

September / October 2004



Positively Aware

The Journal of Test Positive Aware Network

International AIDS Conference News



**XV INTERNATIONAL
AIDS CONFERENCE**

BANGKOK, 11-16 JULY 2004

- The Politics of Leadership
- Update on the U.S.
- HIV and Aging

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in this issue by Charles E. Clifton*

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Charles Edward Clifton

1959 ~ 2004



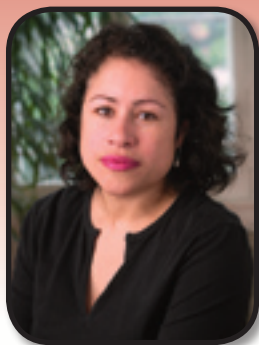
Charles E. Clifton, Claudell Clifton Weaver and Kurt Kausch.

Test Positive Aware Network Executive Director and Positively Aware Editor Charles E. Clifton, 45, passed away on Sunday, August 15, of a pulmonary embolism. He leaves behind his loving partner, Kurt Kausch, of Chicago and dear mother, Claudell Clifton Weaver, of Louisville, Mississippi, and many family and friends.

Born February 11, 1959 in Milwaukee, WI, Clifton earned a B.A. in U.S. History at San Francisco State University in 1993, an M.A. from both Dartmouth College, 1995 and University of Chicago, 2002. Clifton joined TPAN in 1995, and in 2000 assumed the duties of editor of Positively Aware. In July of 2002, Clifton was appointed executive director of TPAN. He worked with the Chicago Department of Public Health's STD/HIV/AIDS Public Policy and Program division on numerous important initiatives, including serving as a member of the HIV Prevention Planning Group. He served as co-chair of the Policy Committee and as a member of the Executive Committee for the AIDS Foundation Chicago's Service Providers Council for the past several years; served on the Editorial Advisory Board of PositiveWords.com; was a member of the Steering Committee of the national AIDS Treatment Activists Coalition (ATAC); chaired the Community Advisory Board of the Conference on Retroviruses and Opportunistic Infections; and chaired the Executive Committee of the North American Treatment Action Forum (NATAF).

His passing is a tremendous loss to the TPAN family and HIV/AIDS community. Charles was a wonderful human being and much loved. He was also well respected, and a passionate advocate for people living with HIV.

Memorial donations can be sent to
The Charles E. Clifton Memorial Fund,
c/o TPAN, 5537 N. Broadway, Chicago, IL 60640.



by Enid Vázquez

ABBOTT VIOLATIONS

Since Abbott Laboratories jumped the price of its HIV protease inhibitor Norvir by 400%, the company has come up with a million reasons why they were right to do so. Now the U.S. Food and Drug Administration (FDA) chastises Abbott for distributing a price chart that compares apples to oranges.

In its chart, Abbott claims that Norvir is the least expensive of all the HIV protease inhibitors. This is “false and misleading” and in violation of government regulations, the FDA said in a warning letter to the company on June 10. The FDA notes that the Norvir cost listed is for a partial dose of the drug, while the costs of the other drugs are for full doses. (The smaller dose is not used for treating HIV, but to boost the levels of other antiviral drugs.) Moreover, the chart does not explain that Norvir can only be taken in combination with other HIV drugs. The FDA noted that the information “raises significant public health and safety concerns” for the HIV community because it’s referring to a sub-therapeutic dose. Moreover, the chart “minimizes the risks of Norvir.”

POSITIVE ORGAN DONORS

It’s a done deal—people with HIV can now donate their organs to other positive people in Illinois, the first state to allow such donations. Special thanks and congratulations to the HIV specialists at Northwestern Memorial Hospital, especially Dr. Robert Murphy and Dr. Patrick Lynch, for championing the idea and to HIV-positive State Rep. Larry McKeon (D-Chicago) for spon-

GENERIC MEDS: POWERFUL

Critics claim that generic HIV drugs used in foreign countries may not be as effective as the brand name drugs. A new study, however, found that a generic successfully controlled HIV.

French researchers teamed up with Doctors without Borders (officially called *Médecins sans Frontières*) to study a three-in-one combination of Zerit, Epivir and Viramune. The fixed-dose combination (FDC) pill, called Triomune, is made by Cipla in India, and is widely used in Africa. (Foreign companies successfully combine the active ingredients of HIV drugs from different companies, which is not done in the developed countries due to competition and until recently a refusal to work together. Gilead Sciences and BMS recently announced plans to combine Viread/Emtriva and Sustiva into one once-a-day pill.) Generic drugs are not necessarily as effective as their branded counterparts. They must be studied to prove effectiveness.

Sixty patients in Cameroon took one pill twice a day. After 24 weeks, 80% had less than 400 viral load (undetectable).

“Generic fixed-dose combinations of such regimens are widely regarded as crucial for scaling-up AIDS treatment in developing countries,” the researchers noted. “These treatments improve adherence owing to the fewer daily doses relative to individual formulations. Supply, storage, and distribution are also easier because the range of products is smaller. Generic drugs are generally much cheaper than brand-name formulations.”

They also reported that, “Despite wide intersubject variability of the plasma concentrations of the three drugs in the fixed-dose combination, the ranges were as expected and consistent with those previously described for the approved drugs.” The study was published in the July issue of *Lancet*. Triomune costs \$20 per month in Cameroon, compared to \$35 for the brand name drugs with pharmaceutical company discounts. The brand names would be six pills (three twice a day).

In a commentary in the *Lancet*, Dr. N. Kumarasamy, the principal investigator for the U.S. National Institutes of Health (NIH) trials in Chennai, India, discussed the benefits and problems of providing HIV antivirals in resource poor countries, and concluded that, “Starting, monitoring, and managing the toxicities of antiretroviral drugs is an art and needs tremendous experience and dedication. Physicians need to be trained properly before we scale-up antiretroviral programs. We need to emphasize that physicians should adhere strictly to standard treatment guidelines to avoid antiretroviral failure and resistance which will be a future public-health challenge in the presence of increasing use of generic antiretroviral drugs.” ☒

soring the bill. Thanks also to all the legislators who supported the bill, and to Gov. Rod R. Blagojevich for signing it into law (on July 15). Many people with HIV face a

greater risk of dying from liver disease than from AIDS.

PRISON SUIT SETTLED

The Associated Press (AP) reported that, "Substandard treatment of HIV-infected prisoners contributed to early deaths at Alabama's Limestone prison, U.S. Magistrate Judge John Ott wrote in a 28-page opinion after the state prison system agreed to settle a lawsuit filed on behalf of the inmates." Ott said medical mismanagement lead to deaths among positive prisoners. (An independent report noted that 38 out of 300 positive prisoners died between 1999 and 2002.) According to the AP report, the settlement will add medical staff and have a monitor investigate the medical care for a period of two years. Among the problems reported: the 200 men in the HIV unit were exposed to tuberculosis, which then kept them from educational and vocational programs available to the general population.

INFANT TREATMENT

Treating HIV-positive infants before three months of age was better than waiting until after three months, according to a study from the Pediatrics AIDS Clinical Trials Group (PACTG).

"Our data and others' provide increasing evidence that several regimens of antiretroviral therapy are safe, effective and well-tolerated during years of administration when started in infancy," the report noted.

The study also found that the children's viral load drop was greater when they were given a triple combination of medications from different drug classes, rather than using two drugs from only one class. This is the same as for adults.

Sixty-percent of the children who started therapy "early" had less than 400 viral load (undetectable) out to 200 weeks (approximately four years).

This compared to a third (30%) of the children in the so-called "delay" group.

In this study, the triple combination drugs used were Retrovir (AZT), Zerit, Epivir, Viramune or Viracept. (Retrovir and Zerit cannot be taken together.) The dual drugs used were from the nucleoside analogs class of medications (Retrovir, Zerit and Epivir). The researchers wrote that "treatment-associated adverse effects were infrequent."

The results from this group of 52 children, from 25 centers in the U.S. and Puerto Rico, were published in the June 16 issue of the *New England Journal of Medicine*. The study continues, and the researchers hope to get a better idea of the best time to start therapy in children.

GETTING TESTED

The Kaiser Family Foundation in June released the results of their national survey showing that "among all U.S. adults, almost half (48%) report having ever been

tested for HIV, including 20% in the last year. Among non-elderly adults, more than half (55%) say they have ever been tested for HIV, an increase from 43% in 1997. Non-elderly African Americans are the most likely to say that they have ever been tested (71%), followed by Latinos (54%) and Whites (51%). Among these groups, however, the percentage who say they have been tested in the last 12 months has remained relatively stable since 1997, at 38% (African American), 30% (Latino), and 18% (White)." Visit www.kff.org. ☒

ONE WEEK ON, ONE OFF

The following is from an NIH press release, May 25.

In a small study conducted at the U.S. National Institutes of Health (NIH), researchers have shown that it may be feasible to treat HIV-infected patients with a simple, once-daily regimen of anti-HIV drugs given in pre-planned, 7-day-on, 7-day-off cycles. This approach is known formally as "short-cycle structured intermittent antiretroviral therapy" (SIT) or colloquially as the "7-7" approach.

"Our data suggest that the 7-7 approach, used with well-chosen drug regimens in settings where patient adherence is high, could be a powerful and cost-effective tool in treating HIV-infected individuals," says study author Mark Dybul, M.D., of the National Institute of Allergy and Infectious Diseases (NIAID), a component of NIH. "By using half as much antiretroviral medication, drug costs are reduced and drug-related toxicities may be less in the long run." He adds, "The 7-7 approach may have particular relevance to resource-poor countries around the world."

Dr. Dybul, NIAID Director Anthony S. Fauci, M.D., and their colleagues report their findings in the June 1, 2004 issue of the *Journal of Infectious Diseases*.

In their study, the NIH investigators enrolled eight HIV-infected people who had been successfully treated with a combination of three or more antiretroviral drugs for at least 6 months. Upon enrollment, the patients began following a treatment regimen of 7 days without antiretroviral therapy, followed by once-daily treatment with the drugs didanosine (ddI) [Videx], lamivudine (3TC) [Epivir] and efavirenz [Sustiva] for 7 days, followed by 7 days off the antiretroviral drugs, repeating the off-on cycle for more than a year. One patient withdrew from the study for personal reasons at week 24; the other seven patients receiving the 7-7 regimen maintained undetectable levels of HIV in their bloodstream (<50 HIV RNA copies per milliliter) for 60 to 84 weeks. During this period, the study volunteers had no significant changes in their CD4+ T-cell counts, and no evidence of resistance to the antiretroviral drugs in their treatment regimen.

Unlike a previous NIH 7-7 study using a different drug regimen, the investigators did not observe transient "blips" during which bloodstream levels of HIV rise above detectable levels, a finding they attribute to the persistence of efavirenz in the blood throughout the 7-day-off-therapy cycle in the current study.

The authors note that strict adherence to the prescribed regimen in the 7-7 approach is necessary. Of note, the once-daily regimen used by Dr. Dybul and his colleagues may allow for enhanced adherence compared with the twice-daily regimen that the researchers used in a previous study. ☒



Access For All

The Politics of Leadership

by **Charles E. Clifton**

The 15th International AIDS Conference (IAC) in Bangkok brought much needed focus to an estimated 10 million impoverished people living with HIV and AIDS in Asia and the Pacific region. The conference's theme, "Access for All," was aimed at exploring the link between the spread of HIV, poverty and affordable treatment options. In bringing the conference to Thailand and Asia, it was hoped that additional efforts to combat HIV/AIDS would shift to the region, as occurred when the 13th IAC was hosted by Durban in South Africa in 2000.

An estimated 38 million people are living with HIV/AIDS worldwide. In 2003 alone, 2.9 million people died and another 4.8 million were newly infected with HIV. There are 14,000 new infections each day, more than 40% are among young people 15-24 years of age. One in four infections last year occurred in Asia.

Thailand was also chosen to host the conference in part because the government is widely acclaimed for its early success in stemming the spread of HIV in the country through innovative prevention efforts. However, in recent years, many AIDS activists have been critical of the government's controversial responses to the intravenous drug-using community. The United States continues to be passed over as a host country for the conference because of discriminatory federal laws that restrict the entrance of HIV-positive people.

