

## Crossing Borders: Global AIDS

It's finally happening. After years of pressure from people with HIV and AIDS activists around the world, treatment is becoming available to those living in poor countries. Though access is still limited – only 24% of the nearly seven million people who need HIV meds can get them, far less than accepted international goals – these numbers were unthinkable just a few years ago. We are grateful for private funding sources, including the Clinton and Gates foundations, for developing and supporting workable, community-based solutions to treatment delivery over the long term. Good things are also being done by local organizations, such as New York City-based Aid for AIDS, in recycling medications as discussed in an article by Roberto Perez.

As widely reported in the press, a major focus of the recent international AIDS conference in Toronto was delivering on the promise to provide treatment and eliminating key impediments to doing so, such as the absence of trained health care workers in many nations where treatment is needed most urgently. Brook Baker writes in this issue about the shortage of health care workers and what we in the U.S. can do to help.

And other obstacles remain. In this issue, people on the front lines of the battle to provide treatment to everyone who needs it describe the numerous challenges that continue to frustrate current efforts. No one escapes their eye: governments, individuals, drug companies, traditional healers, people with HIV themselves. But we recognize that all of these stakeholders must participate in the development of solutions for the nearly 40 million people living with HIV worldwide.

Located in New York City, where more than 800,000 residents came originally from other countries, ACRIA is also sharply aware of the problems immigrants with HIV face. With increasingly harsh immigration proposals before the Congress, these problems can only multiply. For this issue, we asked experts in the fields of immigration and asylum for people with HIV to write about the arduous application process, and whom they can turn to for help. Fiona McKinnon and Ellen Kemp discuss what happens when those living with HIV cross (or attempt to cross) the U.S. border and why that should matter to all of us.

*Daniel Tietz, Editor-in-Chief*

## Baby Steps: The Challenge of Global HIV Treatment

*by Jacqui Patterson*

When I first started doing HIV and AIDS work in Africa, the only option for most of the people I served was making death as comfortable as possible. My most common experience during the first couple of years was, for example, sitting by the bedside of a woman in Zambia named Patience - offering final prayers and then being told a week later that she had passed. Or visiting an organization in Zimbabwe one month and returning six months later to be told that the empty chairs I saw were those of colleagues I knew who had been taken by "Mukondombera," the euphemism for AIDS which in Shona means, "the thing that comes and wipes out entire villages."

Just under two years into my work, I found myself standing in a miner's hospital in Zambia

that was scaling up from treating 50 patients to treating 1,000 in the space of a year with U.S. funding through the President's Emergency Plan for AIDS Relief (PEPFAR). This facility was one of dozens that were slated for similar scale-up, thrilling all of us who had been engaged in advocacy for treatment access. But, I asked myself, is such rapid growth advisable, and at what cost will this be achieved, literally and figuratively?

The first months of rapid scale-up were fraught with problems at all levels. At the global level there was little attempt to coordinate efforts by the various entities, including the PEPFAR, the Clinton Foundation, The Global Fund to Fight AIDS, TB and Malaria, the WHO 3x5 Initiative, and others. One wonders what

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fall  
2006

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## Lauriad for Oral Thrush

People with oral candidiasis will take either Lauriad (miconazole) tablets once a day or clotrimazole troches 5x a day for 2 weeks. Participants must be 18 or older and be on stable HAART for at least 2 months.

## Transacin (NGX-4010) for Peripheral Neuropathy

People with HIV who have peripheral neuropathy will use either Transacin (capsaicin) patches or placebo patches for 30 or 60 minutes a day for 3 months. Participants must be 18 or older and have had pain in both feet for at least 2 months.

## Pregabalin for Peripheral Neuropathy

People with HIV who have peripheral neuropathy will take either pregabalin (Lyrica) or a placebo (dummy pill) for 3 months. Participants must be 18 or older and have had pain in their hands or feet for at least 3 months.

## KP-1461 for Resistant HIV

People with HIV that is resistant to at least 3 of the 4 classes of HIV drugs will stop all HIV drugs for 6 weeks and then take KP-1461 (an experimental NRTI) or a placebo pill twice a day for 2 weeks. Participants must be 18 to 60 years old, have a CD4 count above 100 and a viral load between 2,500 and 50,000.

## IMPACT: Reyataz Resistance

People who have developed resistance to Reyataz will come in for one day of blood tests to study the I50L mutation.

**For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at ext. 124.**

## HIV Treatment Decision-Making Study

African-American men who have not taken HIV drugs will complete a one-hour survey on a laptop computer and receive a \$25 gift certificate. Participants must be 18 or older. **Contact Perion Smith at 212-924-3934 x105.**

## DUET: TMC 114 & 125 for Drug-Resistant HIV (closed to enrollment)

People who are resistant to PIs and NNRTIs will take TMC125 (a new NNRTI) or a placebo (dummy) pill. Everyone will also take TMC114 (a new PI) with Norvir and other anti-HIV drugs. Participants must be 18 or older and have a viral load over 5,000.

## TH9507 for Lipodystrophy (closed to enrollment)

People who have excess abdominal fat and who are taking anti-HIV drugs will take either TH9507 (an experimental growth hormone releasing factor) or a placebo for 26 weeks.

## Maraviroc for Drug-Resistant HIV (closed to enrollment)

People who have taken anti-HIV drugs from three of the four classes of drugs will either take maraviroc (an experimental HIV attachment inhibitor) or placebo with an optimized regimen of anti-HIV drugs for 11 months.

### Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.

- *ACRIA Update* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

## Baby Steps *(continued from first page)*

opportunities to streamline efforts and optimize resources may have been lost by this lack of cooperation. Not to mention the confusion that reigned at beleaguered national governments and facilities bombarded by the intense engagement of these various entities, each with distinct policies and practices.

### Barriers to Care

Here are just a few of the barriers to implementation that still plague the movement:

To start, in spite of the efforts of the Clinton Foundation, access to affordable drugs is still being blocked by regulations established by the World Trade Organization and other trade agreements [see article on page 10]. For example, a letter was recently sent by Boehringer Ingelheim informing Drug Supply Organizations (DSOs) that they are in violation of licensing agreements if they purchase the HIV drug nevirapine from any supplier other than their approved partners. The DSOs complain that those suppliers are not accessible in some countries and that the only affordable sources of this life-saving drug are not on the approved list. They plan to continue procuring from the nonapproved sources, but fear retribution if they persist.

Often nations or facilities have planned a slow rate of scale-up due to a desire to carefully refine procedures, while donor entities are driven by political or other pressures to achieve exponential rates of scale-up.

Organizational culture shifts are a challenge. For example, one facility in West Africa struggled with shifting from the spirit of a virtually all-volunteer facility to dealing with external partners who provided much needed additional resources, but at the cost of the community culture that had made the facility a success for decades.

Some facilities suffered from a lack of absorptive capacity to handle the excessive level of new resources. And the shortage of doctors, nurses, and commu-

nity health workers was pervasive in all of the countries in which I served [see article on page 6].

AIDS is just one of many conditions that burden resource-strapped health systems. With the rush to respond, countries must deal with entities like Pfizer's Diflucan Partnership Program (DPP), which provides crucially needed fluconazole and a support system for tracking diagnoses, dosage, and utilization. However, the DPP is an exceedingly complex donation program. Other programs include the Access program for Determine HIV test kits, the nevirapine and zidovudine donation programs, and various entities supporting HIV meds, etc. Efforts to take advantage

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*“... many people can obtain free medicines but cannot afford the food necessary for maintaining a healthy immune system and for the practical intake of the medicine.”*

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of these disparate programs consume national governments and facilities with the intense energy needed to manage these various resources.

Lack of nutrition is a substantial concern. There are many cases where people with HIV can obtain medicines through free public programs but cannot afford the food necessary for maintaining a healthy immune system and for the practical intake of the medicine. In Malawi, home-based care providers from the Central Church of the African

Presbytery told of families who prioritized food above treatment. Clients told them, “Treatment without food is as good as water without a cup.”

In certain countries, organizations lamented the marginalization of certain groups who aren't commonly in urban areas and thus are not incorporated in roll-out of treatment programming. Examples included the San People of the Kalahari Desert in Botswana and the Maasai in Kenya and Tanzania. Because these groups tend to be nomadic they require specialized outreach and often are not reached by testing and treatment programs based in stationary clinics.

### Personal Challenges

At the community, family, and individual levels, a myriad of other challenges arise:

Issues of trust are paramount. In Swaziland, a member of parliament told me that when people become sick they first go to their tribe's chief, then its headmen, and then to the church - the hospital clinic is often not even considered. One headman came to an AIDS training session and stated, “AIDS is like the wind. You don't know where it comes from and you don't know where it's going, so you have to do what you can.”

A partner in Zambia estimated that 80% of people who are sick go to a traditional healer due to a longstanding trust in this approach and the fear that they have been bewitched and require this kind of attention. One man developed Kaposi's Sarcoma (an AIDS-related skin cancer) and went to a traditional healer who treated him with a variety of procedures including giving him a tattoo. Not only was there no progress, but the tattoo actually became infected. Finally, given his decline, community workers were able to convince him to go to the hospital where began HIV treatment. To prevent the trust in traditional practices from becoming a barrier to people with HIV receiving care and treatment provided in clinics, avenues should be sought to incorporate the alternative practices of traditional healers into national systems.

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## Baby Steps *(continued from previous page)*

People also trust traditional healers to maintain their privacy. Stigma and discrimination in the workplace, community, church, healthcare settings, and their own families continue to prevent individuals from visiting the clinic. And if a person is tested and starts HIV treatment, stigma may prevent disclosure to family and community members. Adherence is difficult in the best of circumstances, and certainly all the more challenging when one is hiding medicine or avoiding the local clinic.

One pastor in Zambia who was deathly ill traveled over 300 miles to Lusaka for care because he feared disclosure would damage his standing as a pillar of his community. He also decided to buy his meds there (his property ownership disqualified him from receiving them free, though his finances were fairly dire). So he had the combined expense of the drugs plus the exorbitant cost of travel. This may have affected his ability to maintain a steady supply, as his health was still fairly poor after some time on treatment. The irony was that people had already guessed his status from his appearance and had asked the local HIV doc to intervene. So all of the covert activity may have been for naught.

Due to PEPFAR's requirement that all drugs used must be approved by the FDA, partners in Kenya, Uganda, and Nigeria reported that some people went from taking two pills a day that combined drugs to taking six separate pills a day. Adherence is challenged by the unpleasantness of repeated pill-swallowing and the confusion of having so many pills to manage. This is further complicated by reports that family members were pill-sharing with other sick family members who were not on treatment, resulting in failed treatment and the need for extremely expensive salvage therapy. Requiring FDA approval of all PEPFAR drugs highlights a bit of double-speak on the part of PEPFAR administrators, who say, "Let Africa lead," but then imply that African governments don't have the technical acumen to judge which drugs are best for their citizens.

### Progress

But there are triumphs via public programs, private programs, and public-private partnerships. Treatment access is a fast-moving train and many are getting on board. A small church in Zimbabwe is working with a sister church in the U.S. whose parishioners each committed to supporting a person on treatment. The Government of Botswana, Merck, and the Gates Foundation joined forces to devel-

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op an initiative that provides support for HIV prevention, diagnosis, and treatment through community groups and facilities. As of last February, 61,000 people were receiving treatment through this program.

The Clinton Foundation worked with several governments and generic drug producers in India to facilitate the availability of low-cost generic HIV drugs as well as lab equipment and supplies. The Global Fund is releasing money to governments to support treatment. When Haiti was facing a human resource shortage, Cuba provided almost 400 doctors

and enabled Haiti to deliver care to thousands. PEPFAR supported the AIDS Relief Program, which provides treatment to thousands in nine countries in over 100 partner facilities, largely faith-based hospitals.

With the onset of treatment scale-up I saw time and time again the “Lazarus effect” in patients, colleagues, and friends. Now I know people who are truly *living* with the virus, not just surviving but actually *thriving*. At the International Conference on AIDS and STDs in Africa I met a man from the Kano State in Nigeria who went from being bedridden and unsure of whether he would still be alive the next month to being on HIV treatment and able to provide for his family through his job as an HIV testing counselor. I met with members of a women's HIV group in Kenya who spoke actively and positively about their future while advocating for the needs of their sisters. Now when I learn that someone has HIV and is not receiving care and treatment, there are options and I know where to make a referral.

