Surviving With HIV

- Transplants for Positives
- Managing Metabolic Syndrome
- Lipodystrophy and Women
- Coping With Depression
- Anal Cancer in Gay Men
## Departments

7 Editor’s Note  
**Healthcare, Stop the Madness!**  
_Surviving with HIV ain’t what it used to be._

11 News Briefs  
by Enid Vázquez

42 My Kind of Life  
**Not Just Another Healthy Drink**  
by Carlos A. Perez

46 TPAN Events Calendar

47 Programs and Meetings

## Articles

14 Lipodystrophy and Women: A Beach Ball on Sticks  
by Barbara Marcotte

18 Managing Metabolic Syndrome  
_Does HIV increase the risk of coronary heart disease?_  
by Edwin J. Benard

23 Diet & Lipodystrophy  
_Is the currently chic carb-free Atkins diet beneficial for lipodystrophy, or is moderation the key?_  
by Megan Nicholson

26 Organ Transplants  
_Promising news for positive people._  
by Enid Vázquez

29 Waiting For a Transplant—One Man’s Story  
by George S. Martinez, as told to Enid Vázquez

31 Surviving Anal Cancer  
by Matt Sharp

33 Will Lawmakers Save ADAP?  
_Despite a record of success, America’s domestic ARV program remains overwhelmed._  
by David Munar and Sara Schmitt

37 ADAP–The Power For Change  
_How I almost died waiting for assistance._  
by Keith Green

38 HIV Treatment Series II  
Part Four of Four  
_Coping with Depression_  
by Ross Slotten, MD

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The older we become and the longer we live with it, the more complications there appear to be.

In the mid-to-late 1980s, who could have even imagined surviving another 15 and 20 years with HIV. Yet here we are in 2004, still advocating for new treatments and new targets for stopping HIV. And oddly enough, we’re now facing complicated health issues that come with aging and disease progression. Cancers. Heart disease. Metabolic syndromes. Depression. Transplants. In this issue of PA we examine several topics that 20 years ago didn’t concern nearly anyone living with HIV.

But the real messed up part about surviving with HIV for decades, or any life-threatening disease for that matter, is that it’s getting more difficult by the day to find and maintain affordable health insurance and drugs, quality healthcare and reliable support services.

U.S. Rep. Nancy Pelosi (D-CA) and U.S. Rep. Jim Leach (R-IA) in the U.S. House of Representatives introduced the Early Treatment for HIV Act (ETHA), a bill that would expand Medicaid to protect people with asymptomatic HIV, in late February. If passed, the law would give state Medicaid programs the option of providing services to people with HIV, rather than waiting for the individual’s condition to progress to AIDS. U.S. Senator Hillary Rodham Clinton (D-NY) and U.S. Senator Gordon Smith (R-OR) introduced a similar bill in the U.S. Senate in 2003. ETHA has widespread bi-partisan support.

Speaking to The Advocate, Paul Feldman of the Washington-based National Association of People with AIDS (NAPWA) said, “The cruel irony of the current situation is that poor people living with HIV are denied treatment and care under Medicaid until they develop serious AIDS-defining conditions [that would have] often [been] preventable if Medicaid coverage had been available to them sooner.”

The insurance industry isn’t making the decision to return to work any easier for individuals who might find themselves uninsured for a period of time. Here at TPAN, our health insurance carrier informed us at the beginning of the year that any uninsured individuals hired by the organization with a pre-existing condition (say, oh I don’t know, maybe HIV) would now have to wait 18 months before having their pre-existing condition covered by insurance. Previously, the wait was twelve months. Nevertheless, the employee still has to make monthly insurance premium payments towards a policy they can’t use to cover visits to the doctor and medicines for a life-threatening illness. In addition, the escalating premiums for health insurance are also making it difficult for small community-based organizations like TPAN to maintain adequate, affordable coverage for its employees.

And please don’t get me started on the price of medicines in this country. When my health insurance plan changed in December 2003, my out-of-pocket monthly expenses for medications tripled!

In early March the federal government announced its grant awards under the Ryan White CARE Act to 51 local municipalities. According to reports, 40 metropolitan areas, including Los Angeles and San Francisco, saw their funding cut by 3 to 14 percent. Only 11 cities saw an increase in their grants, with New York City leading with a 17.5 % increase.

The grant application process is competitive, where cities compete against each other for the best application. Federal funding is directly linked to the number of people living with AIDS, a number that has slowed in the last decade, while the number of people living with HIV continues to increase. Again, who would have thought 20 years ago that more people would be “surviving with HIV” and fewer “dying from AIDS”?

The CARE Act targets low-income patients who lack medical insurance or whose coverage is insufficient. The grants are used for everything from a visit to the doctor and obtaining medication to alternative health care and mental health counseling. The total Ryan White CARE budget for the year is $595 million, a $5 million decrease from last year! This is not good news for local and state governments experiencing record deficits and exploring cuts to public health services.

It is so obvious that Medicaid policy, the medical insurance industry, and funding for the CARE Act are outdated and in need of a major overhaul. With hundreds of thousands of people living with HIV and other life-threatening diseases here in the U.S. being left behind, uninsured and/or forced to make critical choices between food, meds and housing, it’s time that our political representatives step up to the plate and do a better job of representing us.

Make your voice heard this year. Make your vote count.

Choose to Vote in 2004

Charles E. Clifton
Executive Director / Editor
Send comments and reactions to ed@tpan.com
Corretion 1

The Editor’s Note of March/April incorrectly stated the prices of Reyataz and Lexiva. The correct average wholesale costs for Reyataz is $10,074 and $14,600 for Lexiva. Positively Aware apologizes for the mistake.

Corretion 2

The News Briefs of March/April incorrectly stated that the U.S. Food and Drug Administration (FDA) updated the black box warning label for Viramune (nevirapine). Viramune’s manufacturer, Boehringer Ingelheim, updated the warning label on its own. Said one leading HIV researcher, “To their credit, without being prompted by the FDA, they changed their label.” Positively Aware apologizes for the mistake.