Stigma, discrimination and isolation due to one's HIV status are as much a problem in Thailand and other parts of Asia as it is elsewhere. Women are stoned to death, neighbors shun families, and children are ostracized in school. This goes on largely without the influence of media and the politicization of AIDS that has occurred in the U.S. The 15th IAC tried to address this issue. The conference brought people living with HIV and their supporters from all over the world together for one week to share experiences, discuss challenges and exchange ideas, all in the hope of better understanding the condition of HIV-positive people and to prevent millions of children and adults worldwide from dying from the disease, by gaining commitments to improve prevention strategies, providing access to affordable drugs and ending the stigma people living with HIV face on a daily basis.

About 1,000 Thai and international demonstrators protested prior to the opening ceremonies in a call for increased accessed



In his speech at the opening, Shinawatra called for treatment instead of incarceration, a long overdue change in policy. Currently, treatment for substance abuse is generally unavailable in Thailand and thus far the government has not supported needle exchange or methadone programs. Because of past policy, activists, who carried signs saying, “Clean Needles, No More Lies,” heckled Shinawatra. The Prime Minister is held responsible for a six-month war on injection drug users last year in Thailand that left more than 2,000 dead. The government-led campaign forced many addicts further underground, instead of seeking support. It is estimated by the Public Health Ministry of Thailand that needles shared with drug injection partners cause 47% of HIV/AIDS cases.

In Thailand, more than 100,000 people are living with advanced stages of HIV and AIDS and require anti-retroviral medicines. Yet, some 70,000 individuals are not receiving anti-HIV meds. The government plans to provide the “first-line” drug, GPOvir, produced by the Government Pharmaceutical Organization for 50,000 HIV-positive people by the end of the year.

to antiretroviral drugs. The protestors chanted, “Free medication for every nation” and “Access for All,” and called for the end of the free trade negotiations between Thailand and the United States. The demonstrators presented a letter to conference organizers demanding that the Thai government ensure antiretroviral drug coverage and avoid signing free-trade agreements.

At the opening ceremony for the conference, Thailand Prime Minister Thaksin Shinawatra and United Nations Secretary-General Kofi Annan urged international agencies and donor nations to provide more support to developing countries in the fight against HIV and AIDS. Shinawatra, who has been highly criticized by the Thai Drug Users Network for abusing the human rights of users, promised to increase the availability of GPOvir (a generic anti-HIV drug containing Zerit, Epivir and Viramune) to HIV-positive people in Thailand and to expand campaigns on condom use and education for sex workers.

The Bush administration faced heavy criticism from activists at this year’s conference who accused the government of not living up to its commitments in the global fight against AIDS.

POLITICS OF AIDS

Activists also called for an end to Thailand and U.S. free-trade talks, especially around the issue of the protection of drug patents by U.S. pharmaceutical companies. Activists fear any such agreement will raise the price of anti-HIV drugs in Thailand. Activists maintain that if Thailand’s government

enters into a free trade agreement with the U.S., many second-line drugs will remain under patents currently owned by U.S. pharmaceutical companies. They argue that the costs of these drugs will place them out of reach of HIV-positive individuals when “first line” generic drugs are no longer active against the virus. In daily demonstrations that closed pharmaceutical booths in the exhibition



hall during the conference, activists carried banners with slogans such as, “Bush’s free trade deals kill generic AIDS drugs,” “Greed kills,” and “You talk, we die.”

Hank McKinnell, the chairman and chief executive officer of Pfizer, was forced to abandon his speech before conference attendees. Mr. McKinnell, who also serves on PACHA (President’s Advisory Council on HIV/AIDS), has been very active in domestic and international AIDS policy over the last five years. Activists

The U.S. seemed mystified by its reception in Bangkok.

charge that pharmaceutical companies are more concerned about their property rights and profits margins rather than saving lives. McKinnell countered by saying that Pfizer is willing to cooperate with any governments and poorer countries in order to make anti-HIV drugs available to people living with HIV/AIDS.

The Bush administration faced heavy criticism from activists at this year’s conference who accused the government of not living up to its commitments in the global fight against AIDS. The main focus of the anger expressed by activists was the administration’s failing to provide significant financial support to the Global Fund to Fight AIDS, Tuberculosis and Malaria as promised. Originally, President Bush pledged \$15 billion for AIDS relief through the Global Fund. However, the administration has instead decided to move forward with its own plan—the President’s Emergency Plan for AIDS Relief (PEPFAR)—to provide financial support for governments and community groups in developing countries. Randall Tobias, the U.S. Global AIDS coordinator, stated at the conference, “PEPFAR is an effective mechanism to ensure that small and effective organizations can improve their work and get money fast in order to address urgent needs within communities.”

Activists criticize PEPFAR because it allows the Bush administration to handpick governments and community groups whose prevention and treatment policies coincide with the Bush admin-

istration. The policies that are favored by the administration are primarily those promoting sexual abstinence instead of condom use and safer sex education and that attempt to block development and access to cheap (generic) drugs in poorer nations.

Although the U.S. continues to be the largest donor to the Global Fund, it is not enough according to many activists. The Global Fund remains about \$100 million short of its targeted \$1.65 billion budgeted activities for this year.

“The U.S. seemed mystified by its reception in Bangkok—everyone from the activists to Kofi Annan to Jacques Chirac and Tony Blair was criticizing their policies on HIV/AIDS,” stated Gregg Gonslaves, Director of Treatment and Prevention Advocacy for Gay Men’s Health Crisis (NYC). “Despite the President’s announcement two years ago that he was mounting a new \$15 billion international HIV/AIDS initiative, nowhere near that amount has been asked for by the Administration from Congress and its AIDS program has been perverted by arch-conservatives in the Administration and in Congress who are pushing abstinence-only education (despite the evidence that this kind of stand-alone programming doesn’t work), questioning the effectiveness of condoms and generic versions of antiretroviral drugs and shortchanging the Global Fund to Fight AIDS, TB and Malaria. The Administration once again, like they’re doing in Iraq, prefers to go it alone and ignore the best advice of its partners and experts in its own country and around the world.”

The World Health Organization (WHO) continues to move forward with its “3 by 5” program—a project to provide treatment to three million persons living with HIV by 2005. Currently about 440,000 individuals are now receiving treatment under the program. With current drug availability, the three million target would not be reached until 2009. Officials say that the goal can still be reached, but there are many obstacles. Funding shortfalls, with a \$62 million shortage in the \$218 million needed to support the program, has been the major barrier. Another is due in part to the additional time needed to train health care workers and develop standards of care.



WOMEN AT RISK

The Global Village was a community project developed for the conference to provide an accessible space for people, many living with HIV/AIDS. The Global Village included meeting and discussion forums, community markets for Thailand merchants, and space for PWAs (people with AIDS) to share experiences and rest.

In the Global Village, I had the opportunity to speak with one young Thai woman living with AIDS. Noi (not her real name) blames the government for failing to provide proper education to the broader community about HIV prevention. Women in particular, she fears, are not learning how to protect themselves against the virus. Noi married her husband at her family's request without knowing he had HIV. He died three years after they married. "So long as this cycle continues, women will not survive AIDS," Noi stated.

This year's conference also brings focus to what Lucita Lazo, regional director of the United Nations Development Fund for Women (UNIFEM), calls the "feminization of HIV and AIDS." For two decades there has been a noticeable neglect to address gender issues at AIDS conferences. On a global level, 48% of HIV cases are attributed to women and in many regions, including Southeast

CHALLENGES AND EXPECTATIONS

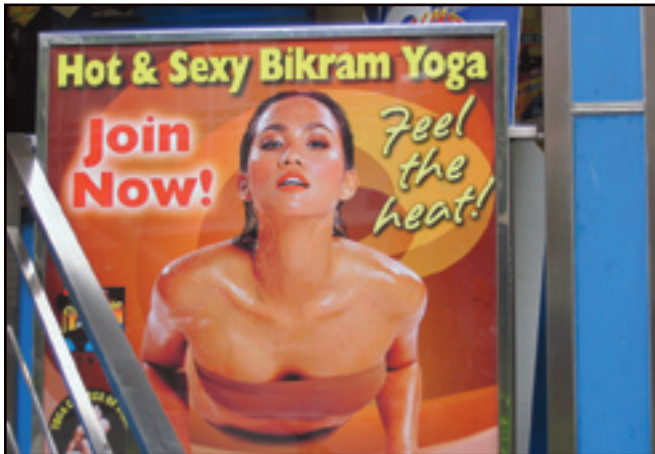
The conference organizers, the International AIDS Society (IAS), had high expectations to meet and difficult challenges to overcome this year. The overarching theme of this year's conference, "Access for All," in theory speaks to the expectation that all people living with HIV/AIDS, scientists, community workers and leaders from the public and private sectors, have access to all resources at hand after 20 years of AIDS. As our experience and knowledge of

HIV grows each year, our need for access to information from a conference of this magnitude grows as well. This year's conference presented an opportunity to hear some of the exciting scientific discoveries in treatment and vaccines, successes in prevention and expanding access to treatment in developing and developed nations. It provided an expected 17,000 diverse individuals from over 160 countries—dedicated to the global struggle against AIDS—an opportunity to discuss their respective challenges and share success.

Speaking at the conference opening on the need for leadership to fight AIDS, United Nations Secretary-General Kofi Annan said, "We need leaders everywhere to demonstrate that speaking up about AIDS is a point of pride, not a source of shame. There must be no more sticking heads in the sand, no more embarrassment, no more hiding behind a veil of apathy. Leadership means respecting and upholding the human rights of all who are

"We need leaders everywhere to demonstrate that speaking up about AIDS is a point of pride, not a source of shame."

Asia, women are more vulnerable to HIV because of their economic and social dependence on men. Many women cannot negotiate safer sex relationships with their partners and others are routinely exposed to physical violence and sexual abuse. The 2004 conference included the highest number ever of workshops and panels focusing on gender and HIV.



vulnerable to HIV/AIDS—whether sex workers, drug users, or men who have sex with men.”

The conference was divided into three programmatic sections this year. The Scientific Program provided highlights on the new

discoveries in prevention and treatment, results of vaccine trials, evaluation of HAART (highly active antiretroviral therapy) in countries such as the U.S. that has had widespread access for many years, and in developing countries that are slowly gaining access to anti-retrovirals.

The Community Program emphasized inventive programs and community-based involvement in the prevention, treatment and care of HIV/AIDS. New to this year’s conference is the “Global Village”—a space for conference attendees to share challenges, ideas and successes.

The Leadership Program brought together leaders from all walks of life committed to fighting AIDS on a global level.

The conference faced difficult logistical challenges, including the sheer magnitude of moving 20,000 people daily through a city infamous for its gridlock, air pollution and humidity to an isolated convention center. With over 10,000 abstracts submissions to consider, the conference organizers and reviewers also had difficult decisions to make to attempt to satisfy the needs of scientists, activists, policy makers, people living with HIV/AIDS and other interested individuals.

VISION—COMMITMENT, LEADERSHIP AND ACCOUNTABILITY

At the end of the day, this conference will be judged by the success of the vision outlined by the organizers. However, as a third-time attendee of the International AIDS Conference, I have several

concerns that I hope will be addressed in the conference’s aftermath. After 20-plus years of struggle, I am concerned about our commitment as a community of scientific, private and public partners in the fight against this pandemic. If we are going to prevail, our success will depend not only on scientific developments, educational programs and community support, but also on a commitment to act locally and globally, and not pit the two needs against one another.

While weapons of mass destruction and terrorism have the capacity to kill in a moment of violence, AIDS has proven that it can and does destroy the social and economic structure of communities and countries—slowly and silently.

Where is the leadership to combat AIDS? From the highest level of the world’s richest nation to the poorest child in a Thailand village, it will take a global effort to develop a comprehensive plan to succeed against HIV/AIDS. At this year’s conference the U.S. government was unfortunately under-represented from a scientific and leadership stance. The administration made a conscious decision to not send leading researchers and public health experts to the conference. How does this reflect on the U.S. overall commitment and ability to provide leadership in the fight against HIV and AIDS? A strong presence could have sent a compelling message of solidarity and made the conference more productive.

