7 years. In its publication entitled "Africa's Orphaned Generations", UNICEF states that there were 782 000 children orphaned by HIV/AIDS in Zimbabwe in 2001, and estimates that the number will rise to 1,3 million by 2010.

To say that the situation in the country is grim would be an understatement. The epidemic has struck at all sectors of the society and has wreaked untold havoc on a country already struggling with a myriad of challenges. Ever since the first case of HIV was diagnosed in 1984, HIV/AIDS has affected every individual, every home, and every family. However, civil society quickly realised the devastating potential of the pandemic, and moved in early to mitigate its impact. This network of non-Governmental organisations, community-based organisations and faith-based organisations have toiled, at times with the barest minimum of resources, to combat the scourge right down to grassroots levels, and have been credited with raising awareness on HIV & AIDS at a time when stigma meant that the disease was only mentioned in whispers.

One of the first AIDS service organisations to be formed in Zimbabwe, Family AIDS Caring Trust (FACT), has grown to be the largest anti-AIDS NGO in the country. It has succeeded in implementing programs that cover basically the whole spectrum of HIV/AIDS interventions, including prevention, ongoing psychosocial support for people living with HIV/AIDS (PWAs), home-based care, voluntary counselling and testing, clinical services for PWAs, capacity-building other AIDS service organisations, assisting orphans and other vulnerable children, and is planning to launch a program on access to antiretroviral therapy. Through its varied activities, FACT has played an important mitigatory role for people and communities infected and affected by HIV/AIDS, as well as being a vanguard for other AIDS service organisations. Another organisation that has been crucial in the fight against HIV/AIDS in Zimbabwe is The Centre. Founded by Lynde Francis who has lived with HIV for nearly 20 years, the organisation provides ongoing counselling, nutritional support, home-based care, clinical services for opportunistic infections, vitamin supplements and ARVs for PWAs. The Centre employs HIV+ counsellors, and this has contributed to its nationwide recognition as the country's finest organisation for PWA counselling and support. Other organisations that have done a lot of commendable work include Midlands AIDS Service Organisation (MASO), Matebeleland AIDS Council (MAC) and the Zimbabwe National Network For PWAs (ZNNP+). Unfortunately, the latter organisation has since scaled back its operations drastically and no

longer reaches as many people as it used to during its heydays in the 1990s.

The response of the Government, on the other hand, has been tardy and ineffectual. During the 1980s when HIV was first discovered in Zimbabwe, the Government failed to move quickly to contain the pandemic. When the response came, it was a case of too little too late. In 1999, a National AIDS Trust Fund was created through the levy of tax on all taxpayers, but the fund has been mired in endless allegations of abuse and bias in its disbursement to communities. Early this year, the Government started an ARV rollout scheme that would have seen 171 000 people on antiretroviral therapy by the end of 2005. However, the number of people currently on Government-funded therapy is so negligible that the goal is no longer attainable. Further, the Government's proposal to the fourth round of the Global Fund was recently turned down, thus effectively putting paid to the plans for the scaling up of the proposed massive ARV rollout.

Whilst the battle against the HIV/AIDS pandemic was raging, another more sinister war was being waged on the political front. It was inevitable that civil society would be sucked into the vortex of this political storm. In early 2000, a referendum was held on a proposed new Constitution that was perceived by groups on the other side of the political divide as entrenching State power, and a vigorous campaign was launched against it. The resultant defeat of the Government, its first defeat in any plebiscite of any sort since Independence in 1980, created a backlash with the ruling ZANU (PF) party embarking on a putsch to

crush its political opponents, including the nascent MDC party.

The immediate reaction of the State was to sanction the invasion of white-owned farms as a counter-measure against the whites who were accused of bankrolling the opposition MDC party as well as being the architects of the Government's defeat in the referendum. This was followed by a raft of draconian legislation that shut out the airwaves to private players, leaving the Government with a total monopoly in the electronic media. All forms of political protest were outlawed and three private newspapers were shut down, rendering of hundreds of journalists and media workers redundant. Against this background of State-sponsored anarchy and violence, a number of donors withdrew from the country, thus dealing a major blow to the HIV/AIDS sector of civil society.

The intended effect of this legal juggernaut was undoubtedly the gradual attrition of the opposition MDC and its backers. Despite efforts to handicap the party financially by outlawing foreign funding of political parties, the MDC somehow managed to survive. Speculation within ruling party circles gradually turned to the secret conduits of funding that the opposition was using, and the NGOs were finally in the cross hairs of the Government's rifle. True, the relationship that existed between the Government and some of the politically inclined NGOs like Amani Trust, Crisis in Zimbabwe and the National Constitutional Assembly was frosty. Some of these NGOs persistently unearthed and published human rights abuses by the Government, pictures and all, and the Government in turn accused them of being mere mouthpieces of its foreign-based enemies.

