

March / April 2003



Positively Aware

The Journal of Test Positive Aware Network

THE UNDECLARED WAR



- **One-on-One with Dr. Peter Piot, UNAIDS Executive Director**
 - **China—At the Crossroads**
 - **Africa's Most Vulnerable**
 - **Haiti's Battle—HIV and Poverty**
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Editor's Note

A Busy Little Bush



In early January, Tennessee Senator Dr. Bill Frist, a physician and the new Senate majority leader, called for intensifying the fight against the spread of HIV in Africa and improving domestic health care for African Americans and other minorities. Secretary of State Colin L. Powell has long been outspoken on the need for nations to spend more to fight AIDS, which he cites as being more threatening than terrorism.

"Today, on the continent of Africa, nearly 30 million people have the AIDS virus including three million children under the age 15. There are whole countries in Africa where more than one-third of the adult population carries the infection. More than four million require immediate drug treatment. Yet across that continent only 50,000 AIDS victims—only 50,000—are receiving the medicine they need," President Bush, State of the Union Address, 2003

AIDS victims. I thought we left that phrase in the 1980s, but obviously I was mistaken. Mr. Bush, since we have victims, do we also have the "AIDS guilty?" You know, those communities and nations that are deserving of AIDS. I digress.

Bush pledged \$15 billion to the global AIDS effort over the next five years. This is not to be interpreted as a commitment to the Global Fund, established in 2001 by United Nations Secretary-General Kofi Annan. Under the Bush pledge, \$200 million would go to the Global Fund each year, a decrease over this year's \$380 million.

Food for thought: evangelical Christians have taken the AIDS epidemic in Africa and the Caribbean as their calling and are establishing missions in Africa; the administration prefers abstinence only, no condom and no birth control for HIV prevention efforts; U.S. Secretary of Health and Human Services Tommy Thompson was "elected" as chairman of the Global Fund. Call me cynical, but maybe the administration has other plans for the Global Fund. Will HIV prevention

Bush-style emerge as a 21st century form of neo-colonialism?

Bush also announced his intention to ask for a \$100 million increase in funding for the AIDS Drug Assistance Program (ADAP) beginning with fiscal year 2004. This is a good thing. However, for the third consecutive year, the Administration is flat funding the Ryan White CARE Act. This means no increase in funding for medical and other services for HIV-positive individuals. In addition, the budget actually reduces the funding by \$858,000 for the domestic HIV prevention programs supported by the Centers for Disease Control and Prevention (CDC). These are really bad things.

The administration also announced plans to revamp the current Medicaid system. Under the Bush plan, states would have the flexibility to make almost any changes in coverage of some 15 million beneficiaries who are considered "optional" under Medicaid law, including increasing the costs patients must pick up, and eliminating certain benefits, as well as being selective about who receives benefits. While the administration says it hopes states would use the plan to expand coverage, how can this possibly occur given the fact that nearly every state is operating with massive budget deficits. Rather than truly reforming the Medicaid system and providing an increase of federal matching funds for Medicaid, the administration has proposed a plan that would leave an outdated, broken system in place and state governments left holding the bill.

While we as a nation "police" and "care" for the world, we must not lose sight of the fact that here in the U.S. for the first time since highly active anti-retroviral therapy (HAART) became available, thousands of uninsured Americans living with HIV/AIDS are having difficulty obtaining care, treatment, or medicines to combat the side effects and metabolic complications associated with HIV

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Readers' Forum

Positively Aware will treat all communications (letters, faxes, e-mail, etc.) as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style or clarity.

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DRUG PRICES

It seems that a couple of prices listed in the survey (see Drug Prices) in the January/February issue were incorrect. I did some checking and got for Fortovase (540 capsules) \$659.49 from CostCo and \$610.79 from Drugstore.com. For Invirase (270 capsules) I got \$592.19 from Costco and \$562.87 from Drugstore.com.

Prices always have to be compared apples to apples (same quantity and strength). All pharmacies (retail or Internet) pay within a percentage or two the exact same price for merchandise. This is a federal law. A hospital can contract for different prices, but is not allowed to sell directly to the patient. These drugs are purchased and used within the hospital. Mail order pharmacies also can contract with manufacturers, but they are not allowed to sell the drugs in a retail setting.

The AWP (average wholesale price) is set to become a level playing field for payers (insurance and 3rd party payers). For example, Aetna contracts with all retail pharmacies to give AWP less 13% plus \$8.00 to fill a prescription for Norvir. The drug is purchased from the manufacturer for about AWP less 15%. This figure is negotiated between the drug wholesaler and the retail store. Walgreens probably gets 1-2% better prices than a mom-and-pop store. The pharmacy profit is the 2% difference plus the \$8.00. There is very little room to have much of a price swing.

Most reputable retail pharmacies will be in the same ballpark with prices. Of course, if you shop long and hard enough it may be possible to save some money.

I hope this helps clarify the subject.

Glen Pietrandoni, R.Ph.,
Chicago

BUSH ON DRUGS

Am I the only one who heard President Bush say this during the State of the Union address? "AIDS can be prevented. Anti-retroviral drugs can extend life for many years. And the cost of those drugs has dropped from \$12,000 dollars a year to under \$300 dollars a year." This statement about knocked me to the floor. I used last year's *Positively Aware* to check wholesale prices and my own private health insurance statements to see if I was missing something. Here's what I found.

My current anti-viral medications (taken every day, wholesale prices): Zerit (d4t) \$3,960 a year, \$330 month (retail price as of May 2001 was \$489); Epivir (3TC) \$3,435 a year, \$286 per month; Crixivan (indinavir) \$6,280 a year, \$523 per month.

President Bush was misguided in his speech, and this just proves there is little research to prepare such speeches, or that no one cares because the masses are not really affected by AIDS (in the U.S.). His pep rally proves the point, however his words will stick like glue. He reported that HIV can be treated with pills for little more than the cost of a trip to the doctor for some pills to stay well. Of course the focus on the speech was the Iraq issue and the start of his speech was mere fluff, that at this time doesn't interest most. I have a private insurance plan funded by state payments of my premium under Ryan White, otherwise I would have no prescription plan. As it is, my out-of-pocket is stifling at \$1,500 a year, based on my yearly income on SSDI [Social Security Disability Insurance], which is all I have for now. Tell

me please where can I get in on this \$300 a year plan for my antivirals? Where did Bush get that figure in his speech? It is very upsetting to hear a positive approach being proposed by our President with regards to possible help for Africa's mega-doom and then in the same speech give incorrect information regarding drug prices. How is one to believe anything said?

Name withheld
via the Internet

Editor's Note: As you can see from the article "Drug Prices" in the January/February issue, there's no HIV antiviral in the United States that costs \$300 a year. Never mind a combination regimen (which is the standard of care). There are generic combinations available in developing countries that can cost about \$300 a year. That was probably the reference Bush made. However, the Bush administration and many pharmaceutical companies have opposed generic manufacturing of anti-HIV meds. Furthermore, even at those prices, therapy still remains unaffordable to the majority of people in those countries.—Enid Vázquez

TALKIN' 'BOUT MY GENERATION

Just a quick word of thanks for your website and the recent article by David Weeks (November/December). My diagnosis came in July, and it's taken me this long to catch my breath after the news. I was just referred to your site by a friend last week, and already, it has been a great resource for me. David's article struck a chord with me, probably because we're close in age and he grew

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News Briefs

by Enid Vázquez



DRUG GUIDE CORRECTIONS

The activist section of the HIV Drug Guide (January/February) incorrectly stated that Videx is associated with “the common discoloration of the finger nail beds of African Americans.” That side effect is seen with Retrovir (AZT). Under Kaletra, the activist statement that “the company reports...[no] resistance” refers only to people on therapy for the first time. Also, the drug guide failed to note the only approved once-daily dose of a protease inhibitor: Agenerase when taken with Norvir. The recommended dose of Viracept is 1250 mg (five 250 mg tablets) twice daily. We apologize for the oversights.

ZERIT XR APPROVED

The U.S. Food and Drug Administration (FDA) in late December approved a once-a-day, extended release formulation of Zerit (stavudine, d4T). The dose is 100 mg for people weighing 132 pounds or more, and 75 mg for those weighing less. In a large trial, the new formulation was equally effective to standard Zerit. Side effects were also similar. The primary side effect of Zerit is peripheral neuropathy, numbing and tingling in the hands and feet, which can become permanently debilitating if left untreated. Several studies also suggest that Zerit, as well as other antiretrovirals, is associated with facial atrophy (wasting).

T-20 SIDE EFFECTS

The promising experimental HIV drug T-20 (brand name Fuzeon) has been associated with a low incidence of eosinophilia and a hypersensitivity (allergic) reaction. Eosinophils are a type of white blood cell. An increase is associated with allergic reactions. The manufacturer reports that eosinophilia was found in 10% of patients on T-20 in two large clinical trials (TORO 1 and 2). It was found in 2% of the control group (the participants not on T-20). The reaction may be associated with an inflammatory reaction, and people with asthma

and dermatitis may get it more regularly. Two cases occurred on re-challenge (when patients are put back on a drug after having gone off it). One person experienced kidney and respiratory failure. Both re-challenged individuals had rash, fever and vomiting.

AVOID SMALLPOX VACCINE

The smallpox vaccine so much in the news over the past year should be avoided by people with HIV and those in close proximity to them. People who get a shot might be contagious for up to about three days, so they should avoid contact with those who are immunosuppressed and people with skin conditions. There is medication that, if taken soon after exposure to smallpox, may prevent infection. (see *The Buzz* on page 40.)

LESBIAN TRANSMISSION

A report in the February 1 edition of *Clinical Infectious Diseases* discusses a case of female-to-female sexual transmission of HIV. Such cases are very rare. Researchers believe transmission occurred through the sharing of sex toys. Other risk factors were ruled out. Although the objects were not used during menstruation, bleeding sometimes occurred through vigorous use. Testing for the presence of drug resistance in the virus of both women helped confirm the transmission from one woman to the other.

ASHE REMEMBERED

February marked the tenth anniversary of the death of famed tennis player, Arthur Ashe. He died of complications of AIDS after having contracting HIV in a blood transfusion during heart surgery. The publicity that Ashe brought to HIV/AIDS helped transform the way that “mainstream” America viewed the disease. A role model to so many young African Americans, Ashe was the first black man to win Wimbledon in 1975. He was the first black male to win U.S. national titles, both the

U.S. Open and U.S. amateur championships. He would have been 59 years old.

ORAL SEX RISK

A study reported late last year, in the November 22 issue of *AIDS*, clarified issues related to HIV transmission in oral sex between men. The researchers noted that after one study which found an 8% transmission through oral sex [out of a group of about 110 men], people began to think that in general, 8% of transmission between men could be through oral sex. In preliminary results with 239 men from this longitudinal study, they found a zero percent transmission due to oral sex. However, using a different analysis, the risk could be greater.

In their conclusion, the researchers stated, "These data confirm that the risk of HIV infection attributable to fellatio among MSM [men who have sex with men] and in the MSM population is especially low. It is important that health professionals, including HIV counselors have valid information to impart to their sexually active clients. If individuals believe that the risk of HIV from fellatio is high or on a par with well-documented high-risk exposures such as anogenital sex, they may not feel that sexual behav-

ior choices make a difference... one's choice of sexual practices do matter."

"I'M REALLY BEGINNING TO LOATHE THE CDC"

So says *Positively Aware* columnist and sexual health activist Laura Jones about the U.S. Centers for Disease Control and Prevention (CDC). In an e-mail to the staff on December 23, she writes, "The following item is under 'Medical News' in today's [HIV/STD/TB Prevention News Update]. The 'Medical Institute for Sexual Health' is one of those abstinence-only places, based in Austin, that is putting out public-ed materials based on selective interpretation of research data (and I don't even know what *Virus Weekly* is). There's no mention of the fact that we already *know* that the effectiveness rates of condoms are less for viruses transmitted by skin-to-skin contact (HPV, herpes) than for infections transmitted through contact with body fluids, and no mention of why this is so (condoms only cover a limited area of skin, la la la). They aren't talking at all about breakage or improper use when they're discussing these findings, either. Reading this stuff is more and more like reading HIV dissident writings

that quote Dr. [Peter] Duesberg as some sort of HIV/AIDS research wizard."

The item was taken from a source called *Virus Weekly*. It begins, "A new scientific report, 'Sex, Condoms, and STDs: What We Now Know,' released by the Medical Institute for Sexual Health, reveals that condoms, even when used 100 percent of the time, fail to reduce the risks of some of the most common STDs to an acceptable level. One of the key findings listed in the item: "There is no evidence of any risk reduction for sexual transmission of HPV [human papillomavirus] even with 100 percent condom use.]"

Says Jones: "This is complete crap! There's evidence that use of even diaphragms and cervical caps reduce the risk of cervical HPV infection because they cover the cervix, so there's obvious benefits to use of condoms in protecting the cervix and rectum. Plus, no one can ever know for sure when they picked up HPV, so it's hard to do conclusive research now that this infection is so widespread. It's also virtually harmless in quite a few cases, depending on the strain you pick up and the functionality of your immune system. They aren't talking straight about HPV at all."

In the past year, members of Congress and health advocates have attacked the Bush administration for promoting scientific misinformation through the CDC. "Simply put, information that used to be based on science is being systematically removed from the public when it conflicts with the administration's political agenda [such as abstinence-only education]," 14 Democrats wrote in a letter to the U.S. Department of Health and Human Services.

AROUND THE GLOBE

WOMEN MAKE UP HALF...

...of all HIV infections. The annual UNAIDS and WHO report (United Nations Joint Programme on AIDS and World Health Organization), released in December, showed that women living with the virus almost equaled the number of men with

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THE IMPACT OF HIV/AIDS ON STARVATION AND SURVIVAL IN SOUTHERN AFRICA

From a statement from UNAIDS and the Inter-Agency Standing Committee

As heads of the world's major humanitarian agencies, we call on the international community to respond appropriately to the human tragedy now unfolding in Southern Africa. While exact figures of morbidity and mortality are difficult to gauge, all indications point towards nothing short of a decimation of populations in their most productive years, and the prospect of economic collapse and insecurity in the foreseeable future. Famine is but one symptom of a crisis that has been exacerbated by the scourge of AIDS and increasing poverty. The compounded impact of HIV/AIDS and mentioned factors is rapidly eroding the coping strategies used by communities to survive and destroying human capital necessary for the recovery from frequent drought and natural disasters. AIDS kills young adults, especially women, who are the backbone of their families and communities. It leaves behind orphans in large numbers with few prospects for a healthy future. Entire communities are collapsing under the strain of caring for the ill while maintaining productive livelihoods. Without a massive infusion of money and a greatly expanded effort by the affected countries in collaboration with the international community, the future prospects for the 60 million people living in Southern Africa hold little hope. Unless prompt and decisive action is taken now, it is estimated that, just due to HIV/AIDS 20% of the adult population will die prematurely. This number will definitely increase with the combined impact of food shortage, malnutrition and weakened health services.

Positive Empowerment

Fighting Terrorism on Religious Grounds

by Kenneth Dantzer

This article is a tribute to all the unheard voices that have passed on from life to death. Spiritually, death is not the end of those individuals who died of AIDS related conditions. As an activist and minister, I continue the fight against AIDS and dispel the ignorance about how the disease is contracted.

I live in Kansas City, Missouri. Kansas City is a very traditional Midwestern city. However, there are many individuals and organizations fighting against the spread of AIDS. AIDS is a disease that does not discriminate. My concern and advocacy work is with the Latino/a, African-American, and Native American communities. I often ask myself: Why these people? The answer is they are a part of my ethnic make-up and I cannot stand silent and see them denied services or care.

I work at the Kansas City Free Health Clinic as a Peer Counselor. As a Peer Counselor, I work hard helping individuals keep their doctors' appointments, case worker appointments and I share up-to-date information about HIV treatments as well. My goal is to also help clients to empower themselves by asking questions such as: Do you know how you contracted HIV? Do you know what your medications are? Are you familiar with the side-effects? What is your goal three months from now and how will you arrive at your goal in your health care? Do you inform your doctor about how you are feeling? Do you know what your CD4 count and viral load are? In case there is an emergency, do you have a card with your

medications and personal information on it with you at all times? What are you doing to keep from being re-infected?

As an activist, I am very proactive in the community. I am now the Chair of the African-American AIDS Project of Greater Kansas City. I realize that HIV/AIDS is a problem in the African American and Latino/a communities.

Sometimes I have to just speak up and out and let the chips fall where they may. I make no apologies for sacrificing my energy and time because I believe it is making a difference in Kansas City. I am appointed by the mayor of Kansas City to be a part of the Ryan White Planning Council which deals with both prevention and care. In the past I have served as the vice-chair of Ryan White Title I for the Greater Kansas City area. I am also a new correspondent for the *Mokan Plus*. *Mokan Plus* is circulated in Missouri, Kansas, Denver, Iowa, and Nebraska.

Because this disease surrounds many political facets, I have to be a strong-willed individual in order to help those who are facing difficulty.