At Selian Lutheran Hospital in Arusha, Tanzania, the program to prevent mother-to-child transmission has raised the rate of women being tested from zero to 85%. They attribute the increase to the advent of hope from treatment options for the parents and the availability of drugs to reduce the chance of transmission to the infant. One key strength of this program is that it is a community-based model featuring outreach to demystify the services offered at the hospital.

### Unanswered Questions

But what about the people we don't see? What about the people who aren't near urban centers and have far less access to treatment centers? What happens to the people whose treatment center is just over the hill - relatively close but far enough away as to not be there at all? What about the person who may even live right next door to a treatment center but hides in shame for fear of being ostracized? What about the man who only trusts the traditional healer network that has cared for

his family for as long as he remembers? What about the woman who knows something is wrong but does not want to be treated because she knows she will be blamed for bringing the disease into the family and may be beaten and cast out?

What about the lack of pediatric formulations? When I was in Tanzania one doctor told me that the only treatment option for a child was a dosage of a liter of liquid. When the mother was leaving the hospital with literally a wheelbarrow full of this medicine she was stopped at the gate by the guard, who thought she was stealing due to the sheer quantity. Another doctor told me she was compelled to crush up adult tablets and portion out the amount she prayed was an appropriate dosage for a child. But these extraordinary measures are the exception - for the most part, children just aren't being treated.

### Recommendations

Though there is much progress to be celebrated in treatment access, we have far to go to reach universal access. While appreciating how far we've come, we must not stop until the unreached are afforded the same access to healthcare that many of us enjoy. Treatment should be a basic right, and the battle will not be over until that is achieved. Colleagues in the field largely agree on what is needed to take us down this path:

- Coordination is necessary at global and national levels to optimize the various resources that are available to address treatment access.
- Human resources for health must be a priority.
- We need accelerated access to fixed-dose combinations, cheaper second-line therapies, pediatric formulations, and greater access to drugs that treat opportunistic infections. Not only must resources to purchase drugs be increased, but the patent system that restricts affordable production and distribution of affordable drugs must be adjusted to prioritize access.

- Destigmatization efforts must be intensified, and targeted at the workplace, churches, schools, communities, and families.
- Though access in rural areas is increasing, these areas are still grossly underserved. Efforts must be intensified to expand access there.
- Voluntary HIV testing must expand to accommodate the wide-ranging needs of youth, women, and special populations.
- Treatment programs must be integrated with comprehensive prevention interventions, and must address the link between TB and HIV.
- Analysis of access issues particular to women and girls, and implementation of identified strategies, must be priorities.

Dialogue about what's working and what's not must be strengthened. At a recent meeting of the Ecumenical Pharmaceutical Network, I heard that pseudo "gag orders" are being issued to certain facilities. They sense a threat of funding withdrawal if they speak out on flaws in the policies imposed by certain sources. Everyone must be heard, from administrators to patients, if we are to evaluate and improve systems for providing universal treatment. Meaningful engagement of people with HIV in policy, planning, and implementation is essential, with emphasis on "meaningful" as opposed to the tokenism that currently reigns.

A coordinated response from civil society is the key to applying pressure on established structures for the above changes. Attitude change is necessary, from educating the individuals who stigmatize people with HIV, to a metamorphosis at the community level, to a global increase in the political will demanded by this crisis.

### Local AIDS, Global AIDS

As an African-American, both my personal life and community have been ravaged by AIDS. My home, Washington, D.C., has an HIV prevalence rate of 6% for people aged

15 to 44, and HIV infection rates have skyrocketed among African-Americans. The dynamics of AIDS in Africa and the US, particularly in African-American communities, have many commonalities. As in Africa, stigma has driven this disease underground and caused many to die hiding in shame. As in Africa, African-American communities in the US are losing thousands to HIV and AIDS. Meanwhile, available resources, such as social programs and treatment, are not reaching people with HIV because they are not tested nor seeking access to what is available. As in Africa, HIV in the US is predominantly taking the lives of black people.

One of my closest friends, Adisa, lost his best friend to AIDS. He only learned that Malcolm had AIDS when he was in the hospital with diminished eyesight and dementia. The doctor, assuming that Adisa knew the cause, spoke casually about Malcolm's HIV. Malcolm hadn't disclosed to anyone, but had instead withdrawn from his social circles and deprived himself of support as well as medical treatment. Malcolm's health rallied soon after Adisa's visit, with the help of medication and increased support from Adisa. However, a few months later, my friend was standing by the gravesite offering comfort to Malcolm's mother, the only other person in the world besides me and the medical team who knew about Malcolm's status.

It still pains me deeply that I was not there for Adisa during these times because I was spending all of my time on the other side of the world in the albeit worthy endeavor of working with my brothers and sisters in Africa. Sometimes it seems that there are not enough arms in the world to go around the many who are in need of comfort. There are certainly not enough voices turning up the volume on the outrage that in this world of plenty and excess, relatively little is being done to prevent thousands of daily deaths, particularly in communities of color around the world.

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# Pills Without Providers: Where Are The Health Workers? *by Brook K. Baker*

It can be hard for people with HIV to get to their doctors. When you're poor, with no car, and not feeling well, you'll be looking for quarters and wondering if you have the energy for a long trip on a crowded bus. If you live in an area of a city underserved by public transit, if you live in the poor section of a suburban town with no bus service, or especially if you live in a rural community, you may find it hard to travel to your doctor's office, to testing centers, or to the pharmacy. And in some parts of the country, HIV docs are hard to find outside of major urban areas.

But even if you are poor, the U.S. has enough doctors, nurses, and technicians specializing in HIV care. If you live in rural KwaZulu Natal province in South Africa, though, or if you live a little further north in Limpopo, you're in trouble - real trouble - if you have HIV and need life-saving care. The paradox of recent successes in lowering the cost of medicines and increasing global AIDS spending tenfold is that we now confront a new crisis - low numbers and misdistribution of health workers and tattered health systems that provide almost no access to care for rural communities in Africa.

I traveled to South Africa this past summer and visited a rural school in the Valley of a Thousand Hills, 20 miles from Durban. As my wife and I descended a windy hillside in the late afternoon, we saw lines of schoolchildren beginning their five-mile walk home. Teachers told us that this school had many children whose parents had died of AIDS and who now lived in child-headed households. In fact, the valley was full of people living with AIDS - the adult HIV infection rate in the region is over 35%. And those PWAs were a long walk, a steep hill, and many bus rides away from the closest hospital and a doctor who could prescribe antiretrovirals.

When we went even further into the countryside, to a tented game park in rural Limpopo Province, we met a wildlife tracker who told us about a fellow tracker, Vincent, who had died of AIDS just a month earlier. This man worked from 5:30 a.m. to 9:30 p.m. every day for six weeks in a row before finally getting a week off. The game park had a nurse who administered first aid, but little else. The nearest health facility that could prescribe medicines was over 40 miles away. This is in a province in which 20% of new mothers are HIV-positive.

Health systems in poor and middle-income countries are unable to respond to the AIDS pandemic and other persistent health care needs like tuberculosis, malaria, and the increasing burden of chronic diseases like diabetes and heart disease. Developing coun-

tries have 84% of the world's people, 90% of global disease burden, but only 20% of global GDP and only 12% of global health expenditures. Africa is particularly under-resourced - it bears 24% of the global burden of disease, with 3% of the world's health workforce, paid with less than 1% of global health expenditures. High-income countries spend 30 times more on health care than low-income countries. North America has one health workers for every 25 people, whereas Africa has one for every 500.

## A History of Neglect

Even after developing countries tried to reverse a century of colonial neglect in health services for indigenous populations, the debt and oil crisis of the late 1970s and early 1980s gave the World Bank and the International Monetary Fund leverage to impose draconian policies that reversed two decades of increased investment in health system strengthening. The resulting disinvestment in health and education, reductions in the public workforce, stagnant wages, and eroding support systems left developing countries with fewer and fewer options for responding to escalating public health care needs.

As health budgets shrank, health service provision focused on the urban core and local elites - rural, township, and urban informal settlements were left to traditional healers and substandard medicines. As working conditions and pay deteriorated, low- and middle-income countries hemorrhaged skilled doctors, nurses, and pharmacists to rich countries, creating a perverse brain drain whereby developed countries' health care training costs are subsidized by some of the poorest countries in the world. Several countries, including Ghana, have more doctors working overseas than in their own health care systems. Zimbabwe has retained only

360 out of 1,200 physicians trained since 1990.

Even as health systems were crumbling, international financial institutions imposed cost-recovery measures that required governments to charge fees for services that poor people could not afford to pay. As a result, clinic visits for sexually transmitted diseases and child health decreased, out-of-pocket expenses for medicines soared, and the most basic health needs of poor people went unmet. By the time patients finally sought medical care they were often seriously ill, and tapped-out health facilities could offer little hope.

International donors and multilateral institutions responded to this burgeoning crisis with indifference. There were occasional initiatives focused on specific diseases - smallpox and polio

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eradication, childhood immunization, and tuberculosis. But even these initiatives were often shortchanged and highly dependent on international charities and volunteer or short-term contract labor at the local level. Paradoxically, these initiatives sometimes drain human resources from the public and local sectors, offering higher pay and better working conditions for more highly trained health care workers.

**Responding to the Crisis**

After two decades of decay, the global community was forced to confront the burgeoning and long-neglected AIDS crisis in Africa. This crisis was further buffeting the already depleted health care sector with increased demand for medical services – 75% of hospital admissions in some facilities are HIV-related. At the same time, AIDS was killing healthcare workers by the thousands. For example, nearly a quarter of Malawi’s health care workforce is expected to die from AIDS within the next five years. The few health workers left behind have become increasingly demoralized as they watch people die or simply send them home.

In response, African activists and their international allies demanded that existing medical capacity be used to roll out comprehensive prevention, treatment, and care. They demanded that new investments be made to increase capacity to treat first millions and then tens of millions living with HIV. These same activists recognized that responses to AIDS could not be implemented through a fatally flawed and disabled public health care sector. As a result, global attention turned belatedly to evaluating the human resource needs not only for AIDS but also for pediatric and maternal health, for infectious disease control, and for community-centered primary health care.

Once rigorous human resource assessments began, they were brutal. The Joint Learning Initiative (JLI) did one of the earliest and most comprehensive studies of human resource needs and found that developing countries required more than four million additional doctors, nurses, and skilled birth attendants for the minimal purposes of achieving medically safe births. Africa needed to more than double its existing professional level workforce – over a million new doctors, nurses, and birth attendants were required. The World Health Organization (WHO) confirmed the health workforce shortfall found by JLI and outlined the costs of health system strengthening:

Education & training costs (doctors, nurses, midwives):	\$7.7 billion/year for 10 years
Incremental operating costs for hiring new HCWs:	\$17.7 billion/year
Incremental costs for doubling salaries:	\$53 billion/year

Additional unknown costs include: building health education facilities and health infrastructure; hiring, training, and paying community health workers; strengthening procurement and supply systems, health management, and improving working conditions.

In making these calculations, WHO built on its earlier Commission on Macroeconomics and Health, which concluded that donors should provide \$22 billion more per year by 2007 and \$31 billion more per year by 2015. Needless to say, nothing close to close to this amount is being provided by rich countries. Likewise, developing countries were not committing the billions of dollars they needed to provide, mainly because of constrained tax revenues, crushing debt burdens, and warped internal policies. For example, the African Union promised in Abuja in 2001 to spend a minimum of 15% of national budgets on health care. So far, the scorecard is abysmal. Only Botswana spends 15%, and Zimbabwe comes in a surprising second at 14.5%. Tanzania and Uganda are spending 13% and 12% respectively. All other AU members are spending between 7% and 12%, with Kenya at the bottom, spending only 76 cents per capita on AIDS but \$12.92 per capita on debt payments.

Funding and lack of commitment are not the only problems. Doctors take more than six years to train, nurses more than three, and birth attendants two or more. Building human resources for health is not just a function of time - it is also a function of education and training capacity. Unfortunately, Africa and many other developing regions lack sufficient facilities and medical educators to double the workforce in the near future.