New prison activist group

The national AIDS Treatment Activists Coalition (ATAC) in February launched an initiative to help HIV-positive prisoners and their advocates. In a press release the volunteer organization reported that, “HIV/AIDS in prisons is sometimes described as the single most challenging field in domestic AIDS activism.” For more information about the working group, contact Julie Davids at 1-212-966-0466 x 1226 or jdavids@champnetwork.org. Visit www.atac-usa.org.

Guidelines update

The U.S. Department of Health and Human Services (DHHS) in March updated its “Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents.” The table of treatment for people taking HIV medications for the first time now lists Lexiva and Norvir-boosted Lexiva regimens in the “alternative protease inhibitor-based” treatments (Kaletra is the protease inhibitor of first choice). Information on Lexiva, the newest protease inhibitor on the market, was also added throughout the guidelines. Norvir-boosted Agenerase and Crixivan taken without Norvir were both removed from the table (Agenerase is the older formula of Lexiva). Also added is the recommendation of the combination of Ziagen and Epivir to the alternative dual nucleoside backbones of HIV regimens.

A safety update was added regarding Viramune, noting that there was a higher rate of liver toxicity (11%) in women with more than 250 T-cells and men with more than 400 T-cells. The guidelines state, “Use [Viramune] with caution in these patients, with close clinical and laboratory monitoring, especially during the first 18 weeks of therapy.” Also, “Severe, life-threatening, and in some cases fatal hepatotoxicity [liver toxicity], including fulminant and cholestatic hepatitis, hepatic necrosis, and hepatic failure, has been reported. Patients may present with non-specific prodromes of hepatitis and progress to hepatic failure.” At the same time, the guidelines add the statement that Viramune has “More safety experience in pregnant women with no evidence of increased adverse [liver] events in women who received single dose nevirapine [Viramune] for prevention of mother to child transmission (PMTCT).” A new table has been added for HIV drug dosing changes in people with kidney or liver insufficiency. To see the guidelines, visit www.AIDSInfo.nih.gov or call 1-800-HIV-0440 (448-0440) to request a free copy.

There oughta be a law

HIV specialists at Northwestern Memorial Hospital in Chicago, IL have teamed up with HIV-positive Illinois State Rep. Larry McKeon, a Democrat from Chicago, to promote a revolutionary idea: allowing people with HIV to become organ donors to other HIV-positive people. McKeon wrote the bill after talking with his HIV specialist Robert Murphy, MD of Northwestern. The bill passed the Illinois House of Representatives in February and the Illinois Senate in March. The governor could sign it into law in May. The U.S. Department of Health and Human Services (DHHS) reports that there are 81,000 people on the list for a transplant in the United States, and someone dies every 90 minutes while waiting for an organ.

New-Fill update

A panel convened by the U.S. Food and Drug Administration (FDA) in March recommended the approval of New-Fill (injectable poly-L-lactic acid) for treatment of facial wasting in people with HIV. If approved, Dermik Laboratories plans to market the product in the U.S. as Sculptra.

Lamictal for peripheral neuropathy

The recent conference report on treatment for peripheral neuropathy (See “More Retrovirus Updates”) brings up another treatment successfully used by a staff member at Test Positive Aware Network. Not to outdo the researchers or study participants, here is his story.

“I suffered (still do to some extent) from neuropathy for years. There were periods that my legs/ankles/feet were in casts and I was on crutches. The pain was unbearable even on heavy painkillers. I tried antidepressants, anti-seizures, anti-everything. I tried every natural supplement recommended with no response: heat and cold therapy, creams and ointments, magnets,
physical therapists, acupuncturists, massage, etc. I went into more than one clinical trial, including one for nerve growth factor that not only gave no help, but was also shut down.

“I began getting The Neuropathy Association newsletter, from a not-for-profit organization, in the mail. Readers always touted different remedies they were trying. People were beginning to mention using a drug that had previously only been used as an anti-spasmodic. It’s called Lamictal.

“I reluctantly tried it, and within three weeks I was noticing a huge difference in the pain. I was able to reduce the recommended dosage and within two months (after six years of excruciating pain) the pain was actually subsiding. I no longer have the sharp, aching, biting, stinging, and burning pain associated with neuropathy. My walk has pretty much stabilized (except for the slight swish). I still have some numbness, especially after walking or standing for lengths of time, but it’s been a great relief. I don’t even take the stuff anymore and it’s not come back.” [Editor’s Note: he does not swish.]

People should know that Lamictal has caused cardiovascular complications in animals, which is not expected in humans unless, possibly, they have liver disease. It can also lower blood levels of folate, which is needed by pregnant women to prevent birth defects. Finally, Lamictal may cause a hypersensitivity reaction that can be serious. Symptoms include rash, fever, and liver abnormalities, and should be reported to a medical provider right away.

Late Breaker
Boehringer Ingelheim announces the expansion of Tipranavir Open Label Safety Study. Tipranavir is an investigational non-peptidic protease inhibitor in Phase III development. All full listing of study locations will be available at www.clinicaltrials.gov.

More Retrovirus Updates


Treatment Interruption in newly-infected people

Dr. Bruce Walker of Harvard University and colleagues years ago reported that early treatment in newly infected people was associated with undetectable viral load when the treatment was stopped after a short period. In this update, the researchers report that control of the virus did not last.

Although 11 out of 14 people (79%) had undetectable virus for at least three months, eventually viral load went up and T-cells went down.

Study participants took antivirals again if their viral load remained above 5,000 for three consecutive weeks or if it went up to more than 50,000 at any point. Two persons were able to stay off antivirals for two years, and most were off meds for six months or one year. The report noted, however, that viral load benefit could not be determined because of the small number of people in the study and the lack of a control group that did not receive treatment.

The researchers found that HIV-specific CD8 cells continued to go up throughout three treatment interruptions. Also, the viral control seen existed despite the lack of protective HLA (human leukocyte antigens) alleles. HLA prevents the immune system from fighting the body’s own cells, which HIV causes it to do. The group reported that, “These data are relevant to current efforts to develop an AIDS vaccine designed to retard disease progression rather than prevent infection, and indicate that durable maintenance of low level viremia may be difficult to achieve.”

Newly infected people: resistance lasts a long time

HIV specialists are planning to change the course of treatment and opt for genotype tests in newly infected people before putting them on therapy.