As a minister, I work with a wonderful group of individuals at St. James United Methodist Church. Covenant to Care is a caring group of people that work hard on ministering to those who are living with AIDS. They provide words of inspiration,



and make their presence known with open arms and many times go out of their way to make life more comfortable for those who are living with AIDS.

As a spiritual person, I believe in the power of prayer, meditation and making daily affirmations to feed my inner spirit.

There are always those who are out to dispel and pull you down, but I do not allow them to define who I am. Each day to me is a day of thanksgiving. I am often confronted with discrimination and marginalization, but through it all I maintain a positive attitude and remain on top because I am here for a purpose. I have no problem sharing my inspiration with those who are down in spirit because I know that there is someone greater than any problem that confronts me.

If you are a minister, case worker, or community activist, you are under a terrorist attack by those who have no knowledge about HIV or of the feelings of those who are living sad lives. Many of our sisters and brothers have died because of the ignorance and we who are alive have the power to change things. Personally, until some churches repent of their discrimination and prejudices, humankind will always be under attack on religious grounds. ☩

“On current trends, AIDS will kill tens of millions of people over the next 20 years. But this need not happen. We know prevention works. We know that HIV treatment and care work. The global AIDS response is poised to enter a new era: where leadership and commitment are at long last matched with the resources needed to get on with the job. Investment in AIDS will be repaid a thousand-fold in lives saved and communities held together.”



Photo: UNAIDS/P. Piot

One-on-One with **Dr. Peter Piot**

by Charles E. Clifton

Executive Director of UNAIDS since its creation in 1995 and Under Secretary-General of the United Nations, Dr. Peter Piot comes from a distinguished academic and scientific career focusing on AIDS, other communicable and sexually transmitted diseases, and women's health in the developing world.

Using his skills as a scientist, manager and activist, Dr. Piot has challenged world leaders to vision AIDS within the realms of social and economic development as well as human security.

Under his leadership, UNAIDS has become the chief advocate for worldwide action against AIDS, with the global mission of leading, strengthening and supporting an expanded response to the epidemic. It has brought together eight organizations of the United Nations system around a common agenda on AIDS, spearheading UN reform.

Charles Clifton: *Why AIDS? Why are you so intimately involved in this global cause? Would you please speak a bit about your background, your interest in AIDS and how/what UNAIDS is all about?*

Dr. Peter Piot: Perhaps unusually, the things that I thought were important when I was first starting out as a medical researcher were the unfashionable areas, but which were responsible for a great deal of illness, especially in tropical Africa.

So I was working on women's health and sexually transmitted diseases (STDs) in the early 1980s, when AIDS first appeared. I had been working in the then Zaire. I vividly recall returning in 1983 to see the wards of the largest hospital filled with both men and women suffering from this new disease. From that moment on, it was clear that there would be a new crisis we had to deal with, but I don't think anyone could have foreseen just how comprehensive and devastatingly AIDS would spread globally.

In 1994, it was becoming clear that the epidemic was much more than just a health problem, and needed a new kind of coordinated UN (United Nations) response. UNAIDS was created, beginning officially on 1 January 1996, and at that stage was the leading edge of UN reform. We bring together eight co-sponsors in a joint focus on AIDS, ranging from the World Bank to UNICEF and the UN Development Programme. UNAIDS has a fairly small secretariat, with much of our staffing comprising UN country AIDS coordinators in high priority countries around the world. With the secretariat and co-sponsors, we provide global leadership and advocacy, and the world's information about the state of the epidemic and best practices in response.

CC: *Politicising AIDS: There is a lot of noise in the U.S. media about what the Bush administration is and isn't doing to adequately address the AIDS epidemic and that HIV prevention isn't being driven by scientifically sound approaches. In addition, AIDS activists from around the world are directing pressure on pharmaceutical companies and governments to do more on the international access to treatment issue and especially in regards to allowing for the production and distribution of generic drugs. However, other than the problems in South Africa and occasionally Brazil, we very seldom hear about where AIDS is on the political agenda in other countries. Can you speak about where is AIDS on the political and social agendas of China, other parts of Africa, the Caribbean and Central America? What are the broad issues as they relate to care and support, and specifically access to antiretrovirals and treatment?*

PP: Over the past six years, we have seen more and more governments make AIDS a political priority, breaking down the walls of silence surrounding the epidemic. Today, we see presidents and prime ministers throughout Africa, the Americas, the Caribbean, Asia and Eastern Europe publicly displaying personal commitment to the fight against AIDS. They have recognized that AIDS is not just a health issue; it is fundamental to development, progress and security. Dozens of countries now have national AIDS commissions and strategies in place. In almost 30 countries, presidents or prime ministers head them—an indication of the priority they per-

sonally attach to the problem. Of these, 13 countries are in Africa. These are encouraging signs.

In the Caribbean, for example, the region's Heads of State came together to form the Pan-Caribbean Partnership on HIV/AIDS in February 2001. As part of the Partnership, governments work closely with the international community and civil society to boost national and regional responses to HIV/AIDS.

In Africa, the Heads of State from several countries (including Mali, Nigeria, Rwanda, South Africa and Uganda) have come together to form AIDS Watch Africa. This initiative enables members to alert other Heads of State to the threat AIDS poses to development, and to encourage them to tackle the epidemic.

China appears to be on the brink of an explosive and generalized HIV epidemic if wide scale, effective prevention programs are not implemented very soon. There are already serious HIV epidemics among injecting drug users and sex workers, and HIV is likely to spread to the general population due to high rates of STDs (sexually transmitted diseases), ignorance about HIV, lack of access to condoms and sexual health services, and large-scale internal migration. Official estimates put the number of people living with HIV in China at one million in mid-2002. Extensive HIV infection, of 150,000 people (and possibly many more), has also occurred among blood donors in rural areas of central China. The government has acknowledged the situation and is trying to remedy it. However, there is need for greater openness about the extent of the problem, as well as greater efforts to address it and support those affected. UNAIDS and others are working, for example, in the highly affected Henan Province to increase access to care and support.

Increased access to comprehensive HIV care and support, including antiretroviral medicines and treatment for HIV-related opportunistic infections, is a global priority. As drug prices drop and health systems improve, significant progress is being made in these areas. But treatment and care are not yet reaching the vast majority of people in need.

A new analysis of access to treatment shows that of the six million people in the developing world in need of antiretroviral drug therapy, just 230,000, less than 4% were receiving antiretroviral drugs at the end of 2001. In high-income countries, where an estimated 500,000 people were receiving antiretroviral treatment, 25,000 people died of AIDS in 2001. In Africa, however, where only some 30,000 of the 28.5 million people infected were receiving antiretroviral treatment, AIDS killed 2.2 million people in 2001.

Access to adequate care and treatment is a right, not a privilege. Although real progress has been made in lowering the price of antiretroviral therapy in the developing world, far greater action is needed by both governments and the private sector to ensure that treatment reaches those in greatest need. The cost of treatment must continue to fall, and governments in both the developing world and donor countries must create sustainable funding streams to provide treatment, while strengthening the healthcare infrastructure.

CC: *I attended my first International AIDS Conference in Durban nearly three years ago. A week prior to the conference I had the opportunity to visit the townships outside of Capetown and clinics in Durban. I was completely overwhelmed by what I saw and couldn't imagine any type of substantial response to the sheer numbers facing the country. However, by the time the conference had ended my attitude had completely changed, I had had a chance to visit and talk with people working at the grassroots and community level. Only then did I begin to understand that, yes there is hope. There is life. There is a chance. In your work with non-Western countries, in countries that have been defined in the U.S. as resource-limited, what successes have you witnessed in how people and communities have responded to this epidemic over the last few years?*

PP: Despite the fact that the epidemic continues to grow in most regions of the world, we do see some signs of hope where countries have managed to reduce HIV prevalence and/or provide affordable care for people living with HIV/AIDS.

A number of African countries are continuing to register success in fighting the epidemic as a result of increased commitment from governments, businesses and communities. HIV prevalence continues to drop in Uganda—down to 5% at end-2001, compared to 8.3% at end-1999. HIV prevalence is falling among young urban women in Zambia—from 28% to 24% among 15-29 year-old urban women between 1996 and 1999, and from 16% to 12% among rural women ages 15-24.

Cambodia, like Thailand, is showing that the “natural” course of the epidemic can be changed. Strong political commitment and large-scale prevention programs have helped lower adult HIV prevalence from 4% at end 1999, to 2.7% at end 2001 in Cambodia.

By mounting a strong national response, the Polish government has successfully curtailed the epidemic among injecting drug users and prevented it from gaining a foothold in the wider population.

Latin America and the Caribbean show that middle- and low-income countries (where HIV prevalence is still relatively low) can provide treatment and care through the public sector. Eleven countries in Latin America and the Caribbean now have policies and laws that guarantee antiretroviral therapy for their HIV-positive citizens, although this does not mean all in need receive treatment yet. Across the region, about 170,000 people now receive antiretroviral treatment, of which 100,000 are in Brazil.

The key to cracking this epidemic seems to be a specific combination of community action from the grassroots meeting leadership, not only from governments but also from civil society, religious organizations, women's and youth groups, and business.

CC: *Money. There never seems to be enough. It's been reported that something like \$10 billion is needed annually to address HIV and AIDS in developing countries. How much money is currently being directed towards the Global Fund? Who is at the table supporting the Fund at the corporate, governmental and public level? Who is miss-*

ing and why? And what can we realistically expect to be accomplished over the next few years?

PP: The Global Fund to Fight AIDS, TB and Malaria has received total pledges over five years of US\$2.2 billion, the first \$1 billion of which was available in 2002, with a further \$650 million becoming available in 2003. In its first two rounds of grants, the Fund committed itself to disbursing \$1.5 billion in 2003 and 2004.

The idea behind the Fund is to build an independent global/private partnership to attract, manage and disburse new resources to fight AIDS, TB and malaria. The Fund is not meant to replace current efforts but to raise additional resources from new sources, at the same time as support for current efforts is increased. The Fund's partners—national governments, multilateral organizations, NGOs (non-government organizations) and the private sector—are equally committed to supporting and assisting the Fund in its operations, and to ensuring that resources flow rapidly to where they are most needed.

To date, governments have been the major contributors to the Global Fund, although there have also been significant contributions from some businesses, foundations, and individuals. The Fund publishes an up-to-date list of the pledges it has received, so is very easy to see where the money is coming from (www.unaids.org).

The Fund has been established very quickly and made its first disbursements in near record time, given the international context in which it is working. The coming year is critical to maintain the Fund's momentum. It will be the most challenging in attracting new pledges in a period when it is still too early to demonstrate that the current disbursements have made a difference. UNAIDS is working closely with the Fund, in particular to help ensure that developing countries have the right support to make good proposals for funding.

CC: *2004 International AIDS Conference, Thailand. If you were to look into a crystal ball, what would you like to see at that time?*

PP: At the Barcelona conference last year, there was for the first time a Leadership Track. I would like to see the leadership efforts at the conference greatly expanded. Heads of state need to be there, together with major decision makers—we'll know we're really getting somewhere when finance ministers see that this sort of conference is important. But as well, the conference needs to bring together trade union leaders, women's leaders, intellectuals and activists—not necessarily just those currently in the AIDS movement.

I'd like to see the conference reflecting a truly scaled-up response from around the world. That means a lot more attention to the politics, economics, and implementation research, which ought to accompany broad-scale AIDS responses.

I hope there will be some good news on vaccines, microbicides, and more effective and simpler treatment regimens. With the twin messages of technological advances and political progress, we would all be given reason for hope. ☩



AT THE CROSSROADS—HIV AND THE PEOPLE'S REPUBLIC OF CHINA

BY SCOTT COOK, PH.D., JOHN FLYNN, SHAILEY MERCHANT, MPH AND GLEN PIETRANONI, R. PH.



Developing and implementing a model HIV prevention program at the grass-roots level in the People's Republic of China is a very difficult undertaking, but this is the task we have agreed to with the Health Bureau of Zhejiang Province in China. The U.S. Centers for Disease Control and Prevention (CDC), World Health Organization (WHO) and various universities in the U.S. are actively involved with HIV/AIDS in China; but all of these undertakings are between professionals, usually physicians, or high level administrators on all sides. What has not been done, and what is unique to the relationship that Howard Brown Health Center (HBHC) is developing, is to work directly with the people in China who will implement the treatment and prevention programs among the Chinese population. Getting out in the field among the Chinese populations most at risk—men who have sex with men (MSM), intravenous drug users (IDUs), and female sex workers—is a major milestone.

Here is how this happened. For approximately 20 years, I have traveled to China over 25 times. All of my work there has been in health care—health administration and health policy, cardiac surgery, telepathology, etc.—and all of this work was in Zhejiang Province, a relatively wealthy southeastern coastal province with advanced educational and health care systems. The capital city is Hangzhou, with a metropolitan population of about four million.

In order to do business effectively in China, the Chinese people you work with must first trust you, and, secondly, you need a "mentor," or high level official to support you. I have been lucky on both accounts, being a close personal friend of the director of foreign affairs for the Zhejiang Provincial Health Bureau, who is also a respected official throughout the province. This is the reason that HBHC is "allowed" to initiate discussions around HIV disease and prevention among the

Chinese people and with the three high-risk groups mentioned above.

It is also important to understand that working with these high-risk groups in China has its own particular set of problems. The first is that both IV drug use and sex work are illegal activities in China and are prosecuted more consistently and severely than in the United States. As a result these populations are much more "hidden" in China than they are here. Another barrier to reaching these groups is the potential or actual conflicts between the Chinese provincial health departments and the police departments. Whereas the police or security department are charged with arresting IV drug users and sex workers, the health department has a different goal, which is to provide prevention and treatment; and the two bureaus are often in conflict.

To be gay in China is not illegal. However, the problem with providing outreach to gay men is that the gay population is off the radar screen for most Chinese officials and the population as a whole. They vaguely know that they have a gay population, but they have no idea of the venues where people meet. It is very easy for the Chinese to think that the gay population is quite small because they never hear anything about it. In fact, there is only one or possibly two officials in the Zhejiang Provincial Health Bureau who know of the gay bars and clubs in the capital city of Hangzhou. It is important to have the support of these individuals in order to identify the bars and meeting places for gay men.

In 1999 my partner and I lectured on HIV/AIDS in Hangzhou and then in April 2000 we were visited by a group of Chinese health officials from Zhejiang Province about HIV/AIDS prevention. A team from HBHC traveled to China in September 2002 to meet with these same officials and many of their colleagues. The ostensible purpose of these trips was to provide information about HIV/AIDS; however, another very important factor was to provide the health officials with information to take to the central provincial government to argue the case of

providing outreach activities to these at-risk populations who are engaged in illegal activities, without the threat of arrests from the police.

Howard Brown Health Center has been asked by the Chinese government to develop model HIV prevention programs for two to three cities in Zhejiang Province. The next step is to work with three to four Chinese outreach workers in Chicago in April or May of 2003 for a period of about a month. They will work with our outreach workers in the field conducting prevention activities in the venues for gay men, IV drug users and female sex workers.

We will then return to China in the Fall to help them develop printed materials for distribution and will expand training to other Chinese outreach workers. We will also work with the Health Bureau to set up confidential HIV testing sites, as well as work with several hospitals that can accept referrals for people who are HIV-positive. Finally, over the next couple of years, we plan on setting up working model HIV prevention programs and HIV testing sites in three major cities in Zhejiang Province—Hangzhou, Wenzhou and one other city—with the intent that the provincial Health Bureau will use these models throughout the rest of the province and then in other provinces in China.

We have a huge and serious task ahead of us, but we are committed to seeing it through.—Keith J. Waterbrook, Executive Director, Howard Brown Health Center, Chicago.

AT-RISK POPULATIONS

Recent reports and data paint a dismal picture of HIV/AIDS invading regions of the globe, where for many years experts believed that some populations might be less susceptible, or even immune, to the infection. China was thought to be one of these countries, with its traditions, rich culture and government regime. To everyone's surprise, HIV infections are spreading at alarming rates all throughout the country, even within its mainstream population. Where HIV was "virtually nonexistent" a few years ago, there are now one million people in China with HIV, and the United Nations (UN) predicts that this number could well rise to ten million by the end of the decade.

The most frequent modes of HIV transmission in 2001, according to the UN, are sharing of contaminated needles among injecting drug users (IDU) and unsanitary practices during paid plasma collection. However, the spread of HIV is quickly gaining momentum through sexual intercourse, both heterosexual and homosexual. Underlying vulnerability factors include the widespread lack of knowledge and protective life skills, internal labor migration, underprivileged minority communities, poverty, youth, and of course gender inequity.



Shailey Merchant writes, "there is a large difference in attitudes towards men and women's sexuality, both within and outside of marriage. Promiscuity in men is much more acceptable. This exposes men to an increased risk of infection, and increases the possibility that they will transmit HIV to their partners. Messages focusing only on 'faithfulness' and 'one partner' prevention delude people into false safety. Taking into consideration the increasing number of men paying for sex, it is devastating to the women who believe that they are protected as long as they only have one sexual partner.