**Community Health Workers**

A partial solution to the immediate crisis is to implement a community health worker (CHW) program. Such a program would train both HIV-positive and negative community members to be proactive agents of public health initiatives and to be a link between struggling communities and a strengthened health care system. The bare outline of such a proposal is relatively straightforward. Training would include HIV-specific interventions such as HIV prevention, treatment literacy and preparedness, counseling and testing, treatment adherence, psychosocial support and peer group activities. It would also include basic elements of health such as clean water and sanitation, good nutrition, and child and maternal health.

CHWs can provide respite and support to primary caregivers in the home and help strengthen social and material support for orphans and vulnerable children. But they will not be able to perform their functions reliably unless they are supported by a system that is responsive to their needs and limitations. And CHWs must have direct access to systems of referral for medical, social service, and child-well-being services.

**International Efforts: Help or Hindrance?**

A major barrier to cost-intensive efforts to expand human resources for health and to strengthen health systems at the community level is the economic policies of the International Monetary Fund (IMF). These policies prevent poor countries from devoting additional resources to AIDS programming and health system strengthening. Paradoxically, these same policies may prevent countries from spending money from the U.S. PEPFAR initiative or the Global Fund to Fight AIDS, TB, and Malaria.

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## Pills Without Providers *(from previous page)*

For the IMF, ensuring economic stability means ensuring the ability to repay international creditors and imposing “structural adjustment” policies, which include low inflation and low deficits. This leads to public spending caps for health and education that restrict countries’ ability to invest either domestic or donor funds in comprehensive HIV prevention, treatment, and care. Likewise, they restrict the investment needed to rehabilitate weak health systems and to hire sufficient numbers of health care workers. Instead of encouraging investment in health care, the IMF preserves an economic order that has resulted in low growth, greater inequality, and a raging AIDS pandemic in Africa and elsewhere.

Similarly, the U.S. and other donors are reluctant to pay for recurrent costs like public sector salaries. Instead, the U.S., particularly Senator Frist, hopes to rely on international volunteers and a relatively small contingent of short-term, high-cost health consultants. Although the U.S. will pay consultants \$140,000 a year to work in a country receiving PEPFAR funds, it will not hire a hundred CHWs for that same amount of money. Likewise, it will occasionally hire and place contract workers in public sector positions for a period of time, but it will not support funding approaches that would allow a developing country to institutionalize human capacity in needed areas. These policies must change before developing countries can sustain the human resources needed to strengthen health systems.

### An Urgent Call

Activists and public health analysts have launched an international campaign to mobilize commitment, resources, and expertise to treat, train, and retain an expanded corps of health care workers for Africa and other developing countries. In the U.S., activists have launched the demand at left. People with HIV in the U.S. and their allies have increased their solidarity with those living with the disease around the world. They have supported campaigns to lower drug costs, increase global funding, and prioritize access to treatment. At this point, treatment rollout is hitting the wall – the outer limits of existing health care capacity. Once again people concerned about the global AIDS pandemic must raise their voices, and ask “Where are the doctors? Where are the nurses? Where are the billions of dollars?” If they succeed, the deaths of millions can be averted. If not, relatives will continue to bring dying loved ones to distant facilities in wheelbarrow ambulances. Once there, they will find patient wards overflowing and doctors and nurses few and far between.

My hope is that when I return to the Valley of a Thousand Hills there will be clinics dispensing medicines and a vibrant network of community health workers building an AIDS-resistant community. When I return to Limpopo, I hope mobile clinics can reach distant rural communities and worksites to promote access to care.

But these hopes will not be realized in South Africa or anywhere else in the region unless well-conceived strategies are undertaken on a massive scale to treat, train, and retain a greatly expanded

## Urgent Call for U.S. Health Workforce Strengthening Initiative in AIDS-Impacted Countries

We urge the President of the United States and Members of Congress to lead a global health workforce initiative in AIDS ravaged countries. The U.S. should:

1. Invest significant new resources (\$650 million in 2007 and more in ensuing years) to recruit, train, support, and equitably distribute the number of health workers in specific sub-Saharan countries needed to achieve universal access to AIDS treatment for all in need by 2010 and to enhance primary health care by 2012.
2. Cover costs to public health systems of implementing PEPFAR and other U.S. initiatives.
3. Launch a substantial community health worker initiative to train, compensate, and deploy community members, especially women and PLWHA, to provide basic care, treatment, prevention services, and referrals.
4. Reduce brain drain by increasing the number of U.S. health professional graduates and improving U.S. health worker distribution. (Some experts estimate that the U.S. will need to increase the annual number of medical school graduates by at least 5,000 and of nursing graduates by at least 25,000 over the next 10-15 years.)
5. Create new possibilities for U.S. and diaspora health workers to serve abroad to help meet immediate care and treatment needs while providing training and support to strengthen health systems.
6. Convene and support country-level teams of all stakeholders to devise, cost, and implement nationally coordinated plans to achieve universal access to health services.
7. Contribute 1/3 of the predicted need of the Global Fund to fight AIDS, Tuberculosis and Malaria.
8. Reform IMF-supported spending and wage policies that limit national and donor investments in health and education.
9. Remove Congressional and bureaucratic limitations on sector-wide funding, recurrent expenses, and salary support.

To sign on: [healthgap.org/hcwwcall.html](http://healthgap.org/hcwwcall.html)

and more diverse corps of healthcare workers at the community level. Stingy donors must commit predictable and sustainable resources; developing countries must implement bold human resource and health system strengthening plans; and the IMF must take its foot off the fiscal brake so that scaled-up resources can be invested wisely. Anything less is medical apartheid.

*Brook K. Baker is a Professor at the Northeastern University School of Law and a policy analyst for Health GAP (Global Access Project).*

## Personal Perspective: **Stigma in Zambia**

by Noel Mukuka

In my country, we look at AIDS in a traditional way. We have unrealistic beliefs - when you have HIV they think it may be the ghost.

But I was in a dilemma. I was sick on and off for a long time. My wife was pregnant and tested negative but I kept asking myself, "Why am I always getting sick?" When I went to the hospital they told me I had TB, but after being treated I wasn't getting much better. I was afraid to be tested for AIDS because I was told, "If you have HIV, you are going to die." Then I decided I was thinking too much about the illness and I wanted to know what was the problem.

As to the stigma, it was bad. The church did a very bad thing to me: after I told the church leaders about my situation, the preacher spoke from the pulpit saying, "Some of you were doing bad things and now you are sick." I felt stigmatized - everyone was distant with me. When I was with them they didn't talk, but they talked to others about me. I would walk by and they were quiet but as soon as I passed they would start speaking quickly and in low voices. Only one of the elders was supportive.

Our Vice Bishop died. When I had confided in him, he told me I was lazy. Then he ended up in bed because of his illness and was stigmatized by the same pastor who spoke about me from the pulpit. He had trusted the Bishop, but now he was stigmatizing him. It is a cycle.

I think there is some justice because nine of the people who shamed me are now dead, and they died quickly. I have found that people who shame others tend to die quicker. You find out they are sick and then they are dead. But I am still alive.

Traditional healers have also brought a lot of calamity. When some people come for testing, they say they were told by the traditional healers, "I have the medicine and I can't get the HIV. I can help you, too." We must send the message that people shouldn't mix traditional medicine and HIV meds. We must start a project to educate the traditional healers and the people in the communities who listen to them.

Before there was fear, because there were no drugs. So when you went for testing and found out you were positive, you knew you were going to die. Now the idea that the drugs must be taken for life gives a lot of fear to people. That's why other people don't want to take it. They also see people who take it and then die. I had seen many people who were very sick who seemed like they were going to die, but then they took the drugs and they didn't die. So I thought if I took it, I wouldn't die. That was my focal point. I wanted to live. At first I had problems adjusting, but now I have a good appetite and everything is normal. Now I look good and feel great.

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***"When some people come for HIV testing, they say they were told by the traditional healers, 'I have the medicine and I can't get the HIV. I can help you, too.'"***

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I am trying to get my own income-generating work because a lot of jobs expose you to things that aren't healthy if you have problems with your immune system. I could get sick if I did one of those jobs.

My wife is now positive. She kept on being tested and now she is positive. She and I usually chat between ourselves to keep our emotions safe. For us, having enough food is the most important thing to our HIV status. It helps us to stay healthy and it helps us to avoid opportunistic infections because we are stronger. My wife's CD4 count is still high so she is not taking meds. When I first tested positive my CD4 count was 120. After they put me on medication it went up to 350.

A lot of people have the problem that when they are feeling good, they stop taking the medicine. I won't do that. Food, medication, and income generation are the three most important things for me and for most positive people.

Support groups encourage people who aren't tested. To help more people get tested we can prevent stigma by going from door to door educating people. People must understand the problem. It is just an infection which can be treated with medication. Seeing positive people who have declared their status and are healthy and productive, will lessen stigma.

*Noel Mukuka is a former bricklayer who resides in the Bauleni Compound of Lusaka, Zambia.*

# Free Trade, Expensive Drugs

by Robert Weissman

*“It is crucial for us to stop the [trade] negotiations, because our lives are at stake. We are fighting against drug patents with our lives. I know I might get arrested or injured in clashes with police, but we are all willing to face that, because we have more to lose if the talks succeed.”*

Nopparat Sa-ngiemjitr, an AIDS activist in Thailand, expressed the views of over 2,500 people with HIV who had joined a protest march against the proposed U.S.-Thailand Free Trade Agreement (FTA). The turnout was extraordinary, but it is no longer unusual to see people with HIV leading protests against free trade proposals.

Around the world – from Guatemala to South Africa, from South Korea to Brazil – people with HIV have learned that the terms of FTAs can be a matter of life and death. And they have hit the streets demanding life.

Unfortunately, they are usually protesting policy demands from the U.S., which typically mirror the demands of the brand-name pharmaceutical industry. Indeed, at times the industry has stated that it effectively drafted U.S. positions in trade negotiations. The office of the U.S. Trade Representative, which negotiates trade treaties on behalf of the United States, views itself as representing the interests of U.S. exporters, so it is very sympathetic to recommendations from the drug industry, a major campaign contributor that employs hundreds of lobbyists.

The drug industry’s wish-list in trade agreements covers an array of technical issues, but most of them boil down to rules that would extend their patents and delay generic competitors from entering the market.

The U.S. has negotiated such provisions into FTAs with Australia, Bahrain, Canada, Chile, Colombia, Israel, Jordan, Oman, Mexico, Morocco, Singapore, Peru, Vietnam, and six Central American parties (Costa Rica, Dominican Republic, El Salvador, Guatemala, Honduras, and Nicaragua). Negotiations for new agree-

ments are under way with Thailand, Malaysia, South Korea, and Panama, with many others proposed.

## Access To Medicines For All?

Patents give brand-name drug makers monopolies that enable them to price drugs far beyond the cost of manufacture. But until 1995, many developing countries did not allow drugs to be patented. That changed with the adoption of the World Trade Organization’s (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). This international treaty required every member of the WTO to adopt certain patent rules, such as 20-year patents on all inventions, including pharmaceuticals.

But there are two important exceptions in TRIPS rules. First, developing countries were given a transition period. Some were given until 2000 to come into compliance with the treaty, while others were given until 2005 (a deadline now extended to 2016 for the poorest countries).

Second, TRIPS included some flexibilities and safeguards. The most important of these is known as “compulsory licensing.” Compulsory licensing enables a government, without the consent of the patent holder, to issue a license allowing a company to use the patented invention. Kenya, for example, could issue a license to a local company for a drug manufactured by a brand-name company. The Kenyan firm would then manufacture the drug for sale in Kenya under a generic name, and it would pay a royalty to the drug company on each sale. Or the Kenyan firm might import a generic version of the drug, paying royalties on what it sold.

Compulsory licensing works to speed up generic competition – the most effective way to lower the price of drugs. Generic competition has brought down the price of first-line HIV drugs in developing countries from more than \$10,000 a year per person to \$132 a year or less – a decline of more than 98 percent! That price reduction, in turn, has made it possible for international donors to pay for treatment of people with HIV on a vast scale.