Dr. Susan Little of the University of California at San Diego and her colleagues followed 11 newly-infected patients not on therapy. They found that in these people infected with drug-resistant virus from day one, the resistance stayed around for a long time. (Normally, people start out with wildtype virus—one that’s not resistant to drugs—and their virus only develops resistance to medications after being on those meds.)
In one of the 11 people, it took three years for a resistant mutation to non-nucleoside drugs (Sustiva or Viramune) to revert back to wildtype virus. In the four people with resistance to protease inhibitors, there was no reversion to wildtype at all, although none of them had passed their first year of infection. Dr. Joseph Eron of the University of North Carolina at Chapel Hill called that “astounding” and said, “This tells me that genotyping may be useful even if infection occurred a year or two ago.” He pointed out, however, that transmission of resistance virus differs from one geographic area to another.

Dr. Kimberly Smith, of Rush-Presbyterian hospital in Chicago, noted that, “If people stop taking their medications, their virus reverts to wildtype faster. This resistant virus sticks around for a long time.” Dr. Smith said that it’s important to do resistance testing, even if patients are not starting therapy. “Take that information and bank it. I think it’s worth it.”

For the record, U.S. guidelines for HIV therapy state that, “Transmission of drug-resistant HIV strains has been documented and has been associated with a suboptimal virologic response to initial antiretroviral therapy. If the decision is made to initiate therapy in a person with acute HIV infection, it is likely that resistance testing at baseline will optimize virologic response, although this strategy has not been tested in prospective clinical trials. Because of its more rapid turnaround time, using a genotyping assay might be preferred in this situation. Since some resistance-associated mutations are known to persist in the absence of drug pressure, it may be reasonable to extend this strategy for 1–2 years post-seroconversion.”

Doctors and patients now have more evidence upon which to base their treatment decisions.

**Neuropathy treatment**

Peripheral neuropathy (PN) is one of the most common and difficult of side effects associated with HIV and its treatments. This damage to the nerves starts with numbing or tingling of the hands and feet and can progress to permanent and debilitating pain if not treated in time.

Previously, use of a topical (on-the-skin) treatment called capsaicin (pronounced cap-SAY-sin), a derivative of hot chili peppers, produced disappointing results. Several years ago, however, the University of California at San Francisco (UCSF) found good results in 10 people with HIV using high-dose capsaicin cream (5 to 10% concentration; normally the cream comes in a 1% concentration).

In a pilot study presented at CROI, one high-concentration patch of capsaicin effectively reduced PN in patients with HIV. Twelve study participants used a topical anesthetic for one hour followed by high-concentration patches of capsaicin for one hour on the most painful parts of their feet. They experienced pain relief from week one, which remained stable throughout the three months of the study.

The average pain decrease was 40%, with 66% of the participants reporting at least a 30% decrease in pain and the rest reporting at least a 50% decrease. A larger study is being planned.

Both the earlier UCSF trial and this study used pre-treatment topical painkiller to control the burning sensation of capsaicin, which led to great tolerability. Studies with the high-concentration patch in HIV continues in 19 states, and includes the cities of Chicago, New York, Baltimore, Miami and San Francisco. Visit www.ClinicalTrials.gov. (See “Lamictal for peripheral neuropathy.”)

**Bisexual men**

The New York City Department of Health and Mental Hygiene reported that while the majority of new HIV infections in women are heterosexually acquired, the risk factors for their male partners are unknown. Believing that bisexual men might be a big risk factor for women, the department conducted a study of 363 men in gay bars during 2000 – 2001. Of these men, 85 (23%) identified as bisexual. However, only 41 were “behaviorally bisexual” according to the department’s definition: having had sex with both men and women within the previous year. Nearly a third of these men had high-risk sex (defined as unprotected vaginal or anal sex, or multiple partners) with both men and women. The report concluded that, “HIV prevention messages to men and women should acknowledge the intersection of MSM [men who have sex with men] and heterosexual women. Larger and more diverse samples of bisexual men are needed to explore the extent of the HIV risks for both bisexual men and their female partners.” (MSM is a term developed to better define this group, as opposed to “gay,” which many of the men reject as their identity.)
When HIV enters a women’s life it is accompanied by so many thoughts and fears. We think about loss. We think about dreams that we fear will never come true. Will I have children? Will anyone love me? Will I grow old? How will this virus affect my body and my beauty? One learns over time that many of our hopes and dreams can still be reality. Yet the physical changes will likely happen... or will they?

Society programs us as little girls that we need to look like the models in fashion magazines and actresses on the movie screen. Early on we become convinced that something is wrong with us if our breasts are just A cups or our hair looks like a fur ball that the cat just threw up. As teens, young women and adults believe that we have to be thin and perfect just like those women. We grow up with an image of how we should look, but the following are some real facts regarding American women:

- The average American woman is 5'4" tall and weighs 140 pounds.
- The average American model is 5'11" tall and weighs 117 pounds.
- Most fashion models are thinner than 98% of American women.
- Four out of five American women say they’re dissatisfied with the way they look.
- On any given day, almost half of the women in the United States are on a diet.

Marilyn Monroe would be considered fat by today’s standards. Her size fluctuated between 14–18. Many women suffer from body dissatisfaction and diet relentlessly in pursuit of thinness and acceptance. Eating disorders develop, low self-esteem occurs and before you know it BAM you’re with a man that smells bad and has
no teeth. We equate self worth with how we look or how someone tells us we should look.

So you think that all of this is bad enough? Well put HIV on top of it. Women with HIV go through so many emotions. HIV can make us feel ashamed, ugly, dirty and unwanted. If you had negative feelings about how you look it can really make you dislike your body more than you may already. I know this because, most of my life I have struggled with my weight and appearance. I bought into the magazines that I read and believed I was supposed to look that way. When I discovered I was HIV-positive it did not help the situation.

What is Lipodystrophy?