"So what happens to those women who are forced to deal with HIV? Women known to have HIV/AIDS are more likely to be rejected by their family, denied treatment, care and basic human rights. Yet women and girls will tend to bear the main burden of caring for sick family members, including their spouses, brothers, or fathers living with HIV/AIDS. Many women in the villages whose husbands were the primary breadwinners are being left widowed and/or are forced to search for work to care for their sick husbands. In rural areas, finding work can be difficult, thus forcing many women and their children to turn to the sex trade industry and other harsh work conditions. Many individuals are forced to move to a different region of the country in fear that their HIV status will be revealed to those around them. Movement not only facilitates the spread of HIV infection but poses as a barrier to adequately tracking the number of individuals testing positive.



“It is often reported that those who test HIV-positive are denied treatment or access to care due to their sexual practices or involvement in ‘illegal acts’ such as prostitution, homosexuality, drug use and/or other criminal activity. For female inmates, ‘education centers’ have been created. Unfortunately, the centers usually provide scarce information on sexual health and miss the opportunity for motivating behavior change that could improve women’s health. Condoms are rarely used in sexual encounters, and some sex workers believe that they can contract HIV only from a foreigner, but not from a Chinese customer. Condom use is made more difficult by the fact that, in practice, local police may arrest women carrying condoms in their purse as ‘proof’ of prostitution.”

John Flynn writes, “as a gay male, living with HIV for the last five years, I had two goals to achieve during my visit to China. The first was to work with the Chinese Center for Disease Control and Zhejiang Health Bureau on HIV prevention and education for men who have sex with men (MSM). Second, and more importantly, to generate opportunities to discuss how to reduce the stigma attached to HIV affected populations. I thought it would be interesting to disclose my HIV status to other healthcare professionals, to gauge their reactions, and to try and generate some discussion around living with HIV including the challenges and rewards of taking medications and managing therapy.

“Our team’s presentation to the Health Bureau included basic public health theory around HIV prevention and education for MSM. After a theoretical foundation was introduced, I offered specific examples of the type of work we do at HBHC, including basic venue outreach at bathhouses and on the Internet, as well as our Treatment

Advocacy Program, which is a behavioral intervention for HIV-positive MSM.

“The dialogue was respectful, and I felt a genuine interest in our work from the Chinese contingency. At one point during



one of the breakout sessions, it became evident that there was an opportunity to disclose my HIV status. Having dealt with HIV medications for the past five years, I thought I could give the group some personal insight. Yet this self-disclosure was not only to give a perspective on the side effects of the drugs—I wanted the contingency to get a sense that it was important and critical to talk openly about HIV and being HIV-positive. I wanted them to understand that it is O.K. to be positive, to share personal experience, and to engage in conversation to nurture understanding and growth. The reaction was mixed. Some people were obviously shocked; others pulled me aside during breaks to engage in meaningful conversation.

“Shanghai, one of the nation’s largest and most progressive cities in China, has approximately eight million people. During the meeting someone mentioned that 60%

of all new cases reported in the Zhejiang Province are among men, yet officials claim that there are only 20 gay men in the entire province. However, after only spending a few days in Shanghai, the team was able to identify a few sites for outreach and education efforts to the MSM population, confirming that there were more than 20 gay men in the entire province.

“While walking back to our hotel after an evening dinner, we noticed that several hair salons were open late night, yet there seemed to be very little work being done. After some investigation, we found out that many of these salons actually have ‘back rooms’ for sexual encounters. Shanghai actually does have some gay bars, one of which some of us had the chance to visit. While the décor was contemporary by U.S. standards, we had to go ‘underground’ as if we were back in the 1970s to find it. Back at the hotel, a few of us were fortunate enough to afford a massage, due to the strong U.S. dollar against the Yen. While being massaged, some of our team members were propositioned by a male massage therapist for ‘an extended massage’ in their room.

“Perhaps one of the most difficult aspects of HIV prevention work in China is with the IDU community. They often face multiple ‘life-stressors’ which, because of their immediate survival nature, can take precedence over protecting themselves from HIV. As in the U.S. these stressors include,





but are not limited to, financial distress, the impact of substance use on overall judgment and decisions about HIV risk-reduction, inadequate housing and medical concerns related to substance use and abuse, and overall neglected health. In addition, there are many cultural taboos and myths in China associated with providing prevention services to IDUs, particularly the needle-provision or exchange aspects of programs (e.g., the myth that providing sterile or new needles to IDUs will increase their substance use). Because of these multiple issues, if HIV-prevention with IDUs is going to be successful it must be more than simply educating individuals about HIV and AIDS, how HIV is transmitted and how to protect oneself against infection.”

ACCESS TO TREATMENT

Last July, the International AIDS Conference held in Barcelona brought out activists from all over the globe. Their primary concern centered on increasing the availability of HIV drugs for under-developed and developing countries at reasonable prices. ACT UP/Paris and U.S. activists demonstrated at the conference daily, demanding that governments and pharmaceutical companies give up their patent rights and allow generic drug companies to produce the life-saving drugs for use in countries in Asia and Africa for pennies on the dollar. Successful generic drug programs to treat patients in countries not able to afford expensive brand name drugs was highlighted in Brazil’s example.

An idea of a good time, while in China, Glen Pietrandoni writes, “was to visit a Chinese pharmacy, weird, I know. A section of one particular store was devoted to prepackaged Western medicine that a pharmacist prescribed over the counter. Most interesting to me were the herbal and natural items for sale. These included dried pieces of animal parts, all kinds of teas and herbs, and my personal favorite were large glass jars of snakes and worms swimming in an alcoholic liquid. The pharmacist sold ‘shots’ of the liquid to cure ailments. In another section was

a compounding area where the pharmacist weighed out and mixed different herbal items together to prepare a ‘designer’ solution to the patient’s illness or complaint. Through a translator, I asked the pharmacist about HIV/AIDS. I wanted to know how he



could help someone with HIV using natural products. He seemed stunned at first, but then mentioned how natural products boost the immune system and help cleanse the liver. It was obvious that his overall experience had not prepared him for such a question; but how different is that from asking similar questions to a pharmacist in the United States who has never seen an HIV patient?

“Still, I was a little stunned when a Chinese doctor asked me, ‘What is the best drug for HIV?’ The question itself told me that this physician did not have any experience or information on how drugs are used to treat HIV. Obviously, we have known for about 8-10 years that in order to prevent drug resistance, pharmaceutical agents must be used in combination. We also know that there is not one answer that fits all patients. The ‘art’ of using drug combinations evolves every time new treatment options become available. Because the question was too complex to reply with a simple answer, I questioned which drugs were available in China. He stated that only two nucleosides were available in China, although he was not sure.

“The Chinese Health Ministry announced that beginning in January 2003,

that four drugs would be mass-produced in China by local pharmaceutical companies, with permission of the drug’s originator and in compliance with international law. At this time, it appears that the only true regimen that will be available is ddi (Videx) + d4T (Zerit) + nevirapine (Viramune). AZT (Retrovir) is mass-produced by many companies in China. In addition, the Chinese government is negotiating with the pharmaceutical companies to reduce the prices of other patented drugs by as much as 90% and reduce the import taxes. With these agreements indinavir (Crixivan) and efavirenz (Sustiva) could also become available in China at lower prices. This is great news of course, but many doctors are unsure when the drugs will actually be available.

“Even with drastically reduced prices, anti-HIV therapy will very likely remain unaffordable for most HIV-positive Chinese citizens, unless the government can help pay for the drugs. Currently, only government employees are covered by national health coverage, leaving most of the country’s rural populations without health care. Some expect that only 10–20% of the one million plus Chinese infected with HIV will be able to access the newly available treatments. In the U.S., state Medicaid programs, AIDS Drug Assistance Programs (ADAP) under the Ryan White CARE Act, or private insurance companies usually pay for antiretroviral drug therapy. Most people in the United States could not afford medications if they had to pay for them out of pocket.

“Everyone is aware of how important adherence is to ensuring successful HIV therapy. It is imperative that the patient receiving HIV medications understand adherence and how the drugs work. In the Chinese culture, this may be more difficult because many Chinese still believe in traditional medication (natural and herbal medicine) to treat illness. Poor adherence to anti-HIV therapy will undoubtedly lead to resistance and lessen treatment options. Obviously much education must be provided to physicians, pharmacists and patients in China if long-term anti-HIV therapy is going to be successful.”



NEXT STEPS

Our experiences in China involved working with medical professionals, administrative staff, political officials and community members in the Zhejiang province faced with an exponentially growing HIV-epidemic among the MSM, IDU and sexual worker populations, in a country that has done little to address HIV prevention thus far. It is a frightening and critical time. Despite the specific cultural differences between China and the U.S., which sometimes appear extreme, part of the

HIV/AIDS challenge facing China is the same challenge faced by the U.S. and most other countries living with the pandemic: How to effectively address the care and prevention needs of HIV-positive individuals, at-risk populations and their sexual partners. These are populations caught at the intersection of public health, cultural values, religious beliefs and political agendas.

Only recently has China directly acknowledged this disease which threatens the stability of the country and which simultaneously forces them to acknowledge the existence of, and the need to work with, people the government and many citizens would prefer to ignore. This conspicuous similarity between the U.S. and China was just as striking as the cultural differences observed. The uncomfortable place that China now finds itself is the same place the U.S. found itself during the 1980s. During those early years of the AIDS epidemic in the U.S., we witnessed the devastation that can occur when government and political leaders turn away from the care and treatment needs of impacted communities. And while the U.S. has made great strides, in many ways we are



still anxiously negotiating this difficult intersection of conflicting values, political agendas and public health.

The Chinese are making great strides to overcome obstacles, including cultural, to deal with the threat of the HIV epidemic in their country. The Health Bureau has committed to allow four outreach workers to take part in a four-week visit to the U.S. to exchange ideas with HBHC staff on providing culturally competent health care and HIV risk harm reduction to at-risk populations. Is there a lot of work to be done? Absolutely. Are the Chinese interested and

invested in the health of their people? Absolutely. However, it's going to take time, patience and plenty of resources.

In China, as in the United States, if the wrong choices are made, if fear, intolerance, and profit margins take precedence over sound public health decisions, many unnecessary deaths will occur. If people in China—and more importantly if the Chinese government—make the right choices, new understanding, compassion, inclusion and improved public health can take root and grow. And more important, million of lives will be saved and suffering reduced. China now stands at a crucial crossroads. The choices they make in the next few years regarding how they will attend to the needs of HIV-positive individuals and at-risk populations will determine the future of the entire country for decades to come. Hopefully China will learn from our mistakes and from our successes. This kind of coordination and cooperation will take constant effort and monitoring. ☩

The Howard Brown Health Center team included Shailey Merchant, MPH, Scott Cook, Ph.D. (Director of Community Services); John Flynn (Men's Health Promotion Manager); Keith J. Waterbrook (Executive Director) and Glen Pietrandoni, director of Clinical Pharmacy Services for the Walgreens Specialty Pharmacy, focusing on HIV, located in HBHC.



Neither words nor statistics can adequately capture the human tragedy of children—lost, ignored, abandoned, sick or grieving for deceased parents. Sometimes they are stigmatized by society through their association with HIV/AIDS, and always—plunged into economic crises and insecurity by their parent(s) death. Children have to look after children and struggle without services or an extended support system in impoverished communities burdened by violence.

The Sparrow Ministries Hospice is an interdenominational Ministry of Help caring for “deserted terminally ill” adults and children with HIV/AIDS. They provide in-patient hospice accommodation, medical care, and psychological, social and spiritual support to 15 adults and 30 children. Their out-patient facility offers care to 45 adults and six children, including hospital visits, medication, food pantry, clothing, counseling and help with applications for disability grants. The Sparrow Hospice provides home-based care reaching up to 10 families a week. In addition, they provide home-based care courses, as well as counseling courses, in order to mobilize communities with effective HIV/AIDS knowledge.

The Hospice was founded in the home of the Rev. Corine McClintock in 1992. When I visited in October 2001, they were still in Rev. McClintock’s home, a modest 4-bedroom house just outside of Johannesburg, South Africa. The house has been converted into a hospice with a large room on the rear serving as a nursery for infants and small children. Since opening they have lost over 600 patients to AIDS, and were losing nearly three patients a week.

The reality of AIDS is staring them in the face. From the hopeless, helpless individuals who stand outside their doors in the morning, to the children with their brave smiles, longing to be held by anyone—the hospice seems surrounded by the biggest tragedy in human existence. Sometimes they

get patients from Animal Welfare, who when they go out looking for injured or neglected animals stumble over a human being. Sometimes patients migrate to mine dumps to be left alone or to die, as they do not see their way out of despair and illness. At the time of my visit, there was a tiny two-month



old baby boy, born with AIDS and abandoned in a trash dump whom the hospice had just taken in for care. Regardless of this reality, they have refused to be stunned into passivity by this silent killer. Their motto is and has always been, “Get up and live.”

helps Rev. McClintock run the home and raise donations, and three South African women work in shifts to help with care, cooking and cleaning. There is no anti-HIV therapy and only a few medicines available to help fight opportunistic infections.

Lynette (a volunteer) talking about her friend Juliet, a 10-year-old girl living with AIDS, said that, “every night she falls asleep on my chest. Just to get her more comfortable I move her around on her side of the bed. When I finally doze off I feel her little hand in mine. Two days ago she weighed 15 kg (33 pounds), today it is 14 kg. Her skin is dry and white. I pretend not to see and not to know the signs. A few hours later our midnight run begins. A few nights ago we got up 16 times, forced by a never ending stream of unrelenting diarrhea. Last week she was admitted for two days and sent home. Another day, another hospital. This time they did not even keep her, just sent her home with the terminally ill tag. In the early hours

sparrow ministries— A south African Hospice by charles E. clifton



Sparrow Ministries is supported entirely through charitable contributions. A doctor from a local provincial hospital volunteers his services, a female graduate student

of the morning I cry silently, hating the world, detesting the rift between rich and poor. If only I could get money for her. Yet, there are hundreds of children like her.”

With donations, they give patients the opportunity to live, care for them medically, psychologically, socially, more importantly spiritually—to help them find a way out of despair and discover the meaning of this illness in their lives. The women, men and children I met were sick,

but they were not worried about where their next meal would come from or where they would sleep that night. (see Orphan Resources on page 27) ☪

Before I went to South Africa, I wasn't too, too worried about AIDS orphans. While it's horrible to lose your parents, I expected neighbors and relatives to help.

Instead, in my trip to South Africa for the 2000 International AIDS Conference, I found that orphans were actually mistreated. The stigma of AIDS is so great that neighbors were shunning them, not sending over plates of food. Relatives were converging to steal property—including the houses where the orphans lived. I couldn't believe that people could treat children like this—*children*.

The only time I've cried during seven years of working at *Positively Aware* was at the International AIDS Conference two years earlier, in Geneva. During a presentation, a doctor from India talked about the lack of medicines for her patients. One was a baby girl found by an orphanage in the garbage. When they realized she had HIV, they put her back in the garbage. The doctor showed a slide of a beautiful, smiling little girl, now 4, petting a cow. The thought of this baby being put in a garbage can sent tears rolling down my cheeks for the rest of the presentation.

I had another shock during my trip to South Africa—education is not free. Families must pay to have their children attend school. Orphans must come up with money to *remain* in school, as well as for their school books and endless other fees. How can they do so? They usually can't, and end up without the education they need to become strong adults.

Nor is there free public health care, no county hospitals. No social safety network—no food stamps, welfare, or public housing. Government programs and other assistance do exist to some extent. But not like here—not universal social welfare, not in every country.

One report raised an issue I hadn't even considered—how do you even find an orphan household in order to help them? That's a lot of work in the trenches. There are not just large rural areas to cover, but crowd-

ed, impoverished townships throughout Africa. What about the other continents? The number of orphans numbs the mind—it's in the millions.

Moreover, households with AIDS orphans may also exist *incognito*, not allowing the community to know exactly what happened.

No doubt many neighbors and families help (and many cultures demand it). Two photos from the exhibit "Broken Branches" during the International Conference astounded me. In one you see an elderly



The Most Vulnerable of the Epidemic—Orphans

by Enid Vázquez

woman with the five orphaned grandchildren she is raising. In the next photo, it is three years later and you see her with *nine* orphaned grandchildren. As for younger aunts and uncles, many of them have died of AIDS too. Other times there are just too many children for one household to take in. Or siblings may be sent to separate homes.

Consider some other details. Children may be orphaned while their parents are still alive, due to illness that turns them into caregivers. Then there is the trauma of watching your parents die. Because most people with HIV/AIDS in the Third World are heterosexual, there are even more orphans and potential orphans. Also, advocates find that AIDS

orphans are subjected to more exploitation and abuse than other orphans, and have a higher risk of becoming infected themselves. (The vast majority are HIV-negative.)