Who is accountable for recent shortcomings? What has happened to the pledges of monies to address the AIDS pandemic? What are pharmaceutical partners doing to bring safer and affordable drugs to market and to make existing drugs more accessible to



the millions of people in need? What are community members and organizations doing to deal with AIDS complacency? The continued stonewalling by the government, private sector and community groups will not help reduce the incidence of HIV anywhere in the world. As Annan stated in his address to the conference, “AIDS is far more than a health crisis. It is a threat to development itself.” These groups need to rethink their approach to each other and they need a broader level of cooperation and communication.

Kofi Annan called on the United States to devote as much attention and funding to HIV/AIDS as it does to terrorism and weapons of mass destruction. Annan told conference attendees, “We hear a lot about terrorism, and we are worried about weapons of mass destruction because of their potential to kill thousands of people. Here we have an epidemic that is killing millions of people. What is the response? America has the natural leadership capacity because of its resources, because of its size.”

While weapons of mass destruction and terrorism have the capacity to kill in a moment of violence, AIDS has proven that it can and does destroy the social and economic structure of communities and countries—slowly and silently. More than 20 million people have died from AIDS in the past 20 years, including six million since the last International AIDS Conference in 2002. Today, AIDS is basically spreading unchecked in India, Africa, China and South Asia.

Those of us on the “frontline”—at community-based organizations, volunteers, demonstrators, protestors, activists and advocates for people living with HIV and AIDS—need to re-examine why we are in “it”. Apparently some of us, too many of us, are in “it” for the paycheck, in for personal recognition, in it because we like to hear our own voices, in it because we happened to be in the right place

at the right time five, 10 and 15 years ago and we’re too damn lazy to move on. We scream, we shout, we bitch and moan, but we’re not willing to talk about other perspectives and compromises. Twenty years ago AIDS “die-ins” were powerful statements, as were demonstrations at conferences. Today, many protests appear solely to be acts to intimidate others and to destroy property. We no longer seem to be in “it” to make a real difference in the lives of people living with HIV and AIDS.

We need to re-examine our resolve.

We need leaders to break the silence that still holds AIDS as a political, social and economic hostage. We need leaders to denounce the status quo that feed stigma, discrimination and violence against individuals living with HIV and those who want to help them.

We need leadership that translates into scientifically sound and proven prevention and care interventions. We need leadership that generates substantial resources for testing, prevention and care for individuals living with and impacted by HIV and AIDS. We need leadership that brings government, private sectors, and community to the same table—to foster effective listening and forging even more effective partnerships. We need a commitment to provide access for all.

We are stronger than we were 15 International AIDS Conferences ago, mainly due to the generation of AIDS activists, scientists, and leaders from all over the world who dedicated their lives to partnering with people living with HIV and AIDS to defeat this disease. I hope that as the 20,000 diverse individuals from across the rich field of HIV/AIDS prevention, research and treatment, including people living with HIV/AIDS, return to their lives that each comes away with a better understanding of what it will take to make “Access for All” a reality, and a commitment to do so, sooner, rather than later. ✚

We no longer seem to be in “it” to make a real difference in the lives of people living with HIV and AIDS. We need to re-examine our resolve.



New Drug Development

Medications in the pipeline

by Matt Sharp



20,000 delegates converged on steamy Bangkok for the largest ever International AIDS Conference this past July. The gracious Thai people rolled up their sleeves and rolled out the welcome mats to stage the most enchanting, yet bizarre International AIDS Conference yet. The six-day conference was often compared to a carnival and included five separate day-long informational tracks, a daily leadership forum, daily skills building sessions, daily satellite meetings, an enormous poster room, and non-governmental organization table area, a film festival, a “global village” where local Thai folk sold their wares, and even parading elephants on opening day.

The IMPACT convention center became a microcosm of the world in the most diverse AIDS meeting to date with people of all colors and ethnicities, including Buddhist monks, African tribal women, Thai sex workers, Euro gay men, American treatment activists, children and everything in between. Asian AIDS activists took the opportunity to focus on their own life or death issues surrounding access to AIDS medications, hence the theme of the conference “Access for All.” The pharmaceutical company’s sales booths were a pathetic ploy for profit, but marauding activists closed many down.

Most of the progress in terms of new drugs presented was very preliminary, early stage or preclinical—not ready for prime time.

Some delegates looking for any major scientific news may have been disappointed to say the least. In the whirlwind of community activity and political mobilization, any AIDS medical breakthroughs were lacking.

There was limited drug development progress reported in Bangkok, including information about pipeline AIDS therapies

from new drug generations, and strategies to make current treatments more useful in terms of tolerability and effectiveness. Successes in coping with some complications of AIDS were also presented.

Most of the progress in terms of new drugs presented was very preliminary, early stage

or preclinical—not ready for prime time. Nevertheless, there was some information presented, even though somewhat underwhelming.

NEW DRUG CLASSES

Two new generations of drugs presented in Bangkok that are early in development are the entry inhibitors and maturation inhibitors. The former drugs prevent HIV from entering the cell; the latter drugs stop a later stage of development of HIV.



CCR5 ANTAGONIST

Entry inhibitors known as CCR5 antagonists coat the co-receptor on the T-cell in order to block or stop attachment of HIV. Pfizer's UK-427, 857 is furthest along in development. Five poster presentations showed the effect of food on different dosing levels of the drug as well as the effect on a cardiac signal called QT interval that was previously shown to be impacted by co-receptor antagonists. Other early stage developmental studies were presented that have enabled the drug to move into larger studies. The best news is that UK-427, 857 is shown to produce between 10 and 100-fold drop in virus levels after ten days of treatment. This is a similar potent effect of the protease inhibitors. Pfizer is in a race against Schering-Plough's SCH-D, another co-receptor antagonist that is being studied with a Norvir boost. Both drugs are taken orally and are being studied at either once or twice daily dosing regimens. Pfizer is undertaking a Phase II comparative study and will move into large Phase III studies by year's end. There is an inkling of hope that the co-receptor antagonists will work in synergy with other entry inhibitors.

MATURATION INHIBITOR

PA-457 is being called a "maturation inhibitor" because it inhibits the final stages of HIV protein processing. Three presentations shown in Bangkok have defined the target for this compound and proved in animals and HIV-negative males that the chemical can be metabolized and is well tolerated at various doses needed to reach appropriate blood levels. It appears that the drug will not cross-react with other anti-HIV drugs. It was also presented that PA-457 has potent anti-HIV activity in immunocompromised SCID-HU mice, which is a positive development. The drug

will most likely be a once daily oral pill. The fact that this is a new class targeting late stage HIV is real progress for those who are resistant to the current drugs and need more treatment options from new classes.

REVERSESET

Reverset is a new drug from an older class called nucleoside reverse transcriptase inhibitors. It appears to work against viruses resistant to the older nukes, AZT (Retrovir) and 3TC (Epivir). In Bangkok, updates on information using Reverset in 30 HIV-positive treatment naïve individuals and eight HIV-positive treatment experienced people was presented. The naïve study was a 10-day monotherapy period followed by a 3-dose escalation period with a placebo comparative arm. HIV virus level reductions up to 1.77 logs were seen. No one at the higher doses had toxic reactions. Virus load reductions of .88 log were seen in the experienced group, all who had existing resistance to 3TC or Viread. Even though this is an older class of HIV drug, it may end up being useful for those who have become resistant to AZT and 3TC, offering yet another treatment option. Larger studies will be opening soon in Europe and the U.S.

ENTRY INHIBITOR

A Japanese company presented information on a new entry inhibitor similar to Fuzeon that is an oral formulation. News like this is welcome for those who have to inject Fuzeon twice daily, however the compound is only in pre-clinical stages of development.

Now there is much interest in looking at the treatment interruption effectiveness based on CD4 cell loss.

TREATMENT INTERRUPTION

Strategic therapy interruption may yet prove to be useful in several new studies being





undertaken all over the world. Debate has ensued in the last several years as to whether treatment interruptions will work at all, but newer interruption strategies guided by CD4 counts may demonstrate a better result, especially in chronically infected, stable participants.

Now there is much interest in looking at the treatment interruption effectiveness based on CD4 cell loss, rather than the structured periods researchers have previously studied. The CD4 guided method is treating people based on a CD4 count of 350, which is the standard starting point according to the treatment guidelines. When people fall below 350 CD4 numbers antiretroviral therapy is resumed.

There was good news reported from one large study conducted in Thailand, The Netherlands, and Australia. An interim analysis of 108 weeks with 74 HIV-positive participants randomized to receive continuous therapy, CD4-guided interrupted therapy, or an alternating structure of one week on and one week off therapy was presented. The week-on week-off arm was stopped early because of a 35% rate of virologic failure. The continuous and CD4 guided interruption arms saw similar viral load decreases and CD4 cell counts showing that the guided interrupted therapy was equally effective. The take home point from this study was that in the CD4 guided arm a 54% reduction in antiretroviral therapy was noted, proving less drugs are used at a substantial cost savings.

These and other well designed studies in the coming years will yield more information. CD4 guided treatment interruption may be a useful strategy for cost savings and reducing the risk of long-term side effects in those who are immunologically stable.

At this International AIDS Conference, it seems that science breakthroughs must take a back seat to political progress.

CANCER

Besides the news on antiretroviral drug therapy there was also good news on the complications front. One retrospective analysis of 214 patients in Germany with non-Hodgkins lymphoma showed a better survival rate with use of HAART (highly active antiretroviral

therapy). Complete remission after chemotherapy and treatment with HAART were independently associated with survival. Higher CD4 counts were not associated with survival, however a viral load response due to HAART was.

There were several reports on anal cancer and human papilloma virus. At least two studies showed the benefit of using pap smears for anal neoplasia along with a follow-up with a high-resolution anoscopy and biopsy for definitive diagnoses. If there is a diagnosis of anal neoplasia, another small study showed that using Imiquimod 5% cream (Aldara) is effective in regression of disease by at least two grades and the HPV type most responsible for cancer was also no longer seen.

SUMMARY

After the dust had settled in Bangkok and the activists had traveled back to their respective countries, it appeared that politics played a crucial role at the conference. Due to activist pressure, U.S. and Thai representatives are discussing the possibility of having the generic GPOvir submitted for FDA fast track approval. This is being considered in order to sell the drug in Africa, possibly subsidized by PEPFAR (President's Emergency Plan for HIV/AIDS Relief) here in the U.S. At this International AIDS Conference, it seems that science breakthroughs must take a back seat to political progress. ☒



News on Treatment and Social Issues

Monotherapy, clean needles, and more.

by Enid Vázquez



KALETRA BY ITSELF

Dr. Joseph Gathe, Jr. and colleagues from a Houston clinic updated the results of their small study placing people on Kaletra monotherapy. How exciting—one drug (three capsules twice a day), instead of the two, three or four drug combinations that the general public inaccurately refers to as a “cocktail.” The group presented 48-week data on using the HIV protease inhibitor by itself.

Of 30 persons put on Kaletra and no other HIV drug, 20 were still on it 48 weeks later. All of them maintained undetectable viral load (less than 400 copies). The majority of them (18) had less than 50 viral load. This was their first HIV therapy.

The mean T-cell increase (half of the people had more and half had less) was 317. (Half of the participants started out with less than 169 T-cells and more than 262,000 viral load.)

What happened to the other 10 folks? Two had “virologic failure,” but came back down to undetectable after adding Epivir and Viread.

For the rest, two were lost to follow-up; two did not take the Kaletra or did not take it correctly (they were non-adherent); one was deported and one developed hepatitis B (this is a viral infection and has nothing to do with medication). Information was not provided on the other persons.

Dr. Gathe reported no significant toxicity or drug resistance in the patients.

For a previous report on this study, see the November/December 2003 News Briefs.

MORE KALETRA MONOTHERAPY

There was more good news on using Kaletra by itself.

In continuing efforts to simplify HIV drug treatment, Dr. Gerald Pierone, Jr. (an HIV specialist in Vero Beach, Florida) and his colleagues at the AIDS Research & Treatment Center of the Treasure Coast conducted another study on the revolutionary therapy.

They found that most people were able to maintain their undetectable viral load with the Kaletra monotherapy.

The 18 people enrolled in this tiny study were on triple combination therapy with either Sustiva or Viramune. They continued to take their two “background” drugs during the first two weeks they switched the Sustiva or the Viramune for Kaletra, and then continued to take only the Kaletra.

Of the 14 who were still taking Kaletra monotherapy at the time of this report, 13 had less than 75 copies viral load (as they did before). These people ranged from four to 24 weeks on Kaletra (the study will run for 48 weeks).