On the 20<sup>th</sup> July 2004 whilst opening a Parliamentary session,

President Mugabe remarked: "NGOs must work for the betterment of our country and not against it. We cannot allow them to be conduits or instruments of foreign interference in our national affairs. My Government will, during the course of this session, introduce a Bill repealing the Private Voluntary Organisations Act and replacing it with a new law that will create a Non-Governmental Organisation Council, whose thrust is to ensure the rationalisation of the macro-management of all NGOs."

Paul Mangwana, the Minister of Public Service, Labour and Social Welfare also stated: "Some NGOs and churches are causing too much confusion in the country because they are converting their humanitarian programmes into politics." The Non-Governmental Organisation Bill, gazetted in August 2004, is one piece of legislation that is not so subtle in its intentions, nor is it circumspect about its effect. All NGOs have to be registered with the NGO Council dominated by Government appointees. No unregistered NGO will be allowed to operate, and any breach of this provision will result in the arrest, prosecution and imprisonment of Board members and management employees of such NGOs in their individual capacities. The NGO Council has sweeping and overwhelming powers, including the right to seize monies or assets that it deems to have been unlawfully collected by any NGO, to cancel the registration of any NGO, suspend the executive of any NGO and to request the Minister of Public Service, Labour and Social Welfare to appoint their replacements.

In short, the NGO Bill is a legal instrument crafted in hell. In its attempt to close yet one more perceived conduit of opposition political funding and clamping down on those NGOs which have become nothing but stinging

gadflies, the Government has sought to criminalise charity work and to compromise the positions of those individuals and organisations at the cutting edge of HIV/AIDS intervention.

The potential effect of this Bill on HIV/AIDS-related activities is unprecedented. It is estimated that more than half of all NGOs in HIV/AIDS work are unregistered. Most of these submitted registration papers under the current legislation and commenced activities while the process of registration went on. Delays of more than 10 years in the registration process are routine, but officialdom winked at activities by unregistered organisations. With the proposed law, such organisations have to close shop until they are properly registered. It would also be easy for the Government to close some organisations that are perceived as not being politically friendly. Further, donors have already started to exhibit signs of nervousness at the prospects of having their funding confiscated. Staff flight from NGOs is a possibility given the fact that Government has not hesitated to do battle with any person, organisation or institution that poses a threat to its survival, whether that threat is real or imagined.

As the Swahili proverb goes, when two elephants fight, it's the grass that suffers. The communities that have been benefiting from the immense anti-AIDS work being carried out by the NGOs will bear the brunt of the NGO Bill. With the withdrawal of NGOs from the frontline against HIV/AIDS, suffering and death will follow. The gains and successes recorded over the years against the pandemic will be irretrievably lost.

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## Facing a Dying Nation by Gregg Gonsalves

My first vivid memory as an adult was in my last year of high school. My classmates and I were rehearsing a school production of the hippie, counter-cultural, musical HAIR, when someone ran into the auditorium to announce that President Ronald Reagan, only then just beginning his first term, had been shot. In retrospect, the 1960s and all it represented truly ended in America on that spring day. It was 1981. No one knew it then, but Ronald Reagan would not only survive but lead a transformation of the political culture of the United States: the conservative ascendancy presided over by Reagan would suffocate the liberal impulse that had inspired American politics from Franklin Delano Roosevelt's New Deal to Lyndon Johnson's Great Society and saw its last gasp under Jimmy Carter. No longer were we our brother's keeper. It was every man for himself.

The final years of the 20th century in the US were deceptive. George Bush the elder seemed to move the country back towards the center, albeit on the right of the ideological

divide. In 1992, I was attending a scientific meeting in Washington, DC with over a dozen AIDS activists on the night Clinton was elected. We were thrilled and excited as we watched the President-elect come out to celebrate his victory in front of the governor's mansion in Little Rock. We thought we were seeing the true end of the Reagan era, a time epitomized by the selfishness and callousness of a leader who couldn't bring himself to discuss AIDS until thousands of Americans had already died of the disease.

Yet despite the promise of Clinton's first few years in office-the attempt to ensure that the tens of millions of Americans without insurance had access to healthcare, the boost in the AIDS research budget of the National Institutes of Health, -his accomplishments were ultimately marred by his pandering to the right, by welfare reform that catapulted millions of needy people off the rolls of public assistance, his failure to support federal funding of needle exchange and yes, his anemic requests for AIDS funding for most of his term.