Last year, at a meeting on the orphan crisis, UNICEF executive director Carol Bellamy said, "Almost without exception, children orphaned by AIDS are marginalized, stigmatized, malnourished, uneducated, and psychologically damaged. They are affected by actions over which they have no control and in which they had no part. They deal with the most trauma, face the most dangerous threats and have the least protections. And because of all this, they too are very likely to become HIV-positive."

Once again, the stigma alone kills. Some child advocates tell us not to even say "AIDS orphans," because that marks the children. If you're trying to help them, just say your program is for orphans. Otherwise the families that come to your offices are marked by AIDS. One organization gets around it by saying they help "orphans and other vulnerable children in regions severely affected by the HIV/AIDS epidemic."

Others don't like the idea of orphanages. AIDS orphanages also stigmatize children, and isolate them. It's better to offer community-based services, including home care. Well, sure, but orphanages are necessary in every country on the planet, and not just because of AIDS.

It's no wonder that when protecting orphans, advocates go back to the basics—stop the stigma. Promote education and awareness. As Archbishop Bonifatius Haushiku declared at the opening of Catholic AIDS Action in Namibia, an organization that helps orphans, HIV/AIDS is a disease, not a sin.

Work to establish voluntary counseling and testing, especially for pregnant women. Provide Viramune (nevirapine) or other medicines to prevent mother-to-infant transmission. Provide triple combination therapy to adults and children.

By all means, fight for prevention and treatment. Keep all family members alive *and* healthy. ☞

Orphan Resources

compiled by Enid Vázquez

Alliance for Youth Achievement. Works with small organizations in Kenya, Uganda, South Africa, Thailand, Vietnam and Cambodia that help orphans and/or street children. Site visits ensure that money is used for the purposes agreed upon. 534 Commons Drive, Suite 100, Golden, CO 80401. Visit www.allforyouth.org.

Catholic AIDS Action, Namibian Catholic Bishops Conference. In addition to working with orphans, prevention work includes condom education. P.O. Box 11525, Windhoek, Namibia. Phone (264)-61-276-350. Visit www.caa.org.na.

Children Affected by HIV/AIDS e-mail forum. Excellent real-world information from people working in a variety of efforts related to HIV/AIDS. Established by the U.S. Agency for International Development (USAID). Send an e-mail with "subscribe CABA" in the body to listserv@list.s-3.com. Also has list of resources related to children affected by HIV/AIDS. Visit www.synergyaids.com.

Elizabeth Glaser Pediatric AIDS Foundation. Dedicated to research, works to establish voluntary counseling and testing and prevention of mother-to-child transmission programs around the globe. 2950 31st St., #125, Santa Monica, CA 90405; (888) 499-HOPE (4673) or (310) 314-1459. Visit www.pedaids.org.

Family Health International. Decades of work around the world. Includes HIV prevention and care, voluntary HIV counseling and testing, and policy development and advocacy. FHI HIV/AIDS Dept., 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; phone (703) 516-9779. Visit www.fhi.org.

Firelight Foundation. Focuses on children orphaned or affected by HIV/AIDS in sub-Saharan Africa. 510 Mission Street, Santa Cruz, CA 95060; phone (831) 429-8750. Visit www.firelightfoundation.org.

François-Xavier Bagnoud (FXB) Association. After her son, helicopter rescue pilot François-Xavier Bagnoud, died in 1986 during a rescue attempt in Mali at the age of 24, his mother, the Countess Albina du Boisrouvray, did an amazing thing. She used her grief to start an association in his honor that helps other people's children: the orphans and vulnerable children of the world. du Boisrouvray was awarded France's Legion of Honor for her work on behalf of children with HIV, including impassioned advocacy before governments. The Association operates eight FXB houses for very young children suffering from HIV/AIDS, and provides them with treatment, in Brazil,

Colombia, India, Thailand and the United States. It compiles the Orphans Assistance Database (AOAD), an excellent listing of organizations and individuals (www.orphans.fxb.org). Supports community-based programs which in her talks the Countess says can be run on small budgets but with big results. Provides a bi-monthly update of the AIDS Orphans crisis via e-mail. Hires experts to scientifically document the social and economic impact of HIV/AIDS on a global scale. Conducts income-generating activities for families. Works with street children and also children of sex workers, among many other projects. Through "vocal interventions, written advocacy statements, and at times loud denunciations ... bridge[s] the divide between those working in the field and decision makers who determine policy and funding." U.S. office: (781) 359-3800. Visit www.fxb.org.

Hope for African Children Initiative. Community-based effort for children orphaned by AIDS or whose parents are ill or dying of AIDS-related causes. Coalition of five international organizations. P.O. Box 76154-00508, Nairobi, Kenya; phone 254-2-717-203. Visit www.hopeforafricanchildren.org.

National Community of Women Living with HIV/AIDS in Uganda (NACWOLA). Services include psychosocial support through home visits and counseling to members, their children and communities. Helps establish guardianship arrangements and provide documentation of important family history and memories in a "memory book." P.O. Box 4485, Kampala, Uganda; phone 256-41-269694. Visit www.designer-withoutborders.org/nacwola.html.

Pendulum Project. Describes some organizations they are working with on their website. Visit www.pendulumproject.org.

Treatment Action Campaign. The South African activist group brought the government to its knees, forcing it to provide Viramune (nevirapine) to HIV-positive pregnant women in public health clinics. That alone will do a great deal for the orphan crisis in that country. It also brought the pharmaceuticals to their knees, forcing them to withdraw a lawsuit stopping the government from making generic HIV medications. Visit www.tac.org.za.

Sparrow Ministries Hospice. (see story on page 25.) An interdenominational ministry providing for adults and children with HIV/AIDS outside of Johannesburg. Building homes for families living with HIV/AIDS. P.O. Box 91790, Auckland Park, 2006 South Africa. Visit www.sparrow.org.za. ☩

Almost two years passed before I managed to save the money and return to Ecuador last September. I was trying to follow-up on Doña Carmen, an Ecuadorian woman who had been HIV-positive for 10 years with no symptoms. Her five-year-old daughter had died of AIDS, there being no medicine or treatment available. I met Doña Carmen while she was caring for another HIV-positive woman, Doña Teresa. Doña Teresa had died of HIV com-

In the two years since I left Ecuador, Doña Carmen never responded to my letters. Never told me how she was doing. Never told me how the daughters of my deceased friend Doña Teresa were faring.

The mail system in this Andean nation of some 12 million is, shall we say, sporadic. Some letters and packages get through. Sometimes, lots of times, they don't. Sometimes packages from the U.S. get opened; sometimes letters get read. I won-

I knew who knew her. My former Peace Corps program manager had not heard about Doña Carmen in almost a year. Another person, a wealthy and well-connected German woman who had lived in Ecuador for more than two decades and had been giving money to Doña Carmen to care for my deceased friend's two daughters, was in Germany while I was in Ecuador.

I gave it my last shot. I took the eight-hour bus trip from the nation's capital, Quito, to Guayaquil, the second largest city in the country, where Doña Carmen lived on the outskirts, to see if I could find her or someone who knew her.

Doña María was a professional woman employed by a nationally recognized family planning and health agency in Ecuador, and knew Doña Carmen. She had invited her to come and speak at "talleres" (workshops) on reproductive health and sexually transmitted diseases. Doña María said that she had not heard from Doña Carmen in more than a year. The last she had heard, Doña Carmen had gotten tired of being asked to disclose her status by public health agencies. While Doña Carmen was publicly applauded and much admired and supported for going public about her HIV status, and of the death of her daughter from AIDS, afterward she was reviled, humiliated and made the subject of much negative gossip.

So Doña Carmen went into hiding. She was unavailable due to her HIV status. She was tired of being the only public HIV-positive woman in the entire country of Ecuador! I could imagine what a cumbersome, negative burden that would quickly become. Somewhere in Guayaquil, along with the daughters of my deceased friend, Doña Carmen was living a quiet life. I hoped.

I left Ecuador one day later. In my thoughts and spirit, I sent Doña Carmen and the daughters of Doña Teresa all my long-distance support, compassion and prayers. It was all I could do. They could use that. And so much more. ☩

Corella Payne, M.Ed., MPH, is a returned Peace Corps volunteer (1991-1995). She works with HIV-positive women, dedicating herself to serving the African American community through South Side Help Center in Chicago.

In Hiding—an Ecuadorian Woman

by Corella Payne

plications one month before I had last returned to Ecuador.

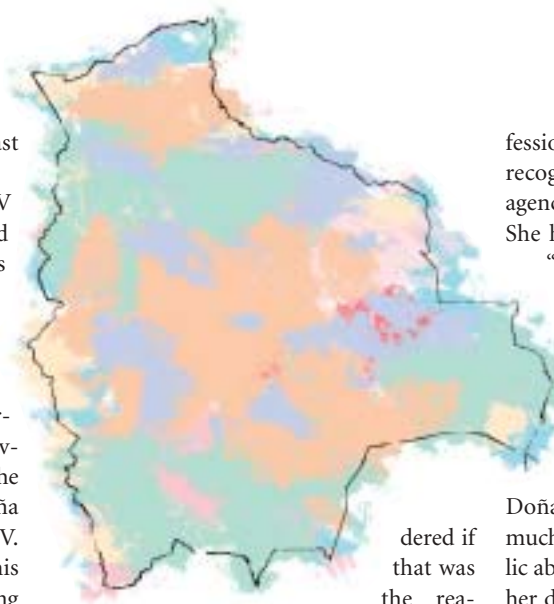
Expensive, intermittent access to HIV meds, no government or social support and shame *will do that* to infected women in less technologically developed countries.

Doña Teresa left two daughters in the care of Doña Carmen. No one else, it seemed, wanted to be bothered with anyone with HIV. It was left to the small, personal, shared caring of those individuals living quietly and socially isolated by having the virus. I simply could not imagine that Doña Teresa had had her children tested for HIV. To have children tested for the virus in this very conservative country first meant having the economic means to do so, and secondly, even more significantly, having to disclose that you yourself had the virus, and risk severe social ridicule and ostracism.

Too, too hard.

I was, then, hoping to see how Doña Carmen was faring. I work with HIV-positive individuals in the U.S., and wanted to see how a woman with HIV and no symptoms (thank goodness, for the only medicines available on a half-assed, arbitrary basis is AZT, which given alone was long ago considered sub-standard in this country) could continue to not progress to AIDS with no antiretroviral medications, be alive, well, and healthy after having HIV for so long.

I wanted to hold on to that sliver of hope that Doña Carmen had not progressed to AIDS. Especially since there is so little HIV medicine, and few doctors in Ecuador who have knowledge of HIV/AIDS to be able to successfully treat patients. Or the personal or medical will to do so.



dered if that was the reason that

Doña Carmen never responded to my inquiries as to her HIV status. Then, too, how often was it that she went to the post office to mail a letter to anyone in the U.S.? *That* would be noted, and remembered. I also assumed that she was literate. Perhaps my formal, academic Spanish was hard to comprehend.

I also remembered that Doña Carmen was barely eking out a living as a health educator. No one paid her a consultant fee or an honorarium for coming out publicly about her status. With no extra funds, buying a pen, paper, envelope and a stamp would be a frivolous luxury. Not to mention the cost of getting on a bus to go to the nearest post office to mail the letter.

Which is why I decided to travel back to Ecuador, to see with my own eyes how my friend was doing.

She was not available. In the two weeks I was in Ecuador, I tried contacting everyone

The gathering crowd at the gate, waiting for our thrice-delayed flight to Bamako, is already forming a line. Mothers and marabouts, new children and new wives, newly successful businessmen, they are all returning home. For them, this departure is a celebration: everyone is beautifully dressed in layers of cloth, or wearing the latest skintight jeans and stiletto heels. The few Europeans in the departure lounge look out of place already. They are pink, rumpled, and anxious.

Why is it that we must land in the middle of the night? All the doors are opened, and we descend steep staircases from the plane. The dryness hits as soon as the doors are opened, along with the smoke of many cooking fires. It's surprisingly cool—only about 60 degrees. Our luggage does not arrive. It is 4 a.m.

The next day in the AIDS ward, a patient died while we were standing near her, talking. The ward nurse covered her with a blanket and we stood, talking over her body as it lay like a bundle of twigs in the bed. I could hear her sister crying, outside. With the other ear I could hear my physician colleague telling me about the tests that were done to try to discover the cause of this woman's illness. Treatment with "tri-therapy," which is what they call AIDS medication here. To no avail. She was dead, here, this morning, as we stood there. Tears are shed. Nothing can be done. Another one will come to take her place.

Dr. Dao told us "while we do not wish for death, we have only 15 beds for the 100,000 AIDS patients in Mali." There is a waiting list. If one patient goes home, or another dies, they are contacted and invited to come to the ward, if they are still alive. I ask—how do you determine which one should be treated first—since they are all so sick as to require admission to the hospital? Another doctor replies—we take them from the top of the list.

Who are these patients? I meet a military man. I meet a deputy. No one has any CD4 T-cells when they arrive—the AIDS virus in their blood has already destroyed these. Some of the counts are as low as 2, or 4, because they do not come for treatment until the end. These patients first go to tra-

ditional healers, then they go to the local infirmaries, then they come here to get wait-listed for a bed. But for every two who die, one survives. Medication can be had—for a price.

Every test is paid for by the patients' family, in cash. A chest X-ray costs five dollars. A CT scan cost 100. Treatment for cryptococcal meningitis (a common fungal infection of the brain) can be had, sometimes, and must be paid for by the family, but sometimes there is no drug available anywhere—not in the pharmacies and not on the black market. Nothing can be done.

Later, these same doctors are stunned when I tell them that most of the AIDS wards in the United States have closed for lack of

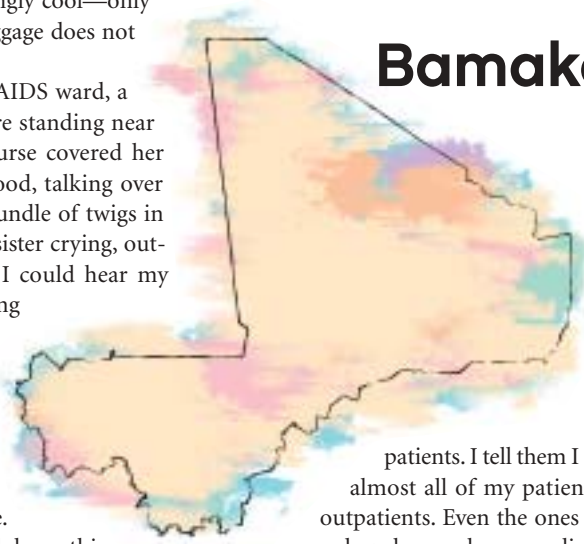
of tin. Small children, chickens and goats scatter at my approach.

Garbage is everywhere on the sides of the road. There are also open sewers in the city. And yet there is beauty and joy. There is music everywhere. The women move beautifully in their long skirts made of cloth with brightly colored repeating patterns. Talk is free, and there is much of that, animated and joyous.

I go to Mali to change the balance, to bring us closer, to extend a hand. I go to push for better care and compassion. I go to insist that pregnant mothers get treated for HIV, so that their children will not be born to die. I go to battle complacency. I go to help make a vaccine.

Bamako, not Timbuktu

by Anne S. DeGroot, M.D.



patients. I tell them I treat almost all of my patients as outpatients. Even the ones they see as hopeless, we have seen live for years after their T-cells reached the abyss. What is the difference? Access to care. Why is there no access? No money.

Consider this. The patients must match the government's expenditure of 4,500 Malian francs for one month's supply of "tri-therapy." That's less than eight dollars, but the average income here is 10 dollars per month. A patient must choose food or treatment. For most there is no possible choice, because they are not chosen to receive the limited supply of medication available through the government, because they are "too sick" or "not sick enough." Therapy can be prescribed directly to the patient, outside of the government protocol, but it costs \$300 per month. There are very few who can afford that price.

A few days later, I use running as an excuse to tour a nearby village. The houses are made of mud brick. The roofs are made

I return to Providence. I am thinking about the recycled, picked-over layer of trash lining the streets in Bamako, about the AIDS drugs that we have and they do not. I wonder how it is that the gulf has become so wide. Are our worlds so far apart because of the great expanse of ocean between us? How do you and I end up on this side and they on theirs? Whatever the reason, ours is not to ask. All we are given is the will to change things. That is why I go. ✚

Dr. Anne S. DeGroot is director of the TB/HIV Research Lab at Brown University Medical School in Providence, Rhode Island. She is working on a non-profit therapeutic and preventative HIV vaccine, with clinical trials in Mali and elsewhere. Dr. DeGroot is also a founder and co-editor of HEPP News (of the HIV Education and Prison Project).

Donations needed: all HIV antivirals except Norvir (which needs to be refrigerated), especially Viramune and Combivir for prevention of mother-to-child transmission. Also: Bactrim (Septra), acyclovir, Cipro, Biaxin and Diflucan. Meds should not be outdated and should be in their original closed containers. Send to: GAIA Vaccine Foundation Mali Project, 16 Bassett Street, Providence, Rhode Island 02903. For more information, contact www.GAIAvaccine.org.