Unfortunately, many developing countries do not understand the details of TRIPS, and have been misled about what TRIPS permits. Their concerns over violating WTO rules, and uncertainty about what is permitted under TRIPS, have deterred them from using the tools available to them.

## The Doha Declaration

In 2001, however, African countries mobilized and forced a breakthrough, leading to a Declaration on TRIPS and Public Health at a WTO meeting in Doha, Qatar. The Doha Declaration clarified that countries have the right to undertake compulsory licensing in circumstances of their choosing. The declaration affirmed that “the [TRIPS] Agreement can and should be interpreted and implemented in a manner supportive of WTO members’ right to protect public health and, in particular, to promote access to medicines for all.”

The Doha Declaration had been preceded by other victories in the campaign for access to essential medicines. In May 2000, under pressure from activists, President Clinton had issued an executive order stating that the U.S. would not pressure African countries to provide patent protections for HIV drugs that went beyond the requirements of TRIPS (this was effectively then extended to all drugs in all countries, and was maintained by the Bush administration). In February 2001, the Indian manufacturer Cipla announced it would sell a combination of first-line drugs for \$350 a year. And in April of 2001, 39 drug companies that had been suing South Africa over compulsory licensing plans announced they would drop the case.

## TRIPS-plus

The U.S. signed the Doha Declaration, but then increased its practice of pushing for bilateral (between the U.S. and one other country) and regional FTAs. These agreements cover huge swaths of national economies – everything from agriculture to services, from food safety to telecommunications. Many developing countries are eager to enter into FTAs with the U.S. because of the promise of

reduced or no tariffs for their exports. The U.S. extracts concessions in return – and one of the unvarying demands is that countries provide patent and other protections for pharmaceuticals that exceed the requirements of TRIPS (these are known as “TRIPS-plus”). Most of these measures keep the price of drugs high by delaying generic competition.

The U.S. is pushing for a long list of TRIPS-plus demands in bilateral and regional FTAs, including: extending the length of patents; “linking” approval to patent status (making drug safety agencies *de facto* patent enforcement agencies); restricting drug importation; giving drug companies the right to sue a government if it issues a compulsory license, and, possibly the most important, “data exclusivity.”

#### **Who Owns The Data?**

All countries require drug sellers to submit data showing their drugs are safe and effective, but generating that data can cost tens of millions of dollars. When seeking approval for their versions of these drugs, generic companies do not usually repeat these studies. Instead, they show their product is “bioequivalent” (meaning it will work the same in the body as the brand-name drug). The generic companies rely on the data submitted for the prior approval of the patented drug to earn approval for their version.

The data exclusivity provisions of FTAs often require countries to maintain a five-year (or longer) prohibition on the right of a generic firm to rely on the clinical data submitted by brand-name drug companies. Since generic firms must reference this data to gain approval, these drugs will effectively be barred from entering the market – even if the patent has expired or the countries have issued a compulsory license – until the monopolies on the use of the data expire.

#### **CAFTA and Guatemala**

The U.S.-Central America Free Trade Agreement (CAFTA) was signed in December 2003, but controversy and protests delayed its ratification until July 2005. It passed the U.S. House of Representatives by only a single vote.

Under CAFTA, data exclusivity could extend as long as 10 years.

Under U.S. pressure, Guatemala had earlier adopted data exclusivity on two occasions. But each time, after health advocates pointed out the dangers, the provisions had been eliminated. As Guatemala was considering ratification of CAFTA in early 2005, John Hamilton, the U.S. ambassador to Guatemala, issued what amounted to an ultimatum: Even though he acknowledged that Guatemala had rescinded

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*“Generic competition has brought down the price of first-line HIV drugs in developing countries from more than \$10,000 a year to \$132 a year or less – a decline of more than 98 percent!”*

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data exclusivity rules “out of its concern to protect public health,” Guatemala had to change its law to provide data exclusivity as required by CAFTA, or the U.S. wouldn’t approve the deal.

Despite intense street protests, including by people with HIV/AIDS, the Guatemalan Congress in March 2005 imposed a data exclusivity regime, and then approved CAFTA.

“In Guatemala today, 78,000 people are infected with HIV,” said Berta Chete, who works with the Association Gente Positiva, an organization of people living with HIV/AIDS in Guatemala. “Nearly 13,500 of us are in urgent clinical need of

ARV treatment. But only an estimated 3,600 people receive it. Most of them get it from the Social Security system and non-governmental organizations. The Ministry of Health only provides treatment to 350 patients.”

The government has the duty to provide treatment, she points out. But, “we doubt that the Government has the capacity to respond to this situation, because, if there is not competition between generic medicines and brand-name drugs to reduce prices, the national budget will never be able to cover the needs of the country in terms of treating AIDS patients.”

The group Doctors Without Borders (known by its French acronym, MSF) offers an example of the possible harm to come from data exclusivity. One drug now protected by data exclusivity is Reyataz (atazanavir), a key part of second-line therapy for people with HIV. It is used widely in the U.S., Europe, and Brazil. But there is presently no generic competition for atazanavir, and the price is over \$10,000 a year.

“If a more affordable generic version of atazanavir is developed,” MSF notes, “it will not be able to enter the Guatemalan market until 2009,” thanks to the data exclusivity rules. “This means that Bristol-Myers Squibb will have a monopoly during the entire period of exclusivity.... It is therefore unlikely that the vast majority of Guatemalans who will need this medicine will be able to access it.”

#### **Fighting Back**

But protests against TRIPS-plus measures are starting to have an impact. The demonstrations in Thailand forced officials to move their meetings to escape the protesters. The negotiations are now on hold, thanks to a stalemate in Thai politics and a recent military coup.

In Southern Africa, the U.S. efforts to negotiate a trade deal with South Africa, Namibia, Botswana, Lesotho, and Swaziland collapsed earlier this year over unbridgeable differences. One of them was concern from about U.S. demands for TRIPS-plus patent provisions concerning pharmaceuticals.

*(continued on page 21)*

## Persona Perspective: Zapping for Drugs

by Mark Milano

On a Sunday afternoon in June of 1999, I got a phone call about a meeting being held that night to plan a “party.” As a veteran of numerous AIDS protests with ACT UP/NY, I knew that meant an action was taking shape, but I had no idea that this meeting and the subsequent actions would reshape the nature of my activism and would play an important part in changing the way the U.S. responded to the global AIDS crisis.

Prior to that night, I had never worked on global AIDS issues. First, we had plenty of problems right here at home (and still do): overly expensive drugs that led some states to restrict access; a continuing epidemic among my fellow gay men; a president who talked a good line about “feeling our pain” but did little to stop it (he barred the use of federal funds for needle exchange programs); and to top it all off, a real burn-out problem among AIDS activists.

And second, the problem of AIDS around the world was just too big for a simple activist to grapple with. When you looked at the enormity and complexity of the problem, where could an activist start? There was only one thing many of us were “sure” of: we could never get HIV drugs to the countries that needed them the most. They were just too expensive: over \$10,000 a year. Well, that’s how much they charged here in the U.S. – we could never find out how much they actually cost to make, since that information was fiercely guarded by the drug companies. But we thought (wrongly) they must cost many hundreds of dollars a year, far out of the reach of countries that spend only a few dollars a year on health care per person.

So I was surprised to find that the action being planned was about getting HIV treatment to Africa. Activists had gotten hold of a leaked State Department document detailing how the U.S. was working to prevent cheaper HIV drugs from being used in South Africa. Here was the deal: in 1997, South Africa had passed the Medicines and Related Substances Control Act, authorizing “compulsory licensing” and “parallel importing” to make or import far cheaper versions of HIV drugs. But the drug companies were not happy – they wanted South Africa to continue to buy drugs directly from them, not import them from other countries or make cheaper generic versions. Of course, virtually no one in Africa could afford the drugs at full price, and without them, millions would die.

According to Jamie Love from the Consumer Project on Technology, the U.S., under pressure from the drug companies, had put South Africa on its “301 Trade Watch” list, a warning signal that trade sanctions could follow.

Ironically, our government was threatening to restore the trade sanctions that had been lifted in 1993 when apartheid had ended! In addition, South Africa had been kicked off the list of countries that had been promised debt cancellation. Clearly, there was serious outside pressure to prevent this nation from doing what was needed to save its own citizens.

But efforts to publicize this problem had met a dead end. AIDS in Africa, compulsory licensing, generic drugs, the 301 Trade Watch list – who could wrap their head around any of this, much less pitch it to reporters on tight deadlines who knew nothing about the issue? A year of work on the story had led to only one article, in the Chicago Tribune. Beyond that, nothing. The Washington Post had been promising an article for months, but it never seemed to materialize.

So members of ACT UP/NY and F.U.Q. (Fed Up Queers) called a meeting to do a “zap” (a surprise protest) that would finally get the issue into the papers. The target? Al Gore. My first thought was, “Wait a minute – do I want to do anything to damage the man who I desperately want to defeat George Bush?” But then I heard that Gore had been personally involved in talks with South Africa’s then Vice President, Thabo Mbeki, as part of “an assiduous, concerted effort” to “repeal the Medicines Act,” according to the leaked document. Turned out one of Gore’s closest campaign advisors was Anthony Podesta, a top lobbyist for the pharmaceutical industry. So I knew we had the right target. He was concerned about how he looked on the AIDS issue, and I was sure that a zap in June of 1999 would have little effect on an election in November of 2000.

Gore was announcing his candidacy in Carthage, Tennessee, that Wednesday and again the next day in New York City. Of course, a zap in NYC would be a lot easier, but some of us argued that if his first announcement was in Carthage, that’s where the cameras would be. So we rented a van and headed to Tennessee, while ACT UP/Philly started working the phones to prep the media.

We had called to see if tickets were needed for the event, and were told they weren’t. But when we arrived at 7 a.m., we found out that those without tickets would be about a block away from the stage – not what people had just driven 16 hours for! I surveyed the ticket-takers, and chose the sweetest-looking grandma there. “Hi! We just drove 16 hours from New York City to cheer Al, but we don’t have tickets! Is there any way we can get in?” She took one look at our “Columbia Students for Gore” t-shirts and said, “Well, sure! Y’all come on in!” We walked right up to the front and

positioned ourselves directly between Al and the cameras. Gore was not scheduled to speak until 11, so we passed the hours making friends with the Tennessee Democrats all around us – some of the friendliest people you could hope to meet. We talked about all the things we mutually held dear, all the while feeling guilty about what we were planning to do to their favorite son.

Finally, the event began – country music, speakers, Gore's daughter, and then the man himself. I had volunteered to blow the first whistle to kick off the action. Al started talking: about women's rights (couldn't disrupt there); about voting rights for blacks (no, not there); about immigrant rights (not yet); and then about "stronger families." Okay, close enough to "family values" for me – I got up on a fence, ripped off my t-shirt to reveal one that said "GORE'S GREED KILLS" and blew my whistle.

All hell broke loose. We began chanting, "Gore is killing Africans – AIDS drugs now!" One of the women we had been chatting with for hours turned to us with tears in her eyes: "I can't believe you're a part of this!" Others became violent, chipping one woman's tooth by pulling out her whistle; punching the only other man in our group in the jaw. But mostly they just tried to drown us out, making far more noise than the 12 of us could ever hope to make. The cameras focused on us immediately, and I could see Gore was furious. He attempted a feeble, "I love free speech!" and then forged ahead, actually announcing his candidacy during our protest.

The media reaction was immediate. Suddenly, our issue was news. Why was Al Gore blocking AIDS drugs? Why was the U.S. bullying South Africa? What was parallel importing? The Washington Post ran its promised article the next day, and we kept up the pressure. Seeing the success of our zap, members of ACT UP/Philly raced to New Hampshire that same day and were able to hold a banner reading "AIDS Drugs for Africa" not two feet behind Gore as he spoke. Inspired by their action, we hurried back to NYC and hit him again the next morning on Wall St. When he came onstage, he looked me right in the eye – I'm sure he recognized me. I smiled as if to say, "Hi, Al, here I am again," and blew my whistle.

We continued to hit Gore fundraisers, and soon our zaps became the story, not his candidacy – a disaster for his campaign. More importantly, people began writing about the possibility of actually providing generic HIV drugs to people in poor countries.