Three of the participants had dropped Kaletra due to diarrhea (at weeks 2, 4 and 8). Another person was switched back to their original therapy and viral load results are not in yet. This person had a viral load increase to 1,067.

Two persons developed diabetes, which is sometimes seen with the use of protease inhibitors. Both had pre-existing blood sugar problems, and both had the diabetes under control and were continuing with the Kaletra monotherapy. Three participants also needed to be put on medication for increased triglyceride levels (fat in the blood).

The report noted that, “This is one of the first prospective [planned] studies showing effectiveness and tolerability of simplification to [Kaletra] monotherapy.”

PREVIOUSLY...

In a previous study, Dr. Pierone and colleagues reported that of 15 people put on Kaletra monotherapy for a variety of reasons, 12 remained on it for a mean of 82 weeks (for a range of 57 to 122 weeks), and of those 12, eleven had less than 75 viral load.

Of the four persons who were put on Kaletra monotherapy for simplification alone (the HIV therapy they were taking was already working well), all four were in the study for 57 to 60 weeks at the time of the report, with a T-cell increase ranging from 68 to 213.

The other 11 persons were given Kaletra monotherapy for “salvage” purposes (eight due to detectable viral load, or virologic failure, and three due to adverse events with their therapy). Of these 11, seven had less than 75 viral load for a range of 8 to 122 weeks (with a mean of 92 weeks, meaning that half of them had less than 92 weeks on monotherapy and half had more). They had a mean increase of 209 T-cells.

Four of the salvage participants, however, did not maintain a viral load under 400 copies. Two of them had a high level of non-adherence. One was undetectable at first, but then had a viral load increase up to 587 at 32 weeks, and was later lost to follow-up upon incarceration. The fourth continued on monotherapy for 60 weeks despite a low but detectable viral load (ranging from 600 to 2,000).

Of the 12 persons continuing on therapy, nine had to be given lipid lowering drugs.

This previous report from Treasure Coast was presented at the 9th European AIDS Conference (EAC), held in Warsaw in October 2003.

More than a third of all people living with HIV/AIDS globally are under the age of 25.

MORE KALETRA ALONE

Meanwhile in L.A., at Tower ID Medical Associates, doctors were also simplifying patients to Kaletra monotherapy. Of the men on the study out to 24 weeks (the number of men was not given), all still had less than 75 viral load. Four of them had experienced viral blips (small increases), which ranged from 150 to 387. (One of the participants had two blips in the six months.)

The 18 men enrolled had been undetectable for at least nine months at the time the study began. They were either on a Kaletra combination or had Kaletra added to their HIV therapy for two weeks. All other HIV medications were then dropped except for the Kaletra.

TRIZIVIR FOR ADHERENCE

Italian researchers reported that patients with adherence problems did well when switching to Trizivir (which is a triple combination HIV therapy in one pill, taken twice a day).

The researchers surveyed 70 patients who had taken HIV therapy for about a year, finding that 25 had problems with their regimen due to its pill burden. These patients did not have drug resistance based on a genotype test, and were switched to Trizivir.

Of the 16 who started the study with more than 50 copies viral load (half of them had more than 25,000), all were under 50 copies out to 120 weeks. The seven participants who started out with less

than 50 remained there. Two persons experienced a viral load blip (at less than 450 copies) at weeks 72 and 80.

The report concluded that, “Switching to a regimen of [Retrovir, Epivir and Ziagen—the three drugs which make up Trizivir] appears to be safe and effective in patients with difficulties in maintaining adherence.” (U.S. treatment guidelines do not recommend Trizivir as a sole therapy for people with high viral load.)

LIFE EXPECTANCY CUT SHORT

AIDS is cutting the life expectancy in countries around the world. So says the United Nations Development Program. UNDP estimated that in seven sub-Saharan African countries, the life expectancy is now less than 40 years. These countries are Central African Republic, Lesotho, Mozambique, Swaziland, Malawi, Zambia and Zimbabwe. The lowest figure was for Zambia—32 years. For the United States, life expectancy was 77 years. The report was based on data gathered as of 2002.

YOUTH AND WOMEN

In announcing conference programs on youth and women, the International AIDS Society (IAS), organizers of the international conference, listed several reasons why these groups are of concern. The following is from an IAS press release.

Why focus on youth?

- Of the estimated 14,000 new HIV infections that occur each day worldwide, about half are among young people aged 15-24. This amounts to one infection approximately every 12 seconds.
- More than a third of all people living with HIV/AIDS globally are under the age of 25.
- Young people are particularly vulnerable to HIV infection and frequently carry the burden of caring for family members living with HIV/AIDS.
- Stigma and discrimination can be particularly damaging to young people at a time when they are trying to consolidate their identity and establish their place in the world.

Ensuring access for women:

- For a long time, AIDS was seen as affecting mainly men. Today, women account for half of the 40 million people living with HIV worldwide. In Africa, 60% of people living with HIV are women.
- Young women aged 15-24 are 2.5 times more likely to be infected than young men. In some southern African countries, for example, girls aged 15-19 are infected at rates as much as seven times higher than boys.
- In India as well, the HIV/AIDS epidemic is increasingly affecting women, with about 25% of all HIV infections occurring in women.
- In wealthier countries, incidence of mother-to-child transmission of HIV has plummeted as a result of widespread use of antiretroviral drugs by pregnant women and by their infants. But these proven strategies are not yet as readily available in the developing world.



Women are vulnerable to HIV for many reasons, including inadequate knowledge about HIV/AIDS, lack of access to sexual health and educational services, inability to negotiate safer sex due to gender discrimination and imbalances of power, and a lack of female-controlled HIV prevention methods such as microbicides. Poverty can also fuel HIV transmission as women engage in unsafe sex in exchange for money, housing, food or education.

PHARMACY NEEDLES

Sure, illicit drug users can now buy syringes from the pharmacy in most states, but how well does this system work?

Researchers found racial differences to access. They sent out what they called racially “visual” black, white and Latino purchasers. They visited 38 pharmacies in three different cities in Rhode Island.

Six of the pharmacies visited (16%, or almost one out of five) presented barriers to access. The barriers were the unavailability of the syringes or sale only in boxes of 100, which resulted in lack of access due to high cost.

None of the six pharmacies gave the same story to purchasers, and five of them told different things depending on the purchaser’s race. For example, in two of these pharmacies, a black man was told that there were no syringes available for sale at all, while the other purchasers were told that syringes were available only in boxes of 100.

The researchers, from Brown University and Harvard Medical Center, reported that while pharmacies differed in the minimum amount of syringes they would sell, the cost of the syringes was about the same in each store, with a price range from 15 cents to \$6.49 per syringe.

In their conclusion, the researchers noted that access to clean needles is arbitrary despite state law. They urged that people look at how a state law is being implemented before evaluating how effective it is at decreasing the rate of HIV infections.

BLACKS AND LATINOS

Dallas researchers wrote that because blacks and Latinos are underrepresented in clinical trials, there’s little data showing whether or not they do as well as whites on HIV therapy.

The group looked at the Parkland [Health and Hospital System] HIV Database. They looked at 653 people of color (438 African American and 215 Latinos) whose first therapy was Combivir with either Sustiva, Viramune, Viracept, or Ziagen.

HIV treatment results were the same as found with white patients in clinical trials. Treatment with a combination of Sustiva and Combivir gave people the greatest amount of time before treatment failure, 2.3 years. (This compared to less than one year with Viracept, 1.1 with Ziagen and 1.2 with Viramune.) Failure was defined as two consecutive viral loads above 400 or not having gone down to below 400 in the first place.

HIV-POSITIVE DOCTORS

Columbia University researchers conducted in-depth interviews with 40 HIV-positive doctors. They reported that “many HIV-positive MDs found it hard to ‘practice what they preach’

concerning adherence to treatment, safer sex, substance use and accessing mental health services. They became more aware of the difficulty of ‘sticking to a schedule,’ and became ‘less hard on patients’: less likely to chastise or lecture them. They struggled with whether and how to ‘come out’ and/or ‘go public.’ Desires arose to do so for educational or political reasons, but could backfire, as these MDs were not protected by the Americans with Disabilities Act. ...Disclosures to parents were hard among gay MDs who tried to succeed professionally; and a few tried to commit suicide. Some felt burnt-out due to over-identifying with their patients.”

For many, fear of discrimination led to feeling “stuck” in their jobs. Disclosure often forced retirement. “Many missed work, but felt they could not return because of loss of disability. Some transitioned to research or administration, but clinical work was ‘all consuming.’ Others volunteered, which buffered self-esteem.”

Access to clean needles is arbitrary despite state law.

HIV AND MENOPAUSE

The Women’s Interagency HIV Study (WIHS) reported that “menopausal women are more likely to correctly assess their menopausal status than are their [health care] providers, especially if they are HIV-positive. Providers may be attributing amenorrhea [the absence of periods] in their HIV-positive patients to causes other than menopause.”

HIV-positive women correctly identified themselves as being menopausal 57.7% of the time, while their doctors identified it 37% of the time. In a group of 272 HIV-negative women, menopause was self-identified 69.2% of the time, compared to 50% of the time by their doctors.

Menopause was defined as having a FSH level (follicle stimulating hormone) equal to or above 40 mIU/ml. Pre-menopause was defined as a FSH level above 25.

WOMEN LONGTERM NON-PROGRESSORS

Of 101 HIV-positive women receiving care at the Miriam Immunology Center in Rhode Island by 1989, 5% became long-term non-progressors. These five women never once had T-cells drop below 500 during a period of 15 to 21 years. Nor did they ever have a viral load above 1,400. They have never experienced an opportunistic infection (one that preys on a weak immune system) and they remain in excellent health.

Two of the women are white, two are African American and one is Latina. Four of them acquired HIV through injection drug use and one through sex. The Brown Medical School researchers reported no differences in these women from the others in terms of baseline health or demographics. ☒



News From the Centers for Disease Control

Update on the U.S.

by Enid Vázquez

The U.S. Centers for Disease Control and Prevention (CDC) reported the results of its new and ongoing studies into epidemiological trends and the effects of disease.

OLDER PEOPLE DIAGNOSED LATER

For people born before 1950, 40% of men and 32% of women who received an HIV diagnosis did so in the same month as their AIDS diagnosis. Researchers said, “These late HIV diagnoses underscore the need for physicians to obtain a sexual and drug-use history from all adult patients, regardless of age, and for expanded access to HIV testing.” The report was based on HIV data from 25 states during 1994 to 2000.

HIGH SCHOOLS: LESS SEX, FEWER PARTNERS, MORE CONDOMS

Based on seven surveys of 14,000 high schools conducted between 1991 and 2003, CDC researchers found a decrease in many HIV-related risk behaviors. The percent of students who had sexual intercourse dropped by 13% (from 54% in 1991 to 47% in 2001). The percent who used condoms

Researchers recommended that cholesterol levels be closely monitored among children taking PIs.

during their last intercourse increased by 37% (from 46% in 1991 to 63% in 2001). The results were published in the May 21 issue of the CDC’s *Morbidity and Mortality Weekly Report*.

Racial and ethnic differences were presented at the international conference. The percent of students reporting four or more sex partners decreased 33% among black students and 27% among white students. Condom use increased by 54% among Latino students, 52% among black students and 37% among white students.

The CDC reports that “the authors attribute the changes in HIV-related risk behaviors to the broad efforts of families, schools, community-based organizations and government to reduce the impact of the AIDS epidemic among U.S. youth.”

CHILDREN’S TREATMENT RAISES RISK

As with adults, children on HIV therapy are at risk of increased cholesterol levels and therefore, perhaps cardiovascular complications. The CDC study of children infected during birth found the increased

risk in those given therapy that included a protease inhibitor (Norvir is the one commonly given children, due to greater pediatric data with that drug).

Of 159 children followed over five years (1999–2003), the 99 children on a protease inhibitor (PI) were four times more likely to have high cholesterol levels than the other children.

The report stated that, “While cholesterol-associated health problems—including heart disease and heart attack—are extremely rare among children, researchers noted that cardiovascular complications might arise in these HIV-positive children as effective antiretroviral therapies allow them to live into adulthood. Researchers recommended that cholesterol levels be closely monitored among children taking PIs, and that the benefit of interventions



such as diet, exercise, and lipid-lowering drug therapy be considered.”