In an address to the United Nations Special Session on HIV/AIDS, Haitian First Lady Mildred Aristide said “the fight against AIDS and the fight against poverty are being dangerously treated like two distinct fights...there is only one fight: the fight against poverty.” This is particularly true in a country like Haiti, where HIV affects 235,000 adults and more than 11,000 children, 80 percent of whom live in abject poverty. As the poorest nation in the Western Hemisphere, Haiti is entirely dependent upon foreign aid, volunteers and the participation of non-government organizations for food and medicines, but a continuing United States-led aid embargo has made the procurement of basic amenities extremely difficult. For those Haitians with HIV this embargo is almost assuredly a death sentence.

Haiti—A Battle Against Poverty and HIV

by Carl Winfield



“I need US \$6,000 per year to purchase medicines,” said Christian Jules, longtime HIV survivor. Christian Jules is one of the lucky ones. Sometimes he receives his meds from institutions like ASON (The Association for National Solidarity). But many more are forced through a combination of poverty and desperation to camp out on the front lawns of hospitals like Zanmi Lesante (Creole Partners for Health) hoping to find some respite from the virus.

“One hundred twenty deaths due to AIDS are recorded in Haiti, while 120 new cases of AIDS develop every day among

those already infected with the virus,” said Jean Saurel Beaujour, Executive Secretary of ASON.

HIV/AIDS in Haiti is mainly transferred through heterosexual contact. Many of Haiti’s large cities like the capital, Port-au-Prince, support a vibrant sex trade where sex workers shun the use of condoms for more money. Though plentiful, many men choose not to use condoms or use them irregularly during sexual contact, exposing their partners and unborn children to the virus.

Migrants fleeing rural areas for eco-

not, in Haiti, and the rest of the world,” Farmer said.

There are some bright spots in Haiti’s fight against HIV. The efforts of non-governmental organizations (NGOs), multilateral partnerships and the United Nations have helped to slow down the spread of HIV/AIDS in some populations. Studies have shown that 98% of Haiti’s population knows about HIV/AIDS and approximately 65% of Haitians, many of them between the ages of 13 and 24, understand how the virus is transmitted. Additionally, condom sales have increased dramatically and the rates of infection among young, sexually active Haitians has fallen from a staggering 7.1 percent to 5.9 percent.

The Haitian government, under the leadership of Jean-Bertrand Aristide, has made HIV/AIDS its top priority. State-sponsored programs are being created in concert with NGOs and multilateral partners to address mother-to-child transmission, vaccine research and care for HIV-positive Haitians. Additionally, the government is active in encouraging people living with HIV/AIDS to participate in the creation of voluntary testing centers (VCT) where those most directly affected by the disease can make information, counseling and support available to those who cannot usually obtain it.

HIV will continue to drain the Haitian Republic economically, socially and politically for years to come: that much is certain. But cooperation between physicians, activists, HIV-positive people and non-government organizations throughout the world is bringing hope back to those who previously had none. “You don’t need to have a lot of money,” says Adeline Benoit, a former cook who had to abandon her career when she discovered she was HIV-positive. “What is important is human assistance...that you have someone on whom you can count. ☚

DYING IN SILENCE— AFRICAN AMERICANS

BY CHARLES MARTIN

“The beginning of the end of life is when we remain silent about things that matter.”

—Dr. Martin Luther King, Jr.

HIV/AIDS is the number one cause of death for both Black males and females, between the ages of 22–45. In the U.S. African Americans make up about 14% percent of the population, yet they comprise over 50% of the newly infected. In one study of young gay men, 30% of the African-Americans were HIV-positive. That’s like the numbers in sub-Saharan Africa. If these statements do not surprise you, you are one of the few. African Americans are becoming infected and dying of AIDS in record numbers. The question to be posed is, why?

Our nation has been in the fight against HIV/AIDS for over 20 years now. The government pours millions of dollars into care, treatment and prevention. Why are there still so many Black people becoming infected and dying from this virus? We know from reports that there are health disparities between communities of color and the white population. We also know that in communities of color there is an inherited mistrust of the system. Do these reasons equate to the disproportionate amount of black people infected by this disease? Yes, they do play a part, but only a part. African Americans have other obstacles, which put them on the frontline of this virus.

Many people in Black communities are under the misguided perception that AIDS is a disease that only affects the gay population and those people who misuse drugs. In the 1980s, the gay and lesbian community did a great job of putting a face on this horrific virus, and should be commended. They refused to let their brothers die in silence. Now the time has long passed for the other faces of AIDS to be brought to the forefront.

Black communities around the country need to rise up and refuse to perish without a fight. We should not pass silently into the night.

Many of those who lose the battle to AIDS in the Black community are not counted as those who have fallen to this virus. Cancer, pneumonia, or heart attacks are causes of death that we tell our family and friends. Those who are infected still fear letting others know on the chance they may be ostracized from family, friends, and the community at large. Many continue to die alone with no one to hold their hands or wipe their brows. Far too many do not seek care fearing that family and neighbors will discover the secret. Still others do not test, wrongly believing that ignorance is bliss. Shame is robbing our community of its life-line and its future.

Even our churches, which have been a bastion of support in the Black community for many worthy causes, have not risen to this fight in appropriate numbers. Ministers continue to blame those who are infected for being immoral and sinners. How sad it is that some of our churches take this view. Some of our politicians are saying teach abstinence-only in our schools. Abstinence-only has been taught for many years and we still have a problem in this country with teen pregnancy. We cannot allow our children to die using antiquated solutions, which have never proven effective. If we do not become educated about this disease, if we do not drag AIDS out of the shadows where it has been able to fester and grow in our communities, then we will perish. The shame and ignorance surrounding AIDS in

Black America could lead to the demise of us all.

We are in a burning building and only a few are shouting for all of us to get out.

What do we need to do to survive this epidemic? We need to shatter the stigma associated with HIV, homosexuality, and substance use. We need to destroy the ignorance that has allowed HIV to grow uncontrollably in Black America. We need to become educated about HIV/AIDS. Teaching abstinence is good, but we should also teach our children how to protect themselves if they are engaging in sex. To do this is not condoning sex. It is condoning life. We must stop treating those with HIV/AIDS as though they are lepers, and give them the support, love and respect that all who have a chronic disease deserve. Our churches and community leaders must be at the frontline of this battle. We need to stop worrying about how an individual became infected and concern ourselves with how those who are infected can live long, loving and productive lives. We need to become the great caring people that we are possible of being and have been for generations. Most of all, we need to stop allowing our mothers, fathers, sisters, and brothers from dying alone and in silence.

Get tested, even if you feel as though you are not at risk for this virus. Get information about treatment options, if you are HIV-positive. Play safe. ☩

Charles W. Martin is the Executive Director of the Julius Adams AIDS Task Force, located in Key West, Florida. He can be reached at Jaatfed@aol.com or (305) 295-2437.

Metabolic Complications Associated with HIV Disease

by Matt Sharp

*The HIV Treatment Series
is sponsored in part by an
unrestricted grant from
Abbott Virology.*



HIV treatment has shown remarkable results starting in 1995 by lowering the death rate, decreasing hospitalizations and lengthening people's lives. But around 1997, following the respite from the years of AIDS despair, a new anxiety came to thousands of people who were doing better, surviving and resuming their lives. A similar, if not different look of AIDS had reappeared despite the use of effective anti-HIV drugs. Physicians began reporting metabolic problems and strange body shape changes in their HIV-positive patients. Media reports of the new syndrome appeared in newspapers. E-mail discussion lists led affected people to the Internet for support and advocacy. Researchers scrambled to find any clue. The new syndrome was as troubling as it was a big disenchantment for those who had survived AIDS. It appeared as if the honeymoon from the positive effects of HIV treatment were over.

At the time we did not know what was causing the metabolic changes, and hype

fueled by fear of the unknown attributed every metabolic and fat redistribution issue to the protease inhibitors. Since 1997, we have learned that advanced HIV disease and monotherapy with NRTIs (nucleoside reverse transcriptase inhibitors) were also contributors to some of the metabolic changes that were beginning to appear in patients.

The metabolic disorders reported are a multitude of symptoms and irregularities that affect some but not all people with HIV. In order to best understand the benefits of HAART (highly active antiretroviral therapy) it may be useful to separate metabolic issues into two major categories in order to understand the subject. There are fat redistribution issues, and there are elevations in cholesterol/triglyceride levels and insulin resistance issues. For example, fat redistribution has long been attributed to some NRTIs and some PIs. It has also been documented in HIV-positive people who aren't on HAART. As far as we know, fat redistribution

is unrelated to increases in blood levels of cholesterol and triglycerides. On the other hand, increased cholesterol and triglyceride levels also occur in HIV-negative individuals. However, certain drug combinations between PIs and NRTIs are recognized to increase triglyceride levels significantly, overlapping to create a metabolic syndrome in AIDS. We understand much more than we did five years ago when the first symptoms were reported, but prevalence, causation and treatment are still not fully understood. It's all very complicated.

It is important to look at how this syndrome emerged in order to get a clearer picture of what is happening. In and around 1997 people with AIDS began noticing a dramatic change in body shape, a look similar to wasting seen in the early years of the epidemic, despite the fact they were feeling healthy and had relative viral control. In some individuals the new "look" took several shapes—thinning legs and arms and/or a gaunt facial look. We now refer to this condition—loss of body fat—as lipoatrophy. In other individuals, body fat was redistributed appearing as a weird paunch in the stomach and/or a disfiguring hump on the upper back. This condition is referred to as lipodystrophy. In addition, lipid levels, cholesterol and triglycerides, and glucose numbers were significantly out of range.

It was a difficult time for patients and doctors between 1995 and 1997. Some doctors were in denial about doing anything about these changes since anti-HIV drugs had been so effective, taking the attitude, "If it ain't broke, don't fix it." However, many doctors were often a part of the community they served and living with the dramatic improvements following 1995. Their concern about increases in lipids or fat distribution may have been tempered somewhat by a relief to finally see lives saved—but not out of professional neglect. Treatment advocates felt an obvious reluctance by many pharmaceutical companies to conduct studies of

their drugs, both approved in trials, because they did not want any bad light shed on them. Yet, it must be remembered that at the time a lot was unknown, and because neither morphologic nor metabolic changes were an issue when Phase IV trials were conducted, they were therefore not included in study protocols.

The HIV community mobilized as it had in the early years of AIDS by creating the Forum for Collaborative HIV Research, forming e-mail lists that provided a forum for people experiencing different manifestations of these metabolic complications and pressuring the pharmaceutical companies to begin looking at their own drugs to see if they were contributing to any metabolic problems. Most of the symptoms related to body fat redistribution are cosmetic and not serious at least in the short term. However, the body shape changes create a new look of AIDS that most of those affected find discomfiting and stigmatizing. On the other hand, more evidence is showing the long-term effect of increases in lipids may be manifesting itself as heart disease, bone problems, and lactic acidosis. The need is becoming greater to find out what is happening and intervene before life-threatening conditions develop.

While guidelines have existed for lowering cholesterol and triglycerides in the general population, up until now there has been no HIV treatment guidance for physicians related to lipodystrophy and lipoatrophy besides the medical journals and conference abstracts. But now one of the results of collaboration in AIDS research is a new report compiled by the International AIDS Society U.S.A. (IAS), a 12-member panel of some of the leading researchers in the field. The guidelines were released in the *Journal of Acquired Immune Deficiency Syndrome* (Volume 31, No. 3) in November 2002. Visit www.iasusa.org for a copy.

The report suggests recommendations that are meant to help guide physicians into

the management and diagnosis of the complications. Before the guidelines so much of the syndrome was misunderstood and baffling to many in the HIV arena. Now there is more understanding as to the cause of lipodystrophy, even though the panelists admit the syndrome is far from being completely understood. They recommend the best that can be done today is to monitor people on antiretroviral therapy and diagnose correctly, treat with lipid lowering agents in some cases, and switch or at worst, stop antiviral drugs if risks outweigh the benefits. There is also data that shows the risk of heart disease in HIV-positive and HIV-negative individuals to be comparable even though race, cigarette smoking, and other factors may lead one to expect a significantly higher risk in HIV-positive people.

The IAS Guidelines report helps to understand metabolic complications by breaking them down into categories and then presenting the medical background, recommendations for assessment and monitoring, and the known therapy that may help treat the symptoms.

DIABETES, INSULIN RESISTANCE AND IMPAIRED GLUCOSE TOLERANCE

Insulin resistance and impaired glucose tolerance—both indications of diabetes, are the first category in the IAS guidelines. Insulin resistance is when the body's cells are not as sensitive to the affects of insulin—it takes more and more insulin for sugar to be transported into the cells of the body [>200 u/day for one week as opposed to 30-50 u/day]. This taxes the pancreas, which ultimately wears out. Eventually, more insulin is required to the point that what the pancreas can produce is insufficient to get the job done. Impaired glucose tolerance is when the body doesn't use insulin efficiently or doesn't produce enough insulin, resulting in excess levels of sugar in the blood. And as we all know, too much sugar causes all sorts of problems. Both are indications of diabetes. It

MY LIPO LIFE

As a dancer, I used to spend every day in front of a mirror perfecting my craft. I became familiar with the way my body moved and I worked hard to maintain my physique. Dancers have to look their best because their bodies are their canvas and the mirror is simply one of their tools.

My goal was always to look as good as I could, but when I look at myself today after retiring from dance 13 years ago, I see the look of AIDS. It's an upsetting feeling seeing myself virtually deformed by anti-HIV drugs. Vanity aside, I admit that much of what I see is the aging process, that which *everyone* has to deal with. But now, as a person living with AIDS for 13 years—as long as my ballet career—I am also coping with the effects of antiretroviral drugs.

Admittedly, along with my will to fight AIDS, the drugs have kept me alive but at the same time I am cursed by their side effects. I have had to pay a price for survival. That price is the craggy faced, pot-bellied look I see in the mirror on a daily basis.

You see the effect of AIDS drugs all around. Those misshapen bodies—flat butts and deep crevassed faces. It's the look of AIDS in the HAART (highly active antiretroviral therapy) era. Yet, many of us are thriving despite the look. AIDS should have taken us a long time ago. Some say it's a double-edged sword. A risk versus benefit. Unfortunately, we are faced with the dilemma of “the look” if we want to survive.

I first noticed a bloated belly about six years ago. I thought it was positive as I had only just recovered from severe weight loss with AIDS wasting. A big belly was as Martha Stewart says, “a good thing.” Little did I know that I was experiencing a new phenomenon, wholly misunderstood by researchers and doctors. Lipodystrophy had set in before my very eyes. The effects were so blatant that I was actually asked by a noted AIDS metabolic researcher to be his “poster boy” for one of his lipodystrophy talks.

I began using human growth hormone to treat the bloated belly and it worked fairly well. But when I would visit family or friends after months being away, they would confide in me that I looked “bad.” I realized I looked a lot like I had years ago when I was sick with AIDS wasting, but mostly I felt pretty damn good.

It's tough these days maintaining my health and my body with a fragile immune system and a virus that refuses to die. And I am constantly aware of the way people stare a little longer, curious as to know what's wrong. I guess I'll have to live with the rudeness. It is totally frustrating to know there is little I can do for my wasted face. Facial implants, the current Band-Aid, are out of the question because of the high cost, and insurance refuses to cover “cosmetic” surgery, which is actually reconstructive surgery to reverse the effects of drugs and disease.

So, I fight for more promising AIDS therapies with fewer side effects. I will force myself to cope with “the look” and just be thankful I am still alive. At least I have lived long enough to be called a long-term survivor and look in the mirror. —Matt Sharp

is still unknown how many people with HIV and insulin resistance will go on to develop diabetes. We know in HIV-negative people that insulin resistance is related to increased risk of heart complications, but whether the same risk holds true for people with HIV is still not established. Before anti-HIV drugs, insulin resistance, glucose intolerance and diabetes were rarely seen in HIV-positive individuals. However, studies show 40% of people with HIV on a regimen containing a protease inhibitor will have increased glucose levels. There are clues as to the potential mechanisms of the effect of protease inhibitors on insulin resistance, but nothing hard and fast. Comparative studies need to be done to tease out this problem. One recommendation is for physicians to determine whether their patients have had abnormal fasting glucose levels and/or have a history of diabetes in their families, before starting them on a protease inhibitor. Research has also shown that nucleoside analogs cause a fat breakdown called lipolysis that can contribute to insulin resistance, so all HIV drug classes are suspected.

In HIV, metformin was looked at in small studies and appeared to help reduce insulin levels, waist circumference, blood pressure and risk of heart disease. Thiazolidinediones increase insulin sensitivity in people with HIV with documented insulin resistance and increased blood lipids. However, the guidelines urge care in side effects related to these drugs. In the absence of more treatments, the IAS guidelines suggest a balanced diet and regular exercise for everyone regardless of HIV status. Also, people with HIV who are overweight are urged to lose weight since obesity is a contributing risk factor for diabetes.