In 1995 I began taking the protease inhibitor Crixivan (indinavir). Within a few months, I started noticing body changes. My breasts were getting larger (I thought alright… finally!), but my abdomen was also getting rounder and my legs and arms were becoming thinner. Enter HIV and The Beach Ball On Sticks… otherwise know as my version of lipodystrophy syndrome. Lipodystrophy can cause fat loss, fat deposits and metabolic changes. Fat loss occurs in the face, buttocks (loss of shape), arms and legs (prominent veins). Fat gain or increase occurs around the abdomen, breasts (in both men and women), on the back of the neck (the buffalo hump) or lipomas (fatty growths in different parts of the body). Metabolic changes can be defined as an increase in lipids (fats) in the blood, which include cholesterol and triglyceride. These changes can lead to increased risk of heart disease. Insulin resistance may also develop which prevents the body from efficiently metabolizing the sugar (and you know we women love our sugar). Insulin resistance can lead to diabetes.

The debate is ongoing as to whether women are at more risk for lipodystrophy syndrome than men. We do know that women are more likely to experience increases in breast size and overall weight gain than men. We also know that fat loss in the face is more common for men than women. Women who experience increase in breast size rarely find this trait to be a good one. It is not like getting some rounded, perfect implants. The gain in the breasts are usually as unpleasant as the gain in the abdomen. The fat forms behind the muscles around the organs and is not soft but rather hard and very uncomfortable deposits.

What causes lipodystrophy? The cause is multifactored. The current theories are as follows:

1. Taking HIV drugs (while lipodystrophy has been seen in people taking almost any type of HIV therapy, there are theories that some protease inhibitors may be involved in fat gain and certain nucleoside analogs may be involved in fat loss).
2. The length of time you are on HIV drugs (approximately 10% of HIV-positive people develop fat redistribution symptoms within the first two years of treatment).
3. HIV disease itself (some HIV-positive people who have body composition changes have never taken HIV drugs).

What can I do about it?

The next question we ask is what can I do about it? Will these changes in my body occur? Can I stop them, slow them down or reverse them? I believe that it is possible to make progress on this issue. I say this from my own personal experience and from the current research out there on ways to address lipodystrophy. (See “Managing Metabolic Syndrome” on page 18 and “Diet and Lipodystrophy” on page 23)

Everyone is different and may experience different symptoms of lipodystrophy.

What we need to recognize and accept is that women come in all shapes and sizes. We need to be realistic about what our bodies look like. Remember that the average American woman is around 140 pounds and 5’4”. I come from an Italian family of wide hips, skinny legs and big butts. Even if I work on shaping these body parts, there is always my genetic build up that tells me, hey girl, be happy with who you are. So that being said, we know that we may be able to treat some of the metabolic complications such as increased cholesterol, triglycerides or glucose levels by switching HIV drugs or by taking lipid-lowering medications.

The body composition changes are harder to address. The following described methods are currently being tested and researched:

A human growth hormone called Serostim is currently being used to treat fat gain that is identified as visceral adipose tissue (this is fat that surrounds the organs rather than fat under the skin). It has been shown to decrease excess fat buildup and increase lean body mass. It also specifically responds to the abdominal fat and
fat pads on the back of the neck. It can, however cause fat loss in the arms, legs or face.

An anti-diabetes drug called Metformin has also demonstrated effectiveness in reducing abdominal visceral fat and insulin resistance.

An experimental treatment using anabolic steroids for the treatment of lipodystrophy is underway. Anabolic steroids are currently used as a standard treatment for HIV related wasting syndrome. Steroids may disguise the visible signs of lipodystrophy rather than stop or reverse loss of fat tissue.

Niacin is a B vitamin being used to treat metabolic and fat disorders with some encouraging early results. Recipients of this therapy have shown reductions in intra-abdominal fat associated with an increase of good cholesterol called HDL. There are many side effects associated with the high dose of Niacin being administered and not everyone can tolerate this method.

Liposuction, a cosmetic surgery procedure can be used to remove fat from the back of the neck and around the breasts. Liposuction cannot be used as a solution for abdominal fat because this fat forms around the organs rather than under the skin and the procedure is considered to be too risky. Liposuction is usually just a temporary solution and more expensive than most of us can afford.

**Exercise and Diet**

Here in America, we always want a quick fix. Give me that pill to cure my weight problem, my cold, my breast size or my sexual drive. Not everything is attainable without some hard work, commitment and dedication. In 1999, I was a pasty blob of 5’7” and 200 pounds. I was very unhappy with my body and how I looked and felt. I would look at myself in the morning and feel a sense of disbelief of how I looked. My breasts were heavy and out of shape (not the usual perky 36 B cup), my stomach was hard and resembled a 6–7 month pregnancy stage (except that I knew that would have to be the second time that immaculate conception occurred) and my skin, nails and hair lacked luster and vitality.

I made a conscious decision to take control of my life. I was determined not to allow this virus to run rampant through my body, destroying not only my physical appearance but in addition my sense of humor, my confidence, my love for life and my energy to tackle whatever was most difficult. I made the decision to attack this virus and what it had been doing to me physically and mentally since 1990. If I could live through the death of a husband at 25 and watch dozens of young friends suffer and die I could do this. It was time that I started living again.

I am fortunate to have a very good gay male friend, who resembles a Greek god. He supported me throughout this process and helped by encouraging and teaching me what I needed to know. I had been reading about exercise and nutrition and its benefits. I was ready and motivated to start this change in my life. I started by learning how the foods that I put in my body react to my metabolism and the facts of how I could balance my diet for life and gain back the person I remembered from years ago. I began a workout regimen that consisted of 3 days of resistance (weight) training per week, which I performed with a set of rusty used weights on my coffee table. I also began walking around my block, getting my heart rate going for 20 minutes 3 times per week. I then began eating 5–6 small meals per day that consisted of a lean protein, carbohydrate and a vegetable. I reduced the amount of saturated fat and increased my intake of water. Within one week, I could tell a difference in my energy level and how I was feeling both physically and mentally.

Every Sunday I began making a big meal consisting of anything and everything that I craved (pasta with cream sauce, crunchy Italian bread and a rich sweet chocolate cake) and inviting my friends over for dinner. After the meal my friends got to take home all of the leftovers. I was careful not to deprive myself of the cravings that I had and used these Sunday dinners to satisfy those cravings. I noticed that as I lost weight and became healthier these cravings were reduced. I instead began to crave good healthy foods like fresh vegetables and fruits.