By the end of the 1990s, many liberals in the United States were disillusioned with Clinton's rightward drift, allowing someone like the third party progressive populist Ralph Nader to claim that Clinton's heir Al Gore was no different in philosophy than a two-time governor of Texas, George W. Bush. How wrong Mr. Nader turned out to be.

George W. Bush has presided over a transformation of American politics that is unprecedented in the history of our country. His agenda is so entirely radical it sets new parameters for American political discourse-if Ronald Reagan was the archetypal conservative, what in God's name is George W. Bush?

I have been an AIDS activist since 1990. In the United States, activists in the 1980s and 1990s wrested a response to the epidemic from an unwilling public and government that were all too willing to watch gay men, drug users, and the urban poor die horrendous deaths. We spent over a decade fashioning legislation that would protect our rights, give us the care we deserved, and pave the way for research advances that would fundamentally shift the nature of the epidemic.

While we had setbacks and didn't achieve everything we had hoped for, the AIDS activist movement saved many men, women and children from dying on the streets, from losing their jobs or their homes because they were HIV+; it prevented thousands of HIV infections through the distribution of clean syringes and condoms, and when the drugs arrived that were finally able to successfully treat HIV infection, ensured that most Americans could have access to drugs they could not otherwise afford. It's a proud and valiant legacy.

When I think of my friends who have died of AIDS and who fought for all of these things-I wish my government would only one day realize what service to one's country is really about-the United States is made up of individuals of teeming diversity and talents, but we are also a community that takes care of each other, we are a nation that doesn't walk away from someone in need.

I have watched in horror over the past four years as George Bush has begun to destroy what many of us have fought for for two decades and export the worst of a new AIDS policy based on religious dogma

and corporate greed. The President and his fellow crusaders have questioned the effectiveness of condoms, threatened and intimidated groups that talk about safe sex and drug use, pushed funding for programs that take a single abstinence-only approach to HIV prevention, twisted science to support their claims and denigrated researchers who disagree with them.

The American republic was founded on a separation of church and state that the Bush Administration would like to reverse. It's no coincidence that the Vatican, the conservative Islamic states and the US all blocked a motion to endorse the rights of gay, lesbian, bisexual and transgendered people at the United Nations General Assembly Special Session on HIV/AIDS in 2001. While I loathe the theocracies in Rome or Tehran, the emerging god-state in Washington, DC, is only different from them in degree.

While conservative religious social mores have driven HIV prevention policy and approaches to the human rights of people with HIV/AIDS and those at risk, a rapacious, robber-baron economics has

guided much else in the President's AIDS policy. Thousands of Americans with HIV/AIDS depend on Medicaid and Medicare, the public healthcare programs for the poor, disabled or elderly put into place in the 1960s. A special program, the Ryan White Care Act and its AIDS Drugs Assistance Programs, underwrites most of the other state-funded care and support for people with HIV/AIDS.

The President belongs to a faction of the Republican Party that believes in supply side, or as his father called them, voodoo economics, in which tax cuts for the rich will spur investment and growth with the initial benefits eventually trickling down to the masses below. George Bush is also in thrall to those in his party that would like to shrink the size of the federal government until, as one prominent conservative has said, "it is small enough to drown in the bathtub."

For the President and his cronies, the federal government has little purpose but to ensure the defense of the country-everything else it has taken on in 228 years is an abomination and encroachment on individualism and self-reliance. Thus, the tax cuts pushed for by the

President have a double purpose—to stoke the fires of the American economy by shoveling back money to the nation’s richest, and to “starve the beast” as New York Times columnist, Paul Krugman, has called it: drain the federal coffers of enough revenue and the abominable social programs put in place since the Great Depression will collapse for lack of funding. All well and good if you’re rich, you can afford private health insurance and live in a gated-community in Cobb County, Georgia, but if you’re a poor, black woman with AIDS a few hours away in a small town, this is tantamount to a death sentence.

I have been told on several occasions by Anthony Fauci, the US’ top AIDS scientist and his protégé Mark Dybul, who is the chief medical officer for The President’s Emergency Plan for AIDS Relief (PEPFAR), that I should be grateful for the President’s generous AIDS treatment and prevention plan for Africa, the Caribbean and now one or two countries in Asia. I have known these two men for a very long time, but they have both become apologists for an Administration that no longer drives AIDS policy

by the standards of scientific evidence and public health principles.