The PACTS-HOPE study examines the medical and psychological impact of HIV on children infected at birth.

OPTIMISTIC RISKS

As previous studies have reported, feeling optimistic about the benefits of HIV treatment is associated with increased sexual risk-taking. The CDC researchers in this report interviewed 1,468 HIV-negative or untested men at gay bars in 13 cities between 2000 and 2002.

Of the 587 men who reported receptive anal intercourse in the previous six months, those who expressed “treatment optimism” were nearly twice as likely to not have used a condom during their latest intercourse. This was true even when the partner was HIV-positive or of unknown status. According to the CDC,

“The researchers stressed the need for innovations in prevention that take into account the availability of effective AIDS treatments and the lessening concern about the consequences of infection.”

MORE RISKS

The CDC’s Young Men’s Survey reported that many of the MSM (men who have sex with men, who don’t necessarily identify as being gay) reported unprotected sex with both men and women.

In the first survey conducted, nearly one in five men (17%) reported having sex with both men and women in the previous

six months. Of these, 22% reported that they had unprotected sex with both men and women.

In the second survey, 9% reported sex with both men and women in the previous six months, and 27% of this group reported unprotected sex with men and women in that period.

The level of HIV infections, other sexually transmitted diseases and risk behaviors for HIV (such as injection drug use or having sex under the influence of drugs or alcohol) did not differ between the MSM with female partners and the men who only had sex with men.

The Phase I survey was conducted with 3,592 MSM ages 15 to 22 in seven cities, between 1994 and 1998. Phase II was conducted with 2,949 MSM ages 23 to 29 in six cities, between 1998 and 2000.

Social anxiety was defined as “the fear of being perceived negatively in interpersonal situations.”

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HIGH HIV RATE

Also from the Young Men's Survey, Dr. Linda Valleroy from the CDC presented data showing a high rate of HIV among men ages 23–29, based on Phase II results.

The incidence was 20% among African American MSM, 10% among those of mixed race; 5% among Latinos, 4% among whites and 3% among Asian Americans and Pacific Islanders.

The overall annual HIV incidence—the number of people newly diagnosed each year—among the 2,906 participants was 6%.

ANXIETY AND INFECTION

The CDC reported that, “A study of 138 HIV-positive men at an Atlanta AIDS clinic found that MSM are significantly more likely than heterosexual men to have social anxiety that can lead to risk behavior.” Social anxiety was defined as “the fear of being perceived negatively in interpersonal situations.” The research team looked at three types of social anxiety:

- fear of being observed by others (in other words, a general self-consciousness),
- performance fear, and
- fear of social interaction.

Among the HIV-positive MSM, fear of being observed made men 15.4 times more likely to have had unprotected insertive anal intercourse with someone whose HIV status was negative or unknown. Fear of performance made this risk 7.4 times more likely, while fear of social interaction made it 4.7 times more likely.

The researchers found that social anxiety among the straight men did not “have a similar impact” on their risk behavior.

According to the report, “The authors conclude that social anxiety, like other mental health issues, affects sexual risk and may play a significant role in HIV transmission among MSM.”

IN LABOR

Rapid HIV testing is being used to help prevent transmission during the time of labor. According to one CDC study, rapid testing of women in labor with unknown HIV status serves as “a timely, feasible and effective method to prevent mother-to-child HIV transmission and ensure that HIV-positive mothers receive life-prolonging treatment.”

The women received a finger-stick OraQuick Rapid HIV test. Of 4,849 women tested, 34 were found to be HIV-positive. They were given HIV treatment to prevent infection of the baby within an average of

It takes more than a passing message to encourage testing among those most at risk for HIV.

one hour. These moms represented a prevalence rate of 7.0 per 1,000 women.

The MIRIAD study (Mother-Infant Rapid Intervention At Delivery) took place at 16 hospitals in six cities during 2001–2003.

BABY DOCTORS

Pediatricians told CDC researchers that they would like to talk to parents about the sexual risk-taking behavior of their teens. The majority, however—85%—said they would only talk with parents if the families raised the issue first. Based on this survey of 510 pediatricians across

the country, the CDC plans to develop brochures with the American Academy of Pediatrics designed for parents that will discuss specific approaches they can take with their children along with a list of resources. Eighty-three percent of the docs said they would like to have such a brochure to give to parents.

THERE'S MORE TO TESTING

...than just media messages. When talking to thousands of people about getting tested for HIV, researchers found that those who had seen media messages about getting tested did not get tested at a higher rate than the folks who didn't see such information. “It takes more than a passing message to encourage testing among those most at risk for HIV,” the report stated. It said that “information-only prevention efforts alone may not be sufficient to encourage testing.” The researchers interviewed 2,491 persons in eight cities in 2000, including MSM at gay bars, injection drug users at needle exchange programs and heterosexuals at clinics for sexually transmitted diseases.

RELEASED FROM PRISON

More counseling on safer sex is better than less counseling for newly released prisoners. Those who were given two counseling and training sessions before release, plus four follow-up, small group sessions after release, reported significantly lower rates of unprotected sex six months later. Another group of young men only received a single counseling session prior to release.

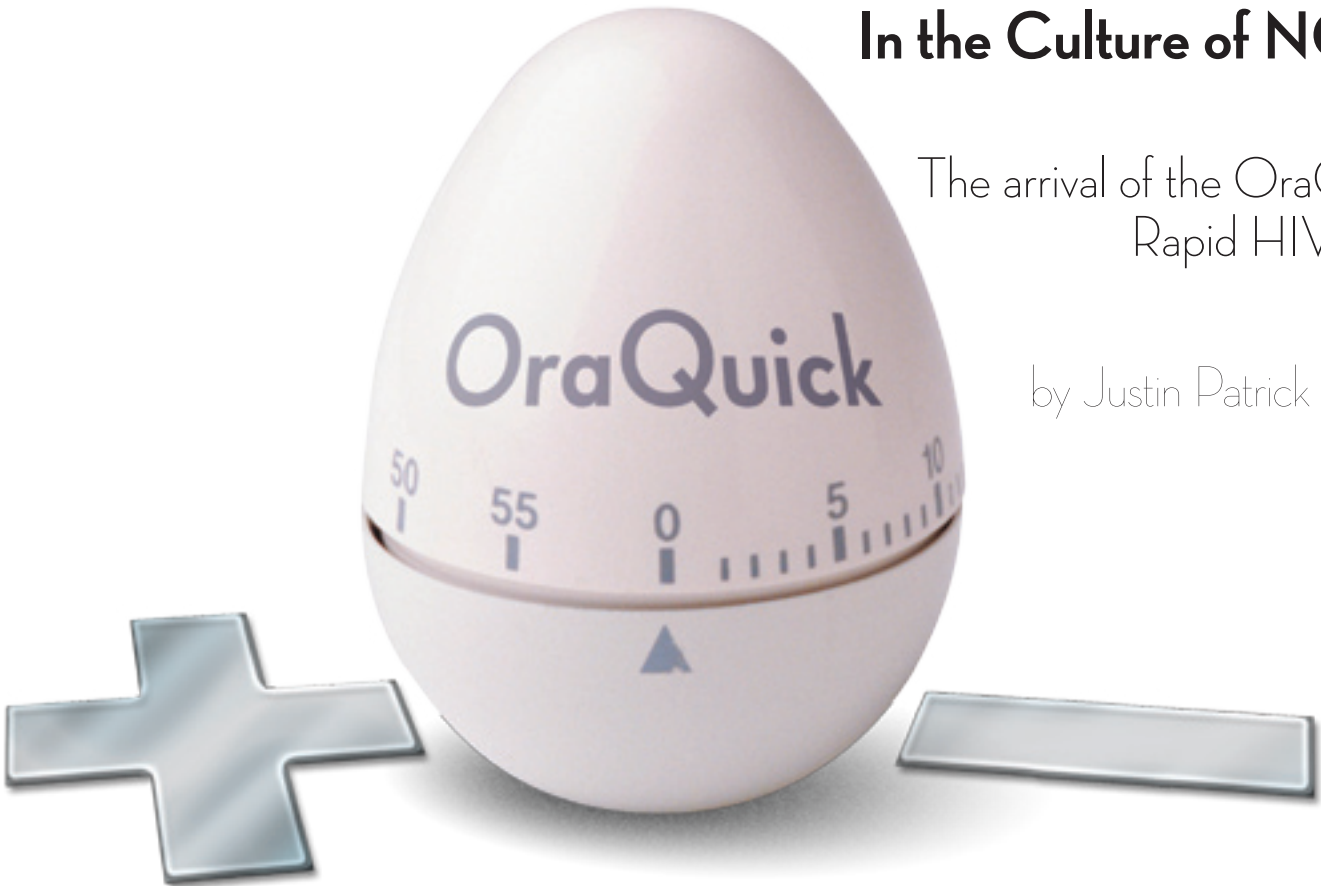
Nevertheless, unprotected sex remained high in both groups: 78% for the group receiving one counseling session vs. 68% for the group with more extensive counseling.

The 522 prisoners, all between the ages of 18 and 29, were counseled on reducing risks for acquiring hepatitis, HIV and other sexually transmitted diseases. The Project START study was conducted in eight state prisons in four states. Half received the extensive counseling. ☒

In the Culture of NOW

The arrival of the OraQuick Rapid HIV Test

by Justin Patrick Jones



Okay, what do we have here? This contains roasted red skin potatoes. Well, that sounds good. It also has seasoned cooked beef steaks. Nothing seems wrong there. We continue with modified food starch product, maltodextrin, sodium phosphate, partially hydrogenated soybean oil, beef fat, high fructose corn syrup, monosodium glutamate, disodium inosinate and disodium guanylate. What the hell is all that? Oh, it takes less than nine minutes to cook in the microwave?!? Sweet! I should buy a lot of these babies so that I am set up for dinner for a week.

Since the advent of the TV dinner, American culture facilitated a necessity for everything in our society to be fast and easy. We complain when our Internet service slows. We gnash our teeth at dryers when our clothes need another thirty minutes to dry. And, somehow in the last one hundred years, time began to move more quickly over American soil, and we no longer have that extra hour to cook a fresh dinner. Amongst other problems in the 21st century, Americans are the most obese people in the world. What have we learned from all this? Faster and easier are not always the best solutions to our problems.

In January 2001, the CDC published a document entitled "HIV Prevention Strategic Plan through 2005." In it, they outlined an overarching goal to decrease new HIV cases from 40,000 annually to 20,000 by 2005. While this seemed lofty, it also seemed possible. To achieve this, they provided four goals to attain the desired outcome. They included "[decreasing] by at least 50% the number of persons in the United States at high risk for acquiring or transmitting HIV infection by delivering targeted, sustained, and evidence-

based HIV prevention interventions; increase from the current estimated 50% to 80% the proportion of HIV-infected people in the United States who are linked to appropriate prevention, care, and treatment services; and through voluntary counseling and testing, increase from the current estimated 70% to 95% the proportion of HIV-infected people in the United States who know they are infected," in other words, mass testing.

In November 2002 the FDA approved a new HIV testing device. It is a rapid test. In just 20 to 40 minutes, a person can know his or her HIV status, sort of. (I will cover that later.) The most common one being pushed presently by the federal government is the OraQuick test, which utilizes a drop of blood obtained via finger stick. In cities all over the country, the CDC funded a project called PCRS (Partner Counseling and Referral Services) Rapid HIV Testing Demonstration Project. As OraQuick is simple to perform, agencies around the country are being trained and funded to add rapid testing to their scopes of service.

To many service providers, it seems as though we are pushing forward with rapid testing without considering all the possible ramifications. One problem facing the development of rapid testing programs involves the legality of it. Many states have yet to approve the use of OraQuick rapid testing. In Illinois, for example, the state testing law requires a confirmatory test to be performed prior to giving a client a positive result. With OraQuick, a negative is a negative is a negative, if your client is not within his or her window period. However, a positive is a preliminary positive. What does that mean? Although the OraQuick is 99.6% accurate, a false positive is possible.