On September 17, after months of zaps and meeting with officials, the U.S. changed its policy toward South Africa. And in May of 2000, after continued pressure (including taking over the offices of the USTR), Bill Clinton expanded the policy to all nations, issuing an Executive Order that "...the United States will henceforward implement its health care and trade policies in a manner that ensures that people in the poorest countries won't have to go without medicine they so desperately need."

Al Gore would later break with Podesta and come out forcefully against the pharmaceutical industry, and after leaving office Bill Clinton would work to lower the cost of triple-drug HIV therapy to \$130 a year. George Bush would renew Clinton's Executive Order and even create a program to deliver generic HIV drugs to people in 15 developing nations. And in 2006, the majority of sessions at the International AIDS Conference would focus on the nuts and bolts of delivering HIV treatment to developing nations – not whether or not we could do it.

But on that day in Carthage, there were only a handful of us saying what is now universally accepted: generic drugs are the only hope we have to save the lives of millions of people around the world. I don't want to give us too much credit, as many others have fought long and hard on this issue, but when I think of those early zaps I'm reminded of what Margaret Mead once said: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

*Mark Milano is a longtime AIDS treatment activist and is Editor of ACRIA Update*

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***"When Gore came onstage, he looked me right in the eye – I'm sure he recognized me. I smiled as if to say, 'Hi, Al, here I am again,' and blew my whistle."***

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# Recycling Medication: Facing the Challenge in Developing Countries

by Roberto Perez

*“The convergence of global stakeholders at AIDS 2006 has provided an ideal opportunity to examine the gap between what society is capable of doing in the face of this unprecedented humanitarian crisis and the actual level of response”*

- Dr. Helene Gayle, President, International AIDS Society, speaking at the XVI International Conference on AIDS in Toronto

Against the backdrop of the 25 million men and women whose deaths from AIDS have devastated communities and orphaned millions of children, more than 40 million people are today living with HIV.

Antiretroviral therapy has been shown to significantly extend and improve the lives of people with HIV, reducing AIDS-related deaths by over 70%, even enabling patients in the final stages of AIDS to return to productive lives. But only 24% (1.6 million out of 6.8 million) of people with HIV in low- and middle-income countries who need medication have access to it.

In the U.S., people with HIV who change their treatment regimens may have unused supplies of one or more drugs. These excess medications are normally discarded, but could instead serve as a lifeline for those without access to treatment. The same is true of unused portions of the prescriptions of deceased patients.

While federal laws prohibit the redistribution of unused prescription medicines to individuals within the U.S., these medicines may be donated to designated not-for-profit organizations that then distribute them in other countries as “humanitarian aid.”

## Organizations involved in recycling medications

One of the largest organizations involved in medication recycling is New York-based Aid for AIDS (AFA), a non-profit committed to improving the quality of life of people living with HIV/AIDS in developing countries and of immigrants in the U.S. AFA works to empower people with HIV, their caregivers, and the community at large by providing access to medication, education, prevention, and advocacy, and by promoting leadership and capacity building.

AFA’s Recycling Medications Program and AIDS Treatment Distribution Program collect, recycle, and distribute excess HIV/AIDS medications, before their expiration date, to individuals in developing countries who do not have access to life-saving treatments. AFA’s programs include antiretroviral medications, medications that combat opportunistic infections, and antibiotics.

In addition to working with organizations outside the U.S., AFA reaches out to physicians who prescribe these medications, enabling them to work with patients and their caregivers to save unused medications.

AFA’s “Be A Hero” campaign also directly targets people with HIV in the U.S. who are on treatment through magazine ads, posters, flyers, and its website, [www.aidforaids.org](http://www.aidforaids.org).

In 2005, AFA collected \$4.2 million worth of antiretroviral medications and another \$1 million in prophylactic meds. At the end of last year, AFA distributed recycled medications to 5,000 people in 24 countries, including Venezuela, Colombia, Mexico, the Dominican Republic, and other Latin American nations, and to countries in the Caribbean, Africa, and the Middle East.

Potential recipients are screened for specific criteria, such as not having other sources of medications, having a CD4 count below 200, having a viral load greater than 100,000, etc. In addition, clients need to be involved in HIV/AIDS work in their communities through prevention, advocacy, policy change, or community outreach. AFA’s programs require that local doctors are available to work with its doctors and staff.

AFA does not receive federal funding for its medical recycling program, and relies on support from the private sector and from foundations such as the Bill and Melinda Gates Foundation (which has taken a very visible role in the fight against AIDS), the M•A•C AIDS Fund, and the Elton John Foundation, as well as AFA’s own fundraising events, including the “My Hero” gala set for this November.

Over the years, other organizations have begun efforts to recycle surplus medicines, benefiting patients in Algeria, Morocco, Tunisia, Cuba, Chile, Thailand, the Philippines, and Zimbabwe, among others. The Recycled Aids Medicine Program, or RAMP ([www.rampusa.org](http://www.rampusa.org)) in San Francisco and Los Angeles similarly gathers unused HIV medicines and delivers them to organizations overseas, which then redistribute these drugs to patients under a doctor’s supervision. RAMP also donates surplus medicines to, among others, AFA.

The Starfish Project at the Center for Special Studies, New York-Presbyterian Hospital/Weill Cornell Medical Center ([www.thestarfishproject.org](http://www.thestarfishproject.org)) gathers unused “leftover” medication from U.S.-based patients who have stopped or changed their HIV meds and sends them to two partner clinics in Nigeria. Started in 1998 by a visiting physician from Nigeria, the program has shipped over 304,000 pills to partner clinics, providing free HIV therapy to over 70 patients in Nigeria, and is a major source of highly active antiretroviral therapy (HAART) provided free of charge in that country. The Project also provides technical assistance to these clinics and training for local health care providers.

These medication recycling programs help improve the lives of people living with HIV by providing the process for, awareness of, and access to life-saving medication that would otherwise be discarded. A huge amount still needs to be done, as only a small percentage of usable drugs are re-channeled to those who need them in developing countries. Yet these programs also demonstrate “what society is capable of doing,” as Dr. Gayle put it at this year’s AIDS conference.

*Roberto Perez is a writer and editor in the New York area.*

# Immigration and HIV

by *Fiona McKinnon and Ellen Kemp*

Foreign citizens living in the U.S. frequently encounter challenges related to their immigration status. Who hasn't heard the plight of a coworker, friend, or family member whose application for a visa, work permit, or green card has been inexplicably lost, delayed, or denied? And any person, foreign or native-born, may experience health-related difficulties – especially those living with HIV.

But people with HIV who attempt to come to the U.S. face many more obstacles than those who are HIV negative. The daunting challenge of navigating the U.S. immigration system and its voluminous paperwork rises to a new level of complexity and delay when living with HIV. Someone in this situation confronts discrimination both for being a non-citizen of the U.S. and for having HIV.

## **The HIV Ban**

Individuals who wish to obtain lawful immigration status in the U.S. must establish that they are not “inadmissible,” or not barred under U.S. law. The Immigration and Nationality Act (INA) lists the grounds of inadmissibility, which prior to 1996 were known as grounds of “exclusion.” Specific health-related problems, including infection with HIV, render a non-citizen inadmissible. This law is sometimes referred to as “the HIV ban” and is the reason that the U.S. has not been selected to host the International AIDS Conference in 16 years. U.S. immigration law permits only limited exceptions (waivers) to this rule. The “comprehensive immigration reform” currently before Congress does not propose lifting the HIV ban.

## **Early History:**

### **Excluding the “Undesirable”**

Non-citizens have been excluded from the U.S. for health-related reasons since 1882, when “idiots” and “lunatics” were prevented from landing on U.S. soil. In 1891, “persons suffering from loathsome or contagious disease” were added to the list of excludable persons, and a medical examination was required of all non-citizens arriving at ports of entry. In 1961, the health-related legal language changed

to “aliens who are afflicted with any dangerous contagious disease.” We refer nowadays to “communicable diseases of public health significance.” Throughout the 20th century, immigration laws relating to health expanded and changed, but the purpose remained the same: to keep medically compromised people, or those otherwise “undesirable” for health-related reasons, from entering the U.S.

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*“Throughout the 20th century, health-related immigration laws expanded and changed, but the purpose remained the same: to keep medically compromised people from entering the U.S.”*

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## **The Political Battle of the 1980s**

Twenty years ago, the Center for Disease Control's Public Health Service (PHS) identified seven “dangerous contagious diseases” – chancroid, gonorrhea, granuloma inguinale, lymphogranuloma venereum, infectious syphilis, leprosy, and tuberculosis – that would bar a non-citizen from entering the U.S. The PHS also recommended including AIDS as a “dangerous contagious disease,” because AIDS was a sexually transmitted disease (STD) as serious as the other diseases identified.

Opposition voices in the non-profit, activist, and health communities criticized the recommendation as contributing to discrimination against people with HIV. They also feared characterizing AIDS as a “dangerous contagious dis-

ease” would misinform the public about AIDS and how AIDS was actually transmitted. The controversy inflamed Congress, but resulted in AIDS – and eventually HIV – being added to the PHS list by Congress in 1987.

But the controversy continued to simmer through the end of the '80s. Members of the international community and even of Congress continued to voice opposition to the prohibitive policy. International NGOs refused to attend the 1990 International AIDS Conference in San Francisco, as well as the International Congress of the World Federation of Hemophilia in Washington, D.C. As the decade drew to an end, Congress attempted to pass a law restoring to PHS the discretion to identify or remove HIV/AIDS from its list of “dangerous contagious diseases,” but the PHS objected. The PHS claimed that only Congress had the authority to remove HIV from the list of “dangerous contagious diseases,” since it was an act of Congress that had originally designated HIV/AIDS as such. HIV/AIDS remained on the list.

## **The Debate Continues**

In 1991, the PHS reversed course and decided to remove almost all diseases, including HIV, from its list of “dangerous and contagious diseases.” In response to immediate and harsh criticism concerning the proposed removal of HIV from the list, the PHS explained that HIV – like the other STDs it proposed to delete from the list – was not transmitted casually, and that “the risk of (or protection from) HIV infection comes not from the nationality of the infected person, but from the specific behaviors that are practiced.” The PHS used its medical expertise to conclude that “admission of people with HIV would not significantly increase the risk of HIV infection to the U.S. population.”

Despite this logic, there was strong opposition to the proposed deletion. Thousands of letters in favor of the HIV ban flooded the administration, and Republican representatives formally requested that the Secretary of U.S.

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## Immigration and HIV *(continued from previous page)*

Health and Human Services not lift the HIV ban. The PHS yielded, and, again, the HIV ban remained.

Hope for the opposition rose during Bill Clinton's presidential campaign. Candidate Clinton's plan for immigration reform promised to acknowledge the expertise of the medical community at PHS and allow them to lift the HIV ban. After Clinton won the election in 1992, the PHS took regulatory steps to do exactly that.

President Clinton's plan reignited the dispute, with disastrous results. Members of Congress focused their objections around the protection of American public health and health care costs. Conservatives claimed that lifting the ban would harm public health by spreading infection. Lifting the ban would also purportedly have a significant financial impact (though non-citizens with other expensive medical conditions were not banned) and would be unfair to the many Americans who did not have access to adequate health care

Despite opposition from some politicians who spoke out against the ban, its underlying context of hatred, and the illogic of Congressional politics trumping medical expertise, Congress acted to prevent the President from removing HIV from the PHS list of diseases. Instead, Congress formally amended the INA itself to include specific language about HIV infection in the health-related grounds of exclusion. This amendment stripped the PHS of any existing or future discretion to decide whether HIV would continue to be a "communicable disease of public health significance." For the first time, being HIV-positive was specifically identified in the Immigration and Nationality Act as a statutory bar to entry.

### **The HIV Ban in the Last Decade**

The mid-1990s witnessed another major reform of the immigration laws, with the Illegal Immigration Reform and Immigrant Responsibility Act of 1996 (IIRIRA). While IIRIRA did not directly affect the HIV ban, it drastically changed the immigration laws, effectively reduc-

ing the already limited immigration options available to people with HIV.