What is so wrong with PEPFAR? Is it the promotion of abstinence-only-until-marriage prevention-programs, or restrictions on critical work with commercial sex workers and drug users, is it the promotion of brand-name American-made antiretroviral drugs rather than equivalent generics that cost half the price or less?

Yes, it is all of these facts that undermine what I believe was an initial humanitarian impulse from somewhere in the Administration, but quickly became a vehicle for promoting religious ideology and protectionist policies on essential medicines. What makes the situation even more horrible is that the Bush Administration is undermining the World Health Organization and Global Fund to Fight AIDS, Tuberculosis and Malaria’s own efforts by undercutting or under funding their work. While the WHO and GFATM are far from perfect, a constructive approach rather than the current antagonism from Washington would go a long way towards improving things.

So many countries in Africa, Asia, Latin America, the Caribbean, and the former Soviet Union are dying of AIDS, with millions surely going to their early and needless deaths unless their governments and my government change course in the fight against this disease. I fear under George W. Bush, for these next four years, people with HIV/AIDS, the poor and the powerless in the US will also be at grave, mortal risk, but the US faces another sort of death, the demise of a spirit of generosity and openness that defines my country at its best. But as Nelson Mandela has said, there is no easy walk to freedom anywhere—we will get through this period of darkness and national shame and rise up to seek justice another day.

This article was originally published in the Mail and Guardian, South Africa.

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# TB and HIV: A marriage that must work

by Olayide Akanni

HIV/AIDS is a 'sexy' issue, which is presently attracting donor support in many developing countries, Tuberculosis (TB) is not. HIV affects the rich and poor; TB is predominantly a poor man's disease.

In the last 15 years, different HIV diagnostic kits have been developed, no new TB diagnostic kits have been developed in the last 50 years. HIV is the main reason for failure to meet TB control targets in countries with high HIV prevalence, TB remains a major cause of death among people living with HIV.

Yet, no two diseases could be more inextricably linked. Given, that both find their home in one patient, how can the marriage between TB and HIV interventions work? How can TB programmes be made a more appealing bride?

These were issues tabled for discussion at the recently concluded 4<sup>th</sup> TB/HIV Working Group meeting of the STOP TB partnership, which was held in Addis Ababa, Ethiopia from September 20-21, 2004.

Over 150 researchers, national TB and HIV programme managers, People living with HIV, representatives of multi-lateral agencies and research institutions who gathered to deliberate on strategies to be employed in tackling the dual epidemic.

In his opening remarks, Assistant Director General of the World Health Organisation (WHO), Dr. Jack Chow cautioned: "the TB and HIV epidemics witnessed in many

countries is converging to create a combustible mix".

He however noted that accelerating access to TB treatment when combined with HIV testing and antiretroviral therapy is a cost effective way could save as many as 500,000 Africans living with HIV every year. It is one of the most cost effective ways to ensure the survival of HIV positive people, Chow said. WHO estimates that 8 million out of the 25 million Africans living with HIV also harbour the bacillus that causes TB. But the opening words of Lucy Cheshire, a PLWH since 1994 and former TB patient from Kenya brought the reality of the grim statistics home.

"In the ten years since the years I've lived with HIV, the worst agony, suffering, hopelessness and social ostracism has been when I was diagnosed with TB in 2000. I started experiencing persistent cough, weight loss, night sweats and loss of appetite. Being diagnosed with TB in three different parts of my body was like a death sentence to me. Thanks to the TB diagnosis and the conduct of my CD4 count, I am now on anti-retroviral therapy".

Cheshire charged delegates to come up with recommendations that would further strengthen collaborative interventions to address the epidemics. "TB is our killer. TB agonizes us", she said.

Presenting a global scorecard of the 'TB/HIV marriage', Chair of the Global TB/HIV Working Group Dr. Gijs Elzinga, observed that

although some measure of progress in tackling both diseases, sub-Saharan Africa still faces major challenges. "Health systems in many African countries are weak and lack the human and financial resources required to deliver the interventions required to tackle both epidemics. The quality, quantity and distribution of the health workforce must be prioritized", he said.

Country experiences of Joint TB/HIV interventions in Malawi, Kenya, South Africa, Thailand presented during the meeting revealed that a lasting TB/HIV marriage is one that; delivers treatment and Care for PLWH and TB patients using a patient centred approach, actively engage communities, places high premium on treatment counselling and adherence and ensures active collaboration between HIV and TB interventions.

At the end of the two-day meeting, participants renewed their commitment to making the marriage work.