Because a false positive is possible, testing counselors must tell a client that his or her result is a preliminary positive and a confirmatory test must be performed. “I will never, ever, ever, ever trust the OraQuick rapid test again,” stated Jaime Dircksen of Chicago. In the beginning stages of the current CDC project, she received an OraQuick rapid test with a preliminary positive. In the days awaiting her confirmatory test result, she spent several sleepless, tear-filled nights considering what a positive result would mean for her. The testing counselor told her that the test is 99.6% accurate, so the chances of it being wrong were nil. When she returned for her confirmation test result, she received a negative result. Her OraQuick test yielded a false positive. (It should be noted that the testing counselor read five tests that day as preliminary positive—all of which returned negative. Most likely, the number of false readings rested with the testing counselor and not the test itself.)

For present and future clients receiving positive results from OraQuick, the PCRS project funded by the CDC requires that participating agencies offer partner notification services to newly diagnosed clients. While this service is voluntary, several issues present themselves. At what point are you offering a voluntary service versus coaxing the information out of the client? Where does this information go? If the client engaged in risky behavior with only one person in the last year, will the client reveal another person’s status, thereby committing an infringement on the AIDS Confidentiality Act?

“No court is ever, ever going to say that cooperating with government partner notification is a violation of the AIDS Confidentiality Act,” said Ann Fisher, the Executive Director of the AIDS Legal Council of Chicago. Still, she noted for partner notification to work, a client must trust the person or government to whom he or she is providing such sensitive information. She concluded by saying, “People don’t trust the CDC the way they once did, since they’ve allowed themselves to become so politicized.”

Providers’ concerns over distraught clients and legal complications are valid; however, an agency must not forget the overwhelming task of implementation. Where does an agency start? Charles Martin, the Executive Director of JAATF (Julius Adams AIDS Task Force), one of seven agencies in Florida piloting the use of OraQuick, spoke on implementation and utilization. OraQuick now comprises 95% of their testing program. In regard to implementation, he gave one big piece of advice. “The most important thing with OraQuick is the counselors. A counselor must be very adept.” In Mr. Martin’s opinion, many providers share a common misconception; clients need the waiting time to prepare for a possible positive result. He observed that clients do not need that time. Instead, counselors need that time to prepare. After all, a testing counselor learns the preliminary positive result as the client learns it. Therefore, he suggested that agencies ensure that each counselor is fully prepared for his or her task. He added that a counselor should never feel that his or her job is threatened if that counselor feels uncomfortable performing rapid tests.

After all is said and done, discussed and processed, introduced and implemented, local government agencies coordinate the PCRS project. What outcomes—positive and negative—do they antici-

pate? Andrew Delicata, PCRS Coordinator for the Chicago Department of Public Health, illuminated one of these. “Setbacks will occur mostly on the provider’s side, being that this is a huge shift in the way that we do testing and counseling.” When asked what, if any, good he expects to come from rapid testing, he said, “I expect there to be more acceptability of HIV testing in general. I expect people who test to have a more positive experience.” Granted, he was unfamiliar with Jaime Dircksen’s experience. In addition, he anticipates an increase in testing numbers as well as an increase in people who return for their results.

Clearly, a host of both negative and positive thoughts present themselves with the introduction of rapid testing. As we examine the CDC’s HIV Prevention Plan, are the negative thoughts dispelled? Our infection rate continues to hover at 40,000/year. The CDC hopes to increase the number of people who know their status from 70% to 95%, hopefully decreasing accidental transmission. With those 95%, they want to increase the number of those receiving care from 50% to 80%. Looking at the numbers, the CDC has something really fabulous going here, but is it feasible?

Once we know everyone who is HIV-positive, what are we going to do with them? Nine state AIDS Drug Assistance Programs continue to maintain a waiting list, denying life saving medications to HIV-positive people in need. The federal government refuses to increase domestic funding for HIV services to the level the community needs. Many people do not trust doctors. Many people do not trust the government. Many people still have little or no access to care.

Overall, rapid testing is still a good idea. If more people know their status, then hopefully transmission numbers will decrease. Hopefully more HIV-positive people will gain access to appropriate care. Hopefully, people will begin to make educated decisions about their treatment and sexual health. Unfortunately, that is a lot of hoping. Hope provides no medication, medical care, case management or community support. Until our society renovates and improves the systems of care with which we operate now, rapid testing will only create more problems than it helps. We need to look before we leap, for once, and solidify those systems already in place.

In my home growing up, my father used to say, “There’s your way, my way, and the right way.” I believe that may be the best way to look at rapid testing. Charles Martin’s agency serves a primarily African-American community. According to Mr. Martin, in Florida, one in forty-six African-Americans is HIV-positive. His community finds rapid testing very beneficial to curbing disease transmission. For those who receive a negative result without the stressful waiting period, Andrew Delicata is correct. They will most likely have a more “positive” experience. However, we wish neither to forget nor to invalidate the experience of Jaime Dircksen. For those unlucky few who receive a false positive, many of them will endure days of agony, thinking they contracted HIV.

In the end, one thing is for certain. Rapid testing is here to stay. Whether it is appropriate for you and your community is for you and your community to decide. It is a conversation in which we all need to participate. ☒

“The most important thing with OraQuick is the counselors. A counselor must be very adept.”

Dude - I don't think
that's from
biting
your lip.

Take Note.

That sore could be a symptom of syphilis.

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Just part of the routine.



HIV and Aging

by Andrew Shippy



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

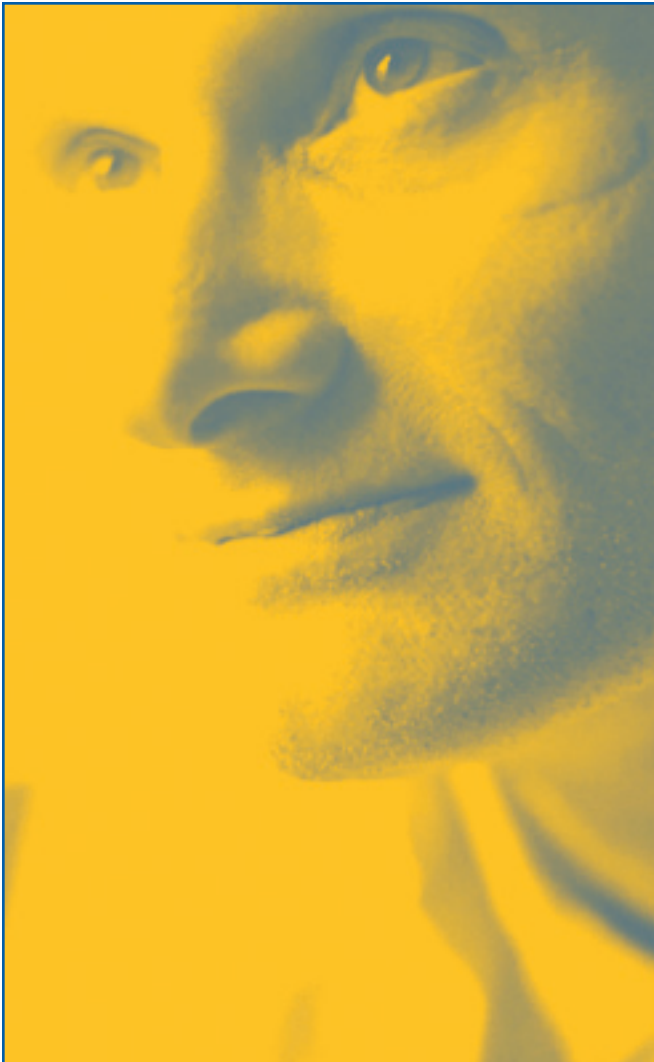
The HIV/AIDS epidemic in the United States is changing. Government agencies, community-based organizations, and even the media are finally aware that HIV doesn't discriminate. Most of us know that women and people of color are at risk for HIV-infection, but older adults are rarely mentioned.

BACKGROUND

Although fewer people are being diagnosed with AIDS in the U.S. and deaths continue to decline, the number of older adults living with HIV/AIDS is larger than ever. Between 1991 and 1996, the number of new AIDS diagnoses rose twice as fast in people over 50 than in those younger than 50. And although the rate slowed from 1996–2000, increases in the older population continued despite great improvements in treatment in HIV that became widely used beginning in 1996–1997. According to the Centers for Disease Control and Prevention (CDC), there are more than 78,000 people age 50 years or older living with AIDS in the U.S. The most accurate statistics about these older adults are based on an AIDS diagnosis. Some states don't include HIV statistics in their reporting, and, among those that do, the incidence of HIV in older adults may be under reported.

For practical reasons early in the HIV epidemic, the CDC defined older adults as anyone 50 years or older. People over 50 often have different experiences and complications than younger people. Over the years, people have continued to use this definition of "50" because it has been useful when scientists study age-related differences between younger and older adults. The information about aging with HIV/AIDS can be confusing, especially when studies report conflicting results. There are many questions that need answers. People have begun to realize that older adults face issues about their health and well-being that we had never considered before.

One of the largest problems all older adults face is ageism—discrimination based on negative attitudes toward aging and older people. Until we correct ageist assumptions and attitudes about older adults, there will be limits to what we know about how HIV affects their lives. Many healthcare providers don't consider older adults to be at risk for HIV. Thus, relatively few prevention efforts have focused on this age group. One common, but incorrect, assumption is that older adults aren't sexually active or, if they are, they know how to avoid HIV infection. Older adults and their healthcare providers usually avoid discussions of sexual behaviors and substance use. Older adults may be unwilling to discuss risky behaviors because of the stigma that society attaches to these behaviors. Others may be in monogamous relationships with a partner who engages in risky behavior without their knowledge. This lack of communica-



delayed diagnosis of HIV and a potentially critical lag in beginning anti-HIV treatment.

Although specific treatment guidelines have been created for children, pregnant women, and other patient populations, no specific recommendations exist for older adults. This presents a challenge for physicians, particularly when treating older patients with other age-related illnesses. Beginning anti-HIV treatment requires a complex and intensive regimen of at least three medications, in addition to those that people are already taking for other illnesses. This is often at odds with a common process of slowly adding medications to reduce side effects in older patients. In spite of the need to understand how HAART (highly active antiretroviral therapy) will affect the growing number of older adults living with HIV, they have often been ignored in clinical research. Since older adults are rarely included in controlled medication trials, little is known about age-specific drug actions, possibly dangerous interactions with other medications, or side effects. Older adults often have medical problems (for example, high cholesterol, triglyceride, or blood sugar levels, and/or liver or kidney disease) that disqualify them from participating in many trials. Because the number of older adults with HIV is growing, clinical trials should either be modified to include older adults, or separate studies should be designed specifically for older adults.

QUALITY OF LIFE

HIV-positive people are now living longer and healthier lives than before the widespread use of HAART. In the U.S., HIV is becoming more like a chronic illness than the acute crisis it once was. The incidence of opportunistic infections has dropped dramatically, but now other physical and mental illnesses have increased as people live longer. Research efforts during the first two decades of the HIV epidemic mostly focused on keeping people alive and relatively healthy. Given the success of HAART, it is now important for researchers to focus on the quality of life of people living with HIV. There's more to life than undetectable viral load and high CD4 counts. Much of the HIV/AIDS literature is based on a medical, or disease, model of wellness. In other words, if a person doesn't have a particular set of symptoms, then they aren't sick. In some cases, this is the best we can expect from a healthcare system, especially one that is stretched thin by budget cuts, escalating insurance costs, and increasing numbers of patients with multiple and complicated illnesses. However, biological markers don't tell the whole story, particularly in research studies designed to understand the quality of life of older HIV-positive adults.

tion is particularly dangerous for older adults since HIV-related illnesses can be difficult to distinguish from typical age-related health problems. As people age, various illnesses become more common. Alzheimer's disease, arthritis, diabetes, breast or prostate cancer, high blood pressure, and vision/hearing loss affect millions of older adults each year, and many of these diseases share common symptoms with HIV/AIDS. The lack of discussion about risk factors and HIV-related symptoms can lead to misdiagnosis or a

DEPRESSION

In the past several years, more attention has been paid to mental health problems among people with HIV. Many of these studies focus on depression. Depression is a common psychological illness, both in HIV-positive people and older adults, but that doesn't mean people have to live with it. Older HIV-positive adults may be more likely to have more symptoms of depression than younger people with HIV and are significantly more likely to be depressed than people their own age who are HIV-negative. Estimates of depression among people living with HIV range from 15-60% depending on what definition is used.