But a few encouraging changes have occurred in the last ten years. In 1996, the legal office of the former Immigration and Naturalization Service (INS) advised immigration officers and judges to grant, where legally appropriate, some forms of immigration relief (such as asylum, stays of deportation, etc.) to qualified applicants with HIV. In 1999, at the behest of the Surgeon General, the INS modified its practice to make it easier for HIV-posi-

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*“Despite opposition from some who spoke out against the HIV ban, its underlying context of hatred, and the illogic of politics trumping medical expertise, Congress prevented President Clinton from removing it.”*

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tive refugees abroad to obtain an HIV waiver. In 2000, the Immigration and Nationality Act was amended to offer more generous waivers to people with HIV in select groups, such as certain applicants from Vietnam, Cambodia, and Laos; non-citizens involved in national lawsuits challenging implementation of a 1980s amnesty program; domestic violence survivors; and victims of human trafficking or other crimes.

Despite these improvements, 13 years after it was codified into law, the HIV ban remains in place.

### **Comprehensive Immigration Reform**

In recent months, both the U.S. House and the Senate have proposed new immigra-

tion legislation. The legislation does not propose lifting the HIV ban. In fact, some so-called “positive” provisions disqualify people living with HIV. For example, the more moderate Senate bill contains an “earned adjustment” legalization program, which provides a path to legalization for undocumented non-citizens who meet certain requirements, including more than five years of physical presence and more than three years of employment in the U.S. (the House bill contains no such program). But the Senate bill would bar applicants with HIV from earned adjustment legalization. The legislation in effect classifies people living with HIV/AIDS in the same category with those accused of criminal behavior, terrorism, and threats to national security.

### **Conclusion**

In a 2004 joint statement on “HIV/AIDS Related Travel Restrictions,” UNAIDS and the International Organization for Migration officially condemned HIV-motivated bans, debunked the myth that such bans protect public health and challenged the assumption that non-citizens with HIV bring about undue economic burdens on host countries. Additionally, a recent World Health Organization report characterized the evolution of HIV “from that of an inevitable, fatal condition to that of a manageable chronic illness,” indicating that people with HIV are living longer, more productive lives.

But non-citizens living with HIV/AIDS continue to endure dual discrimination, and the ongoing debates in the U.S. surrounding immigration reform and health care costs do not make it any easier. Congress is not likely to improve immigration laws and policies that harm non-citizens with HIV until public attitudes improve. Contact a local immigrants' rights or AIDS service organization to find out how you can help. For more information and links to other organizations dealing with HIV and immigration, visit [www.nationalimmigrationproject.org](http://www.nationalimmigrationproject.org).

*Fiona McKinnon is a Haywood Burns Fellow and Ellen Kemp is a legal worker at the National Immigration Project of the National Lawyers Guild.*

## Entering the U.S. with HIV/AIDS

Two major sets of rules prevent non-citizens from entering or staying in the U.S.: inadmissibility and deportability. HIV is not a ground of deportability, but it is a ground of inadmissibility. This means that the Department of Homeland Security (DHS) can “remove” someone from the U.S. for HIV only if the person entered without government permission. The DHS cannot deport someone for becoming HIV-positive, or for having an AIDS diagnosis, if that person entered on a valid visa or now has lawful permanent residence (a green card).

But the DHS does bar many people living with HIV from entering the country. This includes temporary visitors, such as tourists, students, workers, and those who intend to live in the U.S. permanently. There is another potential barrier for many HIV-positive non-citizens: the “public charge” ground, a concept in immigration law which refers to individuals who cannot support themselves and depend on public benefits for income.

People with HIV may qualify for a special “exception,” also known as a discretionary waiver. (The waiver is “discretionary” because the government is not *required* to approve it.) Several different waivers exist, depending on whether the individual is seeking to enter the U.S. temporarily or permanently, or is fleeing persecution. These waivers share an important characteristic: applying for one will lengthen the processing time and increase the red tape of any application. (This description covers several common waivers, but is not completely comprehensive and is not intended as legal advice.)

**Waivers for Visitors under INA §212(d)(3):** Since 1989, the government has allowed people with HIV to enter the U.S. for certain purposes, such as to attend a conference, conduct business, visit close relatives, or receive medical treatment. Agents are instructed to provide waivers to those non-immigrants “who establish that their entry in the United States would confer a public benefit which outweighs any risk to the public health.” This waiver is good only for short visits of less than 30 days.

In 1990, the first Bush administration added a second kind of waiver. This waiver allows the State Department to grant blanket 10-day visas under certain circumstances to persons attending a professional, scientific, or academic conference in the United States. These visas do not require an applicant to declare his or her HIV status.

Many people ask how the DHS would become aware that a non-citizen has HIV. Although the DHS does not test visitors for HIV when they try to enter the U.S., everyone who is not a U.S. citizen or permanent resident must obtain a visa to enter legally. People coming to the U.S. for study, work, or a visit must fill out a “non-immigrant” visa application, which asks, “Have you ever been afflicted with a communicable disease of public health significance?” “Infection with the etiologic agent for acquired immune deficiency syndrome” is specifically listed in U.S. immigration law as a “communicable disease of public health significance.” If an HIV-positive non-citizen knows that HIV/AIDS qualifies as such a disease and checks “no” on the visa application, the DHS may deny the application based on fraud if an agent has reason to suspect HIV/AIDS, such as medication found in luggage. The DHS may also turn away anyone who answers “yes” to this question, unless he or she qualifies for a discretionary waiver. To avoid these problems, non-immigrant visa applicants may request in advance a special waiver for visitors. HIV waivers are not easy to obtain and may result in processing delays or denial.

**Waivers for Immigrants under INA §212(g):** Since December 1, 1987, all immigrant visa applicants 15 years or older have been required to submit to HIV testing. Applicants under 15 are also subject to testing if there is reason to suspect they may have HIV (such as hemophilia or an HIV-positive parent). But a waiver may be available to people with HIV who have certain family relationships. The individual must be the (opposite sex) spouse, parent or unmarried son or daughter of a U.S. citizen, permanent resident, or person issued an immigrant visa. There is one special exception to the “family member” requirement, and that exception applies to certain HIV-positive survivors of domestic violence.

Having the requisite family relationship or qualifying for the domestic violence exception is not enough on its own to obtain this waiver. Applicants must also meet a rigorous series of standards. One standard that must be overcome is the likelihood of the applicant becoming a “public charge.” This ground is designed to prevent non-citizens from becoming dependent on the U.S. government for economic support if, for example, prolonged hospitalization or extensive medical care becomes necessary. Applicants must show they have the necessary means and capability to deal with a potential high-cost health situation.

Moreover, applicants with HIV must pass an “extra test,” which does not appear anywhere in immigration law. They must also show: (1) that the danger to U.S. public health created by the applicant’s admission is minimal; (2) that the possibility of the spread of HIV created by admission is minimal; and (3) that there will be no cost incurred by any level of U.S. government agency without the prior consent of that agency.

Once a 212(g) waiver is granted, it will remain in effect as long as it has not been revoked, no new grounds of inadmissibility have arisen, and the applicant is complying with the original conditions specified in the waiver. HIV waivers are not easy to obtain, however, and may result in processing delays or denial.

**Waivers for Refugees and Asylum Seekers Under INA §209(c):** Regardless of HIV status, those that fear persecution in their home countries because of race, religion, nationality, political opinion, or social group are eligible to apply for asylum (if currently in the U.S.) or refugee status (if abroad). People seeking asylum do not need to apply for an HIV waiver, but those seeking “refugee status” abroad must obtain an HIV waiver. Non-citizens granted asylum, however, may later seek permanent residence and, at that time, must request a waiver.

No family relationship with a citizen or permanent resident is required for the refugee/asylum waiver. Instead, applicants must prove that they merit a discretionary waiver for humanitarian purposes, to assure family unity, or when it is otherwise in the public interest. Refugees and asylum seekers are also exempt from the public charge ground of inadmissibility, but they are regularly subjected to the government’s three-pronged “extra test” aimed at persons living with HIV. Encouragingly, in 1999, immigration authorities issued special guidance regarding HIV-positive refugees to make it easier for them to meet the “extra test.”

## Personal Perspective: A New Life

by Maria J.

I was born in Honduras in a small agricultural mountain village. Due to a rare blood clotting disorder, as a child I needed blood transfusions and came to the U.S. several times through a medical humanitarian relief program. This was facilitated by a woman who was involved in the medical relief program and who returned several times to visit me. She has become like my second mother and I'm eternally grateful that I met her.

I married at 16, got pregnant the following year and had a beautiful baby girl. But she appeared to not be growing properly and was getting sick constantly. The local doctor suggested that we go to San Pedro de Sula's Public Hospital where her blood was drawn for tests. When I returned two weeks later to get the results I was attended to quickly. I was told my child was very sick and that she would need to stay in the ICU. The doctors and nurses at the hospital asked me if I was a "bad woman" (a prostitute), if I had many boyfriends or husbands, if I used drugs – questions I didn't even understand. I had only one man – I had never had any other – and didn't even know what drugs looked like. They were so insistent and angry, pushing me to tell them the truth, as if I wasn't. While everything was happening quickly I was also getting tests done. I was told: "You probably have the same thing your daughter has."

My baby was placed in isolation; I only had a few moments when I was allowed to see her and hold her in my arms. I was told that I couldn't breastfeed her anymore. The nurses appeared to be scared to touch her and went into her room with masks and special outfits. Two weeks later my results came back: I was told that I had HIV, actually AIDS. I had never heard the word before.

The doctors wanted my husband to get tested, but when he arrived he told me he wouldn't. So I went to the hospital alone and was told that my baby had died a few hours ago. I've never felt the way I did that day – like my heart and soul were ripped out of me. I felt numb and I don't remember anything the doctors told me except that I needed to come back to pick up my baby's body. My husband was waiting for me outside of the hospital and I went to tell him. On the four-hour bus ride back, I had to act as if my baby was alive, pretending to feed her and play with her, since the bus driver would never have allowed us on if he knew she was dead – it would have been considered bad luck. We buried my baby the next day in the village cemetery, buried her in a wooden box painted white and placed a small white wooden cross and plaque over her grave.

I became depressed, stopped eating, cried all the time and stopped caring about what would happen to me. I was 18 and all I wanted was to die. Months went by and my second mother returned to Honduras. Being a nurse she was able to explain what HIV was and that there was treatment available in the U.S. She suggested that I return to the U.S. with her to get the medical help I needed. Two weeks later I was on a plane. Before leaving I

stopped by the cemetery and took the cross that was placed over my baby's tomb with me. I still have that cross and it hangs over my bed. I feel it's protected me and kept me safe.

U.S. Customs knew of my medical condition and knew I had Temporary Protected Status, so I really wasn't asked many questions. I now know that if they knew I was HIV positive I might have not been allowed in. Immediately I was connected with treatment and care at the county hospital. My health improved quickly but I still felt sad and cried. Moreover, I didn't have anyone to speak to at the hospital.

I volunteered at a medical center where my second mother worked. She asked a case manager to speak to me about other services like support groups in Spanish, bereavement counseling, and help regarding my legal status. He mentioned political asylum. If I were to apply, he told me it would be important to prove that people living with HIV in Honduras faced discrimination and persecution. I knew that if I returned I would be in danger. I was the talk of the village, as people had found out I was HIV positive and avoided me. There was a young woman who was a prostitute who had been killed because her clients found out she was HIV positive. The community thought I must have been a "bad woman" to have HIV. I missed my family, I was 18 years old, didn't speak English, and I was surviving with my new family's assistance. But I knew if I returned I wouldn't live long without the medications.

We began immigration proceedings a year after I arrived in the U.S. With my case manager's help, I began to take ESL classes at a local college. Two weeks after my immigration case was received I was summoned for a hearing. It was painful to

remember what I had been through in Honduras – as I told my story and shared my experience it felt as if I was reliving all the events. I wasn't able to sleep, eat, and couldn't concentrate much while I waited for the ruling. I felt my life depended on one person's decision and his perception of my situation.

Three weeks later I received a letter stating that my case had been approved, in record time. I was immensely happy.