Today, I continue to eat healthy, exercise and weight train. My schedule consists of 3–5 days of working out at the local YMCA. I still combine the cardio and the resistance training. I eat healthy except for the occasional downfall of chocolate or sweets. I lost a total of 50 pounds and drastically changed the shape of my body. That’s how I turned the beach ball on sticks into the basketball on bats. The biggest change that I see is my attitude. I am confident, more pleasant to be around and happier with not just life but who I am. I know that I have the power and confidence as a woman to succeed in this world. I feel and look good, and most of all I will beat this pesky virus called HIV!

HIV no longer means death. HIV no longer means that as women you cannot have a relationship or children. You can take control of HIV and what it does to you physically and mentally. There are many ways to learn about how to take care of your body and make changes or prevent these changes from occurring. Talk to other HIV-positive women, get support, speak with your doctor or consider attending an HIV and lipodystrophy forum offered at many AIDS service organizations and conferences. The Internet can be an excellent source of information for new treatments that are on the horizon. If you are ready to make changes and feel better then start off slow, at your own pace. Remember that we are all different and HIV affects each of us differently. Most of all find a way to be happy with you.

**Barbara Marcotte is a Treatment Education Coordinator at Test Positive Aware Network.**
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This Retreat will also offer strategies for improving quality of life through HIV/AIDS workshops and open forums.

Supported by an educational grant from Agouron Pharmaceuticals
Can changing your lifestyle or switching antiretrovirals help lower your cardiovascular risk?

Evidence continues to accumulate that HIV does indeed increase the likelihood of coronary heart disease (CHD) and stroke, with HAART (highly active antiretroviral therapy) a contributing, but not sole, factor.

Today, HIV clinicians are increasingly concerned with managing lipodystrophy’s metabolic syndrome, since it can be life-threatening, particularly in regards to the risk of cardiovascular disease.

These include:

- High total cholesterol
- Increased LDL (low density lipoprotein, the so-called ‘bad’ cholesterol)
- Reduced HDL (high density lipoprotein, the so-called ‘good’ cholesterol)
- High triglycerides (another type of blood fat)
- Hyperglycemia (high blood sugar, or glucose)
- Insulin resistance (when more insulin is needed to control blood sugar)
- Diabetes (when the pancreas can no longer make enough insulin)

The logic behind their concern is this: even if HAART doesn’t actually increase the risk of heart attack by 26% for each year of exposure to antiretroviral therapy, as was estimated by the authors of the DAD study, HAART’s uncanny ability to keep us alive means that as an increasingly aging population living with HIV we are, at the very least, subject to the same cardiovascular risks as everyone else.

Who is at risk?

Several factors contribute to the risk of coronary heart disease (CHD) in HIV-negative populations, some of which can be modified (like smoking) and some of which cannot (like gender and age).

HIV disease now means that CHD is no longer simply a problem that comes with middle age. A recent impressive study from California found that, compared with their HIV-negative peers, CHD incidence more than doubled in HIV-positive men aged 25-35 years and was a staggering six-times higher in HIV positive men between ages 18-25.

HIV-positive women were also found to have a significantly increased risk of heart disease, more than double the risk for women age 18-24, and about one-and-a-half times the risk for women between 25-44. This, concluded the study’s authors, put younger HIV-positive people at a risk of CHD “comparable in magnitude with the increase associated with ageing.”

Interestingly, when the investigators looked for evidence of a link between HAART and heart disease they found that 18 to 33 year-olds on HAART had double the risk compared to their peers who did not receive antiretroviral therapy, but that once they reached 34, other factors (like smoking and age) overshadowed HAART’S risks.

First change your lifestyle

In August, the Infectious Disease Society of America published guidelines (www.idsociety.org) recommending that all adults with HIV be evaluated and treated to reduce their risk of heart disease and stroke, and included detailed discussion of how to do just that.

“Clinicians will need to weigh the risks of new treatment-related toxicities and possibility of virological relapse when switching antiretroviral drugs to the risks of potential drug interactions and new treatment-related toxicities from lipid-lowering agents that are added to existing regimens,” the guidelines’ authors warned.

Consequently, these U.S. guidelines prioritize lifestyle changes over drug switching or lipid lowering therapy. Surprisingly, however, stopping smoking was only mentioned in passing despite the fact that smoking is the single most significant modifiable lifestyle choice in the prevention of CHD. Diet and exercise were given most space in the guidelines.

Assessing the risks

The U.S. guidelines review the latest information on the prevalence and incidence of high total, lowered HDL and increased LDL cholesterol, and high triglycerides, and their relationship with cardiovascular disease in people with HIV on HAART, AND recommend that antiretroviral drug switching and/or lipid lowering therapy should be initiated, depending on an individual’s 10 year-risk of CHD, which they base on the Framingham Heart Study risk assessment tool.

However, this may not be sensitive enough for CHD risk assessment in people
with HIV, according to Dr. Devi Nair, the U.K.’s Royal Free Hospital’s lipid specialist who manages many HIV patients with metabolic disorders. “One of the problems with assessing cardiovascular risk in patients with HIV is that because they are mostly young, even though they might have high cholesterol, low HDL and high blood pressure and smoke, they would not be considered at risk according to the Framingham calculation, which weights age as an important factor. In HIV patients, because risk factors cluster at a very young age, we have to be more proactive,” she argues. “I do not use the Framingham calculator; if a patient has a lipid problem, I count up the risk factors. If they have more than one risk factor, I take the problem seriously. If they have three or four risk factors, I treat them.”

**Are high sugar levels more of a concern than high fat levels?**

Although the U.S. guidelines focus on cholesterol and triglycerides, there is a growing concern amongst U.K. clinicians that hyperglycemia, insulin resistance and diabetes (increasingly severe stages of the same disease process—an inability to metabolize blood sugar or glucose) are more risk than increased lipids in terms of CHD risk. “It is important to realize that insulin resistance is not sugar disease; rather it is a cardiac problem,” says Dr. Nair. “Lipid metabolism is linked with insulin resistance and both go hand-in-hand with HAART.