One of the problems in describing the rate of depression among older adults with HIV is that researchers use a variety of measures to identify depression. Some prefer to use a clinical diagnosis of depression (someone who receives a clinical diagnosis has a set of symptoms that don't go away over time and interfere with their daily life), and their results reflect the lowest percentages of depressed individuals. But, just because a person isn't clinically depressed, it doesn't mean that everything's coming up roses. Many HIV-positive people might not meet the criteria for a clinical diagnosis but have several symptoms of depression that can have a negative impact on their lives. This is one case where the glass being half-full isn't so good!

Regardless of the measure used, research has shown that older adults with HIV are more likely to experience symptoms of depression than younger HIV-positive people and older HIV-negative adults. Older HIV-positive adults who are depressed are more likely to have financial problems, have fewer people to turn to for support, lack HIV-related information, live alone, have thoughts of suicide, and experience greater levels of stigma related to HIV and aging than older adults who aren't depressed. Depression may interfere with adherence to treatment, health care visits, participation in social activities, and personal relationships.

It can be difficult for doctors to diagnose depression because many of the symptoms are similar to common HIV symptoms, co-infection with hepatitis C, or drug side effects. The most common symptoms of depression include fatigue, poor appetite, weight loss, loss of sex drive, and sleep difficulties. These symptoms sound a lot like a list of medication side effects and are similar to symptoms

Older HIV-positive adults who don't receive adequate support may feel more isolated and stigmatized than those who get the support they need.

of HIV itself. Healthcare professionals and older adults with HIV need to pay attention to these symptoms, especially if they occur with other warning signs of depression. These can include emotional symptoms (mood swings, having 'the blues' or feeling so sad that nothing can cheer you up) and mental symptoms (sudden or increased forgetfulness, difficulty keeping track of appointments).

SOCIAL SUPPORT

Social support is the emotional and practical assistance that family members and friends provide for people living with HIV. Social support is an important resource for everyone, but it becomes particularly important for people as they age. Older adults living with chronic illness may be even more acutely aware of the beneficial role that social support can play in adapting to the stress related to their changing life circumstances. Social support boosts psychological well-being and can reduce the number and intensity of physical symptoms for people with HIV.

Older HIV-positive adults who don't receive adequate support may feel more isolated and stigmatized than those who get the support they need. They may also have difficulty managing their illness (adherence to medications and scheduling health care visits, for instance). Anxiety, depression and thoughts of suicide are higher among people who lack social support resources. People must rely on formal healthcare providers to get the support they need to cope with HIV. However, HIV-positive adults who don't receive support from family and friends were less likely to use formal healthcare services. This can be a real problem for the large numbers of HIV-positive seniors who live alone and are isolated from family and friends.

Several barriers may reduce the amount of support that family and friends can provide. One such barrier may be an individual's reluctance to disclose his or her HIV status. On average, older adults are less likely to disclose than younger people. Friends and family may not be aware of the older adult's need for assistance because of the stigma and fear associated with HIV/AIDS. Older adults may be at greater risk for negative attitudes from family and friends if they do disclose. Another barrier is the size of many older HIV-positive adults' informal social networks. They may have smaller social networks because they don't keep in touch with

family and friends, while others may be unable to maintain connections because loved ones have moved away, died, or are too ill to keep in touch regularly.

FINDING LIGHT IN THE TUNNEL

Much of this discussion has focused on the challenges that older adults with HIV face. Are there any benefits to being an older HIV-positive adult? As more older adults become infected with HIV and others who were infected when they were younger live longer, healthcare professionals need to be aware that many older adults living with HIV feel that their life experiences have provided them with skills to cope with their illness better than younger adults.

Researchers from Columbia University School of Public Health found that older adults felt that there were some advantages to being older. The sample included 45 men and 18 women living with HIV, between ages 50 and 68. Many participants felt that older adults had more skills because they had been through other challenges in the past and had learned to recognize their strengths and limits. Older people may also feel less cheated because they have accomplished many of the goals in their lives, compared to people who are diagnosed at a younger age. Another potential benefit is that older adults tend to respect their health and their lives more than younger people. The participants in this study said that they were more likely to stay on top of their medications and listen to their doctors than younger adults. They were also less likely to take risks and were motivated to change behaviors to improve their health. Several people also thought that they were more patient and content with their lives than younger adults. They believed that younger people were more likely to get stressed out by daily hassles or routine problems than they were. In addition, some older individuals are less threatened by illness and disability. They may be better able to accept limitations related to HIV than younger adults.

Study participants discussed the fact that it is common for older adults to slow down because of chronic illnesses, while younger people may try to keep up with their friends and family, so adjusting to HIV may be harder for young people. Older adults may also have fewer family or job responsibilities so they can focus on their personal needs better than younger people. Many of the study participants said that taking care of one's health requires a lot of time and attention. Older adults may simply have more time than young people who have to manage family and job responsibili-

ties. Healthcare providers shouldn't assume that older HIV-positive adults aren't able to cope with and adapt to their illness.

WHERE DO WE GO NEXT?

Older adults are one of the fastest growing segments of the HIV population, but relatively little research has focused on seniors living with HIV. There's a lot of work ahead as more and more people live longer with HIV and as new infections among older people continue to rise. One of the biggest challenges will be to change attitudes toward older people and their lifestyles. Obviously someone figured out that older people are sexually active—why else would Bob Dole appear in advertisements for Viagra?

Until healthcare providers and AIDS service organizations recognize that older adults are at risk and need appropriate prevention interventions and treatment education programs, older adults will have to squeeze into existing programs to receive the services they need. Research is needed to better understand both the unique challenges that older adults face and the resources that they need. For many older adults, HIV isn't viewed as one of the most stressful parts of their lives, particularly when they have to cope with multiple illnesses and other personal and emotional challenges. The research that has been conducted to date rarely makes a distinction between long-term survivors who have "aged into" the over 50 group versus those older adults who are newly infected. It is now important to understand the ways in which HIV affects the aging process for these distinct groups of people, especially when age-related diseases begin to affect these adults.

It's good to know that many HIV-positive older adults are able to find happiness and strength while coping with such a challenging illness. It is important to recognize the accomplishments of the past two decades of HIV care. In a way, we're lucky to be in a position to concern ourselves with how older adults will live with HIV. One of the most important goals for researchers and healthcare providers now should be to maximize the quality of life for older adults living with HIV by changing attitudes, asking questions, and offering supportive services for older adults and the family members and friends who help them. ☒

This article originally appeared in ACRIA Update (Summer 2004). Permission to reprint granted by AIDS Community Research Initiative of America (ACRIA). Andrew Shippy is a Research Associate at ACRIA and a doctoral candidate in Applied Developmental Psychology at Fordham University. His research focuses on well-being and adaptation among vulnerable populations of older adults.



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Saturday, September 18, 2004



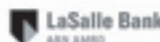
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COPING

When we can't take it anymore
by Tom Setto

"I thought about killing myself this week," Joey blurted out.

"Okay, so what did you do?" Gary asked, kind of jokingly.

"No, really, for the first time in my life I seriously thought about killing myself. Obviously I didn't try, mainly because I was afraid I wouldn't succeed," Joey interrupted. He had tears in his eyes. "I'm totally embarrassed telling you guys, mainly because I'm not sure that I could give you any one reason why I even started thinking about it. I started thinking about my life and where it's going and the thought just came into my head."

"I've thought about it too," Ken said. "I don't know how serious I was about it, but the thought has crossed my mind."

"I think most of us have thought about it, especially when we were first diagnosed," I added.

"No, it wasn't the same. I started thinking about my life. I try to keep it so simple but it just keeps getting more complicated," Joey said. "Sometimes I feel like such a loser."

"What are you talking about?" We all seemed to think and say it at the same time. "You are not a loser."

"Even though you're not working every day," I said, "you volunteer at three different places each week and help out at other projects when you're asked. You don't have to work a 40-hour a week job to be successful. I think you are busier and more involved now than you've ever been."

"I know," Joey answered, "but you all know how much I loved my job. I loved working. I've always taken care of myself, never looked for handouts. Now it seems like I'm just another one of those people living off the government. I thought about going back to work but it's so tough find-

ing a job that will pay me enough to survive, and what about my medical bills? I'd have to find a job with benefits that cover pre-existing conditions. And anyway, who wants to hire someone with AIDS?"

"That can't be the only reason though," Miguel commented. "I know if I would have to quit working it would get me down, but I don't think it would make me want to kill myself. Plus you guys are always bitching about that; even if your health would let you go back to work you doubt that you could find a job that you could survive on let alone challenge you."

Joey responded, "No, there's more to it than that. I'm getting tired. I'm tired of taking the pills, tired of never feeling great, tired of worrying about every lump and pain, tired of fighting the government, tired of being tired. Everything just caught up with me. There's no hope for my future to get any better."

"I know what you're talking about," Ken said. "Early on, I woke up each morning wondering if that was the day that I would get hit by the AIDS bus. Now sometimes I wonder if it will ever happen, that this is the way my life will be until I die of old age. I bet there's a better chance of me getting hit by a real bus."

"I agree with you guys 100%. All this contributes to the emotional roller coaster," Gary added. "I'll wake up some mornings and for no reason just be really down. I hate using the word depressed, I think we all do, but depression is becoming such a part of my life. My mood goes up and down like a roller coaster."

"See, you guys know exactly what I'm talking about. Sometimes I have so much trouble just coping with day-to-day life. It takes all I can do to just maintain, and I sure as hell don't want to start taking

another pill," Joey said. "I guess it's time to start seeing a counselor."

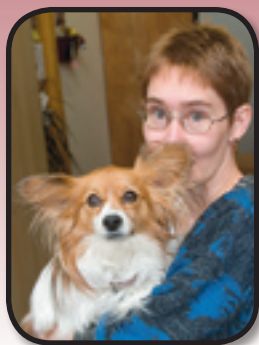
"You know what else could help?" Jerome asked. "Remember back in the day when we were losing friends left and right? We would stop by and wash people's dishes, clean their houses, do their laundry, walk their dogs, just sit there and talk. We were caregivers. We took care of them. Now it's time we took care of each other."

"What do you mean?" I asked. "I thought we were doing just that."

"Obviously, we're not doing it well enough," Jerome answered. "One of our friends thought about killing himself. We all have to be more alert. I know we all have our emotional swings, but we have to be more alert. We have to be able to tell when someone is getting close to losing it. When we ask someone 'How are you today?' we have to really mean it and listen to their answer."

"You're so right," Miguel added. "Our physical health is kind of consistent, usually at the same level most days. It's our emotional health that goes up and down now, and when we notice someone spiking down we have to make ourselves available."

"Wow," Ken said, "it seems like we go through cycles. When folks were dying we were there to make their last days a little easier, a little less painful. Then when the meds came around we were just so happy to still be alive that we kind of just took care of ourselves. Now we have to be caregivers again. Except this time we are mental health caregivers. We have to be able to tell if our friends are just having a bad day or if they really are at wit's end. We have to be there for each other, to help each other cope, to help each other survive." ☘



LYDIA LAZARUS

Pet Therapist Extraordinaire
by Laura Jones

I never expected to write a Heartwarming Pet Story for *Positively Aware*, but a recent experience with my dog Lydia and colleagues who've been through the mill due to HIV/AIDS prompts me to do just that. My husband and I adopted Lydia from the Orphans of the Storm shelter two years ago, when she was maybe six or eight years old. We don't know who had her before she came to live with us, but whoever that was loved her enough to stuff her full of treats and make her very fat and friendly. She loves people, especially babies. She also loves beer, and old men (and old men who are drinking beer), so we theorize that her former owner died or went into a home and no one else wanted to take responsibility for her. But we'll never know for sure, and it doesn't matter, really—we're sure glad she lives with us now.

Because I have the privilege of bringing her to work, Lydia is well known to the staff, volunteers, and clients of TPAN. Unfailingly friendly and affectionate, she serves as TPAN's own volunteer Pet Therapist, dispensing love and tender lickies to all who will allow. She also seems to have this bizarre ability to sense when someone's in pain, and will sniff out the sore area and lick it or lay her head on it if it's accessible. I don't know if it helps, but she apparently considers it part of her job duties on Community Service days (mostly Tuesdays, but sometimes multiple times a week).

Given her sweet personality and agency-wide popularity, you can imagine how awful it was when she nearly died of liver failure in May.