LIPID ABNORMALITIES

Lipid abnormalities, changes in important fat molecules in the blood called cholesterol and triglyceride, are covered extensively in the IAS guidelines. Two types of elevat-

ed lipids seen in HIV are low-density lipoprotein (LDL) and triglycerides, both of which are related to heart disease, although currently very minimal evidence links elevated triglycerides to heart disease. High-density lipoprotein (HDL) is actually necessary to transport lipids from the blood to tissues in the body. HDL is sometimes lowered by use of antiretrovirals. Before HAART many people with HIV had lowered levels of cholesterol, then known as a positive thing. But now, protease inhibitors have been associated with increases in LDL cholesterol and triglycerides. Genetic factors may also have some influence. While a powerful protease inhibitor, ritonavir (Norvir) has the worst effect on lipid levels in studies thus far, the guidelines admit there is not yet enough information to rule out the role of other antiretrovirals. For instance, emerging data links both Zerit (d4T) and Sustiva (efavirenz) with increases in cholesterol levels. As with insulin resistance, it is not at all clear what the mechanism is for increased lipid abnormalities with antiretrovirals. These are important and ongoing research questions given the growing AIDS pharmacopoeia we are faced with, and the general lack of long-term, in-depth analysis of drugs by pharmaceutical companies.

Years of medical research has shown that heart disease is probably the most serious effect of elevated lipid levels. In HIV-negative individuals, age, family history, gender, smoking, diabetes, hypertension and menopausal status among women are factors associated with increased risk of cardiovascular disease. Therefore, the same risks and preventative efforts such as stopping smoking and watching weight are also recommended for people with HIV. Lifestyle adjustments with diet changes and exercise also make sense. Lipid-lowering agents are showing good results thus far for those with severe lipid problems, though they often do not reduce the levels to normal. Longitudinal studies looking at heart disease have not

been performed in HIV since it is a relatively new disease. It may be a while before we can associate anti-HIV drugs with heart disease. Since it is not something we can wait for studies to discern, it makes sense to follow good heart disease prevention efforts anyway. However, for those with a prior history of elevated lipid levels or a family history of heart disease, switching from a protease inhibitor-containing regimen should be considered if it is an option.

Another life-threatening concern is pancreatitis, which can be forewarned by monitoring triglyceride levels. Again, the IAS guidelines will help direct the physician to the best treatment option for the individual patient.

BODY FAT REDISTRIBUTION

Body fat redistribution is seen in 40% to 50% of people with HIV. When talking about body fat redistribution we mean a fat gain in the trunk and breast and/or a fat loss in the face, buttocks, arms and legs. We are also referring to buffalo hump, an increase of fat on the upper back and neck, and lipomas, individual fat nodules that are not necessarily symmetrical. The redistribution is seen at various levels and in different combinations in different populations. In HIV it has been difficult to ascertain just how many people are experiencing these body fat changes because of the variability in reporting. When body fat changes were first reported they were referred to as "Crixbelly" because Crixivan was the most widely used protease inhibitor at the time. But in fact body fat changes were seen before the advent of protease inhibitors so it cannot be certain that Crixivan or any other protease inhibitor is the sole cause. On the contrary, there is a new study by Carl Grunfeld from the San Francisco Veterans Hospital claiming that there is no difference in trunk size when comparing HIV-positives to HIV-negatives. But the study has caused great debate since we have witnessed that this is a glaring prob-

lem in people with HIV. There is no definitive anti-HIV drug that has been related to body fat redistribution. The IAS Guidelines suggest there is an association with nucleoside analogs, and maybe acceleration with an added protease inhibitor. Surely, combinations including the two drug classes were widely used when the syndrome was first recognized.

Other host factors have been characterized to be associated with fat distribution abnormalities. Older age, baseline or change in body mass index, duration of HIV infection, effectiveness of drug therapy, immune restoration with drug therapy, and white race have been documented. One of the cruelties of body fat redistribution in HIV are that women are more likely to see fat gain while men experience more fat loss.

Unfortunately, like a broken record in these guidelines, the underlying cause of fat redistribution has not yet been identified and that is why definitive treatment remains elusive. Possible therapies are listed in the guidelines but should be considered in the context of other metabolic abnormalities in each individual. Switching or stopping anti-HIV drugs has thus far not shown to be effective in reversal of fat gain, however some improvement in lipoatrophy was seen in one study that switched Ziagen (abacavir) or Retrovir (AZT) for Zerit (d4T, stavudine). Mitochondria are microscopic cellular organs that control cell life and are the source of cellular energy. Studies show they become damaged by certain nucleoside analogs. We know that Zerit causes mitochondria damage that may eventually trigger events that cause fat redistribution. Mitochondria damage may also be the cause of drug-related nerve damage and other symptoms.

Metformin, testosterone, human growth hormone and the thiazolidinediones may improve fat gain but there are complexities with each therapy. As with lipid abnormalities, diet and exercise remain areas of intervention also under investigation. In the

“body fat redistribution” scenario much more work needs to be done to discern what is going on and how to treat. Body shape changes are a tangible, visible malady that signify HIV infection and therefore can further stigmatize people with HIV.

Since there is no treatment at all for facial wasting, one dramatic Band-Aid approach is utilizing different types of implants. Few studies have been performed with implants such as New-Fill, and even fewer qualified plastic surgeons are trained to perform them in people with HIV. The procedures are expensive and require many treatments over time. Implants may, however, be the only recourse for those who are severely affected.

LACTIC ACIDOSIS

Lactic acidosis consists of elevated levels of lactate in the blood. It is a serious, mostly fatal condition that has been seen in HIV. The IAS guidelines say that it is only reported in 1.5% to 2.5% of people with HIV on therapy but mortality is 80%. Symptoms include fatigue, weight loss, nausea, abdominal pain, difficulty breathing, and irregular heartbeat. There are no differences regarding gender, race or ethnicity as once suspected, although pregnant women may be at higher risk. There is an association with six months or greater use of antiretroviral therapies. Once again, mitochondria damage is implicated as the underlying factor for lactic acidosis.

For people co-infected with hepatitis C and being treated with ribavirin, there is a greater risk for elevated lactate in the blood. There is no current treatment for lowering lactic acid other than interruption of anti-HIV drugs, and by the time the syndrome is reversed it may be too late to simply stop therapy. Various complementary therapies have shown limited success in other mitochondrial diseases.

BONE DISEASE

One peculiar area related to metabolic dysfunction is bone disease. Many people with HIV are having hip replacement surgery, a serious procedure typically seen in the elderly. Since 1980, osteonecrosis (bone death because of inadequate blood circulation) has been reported in people with HIV, but with widespread use of potent antiretroviral therapy, a discernible increase has been noted. One survey showed 4.4% of people having scans had necrosis of the hip. The condition is also related to corticosteroid use and elevated lipid levels, but has not been associated with anti-HIV therapies thus far. On the other hand, osteoporosis, a demineralization in the bone, was rarely seen before antiretroviral use. The guidelines show osteopenia (bone mineral depletion) in 22% to 50% and osteoporosis in 3% to 21% of those receiving a protease inhibitor containing regimen. Studies to show which anti-HIV drugs are most responsible for bone disorders need to be performed. It is still not clear what is happening with bone disease, so the IAS guidelines do not suggest routine screening. Adequate intake of calcium and vitamin D is recommended to all people with HIV as well as appropriate weight-bearing exercise.

Unfortunately, the IAS guidelines provide little earth shattering or new information. It is clear there is still a lot of ambiguity about HIV metabolic complications and that is frustrating for many who are living with the syndrome, tired of waiting for answers. Despite the frustration, it is also clear that incremental progress is being made. Many studies are underway and more are planned to tease out the incidence, causes, treatments of and risk factors for metabolic complications. One thing is for sure: As people live longer with HIV there will be more problems with long-term side effects, aging and the issues of a broken immune system. Metabolic complications highlight the fact that while we have potent therapies for slowing progression of HIV, the drugs we

have are deficient, and disease progression remains a mystery. We simply must do better. Researchers and pharmaceutical companies need to continue to explore new ways to control HIV and better yet, find ways to bolster and improve the immune system.

The guidelines are geared to help the physician help his or her patients. However, each person must be treated as an individual with the guidelines as a frame of reference. Every patient will have his or her own unique situation. The guidelines can assist by providing the needed resources for monitoring and diagnosis on an individual basis.

At the Barcelona International AIDS Conference a person living with AIDS having suffered from the effects of metabolic complications spoke out in one session. He was a long-term survivor and had suffered side effects and many serious health setbacks. He said, “It is a cruel irony that 5% of those PWAs worldwide who have access to drugs are ambivalent about them because of the side effects, the medicalization of our bodies, and the uncertainty of the long term impact.” Many people on anti-HIV drugs are frightened by the future of life-long therapy. They may even go on drug holidays or stop completely. People who are newly diagnosed see the “look” of people on anti-HIV drugs and delay or refuse to start them. Either scenario poses a serious public health conundrum for care providers and patients alike.

It seems a long time since the days of AIDS wasting, when people with HIV mirrored the look of Holocaust victims. Then anti-HIV drugs brought us the “Lazurus effect”—seemingly reversing the effect of AIDS. Even with so many unanswered questions, it is obvious that the benefits of treatment outweigh the risks. More prospective studies need to be done in order to find the reasons behind metabolic complications, so that living with HIV can be completely manageable. ☞

Would you play a game of poker with your cards facing your opponent? Would you give your football team's playbook to the opposing team? Unfortunately, many people end up fighting their HIV infection in similar ways.

Medicine is making progress in the war against HIV. Today, people live twice as long after an AIDS diagnosis as they did in the mid-1990s. Yet despite these successes, doctors are worried that we're burning through the promise of our best medicines. All too often, HIV finds its way around medicines; it becomes resistant. These days, resistance is becoming more common. The portion of newly infected patients showing high levels of resistance has tripled to nearly one-in-four since 1998. Worse yet, the portion with resistance to *multiple* drug classes, meanwhile, has climbed from 2.5% to 13%.

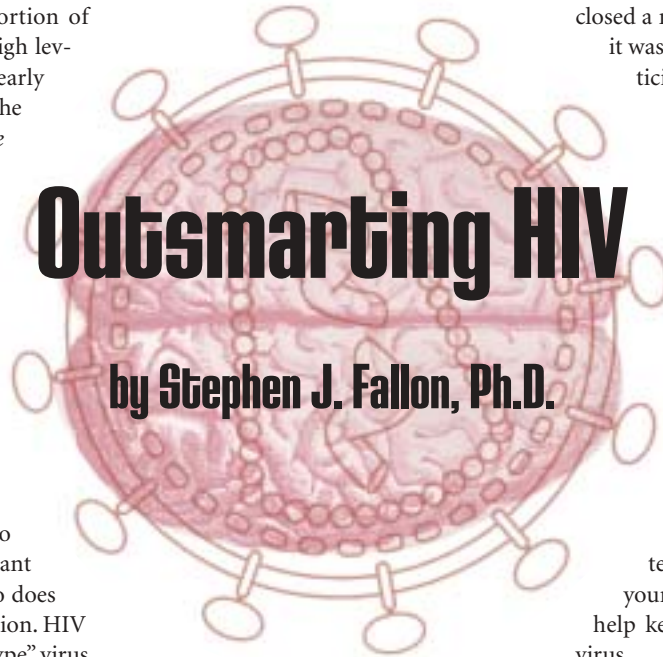
Each time HIV reproduces, it creates up to 10 random mutations in its offspring. Most of these mutations actually harm HIV, but sometimes the virus stumbles upon a mutation that gives it an advantage. Alternatively, HIV can create resistance more deliberately, when medicines don't penetrate deep enough into the tissues to prove fully effective. Just as the mutant *X-Men* have strange powers, so too does HIV gain strength through adaptation. HIV can fully replace its original "wild type" virus with a smarter, resistant virus in just two-to-four weeks.

Ironically, broad access to the most advanced anti-HIV drugs in Western countries may fuel the development of resistant strains. HIV adapts fastest when it encounters a weak obstacle. When persons living with HIV skip medication doses, HIV gets a preview of its new enemy. If the person then accidentally infects someone else, that person inherits this craftier virus. In San Francisco, for example, if trends don't change, 42% of HIV-positive persons will be carrying resistant virus by 2005.

So, what do we do if we want to outsmart this crafty virus? Just as HIV gains an advantage when it can preview the medicines we plan to use against it, doctors can gain an advantage if they preview which medicines your HIV has already anticipated. There are

two different ways that doctors can check a patient's virus for resistance.

The first technology developed is known as a phenotypic assay. Phenotypic tests basically play war games with the virus. Some blood is drawn from a patient, the virus is extracted, and then technicians have it spar in a test tube with one anti-HIV medicine at a time. Researchers measure how much medicine they have to add before they can suppress HIV by 50%. They then rate the virus' susceptibility or resistance to each medicine.



Outsmarting HIV

by Stephen J. Fallon, Ph.D.

The tests are costly because technicians have to run through each medicine one at a time. They also have a weakness, since they can't account for the ways that medicines may interact in the body to work better (or cancel each other out). Still, these tests give us a tool that we didn't have in the fight a few years back.

A newer technology is called a genotypic assay. Genotypic tests essentially play spy games with the virus. Scientists have mapped out HIV's book of tricks along its nucleic acid sequence. They can spot when HIV swaps out one of its parts (called "codons") to mutate. Peeking at HIV's secret codons allows doctors to predict how HIV plans to fight both individual medicines and whole classes of medicines.

Genotypic assays are less labor intensive and costly than phenotypic, since a computer rapidly reads the mutation codons. One

caveat when ordering a genotypic test is to make sure that the assay tests all of the known mutation codons, and not just a select sample.

Doctors then try to shock the virus by utilizing only the medicines that HIV hasn't "seen" before. Does this strategy work? Several major studies have found that when doctors review a patient's resistance assays before choosing medications, the patients are more than twice as likely to keep their virus down low as are those whose doctors don't have the advantage of this test. The benefits are so significant that researchers quickly closed a major study when they determined it was unfair to deny any of the trial participants this tool.

Either way, the tests all face one limitation. They can't detect mutations that are just starting to take hold, making up less than 20-30% of the overall viral population. So new strains of resistance may not show up until a later test. Still, combined with our other tests, resistance assays offer doctors a unique opportunity to box in the virus that would otherwise run wild.

Many states are now providing reimbursement for resistance testing, so be sure to ask whether your doctor can utilize this new tool to help keep your treatments ahead of the virus.

While new medicines and new tests help better target your HIV, the best predictor of treatment success is literally in your hands. This year, researchers reported that patients who take at least 90% of their medications on time every day are four times less likely to die than those who take them less faithfully.

Science fiction movie fans know of a villainous race of aliens called The Borg, who attack humankind while warning that "resistance is futile." With the new tools of medicine, and everybody carefully sticking to their medication schedule, one day we may be able to say to HIV, "resistance is futile." ☒

Stephen Fallon is the President of Skills4, Inc. a health care and disease-prevention consulting firm. www.Skills4.org.

Readers' Forum

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up in central Virginia as did I. It helped me to hear the story of his journey as I sort through where I am now and the many choices ahead. Mostly, it provided a ray of hope in an otherwise dark period for me. And for that, I am grateful. Thanks again for the work you're doing. It's making a difference, one person at a time.

Name withheld,
via the Internet ☒

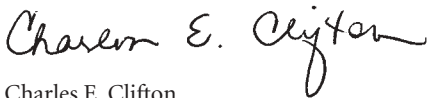
Editor's Note

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disease, in addition to housing and other mental health services.

This issue of *Positively Aware* takes a brief view of HIV/AIDS conditions, treatment, care and prevention efforts currently underway in South Africa, Haiti, China, Ecuador and Mali. To quote again from Bush's speech, "In an age of miraculous medicines, no person should have to hear those words ['We have no medicines.']. AIDS can be prevented ...Seldom has history offered a greater opportunity to do so much for so many."

Be Strong. Stay Safe.



Charles E. Clifton
Executive Director / Editor
Send comments and reactions to
ed@tpan.com

News Briefs

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HIV for the first time. In many African countries, women have outnumbered men for years. The provisional figures show that around the world, there are an estimated 38.6 million adults and 3.2 million children under age 15 with HIV. Women with HIV number 19.2 million.

BILL GATES IN INDIA

Microsoft CEO Bill Gates announced he would donate \$100 million from the Bill & Melinda Gates Foundation to help fight the spread of AIDS in India. Although the money will go through the health department, the health minister cautioned that the projection from Gates and other people from the U.S. of how many people will have HIV/AIDS in India was "spreading panic."

THAILAND

Public health authorities in Thailand earlier this year reported that HIV infection among teen-agers rose from 11 to 17 percent. That's nearly one out of five teenagers.

ACCESS COALITION

The World Health Organization (WHO) in late December helped launch the International HIV Treatment Access

Coalition (ITAC). In a press release, WHO Director-General Gro Harlem Brundtland said, "Does anyone deserve to be sentenced to certain death because she or he cannot access care that costs less than \$2 a day? Is anyone's life worth so little? Should any family become destitute as a result? Should children be orphaned? The answers must be no, no, no and no." ITAC will work with a variety of institutions on medical training, drug procurement and other tasks. Visit www.itacoalition.org.