“The prevalence of insulin resistance is much higher in HIV patients who take HAART,” adds Dr Nair. “Infection with HIV itself does not make people insulin resistant, in fact insulin sensitivity is better if the patient is not treated and has infection with HIV that is not controlled. Only when patients start taking drugs and get better does insulin resistance develop.” Insulin resistance will eventually lead to diabetes, which adds considerably to the risk of CHD: people diagnosed with diabetes have a similar level of heart attack in the past eight years.

**Is switching from PIs the best option?**

A recent systematic review of both the published literature and conference abstracts on the relationship between protease inhibitor (PI) use and cardiovascular risk has found that with the exception of Reyataz (atazanavir), all currently available PIs do appear to elevate risk factors for heart disease. The U.S. guidelines note “lipid abnormalities tend to be most marked with Norvir (ritonavir) and (Kaletra) lopinavir/ritonavir). Agenerase (Amprenavir) and Viracept (nelfinavir) tend to have intermediate effects, whereas Crixivan (indinavir) and Invirase (saquinavir...
The news that HIV alone can increase cardiovascular risk needs to be taken, if you pardon the pun, to heart by everyone living with HIV.

It is still a little early to come to any firm conclusions, but Reyataz (at least when boosted with ritonavir) may also help reduce lipids in the PI-experienced, while keeping viral load under control. The BMS 045 study found that Norvir-boosted Reyataz was equal to Kaletra in terms of anti-HIV potency and still reduced total cholesterol significantly, while keeping fasting triglycerides stable. [The 045 results were from 48 weeks and study participants are not being followed for long-term efficacy and potency.]

It should be noted, however, that Reyataz and Viread should not be combined without Norvir-boosting, according to an August 2003 ‘Dear Doctor’ letter from BMS, since this may risk treatment failure, due to an interaction that reduces Reyataz levels by up to 40%. They suggest that doctors consider boosting Reyataz levels with Norvir, using the 300/100 mg dose, if Reyataz and Viread must be used together.

**Do you want to prove them wrong?**

The news that HIV alone can increase cardiovascular risk needs to be taken, if you pardon the pun, to heart by everyone living with HIV. Simply being young no longer appears to protect people with HIV from diseases previously associated with middle age. Can we afford to rely on only one head-in-the-sand strategy—let the doctors deal with it—when it is becoming clear that changing to lipid-friendly HAART or adding lipid-lowering medications is probably not enough to make up for this increased risk? Are the clinicians right about our lack of motivation to take better care of ourselves? Do you want to prove them wrong? 😃

**Heart-friendlier HAART**

Are some antiretrovirals less atherogenic? Is it possible to switch to these and/or use them as first-line therapy in the treatment-naïve? Preliminary data suggest that both tenofovir and atazanavir may permit the use of more atherogenic agents as part of HAART, on the assumption that either drug exerts a benign effect.

Two years into a three-year study comparing Viread (tenofovir) with Zerit (d4T, stavudine), alongside Epivir (3TC, lamivudine) and Sustiva, the only significant differences between the two arms of the study appear to be higher fasting cholesterol and triglyceride levels in the Zerit-treated patients. Given Sustiva’s tendency to increase lipids, and a lack of previous evidence that Zerit raises lipid levels these results suggest that Sustiva could be the agent affecting lipids, and Viread may actually be exerting a moderating effect, rather than Zerit a negative effect. More data is needed before this theory is proved, or disproved, however.

The only switching study using atazanavir reported so far, found that after switching from Viracept to (unboosted) Reyataz, significant reductions in total cholesterol (16%), LDL cholesterol (21%) and triglycerides (28%) and a significant increase in high density lipoprotein (HDL) “good” cholesterol (5%) were seen. Prior to receiving Viracept, however, the study populations were drug-naïve, and appeared to continue to sustain low viral load without the need for boosting. A Bristol-Myers Squibb (BMS)-sponsored Phase IIIb study is currently recruiting in the U.S. looking at the effect of serum LDL cholesterol when switching from other protease inhibitor regimens to atazanavir.

Hard-gel) tend to have the fewest effects.” Preliminary reports suggest that Reyataz, the latest PI, “appears to have little, if any, effect on lipid concentrations.”

The NNRTIs Sustiva (efavirenz) and Viramune (nevirapine) also cause alterations in lipid levels, “although generally to a lesser degree than has been observed with PIs,” according to the U.S. guidelines. However, the recent 2NN study appeared to favor Viramune over Sustiva regarding cholesterol and triglyceride levels although many clinicians still have concerns about the potency of Viramune compared with Sustiva as well as Viramune’s liver toxicities.

The recently completed NEFA study compared the effects of switching from a protease inhibitor to Ziagen (abacavir sulfate), Viramune or Sustiva. Although this study found a trend toward a higher virological rebound rate in those who switched to Ziagen, failures were almost entirely confined to people who had received dual nucleoside analogue treatment in the past. Ziagen-treated patients were significantly less likely to require lipid-lowering medication by the end of the study and had significantly lower total cholesterol after 48 weeks.

Less is known about the differing effects of PIs on insulin resistance. A 2000 review found that Crrixivan appeared to have more of an effect on insulin levels than Viracept or Invirase, but pointed out that the statistical standards of the study were weak. The NEFA study found that after switching from a protease inhibitor, glucose levels fell in Viramune and Ziagen treated patients, but not in the Sustiva group.

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Despite the recent emphasis on dietary interventions to improve the metabolic disorders associated with lipodystrophy, new studies have explored whether the same diets recommended to improve lipids and insulin sensitivity—which are based on evidence largely drawn from HIV-negative population studies—can help with certain physical features of lipodystrophy, particularly central fat (abdominal) accumulation.

Of course, the jury is still out as to whether the fat gain reported by many people on HAART (Highly active antiretroviral therapy) can even be called lipodystrophy. Although increased abdominal fat is regarded as a core feature of lipodystrophy according to the HIV Lipodystrophy Case Definition Group, recent reports from the ongoing Fat Redistribution and Metabolism (FRAM) Study suggest that HIV-positive men and women with lipodystrophy actually have less visceral abdominal fat than their HIV-negative counterparts.