What happened? We don't know! We left her in the care of various friends and co-workers while we went on a two-week vacation, and when we came back she had diarrhea. No big deal, we thought; that'll

pass quickly enough. And it did—only to be replaced by vomiting and lethargy, dehydration, rehydration, a series of lab tests and IV liquids, and then a full-on liver crash with mushrooming bilirubin counts and a horrific case of jaundice. One day she's just got the runs, and less than a week later she's vomiting orange bile, urinating tea, completely yellow, and unable to eat or drink or walk or do much of anything but lie there with an IV in her leg. The vets don't know what the hell's going on—the toxicology profile shows nothing; the X-ray shows nothing; the belly ultrasound shows nothing; and eventually the needle biopsy of her liver shows nothing either. She's clearly dying, but no one knows why.

Sounds sadly familiar to some of you, I know.

We're running out of money by this time, of course. And her bilirubin count keeps climbing, putting her at risk for convulsions and a very unpleasant death. The vets tell us they can't do anything but keep her hydrated and hope she gets over it (whatever "it" is), but no one's hopeful. So we do what you do when someone you love is suffering and you have the power to end that suffering: We made plans for euthanasia. And then we took her home from the vet's, and made a big bed on the floor so we could all sleep together one last time.

When we brought her back to the vet's the next day, her blood test showed that her bilirubin count was no higher than it had been two days before... still well in the Kill Zone, but significant in the fact that it wasn't still climbing. After the vet assured us that Lydia wasn't in serious pain, we decided to hold off on the euthanasia, learned how to give her subcutaneous hydration with a modified IV unit, and took her back home to see what the weekend would bring.

Against all hope and prediction, she began to improve. First she was able to drink and hold down water. Then she was able to go outside by herself. Then she was able to hold down small amounts of baby food and rice... and then, very slowly, she began to lose all that awful yellow and turn back into her little white-and-pink self under her fur. Eventually she began to growl when we stuck her with the sub-Q needle, and that's when we really started to believe we were going to get to keep her.

A month later, she's fine—you'd never know she'd been sick. We were warned that she might have organ or brain damage as a result of the illness (which we figure was caused by something poisonous that she ingested), but as I type she's healthy as can be, sitting under my feet looking all annoyed because I won't take her out for a walk. She's skinny and tires easily, but back doing Community Service at TPAN.

I was touched and amazed by how everyone was so concerned about her, and by how many people also seemed to identify with her personally from their own bouts of HIV or hep-related illness. I'm holding those personal altercations with Mr. Reaper responsible for the predominant TPAN reaction to Lydia's illness: "She'll pull through. After all, they told me I was going to die, and I didn't." Other people's hope and encouragement helped us to hold off on euthanasia long enough to see her begin to recover. I'm not sorry that we planned to put her down, but I'm thankful for other people's willingness to believe in her slim chance for life when all hope for recovery seemed gone.

So thanks again, everyone. Come by the TPAN and give Lydia some rubbies. ✚

TPAN Events Calendar

All events held at TPAN unless otherwise indicated.
For additional information on these events please contact TPAN at (773) 989-9400.

September 2004

DATE	TIME	EVENT
Every Thursday	6-10 pm	PULSE – Where Positive People Meet - Berlin Nightclub 954 W. Belmont
Wednesday 8	7:30 pm	Committed to Living, Ask the Doc featuring Dr. Todd Hargan of NorthStar Medical Center, dinner before event.
Friday 10	6-11 pm	The Aware Affair, TPAN annual benefit gala starring Broadway diva Karen Mason, hosted by CBS Chicago's Mary Ann Childress and Jay Levine. For more information, visit http://awareaffair.tpan.com .
Thursday 16	7:30 pm	TPAN Legal Clinic from AIDS Legal Council of Chicago, call Abraham El-House at 773.989.9400 for information of topics.
Saturday 18		AIDS Run & Walk Chicago. Visit tpan.com for more information

October 2004

DATE	TIME	EVENT
Every Thursday	6-10 pm	PULSE – Where Positive People Meet - Berlin Nightclub 954 W. Belmont
Wednesday 6	7:30 pm	Committed to Living, HIV and Immune Based Therapies, dinner before event.
Saturday 9	9 am-5 pm	Women Living, The annual one-day event for women living with and impacted by HIV. Ramada Inn Lakeshore. Registration is free, breakfast and lunch provided. Contact Barb at 773.989.9400 to register.
Saturday 16	9 am-5 pm	Man Alive – mind body spirit, The annual one day gay men's health expo brought to you by TPAN. Registration is free, breakfast and lunch provided. Call Jeff Allen at 773.989.9400 to register.
Thursday 21	7:30 pm	TPAN Legal Clinic from AIDS Legal Council of Chicago, call 773.989.9400 for information of topics.
Thursday 28	6-10 pm	PULSE Halloween Party, Great prizes for best costumes. at Berlin, 954 W. Belmont

Getting support for HIV and taking care of your health shouldn't be a hassle.

Now they both just got a little easier.

- HIV Specialty Care
- Free HIV & Syphilis Testing
- HEP Testing & Vaccination to IVDU



offered by
Access Community
Health Network



Monday 10 am-6 pm
Tuesday 9 am-12 pm
Thursday 12 pm-8 pm
drop-in or by appointment
call 773.989.9400

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

Monday

MEDICAL CLINIC

HIV/Syphilis/Hepatitis C testing and full medical care for HIV-positive clients is available. Program is offered by Access Community Health Network. Call for an appointment. From 10 am–6 pm.

TEST AWARE

TPAN's new Rapid HIV counseling and testing program. Learn results in around 20 minutes. Beginning September 13 every Monday 10 am–6 pm. Call for appointment.

TPAN DAYTIMERS

A support group for people with HIV who prefer to meet during the day. Meets from 10:30 am–12:30 pm.

REIKI

Energetic healing practice that utilizes hands-on touch and focused visualization. Mondays 1–6 pm by appointment only.

HEALTH

HIV Empowerment and Living Together with Hepatitis. Support group for people co-infected with HIV and hepatitis. Meets from 7–9 pm.

SPIRIT ALIVE!

Through a collaborative effort of AIDS Pastoral Care Network (APCN) and TPAN, Spirit Alive! fosters discussions on topics such as hope vs. despair or strength in times of adversity. Meets from 7:30–9 pm.

Tuesday

MEDICAL CLINIC

See description on Monday. Call for an appointment. From 9 am–12 pm.

YOGA

All levels of yoga are welcome. Meets from 10–11 am.

POSITIVE PROGRESS

A peer-led group for HIV-positive individuals in recovery. Special emphasis is placed on sobriety as a priority to effectively living and dealing with HIV. Meets from 7–9 pm.

LIVING POSITIVE

HIV-positive individuals discuss how being positive affects life and relationships. Socials and speakers on occasion. Meets from 7:30–9 pm.

Wednesday

NEEDLE EXCHANGE PROGRAM

Through a collaborative effort of Chicago Recovery Alliance and TPAN, a free, anonymous, legal syringe exchange and HIV/AIDS prevention are offered Wednesdays from 5–7 pm, or by appointment.

SHE (STRONG, HEALTHY AND EMPOWERED)

HIV-positive women discuss needs, concerns and issues facing women with HIV. Meets from 7:30–9 pm.

SHE SOCIAL

A social event for women every 4th Wednesday.

Thursday

YOGA

All levels of yoga are welcome. Meets from 10–11 am.

MEDICAL CLINIC

See description on Monday. Call for an appointment. From 12 pm–8 pm.

TPAN DAYTIMERS

See description on Monday. Meets from 10:30 am–12:30 pm.

NEEDLE EXCHANGE PROGRAM

See description on Wednesday. From 2–5 pm, or by appointment.

BUS (BROTHERS UNITED IN SUPPORT)

Support group for HIV-positive gay and bisexual men of African descent. Monthly socials and speakers on occasion. Meets from 7–9 pm.

POSITIVE NOW

Support group for newly diagnosed HIV-positive individuals who seek support, education and the opportunity to share their experiences in a relaxing, empowering environment. Meets from 7–9 pm.

Support groups sponsored by the Chicago Department of Public Health

Peer Support and Buddy programs sponsored by the AIDS Foundation of Chicago

PULSE AT BERLIN

A weekly social for HIV-positive individuals and friends. Meets from 6–10 pm at Berlin Nightclub, 954 W. Belmont, Chicago.

Friday

NEEDLE EXCHANGE PROGRAM

See description on Wednesday. From 2–5 pm, or by appointment.

POZ LEATHERMEN

Support and social group for HIV-positive leathermen and friends. Meets from 7:30–9 pm at Soul Cafe, 1301 West Hollywood, Chicago.

Scheduled By Appointment

FASN (FAMILY AIDS SUPPORT NETWORK)

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

INDIVIDUAL COUNSELING

AIDS Pastoral Care Network (APCN) professionals provide individuals with one-on-one counseling on Mondays. Ask for Sherry or Betsy at (708) 681–6327.

PEER SUPPORT NETWORK/BUDDY PROGRAM

Trained volunteers provide one-on-one peer, emotional support to individuals living with HIV. Call Paula at (773) 989–9400.

SPEAKERS BUREAU

Individuals are available to community groups to educate peers on HIV, safer sex, and harm reduction. Call Matt at (773) 989–9400.

TEAM (TREATMENT, EDUCATION, ADVOCACY AND MANAGEMENT)

Peer-led program integrating secondary prevention and treatment education to provide individuals the training and knowledge to more successfully support other individuals impacted by HIV. Call Montréal at (773) 989–9400.

Miscellaneous

LIVINGPOS18TO24@AOL.COM

An AOL chat room for young adults (ages 18–24) who are HIV-positive. Monday through Friday from 3–5 pm. Contact email livingpos18to24@aol.com



RIVER HUSTON

A DAY DEDICATED TO WOMEN HEALING,
THRIVING AND CELEBRATING LIFE WITH HIV

KEYNOTE SPEAKER - RIVER HUSTON

Author of "Living, Laughing and Life with HIV"

FEATURING WORKSHOPS ON:

- LET'S TALK ABOUT DATING, SEX & RELATIONSHIPS
- HIV, PREGNANCY, BUDDHISM, MEDITATION AND BEYOND: EXPLORING NEW FRONTIERS IN ANCIENT WAYS.
- HIV-POSITIVE WOMEN AND RESEARCH
- HIV-POSITIVE WOMEN AND DEPRESSION
- SEX, LIES AND SUBSTANCE ABUSE
- AND MORE.

REGISTRATION IS FREE

Contact Barb Marcotte at 773-989-9400, or
b.marcotte@tpan.com to register

SATURDAY, OCTOBER 9, 2004, 9 AM-5 PM
RAMADA INN LAKE SHORE

These events are
produced by



Test Positive Aware Network
5537 North Broadway
Chicago, IL 60640
(773) 989-9400
<http://www.tpan.com>

SPONSORS (as of July 30, 2004)

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Bristol-Myers Squibb • Gilead
GlaxoSmithKline



**MAN
ALIVE**

BODY | MIND | SPIRIT

Chicago Gay Men's Health Summit
October 16, 2004

A ONE DAY SHAME FREE SPACE FOR ALL GAY MEN, HIV-POSITIVE
AND HIV-NEGATIVE, ALL AGES, AND ALL BACKGROUNDS.

KEYNOTE SPEAKER - DAVID NIMMONS

Author of "Soul Beneath the Skin"

FEATURING WORKSHOPS ON:

- HIV TREATMENTS
- RELATIONSHIPS
- HEALTHY SEX
- HEALTHY SEXUALITY
- DRUGS IN OUR COMMUNITY
- GENDER IDENTITY
- AND MORE.



REGISTRATION IS FREE

Contact Jeff Allen at 773-989-9400 or
j.allen@tpan.com to register

OCTOBER 16, 2004, 9 AM-5 PM
HYATT REGENCY CHICAGO

2003



5,000,000 new HIV infections
(prevention failure)
3,000,000 deaths
(treatment failure)

THE WORST YEAR EVER.

This election year - you can make a difference.

Vote! on Tuesday, November 2.
Your life depends on it.

design: Kevin Pitz, Toubor Inc. www.toubor.com



We urge you to visit: aidsvote.org or www.vote-smart.org

Test Positive Aware Network and Positively Aware magazine bring this public awareness message to you. For more information, visit www.tpan.com.