As one participant put it, "Its time to move from the boardroom to the bedroom. That's where the action is".

Participants also recommended the utilization of a three pronged approach which focuses on advocacy, collaboration and technical support in accelerating progress as well as in addressing the challenges posed by joint TB/HIV programming.

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# Strengthening health systems to expand treatment access

by Rene Loewenson

Making treatment universally available in southern Africa is an imperative for equity and social justice globally. To achieve this we need functioning and effective health systems that can reach poor communities. This has been called for by heads of state in the Southern African Development Community (SADC) region, the Pan African Treatment Access Movement (PATAM) who resolved in 2004 that 'rollout of anti-retroviral therapy be entwined with rebuilding our health systems' and many others.

Functioning health systems are essential to effectively reach and interact with communities, provide health promoting inputs for treatment, ensure positive prevention of those on treatment, provide entry points for voluntary counselling and testing for HIV, provide laboratory services to monitor patients, ensure the reliable supply and distribution of drugs and other inputs and provide decent and safe working conditions for health workers.

In more recent years health systems in Africa have become weaker for a number of reasons. Some of these include structural

adjustment programmes, economic trade and investment policies that introduce market ideas in health: charging for services used by poor people, privatising essential services and bringing in efficiency reforms that do not take into account the social realities on the continent. For instance as a result of this approach, many countries on the continent now spend much more on servicing and paying back debt than they do on health. In a 2004 report, The joint United Nations Programme on HIV/AIDS (UNAIDS) indicated that in 2002 Kenya spent \$0.75 on AIDS per capita and \$12.82 on debt repayments.

Health services are also generally underfunded. In 2001, African Heads of States adopted the Abuja Declaration on HIV/AIDS, Tuberculosis, and other Related Infection Diseases that amongst many other things, committed spending at least 15% of annual budgets on health care. Despite this initial surveys show that very few if any countries have attained that target. The trends instead indicate that a greater share of health expenditure is coming from households.

We will not address these problems through ART programmes, but

unless we strengthen our underfunded health systems, neither will we have the vehicle to deliver on our treatment goals. Further, unless we address these weaknesses in our health systems and *reach* poor communities and particularly women, we will continue to shift the burden of care onto these groups.

Existing programmes in southern Africa suggest what we mean by an approach to treatment that strengthens health systems. This includes

- Strengthening joint planning between ART programmes and policies and plans for the comprehensive development of health systems.
- Setting and monitoring targets for ART coverage *in conjunction with* targets for the delivery of other key essential health care services.
- Ensuring that treatment programmes are strongly linked to, draw people from and refer people to programmes for prevention, care and mitigation of AIDS and other primary health care interventions.

- Paying attention to the health workers needed and the needs of health workers, particularly to the production and recruitment of personnel for understaffed key service, and working conditions that motivate the retention of staff
- Ensuring that resources for ART are applied in ways that strengthen the wider health system, such as in strengthening integrated laboratory and pharmaceutical systems, and drug information and management services for management of ART and of other major health problems.
- Providing additional community and health service outreach measures to ensure that poor and marginalized groups (including children, youth and women) access and use these treatment services and that services take account of barriers to use in these groups.

How do we avoid inadvertently harming health systems?

We need to avoid inadvertent harm to health systems. ART coverage targets can accentuate existing inequities through preferential targeting of easier-to-reach, higher-income groups, typically living in urban areas. New treatment programmes in urban areas may recruit staff away from already under-resourced rural areas. 'Vertical' treatment programmes (i.e. the establishment of separate and parallel delivery systems for ART) may be set up to roll-out treatment quickly, but can further fragment the health care system,

weaken the effective coordination of different actors, drain skilled personnel from the public sector to the (often) better-paid independent sector, weakening other vital health care services.

### **Strengthening health systems for sustained treatment access**

This calls for treatment activism *and* health system activism, to ensure funding and approaches that strengthen our public health services and systems; and to watchdog areas of inadvertent harm, such as those raised above. Joint activism also needs to jointly confront the wider political economy that is undermining HIV prevention, treatment access and health systems: We should jointly challenge the trade policies and free trade agreements that undermine key goals, like GATS provisions that limit solidarity financing of public health systems, trade barriers and subsidies that undermine local food production, free trade agreements that seek to limit access to drugs or fiscal thresholds that stop the increased spending needed to recruit and pay health personnel. We should be jointly campaigning for the unfair debt burden to be cancelled and debt resources released for health and education.