"MASS MURDER"

"Mass murder by complacency." That's what the United Nations special envoy on HIV/AIDS called the effect of rich countries not giving enough to a global fund on tuberculosis, malaria and HIV/AIDS. Canadian Stephen Lewis also said that a war with Iraq would disable humanitarian efforts needed around the world. "This pandemic cannot be allowed to continue, and those who watch it unfold with a kind of pathological equanimity must be held to account. There may yet come a day when we have peacetime tribunals to deal with this particular version of crimes against humanity." ☒



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Behind the Frontline

Women, HIV and Reproductive Health

by Enid Vázquez

Gynecologist Dr. Patricia Garcia is director of the Women's Program at the Comprehensive HIV Center at Northwestern Memorial Hospital in Chicago. She spoke at the South Side HIV Care Providers Forum in Chicago in January, from which these notes are taken.

SHE'S ONLY 13 ...

This month has been hard for me. I delivered the youngest HIV-positive pregnant patient I ever have—13 years old, with the smallest infant I've ever delivered—15 ounces. The results were good—HIV-negative baby by two PCR tests [viral load]. It's a common story—an older boyfriend. He's 18. He infected her with chlamydia, herpes and HIV all at the same time.

NEWLY DIAGNOSED

Half of the newly diagnosed women at our clinic are pregnant. Why? Because that's when we uniformly test women [with their permission]. I'm sure it's the same throughout the country. What a bad time to get diagnosed.

ADOLESCENTS

In the U.S. in 1999, of the post-natally infected adolescents, 51% were girls. Why? For starters, negotiating for condoms is harder when the boyfriend's older, like that couple—13 and 18.

It's not just behavioral. Girls are at greater risk for biological reasons. The endocervix comes outside [of the uterus] during menarchy [the start of menstruation] and during pregnancy. HIV targets the white blood cells on the endocervix, so it's easier to become infected.

HAVING A BABY

[Another doctor says, "More women are coming to me with the same question—can I have a baby? This includes couples where the man is positive and the woman is negative."]

In February of 2002, the association of reproductive endocrinologists admitted that HIV is a chronic illness and they should help people with HIV like they would anyone else. They help cystic fibrosis carriers, and half the children get it. They also help people with muscular dystrophy.

HIV is not in the sperm. It's in the white blood cells of free virus floating in seminal fluids. So you separate the sperm from free virus and white blood cells. Endocrinologists do this every day [for HIV-negative men].

There was a lot of compelling data at Barcelona [the International AIDS Conference held last July]. The semen centrifuges down. You use regular PBS washing. It centrifuges back up. It's a two-step process, routine lab work. There's not an absolute zero risk. It's \$200 to \$250 to process the sperm. It's more to use PCR to check for [the virus] before insemination.

We used a Boston lab for one woman, but with no success. FedEx'ing the processed semen back and forth is not [good] enough. We're establishing a procedure with a local endocrinologist now who's willing to work with us. Just because the American Society for Reproductive Medicine changed its policies doesn't mean that there are doctors all over the place willing to help people with HIV.

Positive women and negative men can do insemination at home with a syringe. I just delivered twins to someone who did this.

I also think adoption is an important option that needs to be raised.

PREGNANCY HEALTH CARE

It's just like any other disease—control the disease. What if she has 500 T-cells and a 1,000 viral load and she's cruising along on no therapy? If she gets pregnant, she has to face therapy. There's a greater transmission risk at 1,000 viral load.

ACTG 076 found that the heaviest women had only a 26% reduction in transmission to their infants [using AZT during pregnancy]. All the others had a 79% reduction. Together, the reduction was 66%. So maybe we can adjust the dose. [AIDS Clinical Trials Group Study 076 established the effectiveness of Retrovir (AZT) for the prevention of mother-to-infant transmission.]

You can't ignore high blood pressure or diabetes. These are big issues, and HIV may be the least of their concern. Those other diseases could kill them during pregnancy.

If they have an abortion, the sedative is important. They can't be given methergine, because it can cause prolonged sedation if the woman's on a protease inhibitor. I know of one woman who almost died recently because of this.

The CDC [U.S. Centers for Disease Control and Prevention] say there's no difference between opting out and opting in [of counseling to go with HIV testing]. I think that's a big injustice.

The counseling is very important. We'll find very few positive women. But counseling them on how to protect themselves against sexually transmitted disease is the greater public health benefit. ☒

The Threat of Bioterrorism

by Daniel S. Berger, MD

“When you let the politicians back into the anthrax-contaminated U.S. Senate building, there was enough hot air to kill all the spores.” –Physician comment during a bioterrorism session

Since September 11, defense funding has taken priority. This coupled with the stalled U.S. economy has resulted in many dollars being diverted from other needed programs into planning against bioterrorism. Although one can appreciate our need for preparedness and national defense, the national and world AIDS epidemic with all its inherent complications needs to be placed in perspective with the war on terrorism. Countless more lives have been lost to AIDS than all the fatalities of September 11 and anthrax combined. The rise in the incidence of cases of HIV infection in young gay males, African Americans and women in the U.S. as well as the epidemic of resistance to currently available antiretroviral drugs continues.

As the U.S. prepares for war with Iraq at this time [early February], potential bioterrorism and weapons of mass destruction are of serious concern. The threat of bacteria or other organisms being propelled or dispersed within our borders is a horror that needs to be considered. Despite all the hype, little mention has been made regarding the effect biological warfare can have on immune compromised individuals. This is a rather large group of persons. It includes the HIV-positive, infants, elderly, transplant patients and persons being treated with chemotherapy and radiation for cancer. *Planning to help defend these individuals from bio-terrorism should be as important as protecting any other group.* Immune compromised individuals by definition may not be

able to mount the same protective response to some infections that others can.

HISTORY OF BIOTERRORISM

The use of biological agents as weapons is not a new phenomenon. The Romans used corpses of diseased animals to poison the drinking wells of their enemies. During the horrific Black Death of the Middle Ages, the bodies of bubonic plague victims were catapulted over fortress walls of besieged cities. During the French and Indian wars, 1754-1763, the British gave smallpox-infested blankets as gifts to the Indians. During World War II, Germany and Japan produced bacteria capable of infecting humans. In Europe, terrorist groups in Germany began producing botulinum toxin. In the late '80s in Japan, the Aum Shinrikyo cult acquired anthrax bacteria and botulinum toxin and attempted to collect samples of Ebola virus. Following the 1991 Persian Gulf War, United Nations inspectors revealed the vast scope of Iraq's biological arsenal. Iraq was found to possess more than 150 bombs and 25 missile warheads filled with botulinum toxin, anthrax, or aflatoxin. What's more, Iraq had built sophisticated laboratories to study and produce a wide range of biological agents and toxins. Thus, this form of attack is a real possibility.

ANTHRAX

Anthrax is a spore-forming bacteria and commonly occurs in cattle, sheep and other animals, but can also occur in exposed humans. The bacteria can be transmitted to

skin by direct handling of contaminated products, inhaled spores or eating contaminated uncooked meat. Infection is not spread from person to person. Symptoms usually occur within seven days. The cutaneous form (on the skin) develops an itchy bump that turns into a blister and then a painless ulcer that appears black and necrotic in the center. Adjacent areas may swell.

Inhalation form of anthrax begins as flu or cold symptoms with fever, chills, sweats and malaise that progress to breathing problems, chest pains and or shock. Symptoms can also include nausea, vomiting, abdominal pain, dyspnea, chest discomfort, myalgias, headache and confusion. Gastro-intestinal symptoms are usually out of proportion to a primary respiratory infection. Pulmonary (lung) infiltrates usually cause pleural effusion (fluid on the lungs), mediastinal (mid-chest) blood and widening, and abnormal chest X-ray.

There are concerns regarding gastrointestinal exposure to anthrax as well as other agents transmitted through food and water. Several hand held devices can detect anthrax in food. Intestinal symptoms from consumption of anthrax contaminated meat are nausea, vomiting and fever followed by vomiting blood and severe abdominal pain and diarrhea.

For patients who are immune compromised, including HIV-positive individuals, anthrax infection can potentially be more rapid and devastating, spreading to more sites, and perhaps with a higher mortality.

The vaccine for anthrax is a cell-free filtrate vaccine that does not contain live attenuated nor dead bacteria in its formulation. Thus patients with HIV can conceivably be vaccinated for anthrax. The Department of Defense has begun obligatory vaccination in all military personnel who are at risk for biological warfare.

While it is recommended to avoid using the penicillins for treatment of anthrax, many other antibiotics seem capable of fighting anthrax, including ciprofloxacin, doxycycline, rifampin, clindamycin, vancomycin, chloamphenicol and imipenim. Treatment should start as soon as possible, with combination therapy. An antitoxin is in research.

SMALLPOX

Smallpox infection, caused by variola virus, was eliminated from the general population in 1977. The onset of symptoms from time of exposure is usually seven to 17 days. Initial symptoms include high fever, fatigue, and head and backaches. A characteristic rash, most prominent on the face, arms, and legs, follows in two to three days. The rash starts with flat red lesions that evolve at the same rate. Lesions become pus-filled and begin to crust early in the second week. Scabs develop and then separate and fall off after about three to four weeks. The majority of patients with smallpox recover, but historically, death occurs in up to 30% of cases in people with a normal immune system.

Smallpox is spread from one person to another by infected saliva droplets that expose an individual having face-to-face contact with the ill person. Persons with smallpox are most infectious during the first week of illness, because the largest amount of virus is present in saliva during that time period. However, some risk of transmission lasts until all scabs have fallen off. Therefore, if even one individual is found to be infected, it is considered a medical emergency due to the potential epidemic arising from one person.

Routine vaccination against smallpox ended in 1972. The level of immunity, if any, among persons who were vaccinated before 1972 is uncertain. Additionally, there are no reliable tests to determine who is protected; therefore, even these individuals are assumed to be susceptible to infection.

In non-immune compromised individuals exposed to smallpox, the vaccine can

lessen the severity of—or even prevent—illness if administered within four days after exposure. The vaccine against smallpox contains another virus called vaccinia. However, because the vaccine is live attenuated, it is contraindicated for persons who have compromised immune systems. In other words, it is dangerous to administer this vaccine to HIV-positive individuals. When a live virus contained in a vaccine is given to an individual with a damaged immune system, they are at risk to develop the illness itself, since their immune systems may not be able to fend off the virus. With other vaccines, persons who are HIV-positive have been demonstrated to have less benefit because of their inability to mount a normal immune response. Vaccination against smallpox is currently not recommended to prevent the disease in the general public.

There is concern for all health care workers who may be the first to be exposed to smallpox should an epidemic begin. The United States currently has an emergency supply of smallpox vaccine, and the military and health care providers are now actively being vaccinated on a voluntary basis. If one is being vaccinated, there are certain precautions that must be adhered to. First, as the vaccine is live virus being applied to the skin, the injection site is a potential source of infection of the pox virus to others. The injection site should be kept covered with a semipermeable dressing and care should be given so that no other individuals are exposed to the injection site—sick, immune compromised or otherwise. The site should be covered until the scab has fallen off. Therefore, if one's hands are exposed or in contact with the vaccine injection site, they should be thoroughly washed with disinfectant or soap. Any materials contacting the site should be properly disposed of or incinerated if possible. Clothes should be washed thoroughly with hot water and bleach. If you are an HIV-positive health care worker, the risks and dangers of developing actual disease through vaccination is a real one. Thus, vaccination may be contraindicated as in any person who is immune compromised.

There is no proven treatment for smallpox, but research to evaluate new antiviral agents is ongoing. Patients with smallpox can benefit from supportive therapy (intravenous fluids, medicine to control fever or pain, etc.) and antibiotics for any secondary bacterial infections that occur.

An antiviral drug, cidofovir (Vistide), developed for the treatment of cytomegalovirus in AIDS, has broad activity to other viruses, including those in the pox family. Moreover, an often-seen skin complication of HIV disease caused by pox viruses is molluscum contagiosum. We have treated severe and resistant molluscum lesions successfully with the topical form of cidofovir. Cidofovir is administered intravenously. Its use is complicated by the fact that physicians should be thoroughly knowledgeable regarding its protocol for administration. The co-administration of probenecid and intravenous fluids are a necessary part of treatment because of possible harmful side effects to the kidneys. Because cidofovir is long-acting, the potential treatment for smallpox infection or exposure may only necessitate one dose. However, no testing in humans has been published. There is ongoing research proposed for the possible role of cidofovir in combating bioterrorism.

Currently we are not prepared to deal with the potential emergency of a smallpox epidemic. Housing in motels has been proposed for patients exposed to smallpox. The modes of death due to smallpox occurs with bleeding lesions and internal bleeding that may progress to shock and death. Motels would not be the best place to deal with this. A single case is a global emergency. Much planning is in the works.

A great deal is being learned while maneuvering through a maze of issues never before encountered. Most of the learning and decision-making occurs in an incremental way, piece by piece. Clearly, new protocols and expertise need to be in place in more areas than could be imagined. Early response is crucial. Expertise needs to encompass many scientific fields. A full-scale response should include public education that does not ignore immune compromised individuals. Appropriate prevention for them needs to be considered, since their exposure can lead to rapid disease progression. ☒

Daniel S. Berger, MD is Medical Director for NorthStar Healthcare, Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and editor of AIDSInfoSource (www.aidsinfosource.com). He also serves as medical consultant and columnist for Positively Aware. Dr. Berger can be reached at DSBergerMD@aol.com or (773) 296-2400.

Dinner at the Montrose

by Tom Setto

I had no sooner walked in the diner, didn't even get my coat off, and Gary was already starting. "I have to tell you what happened to me yesterday," he said.

You see, we have been meeting at that same corner table at the Montrose Diner just about every Saturday for 15 years. There're six of us now when everyone feels up to coming. Others have come and gone, some have died and some have left town, but Gary and I have been the mainstay. Oh, and one other thing, except for a few through the years, we all have AIDS.

"Can't you wait until everyone gets here?" I ask. "You know I hate to have to sit through your stories more than a couple times." Gary has a tendency to get a bit overdramatic. After a few times through one of his stories it's like the third or fourth time you've seen *Phantom of the Opera*: you know when the chandelier is going to fall—you just don't have the benefit of a different cast.

Within the half-hour Joey, Miguel, and Jerome come in. Jenny, our waitress for the last year, brings us coffee and water and leaves some menus. She knows it will be awhile before we order and she really doesn't mind... we treat her like she's part of our group and always tip her well.

Gary has been chomping at the bit to tell his story. "Well, let me tell you what happened to me yesterday," he starts. "You know how gassy I've been lately." We let him know that we are well aware of his gas. "I was at the mall. Levis were on sale at Sears and I was looking to buy a new pair of 501s. I was feeling pretty good and decided to walk through the mall and do some window-shopping and people watching.

"All of a sudden I got one of those gas bubbles. You know, the kind that start in your stomach and slowly work its way into your

intestines on its way out, the kind that you're not sure if it's just gas or gas and more."

We laugh and start trading tales of gastro-intestinal woes. Ken joins us during our discussion of wet farts and just smiles and shakes his head. He's been with us from almost the beginning and knows anything goes for our conversation. "Wait, there's more," Gary interrupts. "This one was a bad one. I was afraid to let it out and risk having to take the half-hour bus ride home with wet underwear."

Joey agrees. "You know I just changed meds and the diarrhea is back. I hate it. I stopped and had a bagel and coffee on the way home from the doctor last week. Got a half block from my building and panic hit. Guys, I didn't make it. The dam broke as I was putting my key in the door. I'm still depressed about it; I'm 38 years old. I just hate it."

"I've been taking Imodium for so long now it's lost its effect," added Ken. We begin trading stories about our near misses and unfortunate accidents. Jenny comes over to take our orders and hears part of the conversation. Nothing surprises her anymore. She's heard just about everything.

"It must be awful. How do you go out? I'd be afraid to leave the house."

"You wouldn't believe some of the toilets I've sat on." I told her that when I was on pro-tease inhibitors I would only go to places that I was familiar with. I had to know where the rest rooms were and tried to go to places that had stalls with doors. There's nothing worse than rushing in and finding no door, or worse yet, no toilet paper. Jenny laughs and says, "I hate when that happens."

Miguel stands up and says, "Speaking of. I gotta go. Be right back."

When Miguel and Jerome, who says all this talk has made him have to go too, return

to the table Gary continues. "Like I said, this bubble hurt. I tried to walk and clench at the same time but realized that I was walking like I had already loaded my pants, and anyway, the rest room was too far away. My only hope was to stand still and try to let it slowly subside."

"Been there too many times to count. I go through more underwear," adds Jerome.

"Underwear?" I ask. "I made it through the 80's and never wore a pair. Now they're just part of the wardrobe."

"Anyway," I can tell Gary wants to finish his story. "I decide to stop where I am because I don't want people to see me walking like I have a butt plug up my ass, and hope for the best. I think that maybe if I pretend to be interested in what is in the store window I'm standing in front of, that could give me a couple minutes.