**Dietary strategies for managing metabolic disorders**

Both the U.K. and U.S. guidelines on the management of lipodystrophy-related metabolic disorders stress the importance of dietary advice.

The U.S. guidelines generally recommend eating more fiber and reducing fat intake. When high triglycerides are an issue, saturated fats should be replaced with monounsaturated fat or omega-3 polyunsaturated fats (e.g. fish oils). When wasting and lipid disorders occur together, however, wasting should be addressed first (i.e. fat may need to be increased to add calories), since it is riskier in terms of HIV disease progression.

The latest British HIV Association (BHIVA) guidelines also suggest that dietary advice may play a role in the prevention and management of lipodystrophy. The guidelines authors suggest a ‘Mediterranean diet’ rich in omega-3, fiber, and fruits and vegetables. This diet is known to reduce risk factors for cardiovascular disease in the general population.

There is some evidence that this low-fat, omega-3-rich, high-fiber diet can improve metabolic function in people taking anti-HIV treatments. A U.K. study, which compared lipid lowering agents with dietary advice found that the latter showed modest effects. But a Spanish team reported that while a low-fat diet in people on HAART with high lipids had moderate success in lowering lipids it had almost no impact on central fat accumulation. A U.S. study of 62 men and 23 women with lipodystrophy found that, on average, people who consumed more dietary fiber had lower insulin levels. And a laboratory study reported that omega-3 polyunsaturated fats may have a protective impact on fat cells exposed to protease inhibitors.

But will these strategies really help you reduce your risk of cardiovascular disease as well as help you lose (apparently)
lipodystrophy-associated excess fat without worsening fat loss elsewhere?

Unfortunately, more than six years after the first reports of lipodystrophy, there are no reliable studies comparing different dietary strategies in people with HIV. Alternative weight loss strategies such as the Atkins diet and the low glycemic index diet (the GI diet) have not been studied. However, current theories about the causes of central fat accumulation seem to suggest that diets which target insulin sensitivity and sugar metabolism may play a role in reversing this part of lipodystrophy syndrome.

**How HIV meds interfere with metabolism**

The factors driving body fat changes and metabolic abnormalities in HIV-positive people have not been definitively established. Two classes of anti-HIV drugs—protease inhibitors (PIs) and nucleoside analogue reverse transcriptase inhibitors (NRTIs)—are known to contribute to the syndrome but exactly how remains the subject of speculation and research.

There are several theories regarding how HIV and/or anti-HIV drugs might be causing peripheral fat loss (lipoatrophy), fat gain (lipohypertrophy) and metabolic disorders.

- **Mitochondrial toxicity.** Damage to mitochondrial DNA by NRTIs, particularly stavudine (d4T), may disrupt energy metabolism, damage cells and hasten programmed cell death (apoptosis). This theory can account for a range of symptoms including loss of fat tissue, high lactate levels and peripheral neuropathy.
- **Disruption to fat metabolism.** PIs disrupt lipid metabolism, leading to excess production of triglycerides, cholesterol and lactate. PIs and/or NRTIs may interact to undermine the making of fat cells and increase programmed cell death, as well as disrupting production of energy from fatty acids. Possible mechanisms include the disruption of certain cytokines (chemical messengers e.g. TNF alpha) and the effect of PIs on transcription factors (e.g. SREBP1).
- **Inhibition of insulin.** Inhibition of some glucose transporters by most protease inhibitors may be one element causing insulin resistance. This may be compounded by disruptions to fat cells and fat metabolism. Insulin resistance may be driving central fat accumulation and ‘buffalo hump’ by causing reduced uptake of sugar, triggering a release of fatty acids into the blood.
- **Chronic immune activation due to HIV.** May contribute to some or all of these mechanisms.

**Can the Atkins diet help with lipodystrophy?**

The fashionable Atkins diet has four phases: a strict two-week induction period where carbohydrate (carb) intake is limited to 20 grams each day; an ongoing weight loss phase where you can eat up to 100 grams of carbs daily, and the pre-maintenance and maintenance phases where carb intake remains restricted but you maintain a stable weight. Carbohydrates include all foods made up of sugar or starch, including bread, pasta, fruits and vegetables.

Two studies published in the *New England Journal of Medicine* earlier this year found that this low-carb strategy does lead to weight loss and improves metabolic parameters in HIV-negative people. In one of the studies, 132 obese people with a high prevalence of diabetes or pre-diabetes (insulin resistance) were randomized to either a low-fat, calorie-restricted diet or a low-carbohydrate diet. Average weight loss was 5.8 kg [12.78 lbs] in the low-carb group and 1.9 kg [4.19 lbs] in the low-fat group—a statistically significant difference. Measure of metabolic function also improved significantly in the low-carb group—triglycerides fell irrespective of medication and insulin sensitivity improved.

However, despite some anecdotal success stories from HIV-positive people with central fat accumulation, experts unanimously agree that the Atkins diet may have serious health consequences for HIV-positive people in both the short- and long-term.

According to Dr. Devi Nair, a lipidologist from London’s Royal Free Hospital, and two specialist HIV dieticians—Pip Greenop and Simon Sadler from Australia, where the Atkins diet is also currently in vogue—Atkins is an unbalanced and restrictive diet which is not sustainable or safe in the longer term, despite some apparently attractive short-term benefits.

The Atkins diet raises many specific concerns for people with HIV infection:

- **The Atkins diet is high in saturated fats, and thus may contribute to elevated cholesterol and the long-term risk of artery disease.** Dr. Nair suggests that a modified Atkins diet—which reduces, but does not eliminate carbs (replacing extra carbs with more protein and fats that are heart-healthy, like olive and fish oils)—may be a healthier alternative.
- **The body needs glucose.** When glucose consumption is dramatically restricted, the body accesses its glycogen stores. If glycogen stores are not replenished through dietary glucose, fatigue may occur and contribute to muscle wasting. Maintaining muscle is know to preserve immune function and slow disease progression in people with HIV.
• Low consumption of fiber may have negative effects. In people with HIV, treatment with soluble fiber is often recommended to help control cholesterol, relieve treatment-associated diarrhea, and maximize gut health.
• Low consumption of carbs may alter calcium metabolism, causing kidney stones (already a risk in people taking indinavir) or reducing bone mineral density, which is already a problem for certain people with HIV, due to either HIV itself or HAART.
• A high-protein diet may be difficult for people with kidney damage to tolerate, and since tenofovir has been associated with kidney toxicity, caution should be taken if on this drug and eating a high protein diet.
• A low-carb diet may remove many B vitamins and antioxidant nutrients from the diet. Low vitamin and mineral consumption may compound these deficiencies in HIV-positive people.