Rene Loewenson is with Equinet – the Regional Network on Equity in Health in Southern Africa. A network of professionals, civil society members, policy makers, state officials and others within the region who have come together as an equity catalyst, to promote and realise shared values of equity and social justice in health. She can be reached on [rene@tarsc.org](mailto:rene@tarsc.org)

# Bilateral and Regional Trade Agreements: Impacts on access to essential medicines

by Tenu Avafia

## Why a shift to bilaterals?

There has been a strong shift in the trade negotiation priorities of both the US and European countries in the past few years with bilateral negotiations escalating after the spectacularly unsuccessful WTO Seattle Ministerial of 1999. With the launching of a new trade round in Doha two years later, it seemed that the multilateral process was back on track. The Doha Declaration on TRIPs and Public Health was an extremely important outcome for treatment activists and led to the WTO 30 August Decision which, despite its many flaws, allows countries with no or insufficient capacity to import generic drugs. Since the failed Cancun Ministerial meeting, developed countries have shifted their energies to bilateral negotiations rather than the WTO where consensus on trade topics is proving hard to achieve because of developing country concerns.

The proliferation of bilaterals is a worrying development for treatment activists. The Free Trade Agreement (FTA) negotiations between SACU and the US for instance contain a very ambitious list of trade topics ranging from goods, services, agriculture, rules of origin,

intellectual property, investment, government procurement, trade remedies, labour standards, environmental standards and dispute settlement. Some of these seemingly irrelevant issues could have a big impact on facilitating access to essential medicines.

## Possible impact of bilaterals on medicines and health care

### Intellectual property

In other FTA negotiations, the US has been able to obtain bilateral concessions during negotiations that extend well beyond WTO rules. Specific official objectives of the US include in the SACU-US FTA negotiations include the establishing of American IP protection standards in the SACU countries. Some of the more damaging TRIPs plus provisions that may find their way into the text of a US-SACU FTA include:

- a) A limitation on the circumstances under which compulsory licences on pharmaceutical patents may be issued by individual SACU governments;
- b) Extending the minimum period of patent protection to beyond the 20 year requirement of

TRIPs thereby delaying the introduction of generic pharmaceuticals;

- c) Obliging drug regulatory authorities (most of who have a limited expertise of patents) to consider the patent status of drugs before granting marketing authorisation to manufacturers of generics;
- d) The limiting of data on pharmaceutical tests to drug regulating authorities, which generic companies traditionally rely on to prove the efficacy and safety of their products; and
- e) The potential restriction of parallel imports to limited geographical configurations which may prevent SACU countries from sourcing generics from the cheapest global supplier.

### Trade in services

Although health care is not specifically listed, there is a high likelihood of further trade liberalisation in the field of services. It is vital that SACU governments act prudently on services provisions to ensure that FTA provisions are not to the detriment of their wider socio-economic objectives and obligations. South Africa for

instance has a clear right to health enshrined in its Constitution, which has been enforced by a Constitutional Court case confirming the government's obligation to use its limited resources to provide the best healthcare to its citizens possible.<sup>1</sup>

### Investment provisions

Investment provisions in other FTAs recently concluded by the US have entrenched a dispute settlement mechanism in FTA provisions which allow US investors in foreign jurisdictions to sue governments directly. It is conceivable that this provision would apply between multi-national pharmaceutical companies and SACU governments too.

### Reactions by civil society and the way forward

SACU for instance is also currently involved in FTA negotiations with the European Free Trade Area (EFTA) countries<sup>2</sup> while SADC and ECOWAS countries are involved in Economic Partnership Agreement negotiations with the EU.<sup>3</sup> There has been some lobbying by African, European and international NGOs in SACU's FTA negotiations with the US and EFTA. The lobbying is aimed at ensuring that FTA provisions do not endanger the ability of SACU countries to obtain the most affordable essential medicines.<sup>4</sup>

The most recent of these includes a letter written to EFTA ministers by concerned NGOs over the possible inclusion of TRIPS plus provisions in the SACU-EFTA FTA. The letter was a reaction to provisions found in other FTAs involving EFTA as well as statements from Swiss officials indicating that they would be seeking TRIPS plus concessions from SACU countries. Other civil society initiatives in 2004 include a memorandum written by the Aids Law Project and the Treatment Action Campaign and fed into the NEDLAC process on the danger of the US-SACU FTA to essential medicines<sup>5</sup> as well as a submission by a Swiss based NGO, 3Dthree Associates to the Committee on the Right of the Child on the negative impact that the US-SACU FTA may have on Botswana's international treaty obligations, such as the Convention on the Rights of the Child.<sup>6</sup>

Because most bilateral negotiations take place under a wall of secrecy and the draft provisions in both the EFTA and US FTA negotiations with SACU are extremely difficult to obtain, it is difficult for activists to take concrete action until a text is released. Countries involved in negotiations need to continue being reminded that bilateral provisions that hamper the ability to obtain the cheapest drugs are unacceptable. It is extremely important that links between

activists in the developed and developing world continue to be nurtured in the event that provisions that impede access to the cheapest drugs find their way into FTA provisions, and a campaign to have them nullified is required.