In the five years since, I have been able to accomplish some things in my life: I completed my ESL classes, I received a degree in Computer Science, I'm healthy, and I am now in a relationship with a man who is HIV negative and knows that I am HIV positive. I don't know much about the man who was my husband in Honduras, all I know is that he still had not tested for HIV the last time he wrote me two years ago. I always think about my daughter and feel her death was avoidable. I have not been back to Honduras since I arrived, and though I'm able to leave the country I feel as if it will be too painful to return to my village. And I am still fearful of how the Honduran community here would react if they knew I was HIV positive.

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***"I had to act as if my baby was alive, pretending to feed her and play with her, since the bus driver would never have allowed us on if he knew she was dead."***

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# Political Asylum for People with HIV

by Rosa Bramble Weed

There are significant numbers of immigrants living with HIV in New York, receiving medical treatment and other services important to a healthy quality of life. Some arrived as refugees seeking asylum. Others, however, are not aware that in their native countries they lived under circumstances that make them eligible for political asylum. Care providers as well as their clients often have questions about the meaning of political asylum, the process, and available resources.

Immigration laws are very complex and are always changing. Under the 1951 United Nations Convention Relating to the Status of Refugees, nations who signed the Convention Against Torture must grant political asylum to refugees and cannot forcibly return them to their native countries. The U.S. is one of 26 countries that accept refugees, and it granted asylum to about 2,350,000 people from 1975 to 2000.

A “refugee” is a person seeking asylum in a foreign country in order to escape persecution based on race, religion, nationality, or membership in a particular political or social group. A refugee can also seek to escape from extreme poverty, terrorism, famine, and natural disaster. Those who seek refugee status are known as “asylum seekers” and the practice of accepting such refugees is that of offering “political asylum.” Those granted asylum are known as “asylees.”

People with HIV can claim asylum on one of these grounds. Traditionally, political opinion was the primary basis for granting asylum. In recent years, however, the Board of Immigration Appeals recognized that asylum seekers can be persecuted for being members of a social group, one of the more difficult to prove yet widely used criteria. Lesbians, gay men, and bisexuals have been granted asylum based on their membership in a social group. And individual immigration judges have granted asylum to transgendered persons based on evidence that persecution was a result of the applicant being a member of a particular social group.

People should apply for asylum as soon as they learn they are eligible. Under the 1996 Illegal Immigration Reform and Immigrant Responsibility Act, applicants have to apply within the first year of arrival in the U.S. An applicant may apply later if conditions in her or his native country have changed and affected eligibility. An applicant may also be excused from the one-year limit by applying within a reasonable time and proving extraordinary circumstances.

## Political Asylum Eligibility

These are questions that are helpful to ask to explore eligibility for asylum:

- Are you from a country in conflict?
- Do you think you will be discriminated against or harmed by others because of your HIV status or sexual orientation if you must return to your home country?
- Who do you think will harm you? If it is not the police or military, can you show that the government tolerates or approves of the behavior?
- If you were to return to your country, would your life be in danger?  
By From whom? Is there evidence?

Applicants must produce evidence that they were persecuted and will be if they return home, and that the persecutors believe the applicant has political opinions they wish to suppress (such as the opinion that people with HIV should be treated with dignity).

## Non-Government Persecution

Although it may difficult, applicants must show that the government tolerates or approves the action of the persecutors. If it is not the government directly that persecutes people with HIV, or gay or transgendered individuals, then the applicant must show that the government either tolerates or approves of others persecuting these groups. For instance, if bands of vigilantes regularly attack and beat up people with HIV, the applicant must show that asking the police to prosecute the attackers is fruitless. Domestic violence is also grounds for seeking political asylum. Women who have suffered from domestic violence may be eligible under the Human Rights Gender Violence Act.

Applicants often say they have been or will be persecuted and that their group is generally disfavored but fail to show that the reason they are persecuted is because of their opinion or social group. For instance, if the police are harassing a young man with HIV, the applicant must show that they did it because they think he is HIV positive. But this may be difficult to prove, and many immigration applications are denied because of the inability to link persecution to a particular social group.

## Overview of the

### Political Asylum Process

It is important to have an attorney with expertise not only in immigration law but also in political asylum. It is not recommended that applicants go directly to United States Citizenship and Immigration Services (USCIS - formerly part of the Immigration and Naturalization Service or INS) without an immigration attorney because of the complexities of the laws. The fact that an applicant is in the U.S. illegally can immediately jeopardize his or her ability to remain.

If the attorney believes a case qualifies for asylum, the applicant writes a personal statement, or affidavit. Additional statements by witnesses and experts often make the difference between winning or losing the case. Specifics that make the story believable are critical, so contacting relatives, friends, and co-workers in the native country for letters of support, police reports, and witnesses of events, etc., is important. Immigration attorneys experienced in asylum often document claims with evidence from human right groups supporting applicants' cases. In addition, newspaper articles and news coverage can be used as supporting documents.

If an applicant has missed the one-year deadline, a psychological evaluation by a mental health professional is recommended. Many applicants have experienced significant emotional distress, which impedes the actions necessary to complete the application process; the mental health evaluation should describe the client's mental health and how it caused the application to be delayed. The applicant

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# Political Asylum

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should also obtain letters from medical providers, a list of any medications they are taking, and laboratory reports.

The initial interview takes place with a USCIS officer, who asks pertinent questions. Many organizations will assist with an interpreter if needed. Family, relatives, and partners will not be interviewed or allowed in the interview room. The interview can take from 30 minutes to two hours, after which the applicant is told when to return, usually in two or three weeks, for the decision. If the asylum is approved, the process for an Identification Card begins.

If the immigration officer does not grant asylum, the applicant is referred to an immigration judge. This judge either grants political asylum or denies it and begins deportation proceedings. If the application is denied, the applicant has the right to appeal and can remain in the U.S. during the often lengthy appeals process. Recently, applicants have been receiving partial asylum status, which enables them to live and work in the U.S. indefinitely but not to leave the country. They are also not eligible for permanent resident status. Applicants can apply for a work permit 150 days after the USCIS has received the asylum application, and they may also be able to receive public benefits during the asylum process.

Asylees can apply for lawful permanent residence after one year, but due to backlogs, approval can take up to ten years. In the interim, they are entitled to all the benefits of permanent residents, including work authorization, benefits, and the ability to travel to most countries with the exception of their own.

## Guidelines for Service Providers

HIV+ political asylum seekers suffer from multiple traumas. In addition to the ordeal of immigration, asylum seekers differ from other immigrants in that they have been forced to leave their countries. The emigration process, especially for those who enter the U.S. unlawfully, brings additional trauma. The journey may have taken several days or months,

## Finding Legal Representation

There are many organizations that offer free legal services to HIV+ asylum seekers. If clients apply after the one-year deadline, some organizations will represent the case or refer clients to private attorneys whose fees range from \$3,000 to \$8,000. If one organization does not accept the case, go to a second or third. Networking among clients about attorneys is also helpful, and organizations also have lists of private attorneys. Providers can also inquire about in-service trainings on immigration and asylum.

### Immigration Equality

350 W. 31 St., Suite 505  
New York, NY 10001  
212-714-2904 ext.25  
Legal Services for LGBT asylum applicants

### Physicians for Human Rights

Political Asylum Project  
[phrusa.org/compendium](http://phrusa.org/compendium)  
Free legal services

### Gay Men's Health Crisis

Legal Department  
119 West 24<sup>th</sup> Street  
New York, NY 10011  
212-367-1000  
[gmhc.org/programs/legal\\_brochure.html](http://gmhc.org/programs/legal_brochure.html)

### HIV Law Project

15 Maiden Lane, 18th Floor  
New York, NY 10038  
212-577-3001  
[hivlawproject.org](http://hivlawproject.org)

### Aid for AIDS

515 Greenwich St Suite 506  
New York, NY 10013  
212-337-8043 [aidforaids.org](http://aidforaids.org)  
Immigrant support groups,  
attorney referrals

### New York Immigration Coalition

137-139 West 25th Street, 12th Floor  
New York, NY 10001  
212-627-2227 [thenyic.org](http://thenyic.org)  
Legal resources, in-service trainings

### The Association of the Bar of New York

Refugee Assistance Project  
212-382-6680

### National Immigration Project of the National Lawyers Guild

14 Beacon St. #602  
Boston, MA 02108  
617-227-9727  
[nationalimmigrationproject.org](http://nationalimmigrationproject.org)

perhaps through hostile borders and conflict zones, and may have placed their lives at risk or subjected them to rape, robbery, or lack of food.

In the U.S., all asylum seekers are considered illegal aliens and so cannot work legally. Although many may have been technicians or professionals, they are often forced to work in menial jobs in the U.S. This loss of status and professional identity can be very demeaning. Such individuals often describe how their previous work or life experience is not acknowledged by providers. One client, after obtaining asylum, went to a community college in New York to further his education. During intake, he explained that in his native country he worked as computer analyst. The counselor responded, "That was there – it doesn't really count. What have you done here?"

Clients can have difficulty conveying their thoughts and feelings in English. Those who have experienced humiliation and torture may be sensitive to questions they interpret as interrogation. Building trust over time is essential to well being and to explore options.

HIV+ asylum seekers can also be suspicious of providers. The stigma surrounding their lives in their native countries may have damaged their perceptions of themselves and the world. I once worked with a professional woman who experienced humiliation during a hospitalization in Venezuela. A huge sign was placed over her bed: AIDS PATIENT, STAY AWAY, and a psychiatrist extorted money by threatening to disclose her status. Her trust in health care professionals was shattered and took years to re-establish. An HIV diagnosis is stressful in and of itself, but many people seeking asylum also have additional trauma from childhood sexual abuse, or physical and emotional abuse due to gender or sexual orientation.

The asylum process can be traumatic because clients are asked to revisit difficult experiences that may have been repressed for many years or that they may not be emotionally prepared to address. This can lead to anxiety, paranoia, intrusive thoughts, or repeated flashbacks. As much as an individual is eager to obtain asylum status, she or he may resist undergoing the process. One client said, "I thought I would never have to remember this again."

Here at the Positive Life Program, we have developed a socio-therapeutic model to make the asylum process more manageable. We educate the client about the process, anticipating anxiety and preparing for this overwhelming period. The first step is to help the client with relaxation techniques like Reiki or acupuncture. The client's personal affidavit is created during the ongoing clinical interventions. Support groups play an important role, along with information exchange.

Processing the different stages of seeking asylum involves adapting to a new culture and mourning the loss of country of origin. So we let all our clients know that they are not alone in this journey – we are there to provide support and to advocate for their rights. Our clients have shared how this has sustained them in their most difficult moments.

The waiting period between the initial interview and the asylum decision is about three weeks. This period is overwhelming for applicants, who often report increased sleep disturbances, lack of concentration, and preoccupation with the outcome. They report putting their health on hold, forgetting medications, missing medical appointments, etc. They may also depend increasingly on antide-

pressants and sedatives as the asylum process becomes both a priority and an emotional upheaval in their lives.

The navigation of multiple systems can be overwhelming for the client and requires a multidisciplinary approach with case managers, social workers, and health and mental health providers working closely with the immigration attorney. When a person first seeks services from any provider, that provider needs to assess if there is a need and eligibility for asylum, asking the questions outlined above. If the facility does not offer such services, the client should be referred to immigration advocates.

In addition, medical providers need to routinely inquire about clients' immigration process, as it is integral to their medical treatment. Letters of support from medical providers are essential to supporting asylum. The Physicians for Human Rights Political Asylum Project offers a manual for healthcare providers, *Examining Asylum Seekers*.

Social workers are essential to the process, since an applicant may verbalize repressed traumatic experiences for the first time. The person may also be in need of psychiatric evaluation and medications. Social workers can write a letter of sup-

port, including an evaluation to be submitted for the petition. This evaluation needs to include the trauma in country of origin, changes in personality as a result of persecution, and the mental health prognosis if the applicant were to return to the native country. A psychiatric evaluation indicating the diagnosis, treatment recommendations, and the importance of the applicant remaining in the U.S. to psychological well-being weighs in favor of the applicant in the asylum process. Attorneys and mental health providers need to work very closely.