"Wouldn't you know it, I just happen to be standing in front of *Lane Bryant*. Not only am I worried about shitting my pants, now I worry that all the people passing by think that I'm a big old drag queen. The bubble seems like it's taking forever to go away. I feel everyone is staring at me. I finally feel okay to try to walk but end up stopping at almost every window before I finally make it to the rest room and can safely let it out."

"So, did you go back and buy that pantsuit you saw in the window?" I ask. Our food comes and the conversation changes.

After we finish eating we all take turns excusing ourselves to use the rest room. When we're all finished and saying our so longs I say, "Can you believe that six grown men just spent two hours talking about farts?"

"I can," Ken answers. "It's something we can relate to. It's just another thing we all have to deal with. We just learn to live with it." ☛

Radical Red

Beloved Community

by Laura Jones

“We must understand that the AIDS epidemic is, at the core, a human rights and a civil rights issue... If he were alive today, Dr. King would be leading the effort to respond to HIV/AIDS among African Americans and all people. We can only overcome health disparities by ensuring access to care, better prevention, adequate housing and services, an end to stigma and discrimination, and research for a vaccine, better treatments and a cure.” —Terje Anderson, executive director of the National Association of People with AIDS (NAPWA)

In January, I went to a nonviolent civil disobedience training sponsored by a local peace group affiliated with the Iraq Pledge of Resistance, a national campaign opposing the possibility of U.S.-led war against Iraq. The training opened with one of the organizers, a burly Mr. Rogers-voiced man I’ve seen at a million protests, playing an uplifting ditty on the guitar while we all sang off photocopied lyric sheets. Then we went around in a little circle, introducing ourselves and giving brief info as to why we were there and the reason for our intention to civilly disobey if the United States did indeed declare war on Iraq.

The two other organizers, one a professor of Peace Studies at a local university and the other a student, gave their brief bios with the kind of mellow cheerfulness I’d last encountered in Methodist Youth Fellowship group back in junior high. The woman next to me was a special-education teacher at a Christian day school. All three of them talked at some length about their respect for Gandhi and about Dr. Martin Luther King’s concept of the “Beloved Community.”

When it was my turn, I gave my name and said I worked as a grant writer for a small HIV/AIDS community center. Then I said, “I’m here because, in addition to everything else, I’m angry about how much this war is going to cost and how our government is willing to pay out \$100 billion for a war but not for the Global AIDS Fund.”

Mr. Rogers coughed politely and glanced over at the two organizers with this look that flies among Peace People when a meeting is taken over by a member of the Youth Communist League, or someone suggesting we’d make a more effective statement if we set the Federal Building on fire instead of simply occupying its lobby.

Fortunately the next person to speak was a young Jesuit, who said he was pissed too and feeling kind of hopeless. He’d spent the last few years working to end the sanctions against Iraq and said he felt like he was taking on a second war—the first one already with many casualties. We shared a small moment of “Yeah” between us before the circle moved on to Mary, an elderly woman with broken teeth who had been active in the Civil Rights movement. Mary allowed that she too was angry. She’d come out of activist retirement because she felt the nation was going backward from what had been accomplished during the 1960s under the leadership of Dr. King, especially since September 11. “I’m angry,” she said, “because I’m too old to do this kind of thing again, and I can’t let myself sit at home even though I want to.”

They also both validated my statement about the cost of war vs. the cost of addressing a global health crisis the likes of which has not been seen since the Great Plagues.

Mr. Rogers coughed again, said something along the lines of “We can’t let anger have the upper hand” and “Hopelessness gets

us nowhere,” and decided it was time to sing “*Oh Healing River*.”

I didn’t want to sing “*Oh Healing River*.” I wanted to talk with the Jesuit and Mary about what they’d seen and done, and why they too felt comfortable with their anger when Anger seemed to be an unwelcome emotion here at Peace Central, and whether they’d be interested in working with Health GAP (Global Access Project) in their spare time.

I also couldn’t help noticing that the church we were meeting in was located in a neighborhood with one of the highest AIDS rates in Chicago—a church well-known and respected in Chicago peace circles—and yet the organizers of this evening’s training had regarded me blankly when I made reference to that fact.

I bet Dr. King would have known all about Edgewater’s (a Chicago neighborhood) AIDS rates if he was alive today. I bet Dr. King would be calling on everyone who believed in the Beloved Community to rise up against the virus and disease currently decimating communities in the U.S., in Africa, in India, in Russia, and everywhere else where the conditions that facilitate both HIV transmission and the development of AIDS prevail.

Kum-ba-yah, my Lord, kum-ba-yah. ☩

For more information on Health GAP Global Access Project, go to www.healthgap.org.

My Kind of Life

Viacom Comes Through for Me

by Carlos Perez

Worldwide HIV issues bring me to my own backyard where the red ribbons have become passé during the apathetic epoch of the 90s. Today we need new and improved products and ideas. That's why condoms have become anti-fun, anti-sexy, even according to the Centers for Disease Control and Prevention (CDC), anti-one hundred percent effective (which we already knew). Another retired icon of HIV, the red ribbon, is lost in colorful ribbon land, where you need a legend to refer to all the different colors and their respective diseases.

Who's got the time to keep up with all this when we have a crappy economy, a war that may or may not ever get going and the terrorism threat always looming over our heads? It's been 10 years since the 1993 Academy Awards. That was the year Tom Hanks won for Philadelphia. That's when people understood why a person was wasting away and what those little purplish dots on their skin meant. Today, the global complexities of the fight against HIV are mind-boggling. But you would think we could get a better grip. You would think we could unite and do a better job of getting the word back out. Well, I found one excellent example. It's a Public Service Announcement (PSA).

I was watching the season premiere of "Star Search" and was reaching for the aspirin to dull the pain from Arsenio's droning when something caught my attention. It was a public service announcement for HIV. It's titled "Know HIV/AIDS." During this same week I've seen the PSA on HBO and a few affiliates of Viacom. Kudos for Viacom! If you go to the CBS website, www.cbs.com, it's

under their "recommended sites" at the bottom of their front page. The link takes you to the website www.knowhiv aids.org, a joint venture between Viacom and the Henry J. Kaiser Foundation, a campaign of PSAs that began on January 6. It's a jump-start in a country that stopped talking about HIV and STDs, a country that is most powerful but dogged by its own shame about sex.

This led me on a hunt of other stations' PSAs on HIV and STDs. Other than Viacom's huge arsenal of affiliates I saw no more. Other network and cable giants have had PSAs before but right now Viacom rules. Perhaps Disney (who has produced a few titillating movies and cartoons) and who also owns ABC can start a campaign. And where are NBC and FOX's PSAs? I remember the first PSAs on television decades ago before Philadelphia was a hit movie and gay men were dropping like flies. All the media conglomerates need to come together and get the prevention message out more frequently.

I know when I'm getting ready to "get it on" the last thing on my mind is the politics of this world. That is the whole point of "let's talk about sex, baby"—it takes your mind off the madness. The only thing we need is a little help from our big brothers on the other end of the television.

Unintentionally, protease inhibitors brought about a fallacy that AIDS was a problem no more because they helped so many people with no other options. Confusing stories in the media led to the belief that Magic Johnson was magically "cured." Johnson has added his visage to the faces of AIDS and he has about as much power as any media. His message consists of

having good communication with your doctor, having a support system and adhering to your medicine. There are still many people, especially in communities of color, who cannot be seen by a doctor, have no support system and cannot get near the pharmacy. While his efforts are exemplary, we need more educational messages that tell people where to go, what hotline to call and where to run for shelter if your "support" is violent or unhealthy.

The latest revamping of prevention information from the CDC would have one believing that unless you give up sex altogether or find Mr. or Ms. Negative-Wonderful and marry him or her there's no hope. Many people would like to surrender into hopelessness and just go out with a bang and so they bang away.

I'm going to start paying attention to the commercials more and see just how committed America's media is to bring about much needed awareness of HIV and STDs. Unlike print or radio, which requires focusing, the "tele" draws your eyes into its magical glass tube where every subject matter can be transformed, explained and brought to your eyes to sink through to your brain. It is the best communication tool, since not everyone around the globe has access to the Internet. However, even the poorest shantytowns now have television. We watch it while doing everything, including (everybody whisper) having sex. I can't think of a better time for a renewal of interest in Public Service Announcements about HIV and STDs on television than now. ☒

Pickett Fences

Getting to Know You

by Jim Pickett

“So,” I say, “since you want to know more about me... there is something very important I want to tell you.”

Pretty smooth, eh?

You know what came next. And he was silent for a moment, as is the custom, and then he didn't say a word. He just leaned over and kissed me, and he held me, more sweetly than he had ever leaned, kissed or held me prior. In the whole entire week we had known each other, this was by far the best kissing, the best holding ever. And the leaning! My mind was racing, however, amid all of it, good as it was. I wanted to say, “So, are you okay with this?” I wanted to ask, “So do you have any questions?” I wanted to process, I wanted to talk about it, dammit! Let's talk about me and my HIV!

So he's holding and kissing away, and it's really good, as I've indicated, and I'm all up in my head, going, “We're not talking. Okay, fine, we're not talking. We're not going to talk about it. No talking. We don't need to talk about it. What's there to talk about anyway? Why do I have this need to talk about it? There's really nothing to say. He's telling you what he thinks right now. So stop processing shit, ya crazy old hen. You don't always need words for expression, case in point being the tonsillectomy he's performing on you... that is some kind of tongue... proof in the puddin' he's simpatico with your *disease*.”

Our next date was a no-call, no-show. And there were to be no more calls, or shows, thereafter.

Was it my fragrance?

I dated this guy once, he was in his late thirties at the time, about 10 years older than me, and he always had to have his friend and roommate along with us on every dinner, date, outing, whatever. The only place he was never invited along was bed. Anywhere else, and he was there. It was the third wheel from hell, and what made it worse was that I had been there. I had had a little fling sort of thing with the third wheel way back in my spirited, shoulder-padded, high-haired, bangle wearing, you spin me round, round Milwaukee days. Just a lamb off the farm I was. And having him hanging around was just kinda dirty and creepy.

Well, that's HIV, the dirty third wheel that manages to insinuate itself in every seamy, steamy chapter of your telenovela. And getting it drunk and “losing” it in a remote woodland area, for example, still

won't get rid of it. It will come back, it will find you and it will sit its big stank rump roast right up on your grill. “Hi, how ya doin'?”

“Ya know, I didn't have to stay with you and put myself at risk.” This from my most recent ex, who I recently spent some time with over the holidays. He said this calmly and without spite. He was responding to something I had said, probably to the tune of, “You never loved me” or one of those. We were, yes, processing, processing our yearlong relationship which had just ended in September. “Well, you don't have to ever put yourself at risk again,” I said, all tiffed. And then I rehearsed the rest in my head—how any sex with anybody is a risk, and how will he know with other guys, and what if they lie, and what if they just don't know, and how DARE you say that!

But I kept my mouth shut, odd as that sounds, because he was/is right. He didn't have to make the choice he did. He decided to be with me, acknowledging and accepting the risks. “Hi, how ya doin'?”

I'm dating someone new. Yet another negative guy, but he's totally cool with my HIV status. He's informed, he says, so he isn't flipping out on it. He said he might have reacted differently if he hadn't gone to some workshops and classes on the subject. God I'm glad he went. Anyway, he's done a lot more than remove my tonsils since my disclosure. He's more than comfortable I'd hazard.

Yesterday he went to get tested. He has to wait two weeks for the results and he's nervous. He says so, a couple times. I feel a little sick in my heart. I finally ask him, “Are you nervous because of me?” He says he's not, that he was just as nervous the last time he took the test, about a year ago. We've known each other about a month. I ask him if he has always used condoms for fucking, every time? He says he has. I tell him he probably has nothing to worry about, that he'll be just fine. And even if, by some oddity, his test comes up positive, I will help him, it's not the end of the world.

“Hi, how ya doin'?”

The next day I'm checking my e-mail. A brief note informs me that a friend in St. Louis died last week. She had AIDS and died in her sleep.

I'm nervous, too. ☹️

TPAN Calendar of Events

All events held at TPAN unless otherwise indicated.

For additional information on these events please contact Michael Barnett at (773) 989-9400.

March 2003

Date	Time	Event
March 5	7:30 – 9:00 pm	Committed to Living – HIV & Exercise, featuring Patricia Staszak of Andersonville Physical Therapy. Sponsored by BTG Pharmaceuticals
March 11	7 – 9 pm	TPAN Tuesday at @mosphere
March 18	7:00 pm	TPAN Board of Directors Meeting at Ann Sathers Restaurant
March 19	7:30-9 pm	10th Conference on Retroviruses Update
March 27	6-10 pm	End of the Month Party Positive at Berlin

April 2003

Date	Time	Event
April 1	8-11 pm	Bar Olympics, benefiting TPAN and the Center on Halsted, Closing Ceremony and Awards. Circuit Nightclub, Presented by DIAGED-5mirnoff, Captain Morgan, Cuervo and Parrot Bay Rum.
April 2	7:30-9 pm	Committed to Living – Fuzeon and More – New HIV meds hitting the market. Sponsored by Roche Pharmaceuticals
April 8	7-9 pm	TPAN Tuesday at @mosphere
April 15	7:00 pm	TPAN Board of Directors Meeting at Ann Sathers Restaurant
April 16	7:30 pm	Managing Sustiva Side-effects, presented by Dr. Jim Sullivan
April 24	6-10 pm	End of the Month Party Positive at Berlin

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Test Positive Aware Network (TPAN) is a not-for-profit organization dedicated to providing support and information to all people impacted by HIV.

Programs and Meetings

All meetings held at TPAN unless otherwise indicated:

5537 North Broadway, Chicago.

Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm

phone: (773) 989–9400 • fax: (773) 989–9494

e-mail: programs@tpan.com • www.tpan.com

Support groups sponsored by the Chicago Department of Public Health
Peer Support and Buddy programs sponsored by the AIDS Foundation of Chicago

MONDAY

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

SPIRIT ALIVE!

Through a collaborative effort of AIDS Pastoral Care Network (APCN) and Test Positive Aware Network, Spirit Alive! Meets Monday evenings from 7:30–9 p.m. at TPAN. With a respect for people of all faiths, Joe Flint facilitates group discussions around hope vs. despair, strength in times of adversity, the existence of a higher power, and faith as a rich resource for healing.

TUESDAY

LIVING POSITIVE

HIV positive gay men discuss how being positive affects life and relationships. Socials and speakers on occasion. Meets Tuesdays at 7:30 p.m.

POSITIVE PROGRESS

A peer-led group for HIV positive individuals in recovery. Special emphasis is placed on living a clean and sober lifestyle as a priority to effectively living and dealing with HIV. Meets Tuesdays from 7:00–9 p.m.

WEDNESDAY

MEDICAL CLINIC

Free medical care provided by a nurse practitioner. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Wednesdays 10:00 am–6:30 pm.

NEEDLE EXCHANGE PROGRAM

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Every Wednesday 5:00 pm–7:00 pm at TPAN office. In association with Chicago Recovery Alliance.

SHE (STRONG, HEALTHY AND EMPOWERED)

A group for HIV-positive women. Meets on Wednesday at 7:30 p.m. Call Kathleen at (773) 989–9400 for more information.

YOGA

Wednesdays at 7:30 pm.

THURSDAY

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

MEDICAL CLINIC

See description on Wednesday. Call for an appointment. Thursdays 2:00 pm–5:00 pm.

BROTHERS UNITED IN SUPPORT (BUS)

A group for HIV-positive gay and bisexual men of African descent. Thursdays at 7:00 pm.

POSITIVE NOW

Whether newly diagnosed or having been living with HIV, you're invited to join Positive Now. Providing support, education and the opportunity to share experiences in a relaxing, empowering environment. Socials on occasion. Meets Thursday evenings at 7:00 p.m.

THURSDAY CONTINUED

PARTY POSITIVE SOCIAL AT BERLIN

Berlin, 954 W. Belmont, Chicago. Thursdays from 6:00–10:00 pm.

FRIDAY

SAFE PASSAGE

A group for young adults (ages 18–24) who are HIV-positive. Fridays at 7:00 pm.

SCHEDULED BY APPOINTMENT

FAMILY AIDS SUPPORT NETWORK (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 989–9490.

SPEAKERS BUREAU

Individuals are available to community groups and organizations to educate on HIV, safer sex, harm reduction and experiences of living with HIV. Call Rodney at (773) 989–9400.

PEER SUPPORT NETWORK

Provides one-on-one support for recently diagnosed individuals. Volunteers provide support, information and referrals. Call Rodney at (773) 989–9400 to get a buddy!

POSITIVE BUDDY

Volunteers provide individuals living with HIV/AIDS one-on-one emotional and physical support. Call Rodney at (773) 989–9400 to get a buddy!

MISCELLANEOUS

CHICAGOPos18to24 AT AOL.COM

AOL chat room for young adults (ages 18–24) who are HIV-positive. Hosted by TPAN's Young Adult Program. Go to AOL town square. Monday through Friday 3:00 pm–5:00 pm.

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