Tenu Avafia works with the Trade Law Centre of Southern Africa. He can be reached on [tenua@tralac.org](mailto:tenua@tralac.org)

### Endnotes

- <sup>1</sup> Minister of Health v Treatment Action Campaign (No 2) 2002 (5) SA 721 (CC).
- <sup>2</sup> EFTA comprises of Switzerland, Norway, Iceland and Liechtenstein.
- <sup>3</sup> For more information on the EPA negotiations, refer to the EPA Watch website at: [http://www.epawatch.net/documents/doc160\\_1.doc](http://www.epawatch.net/documents/doc160_1.doc)
- <sup>4</sup> An online copy of the letter can be found at: <http://www.naturvern.no/art/.2004.11.10.1.glob.genm.poli>
- <sup>5</sup> An online copy is available at: <http://lists.essential.org/pipermail/ip-health/2004-February/005904.html>
- <sup>6</sup> This document can be found at: [http://www.3dthree.org/pdf\\_word/m579-3DCRC Botswana\\_Sept04\\_en.doc](http://www.3dthree.org/pdf_word/m579-3DCRC Botswana_Sept04_en.doc)

## News in brief News in brief News in brief News in brief

### **Tremendous Work of AIDS Activists Contributes to More Funding from the Global Fund for TB, AIDS and Malaria (GFTAM)**

The 18<sup>th</sup> and 19<sup>th</sup> of November 2004 were important dates for thousands of AIDS activists. The fate of the Global Fund's fifth round of funding was to be determined at the Fund's Ninth Board Meeting to be held in Arusha, Tanzania. There had been developments before the Board meeting to suggest that a Fifth Round of funding would not occur so civil society organisations were at a heightened alert. Other issues such as the performance and composition of Country Coordinating Mechanisms (CCM) – the main conduits for funding applications at country level – were also to be discussed but many felt that launching of Round 5 was the most critical issue since the result would progressively make or brake the Global Fund for TB, AIDS and Malaria (GFTAM).

After two days of intense deliberations and a meeting with presidents of Kenya, Tanzania and Uganda and the United Kingdom Secretary of State for Development, the Global Fund announced it would indeed be granting a fifth round of funding. Although unanimously agreed upon by the Board, this decision was not derived with ease.

At the onset of the meeting and to the horror of AIDS activists, wealthy countries such as the U.S. encouraged the Fund to indefinitely delay grant making due to alleged funding deficits. Activists promptly organized and responded. Approximately 435 organizations called for wealthy nations to increase their contributions to the Global Fund and for the Fund to contribute to new health programs for impoverished communities worldwide. At the same time over 150 Kenyan activists from over 30 organizations mobilised themselves and travelled to Arusha to ensure a fifth round of funding. To their dismay, however, they were met with the barrier of uncompromising police who would not allow the peaceful demonstration to proceed. After traveling the long distance from Kenya, the three bus-loads of activists were forced to return home. In spite of the setback, their voices and input were loud and clear as they were able to deliver a press conference the previous day and issue comments expressing their outrage to the media, which were published in local and international media sources.

Other activists who did manage to attend the meeting spent their time arduously and tirelessly lobbying Board members to acknowledge the urgency of continued funding. The result was a compromise of funding that would be delayed two months which, according to Asia Russel from a US advocacy organisation, Health Gap (Global Access Project), "is a lousy compromise" but is "better than what the US wanted which was first, no Round at all, and then, approval in November." The result is an approval of funding in September 2005 instead of July 2005 which means a delay of actual monies received by those who need it sooner rather than later.

Ensuring the funding exists for round five will indeed be a struggle. "Now that we have won Round 5, even a delayed one," states Russel, "we must demand donors fund it. Two replenishment conferences, in March (when the call for proposals will circulate) and September 2005 (when approvals happen), in Stockholm and the UK respectively, are important fundraising vehicles for Round 5." According to the Global Fund's website:

- The draft of the Guidelines for Proposals will be released on January 30, 2005.
- The Fifth Call for Proposals and finalized Guidelines for Proposals will be issued immediately following the Replenishment Conference in March 2005.