### Conclusion

In summary, the political asylum process is an overwhelming experience, especially for those living with HIV/AIDS. Health care providers, including primary care physicians, case managers, and social workers, play an important part by offering a safe place for clients who are in a critical period of their lives. Advocating for asylum validates an individual's life experiences and struggles. As providers working alongside our clients in this process, we embrace our commitment to our clients' rights to human dignity, respect, and justice.

*Rosa Bramble Weed, LCSW, is the Director of Positive Life Program of the Child Center of Woodside in Queens, New York.*

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## Free Trade, Expensive Drugs *(continued from page 11)*

In South Korea, trade talks have foundered as the U.S. has pressed the government to change its system for reimbursing drug expenditures. The U.S. wants South Korea to pay for more brand-name drugs. Intense pressure from a broad range of public health organizations is preventing the government from acceding to U.S. demands.

Meanwhile, a growing movement in the U.S. is challenging existing trade policy. A very broad coalition – labor and environmental groups most prominent, but including AIDS activists and public health advocates — has come together to oppose future trade deals that look like CAFTA. Their efforts nearly defeated CAFTA, but failed thanks to high-pressure tactics from the House Republican leadership.

For the last several years, Congress has considered trade deals according to a special process known as “fast track.” Fast track prohibits Congress from amending the legislation that implements trade agreements. It expires next year, and because of the broad public opposition to current trade policy, there is little chance of it being renewed, at least before the 2008 elections. Without fast track, the administration will have a very hard time getting new trade deals through Congress.

For a while, then, developing countries may win a reprieve. But it will be short-lived unless activists in the U.S. and developing countries build their power to stop the campaign to extend the drug industry's monopolies on HIV drugs.

The stakes could hardly be higher. As developing countries expand their HIV/AIDS treatment program, they will need access to second-line therapies, which can now cost 10 times more than first-line drugs. These drugs are more often patented in developing countries, and – because they are newer drugs – the patents have later expiration dates. Whether people with HIV in developing countries are able to get these life-saving treatments will depend on whether countries are able to use methods like compulsory licensing to speed up generic competition. Without that, “free trade” may translate to “no hope.”

*Robert Weissman is director of Essential Action, a Washington, D.C.-based group that campaigns for affordable drugs.*

# AIDS Institute/Regional Training Center trainings

For an on-line application please visit our website at [www.acria.org](http://www.acria.org) or call at 212-924-3934 x 129

*(Courses have no prerequisites unless mentioned below.)*

## Building Bridges to Cultural Competency

September 20, 9am-5pm, Manhattan

This one day training explores the broad definition of culture and its relationship to competent and effective healthcare and human service delivery.

**Audience:** All Health and Human Service Providers.

## Basic Domestic Violence

October 3, 9am-5pm, Manhattan

This one-day training gives overview of the interrelationships between adult domestic violence and HIV/AIDS.

**Audience:** All Health and Human Service Providers

## HIV/AIDS Treatment Update

October 5, 1-5pm, Manhattan; November 17, 1-5 pm, Brooklyn

This half-day training will provide updated information for non-clinical providers about advances in HIV/AIDS treatment. Programs are updated regularly to address emerging issues.

**Audience:** All Health and Human Service Providers who work with people with HIV/AIDS.

**Prerequisite:** Prior attendance at a basic training, such as "Overview of HIV Infection and AIDS", is required.

## Introduction to Case Management

October 12, 9am-5pm, Manhattan

This one-day training will provide participants from COBRA and AIDS Institute grant-funded programs with the basic understanding of the case management process.

**Audience:** New Case Management staff and Health and Human Service Providers

**Prerequisite:** Although there is no prerequisite for this course, it is strongly suggested that participants have previous training in HIV confidentiality and basic HIV/AIDS medical information.

## Enhancing the Partnership

October 19, 9am-5pm, Manhattan

This one-day training will provide participants with skills to establish effective partnerships with their clients. This training will focus on what both the case manager and client bring to the case management process. The training will also explore how to address sensitive issues with clients, develop positive confrontation skills and strategies to work with client resistance.

**Audience:** Case Management staff and Health and Human Service Providers

**Prerequisite:** Although there is no prerequisite for this course, it is *strongly* suggested that participants have previous training in HIV Confidentiality, Basic Domestic Violence, basic HIV/AIDS medical information and have taken "Introduction to Case Management."

## HIV/AIDS Confidentiality Law

October 20, 1-5pm, Brooklyn

This half-day training provides information about New York State's HIV Confidentiality Law (Public Health Law Article 27-F). This training is designed to meet provider requirements for initial and annual confidentiality training.

**Audience:** All Health and Human Service Providers

## HIV Testing in NYS: 2005 Guidance

October 26, 1-5pm, Manhattan

This half-day training will provide information regarding the 2005 Department of Health (DOH) guidance on HIV counseling and testing.

**Audience:** Experienced and new health or human service providers who offer HIV testing as a part of their job responsibilities. Staff preparing to offer testing in CBOs may attend this training or "Offering Rapid HIV Testing in CBOs Serving High Risk Communities".

**Prerequisite:** Although there is no prerequisite for this training, it is strongly recommended that participants have previous training in basic HIV/AIDS.

**Additional Training:** Participants who would like an opportunity to practice the skills associated with offering HIV testing services may choose to attend "HIV Testing: Skills Practice Session".

## HIV Testing Skills: Practice Session

October 27, 9am-5pm, Manhattan

This one-day training will provide participants with an opportunity to practice key skills related to offering HIV testing services

**Audience:** Any health or human service provider who offers HIV testing as part of their job responsibilities.

**Prerequisite:** Knowledge of basic HIV/AIDS information and attendance at "HIV Testing in NYS: 2005 Guidance " or an equivalent training.

## Domestic Violence in the LGBT Community

October 31, 9am-5pm, Manhattan

This one-day training was developed by the New York State Office for prevention of Domestic Violence and the New York State Department of Health AIDS Institute.

**Audience:** All Health and Human Service Providers

**Prerequisite:** Although there is no prerequisite for this course, it is *strongly* suggested that participants have previous training on domestic violence, and basic HIV/AIDS information. Participants are strongly encouraged to attend the "Basic Information about Domestic Violence" prior to attending this training.

## Promoting Adherence

November 2, 1-5pm, Manhattan

This half-day training will assist participants to identify and take advantage of multiple opportunities to support treatment adherence in the course of their work.

**Audience:** All non-physician Health and Human Service Providers

**Prerequisite:** It is *strongly* recommended that participants have previous knowledge or training on basic HIV/AIDS information.

## Community Educator Training

Nov. 13-16, 9am-5pm, Manhattan

This four-day training is designed to prepare the participants to serve as community HIV/AIDS educators. Participants will be required to give a presentation to the class on the final day of training.

**Audience:** All Health and Human Service Providers, open to members of the community

*This listing only includes AIDS Institute/Regional Training Center trainings offered by ACRIA.*

*For information on trainings provided by other Regional Training Centers or Centers of Excellence please visit the following web-sites:*

AIDS Institute: <http://www.health.state.ny.us/diseases/aids/training/index.htm>

National Development and Research Institutes: <http://training.ndri.org>

Cicatelli Associates Incorporated: <http://www.cicatelli.org/CALENDAR/Default.htm>

## New Board Members Welcomed

Three new members were voted onto ACRIA's Board of Directors at its September 2006 meeting. They are:

Alphonso B. David, a staff attorney at the Lambda Legal Defense and Educational Fund and an Adjunct Professor of Law at Fordham University School of Law. At Lambda, David prosecutes and defends precedent-setting civil rights cases across the country that affect LGBT individuals and those living with HIV. At Fordham, he teaches "Constitutional Law: Sexuality and the Law."

Christopher Murray, Mental Health Counselor and Project Coordinator of the LGBT Smoke-Free Project at the Lesbian, Gay, Bisexual & Transgender Community Center. A long-time HIV/AIDS advocate and activist, Murray's resume includes work with Cicatelli Associates, the PWA Leadership Training Institute, and GMHC.

Vaughn C. Williams, partner in the prestigious law firm Skadden, Arps. In addition to securities and corporate, class action, and commercial litigation, Williams is active in Skadden, Arps's pro bono practice and is a member of the committee that administers the firm's fellowship program.

## Staff Changes and Additions

Sadly, we must say goodbye to Development Director J.A. Forde. During a remarkable fourteen years with ACRIA, Forde helped the agency survive and thrive and helped to make it the well-known and respected part of the HIV landscape that it is today. We wish him nothing but the best in his new position as Special Events Director at *Interview Magazine*.

Forde is succeeded by newly appointed Development Director Michelle Gerber, who comes to ACRIA from the Coalition for the Homeless, where she served as Director of Development. Her previous

experience includes development work at the Planned Parenthood Federation of America and the World Conference on Religion and Peace.

Gerber will soon be joined by Scott Drevnig, who will fill the newly created position of Special Events Manager. Drevnig brings to ACRIA over fourteen years experience with creative and Fortune 500 companies in building and implementing sales, business development, and marketing initiatives.

The Research Department is also expanding, and Dolores Holman is slated to be ACRIA's new Clinical Trials Manager. Holman has worked most recently as a clinical research coordinator at Winthrop University Hospital and at the Research Testing Laboratories, both on Long Island, and as a research technician at Memorial Sloan Kettering Cancer Center in NYC.

## ROAH Attracts National Attention

The response to the release of ACRIA's Research on Older Adults (ROAH) study (see Summer 2006 *ACRIA Update*) has been phenomenal. ACRIA has been given a prime slot for a symposium on HIV and Older Adults at the prestigious Gerontological Society of America meeting in Dallas this coming November. The symposium will be chaired by ACRIA's Senior Research Associate Andrew Shippy and Marjorie Cantor, Professor Emerita and Brookdale Distinguished Scholar at Fordham University, who chaired the ROAH Advisory Committee. At the conference, ACRIA will also give nine other presentations on various topics from the ROAH study.

Since the formal release of the ROAH data in July, ACRIA has received media attention from over 250 news outlets, including the *New York Times*, *USA Today*, *Time Magazine*, CNN, MSNBC, Kaisernet, NPR, and the BBC. As a result of the publication of the ROAH study, an estimated 94 million people have been exposed to the issue of the graying of HIV.

## Regional Training Centers

ACRIA was honored to be selected by the AIDS Institute as one of its Regional Training Centers, offering trainings for service providers to HIV/AIDS service providers throughout New York City. Information about the courses offered, prerequisites, and schedule is on the opposite page.

## Coming Soon

ACRIA – thanks to its expertise in aging and HIV gained through ROAH and other research and to the education and training abilities of the HIV Health Literacy Program – has been selected to provide technical support and oversight for the planned HIV and Aging program at Gay Men's Health Crisis. The program is being underwritten by the M•A•C AIDS Fund.

Senior Research Associate Andrew Shippy has been invited to write an article on LGBT caregiving in older adults in New York City. The article, entitled "We Cannot Go It Alone: The Impact of Informal Support and Stressors in Older Gay, Lesbian and Bisexual Caregivers," will appear in a special issue of *Gay and Lesbian Social Services*.

ACRIA has been chosen to be part of a research survey on "Patient Preferences for Risk and Uncertainty in HIV Treatments." The purpose of this study of African-American men is to determine what levels of risk – side effects, possible permanent organ damage, effectiveness – affect the decision to begin or not to begin treatment and to engage in medical care. Individuals interested in participating or who want more information should contact Perion Smith at (212) 924-3934 x105.

ACRIA's clinical trials team expects to participate in an upcoming phase III trial of a promising antidiarrheal drug. This follows on earlier phase II studies of the drug that ACRIA had conducted and a presentation by Medical Director Jerome A. Ernst at an important biotechnology conference in London.

# generous contributions

*Thoughtful donations were made in memory of the following individuals:*

Barbara Frey  
Barry Binkowitz  
Charles Lewis  
John Keane  
Thomas Saporita  
Tommy McClain

*Contributions in support of ACRIA's vital research initiatives were made in honor of the following individuals:*

J.A. Forde

*The following persons, corporations and organizations made major donations between July 1 and September 30, 2006 to support ACRIA's research and education efforts:*

Jeff Altman	Laurissa Keane
Frederick Altschuler	The Calvin Klein Foundation
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## AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA



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an unrestricted educational grant from:*