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- A forecast of the resources available for the Round will be announced at the time that the Call for Proposals is issued.
- Round 5 proposals will be approved at the Eleventh Board Meeting in September 2005, following the second Replenishment Conference.

Serious challenges impede upon the Fund's replenishment process as the Bush administration recently announced a reduction of its funding of the Fund from US \$546 million in 2004 to US \$200 million in 2005. Other countries such as Japan and France appear to be following suit. Although an initial step was won in support of the battle against HIV, a long and arduous struggle is indeed ahead for AIDS activists. Health activists and others should consider embarking on a long-term campaign to ensure sustainable and predictable funding for the three diseases. This is the only way to guard against donor whimsicality.

Further information can be found in the Global Fund Observer: <http://www.aidspace.org/gfo/archives/newsletter/GFO-Issue-36.htm> and on the Global Fund's website: [www.theglobalfund.org/en/about/board/ninth](http://www.theglobalfund.org/en/about/board/ninth)

### Update on the Collaborative Fund

Following the International Treatment Preparedness Summit (ITPS) that took place in Cape Town in March 2003, Tides Foundation, in partnership with ITPS participants established a new collaborative funding project, focused on building community-centred education and advocacy for comprehensive HIV/AIDS-related care and treatment.

The "Collaborative Fund for HIV treatment preparedness", is a unique funding mechanism, which makes grants to support HIV treatment preparedness, advocacy and community empowerment projects in community-based organizations throughout Africa, Asia, Latin America and the Caribbean and Eastern Europe/Central Asia. Funding priorities, reviewing of project proposals, and decisions about disbursements from the Collaborative Fund are made by autonomous Community Review Panels comprising people living with HIV/AIDS and community-based treatment advocates and educators in each funding region or sub-region.

The fund has to date raised over US\$ 3 million – including a recent contribution of US\$ 1 million from the Preparing for Treatment Program, based in the Department of HIV/AIDS at the World Health Organisation (WHO) headquarters in Geneva. It is anticipated that the WHO's contribution to the Fund will directly support at least 40 small grants to be made in all regions between November 2004 and December 2005.

The Collaborative Fund has also received funding from the Rockefeller Foundation of \$750,000 for work in Africa and South-East Asia. The Dutch AIDS Fond has also supported the Fund with 50,0000 Euros for the Newly Independent States (NIS).

The Pan-African Treatment Access Movement serves as the coordinating group for Collaborative Fund activities in Africa. As such, PATAM will help to identify leading health advocates and educators from each region of Africa to participate on Steering Committees and Community Review Panels, according to developed selection criteria ensuring the representation of all key organizations, networks and activist groups in the continent as well as ensuring diverse and equitable representation.

Additionally, PATAM will develop mechanisms for dissemination of information about the Collaborative Fund to the local communities, provision of technical assistance to grantees, dissemination of HIV treatment information regionally, communication to exchange advocacy and education strategies and develop opportunities for collaboration.

## News in brief News in brief News in brief News in brief

### PATAM Calendar of Events

#### January 2005

##### **Solidarity and Strategy Meeting for HIV/AIDS Civil Society Actors in East Africa**

This meeting aims to identify common platforms of collaboration and advocacy for PATAM members and others. It will also launch a grant-making process for this region.

Location: Arusha, Tanzania

Contact: James Kamau ([kamaunjenga@yahoo.com](mailto:kamaunjenga@yahoo.com)) or Grace Muro ([gmuro@pactz.org](mailto:gmuro@pactz.org))

#### February 2005

##### **Solidarity and Strategy Meeting for HIV/AIDS Civil Society Actors in West Africa**

This meeting aims to identify common platforms of collaboration and advocacy for PATAM members and others. It will also launch a grant-making process for this region.

Location: Cameroon

Contact: Laure Djueche ([laure\\_djueche@yahoo.fr](mailto:laure_djueche@yahoo.fr)) or Rolake Ngwagwu ([rolakenwagwu@yahoo.co.uk](mailto:rolakenwagwu@yahoo.co.uk))

#### April 2005

##### **Strategic Planning and Operations Meeting for the Pan African Treatment Access Movement**

An Africa-wide meeting of PATAM members to consolidate a long term strategy for HIV/AIDS intervention aimed at further increasing access to treatment for people living with HIV/AIDS. The meeting will also discuss and endorse new governance proposals aimed at improving the decision-making process, accountability, implementation of strategy and other general management issues.

Location: To be determined

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Printing: Salty Print

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