The nature of the weight loss seen in people on Atkins is also suspect. Initial weight loss comes from fluid (water) loss, as the body raids its stores of glycogen.

The low GI diet: a healthier alternative?

Dietician Jennie Brand-Miller from the University of Sydney points out that a randomized study comparing four diets has shown that people on a low glycemic index (GI) diet lose more fat than people on a high protein diet, even though overall weight loss is comparable. The low GI diet also aims to reduce blood glucose and promote insulin function and weight loss. Could this way of eating be a less radical alternative to Atkins?

A case study published last year reported successful treatment of lipodystrophy and metabolic improvements using a high-fiber, low GI diet plus regular aerobic exercise and weight training. The man’s diet was made up of 15% protein, 30% fat and 55% carbs including at least 25 grams of dietary fiber daily. After four months, the man had experienced a 52% reduction in visceral fat and his weight had fallen by a total of 8 kg [17.6 lbs]. His LDL or ‘bad’ cholesterol had fallen by 30%, fasting insulin by 3.5% and insulin resistance by 15%.

Key elements of the low GI strategy have been successfully incorporated into the management and prevention of diabetes, insulin resistance and hyperglycemia.

The glycemic index is a way of comparing foods in terms of how quickly sugar is absorbed into the blood stream. Some foods such as potatoes, white flour products and rice cakes are processed quickly, producing a rapid and dramatic peak in blood sugar levels. These simple carbohydrates are called high GI food. Other foods are turned into blood sugars more slowly, and produce a less dramatic and more enduring rise in blood sugar. These are complex carbohydrates, or low GI foods. Examples include al dente pasta, brown rice, wholegrain bread, apples, chickpeas and oatmeal.

A detailed list of GIs for over 750 types of food can be found free on the Internet in the American Journal of Clinical Nutrition at http://www.ajcn.org/cgi/content/full/76/1/5.

A low GI diet involves reducing your intake of refined foods, potatoes and rice, and eating more fiber and unsaturated fats. Simple changes such as replacing white bread with whole meal bread, or making sure that you never eat simple carbohydrates on their own (by adding unsaturated fat and/or protein), can help reduce blood sugar levels after eating. This may help with sugar metabolism and improve insulin sensitivity.

Food for thought

At this stage, there is no clear scientific evidence that any particular dietary strategy will help you lose your belly while keeping your facial or limb fat loss to a minimum. If you are considering changes to your diet, discussion with your doctor and/or a dietician is recommended. Standard lipid-lowering or fat loss advice is not always appropriate for everyone with HIV.

Additionally, no diet can work in isolation: exercise and other lifestyle changes, particularly stopping smoking, are known to be other key elements in maintaining a healthy heart.

It is also crucial that dietary changes (e.g. reducing fat intake) do not reduce absorption of your HIV medications, or cause you to lose weight if you are already wasting.

The final point to bear in mind is that attempts to lose your central fat accumulation through regular intense aerobic exercise may worsen fat loss in your face and limbs. Although weight training to build muscles may help to offset this problem, adding anabolic steroids to your muscle-building regime can actually worsen facial lipoatrophy.

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ORGAN TRANSPLANTS

by Enid Vázquez
Gone are the days when transplant centers refused patients with HIV. Today, it’s common knowledge that with the powerful HIV medicine available, people living with the virus can expect a much longer and healthier life, making the arduous job of a transplant more feasible.

“Most transplant centers are not looking at HIV as a contraindication [two things that don’t go together], but as a challenge,” says Dr. Patrick Lynch, a hepatologist at Northwestern Memorial Hospital in Chicago. “Although not everyone with HIV will meet all the criteria for a transplant, it’s good to know that it’s available.”

It’s especially good news as conditions like liver disease and viral hepatitis become a greater risk for death in people with HIV. Moreover, not only do non-HIV related conditions become a greater risk as treatment successfully wards off the complications of AIDS, but the treatment itself may contribute to disease. The medications might, for example, lead to stress on the liver.

Dr. Lynch notes that 30% of people with HIV will have some form of liver disease, usually with infection by either hepatitis B or hepatitis C.

According to the National Organ Transplant Act (NOTA), people with HIV who are asymptomatic (without symptoms of disease) “should not necessarily be excluded from candidacy for organ transplantation.” NOTA goes on to state that these persons “should be advised that he or she may be at increased risk of morbidity and mortality because of immunosuppressive therapy [required for all transplant patients].” It also says that, “Administering treatment to patients who test positive for the HIV antibody should not be optional or discretionary for health care personnel.” In other words, NOTA advocates a non-discriminatory policy.

Evaluation

Once a person receives a diagnosis of end-stage disease, he or she can request an evaluation at a transplant center. There are 200 around the country, and each has its own criteria.

The Kovlar Transplant Center at Northwestern is currently evaluating and putting people with HIV on the liver transplant list. The center plans to do more liver and kidney transplants in the future. They are also conducting a study to evaluate the interactions between HIV medications and drugs used to prevent organ rejection after a transplant. (As this will require post-transplant blood work, HIV-positive patients with transplants from other Chicago area centers can join this study.)

“We have the transplant expertise and the HIV expertise. We have Rob Murphy and other infectious disease doctors who’ve conducted groundbreaking ACTG [AIDS Clinical Trials Group] studies. We’re excited about combining the two fields of expertise,” says Dr. Lynch. “Additionally, we are looking into new ways to expand the number of organs available for transplant. We were the first center in Chicago to do living donor liver transplants as well as the first center to do a liver transplant in someone infected with HIV. We are also involved in changing the state law to increase the number of organs available for liver transplantation.”

Dr. Lynch advises that you select “a center with experience in HIV because both conditions need to be treated well afterwards.” He further suggests that you look for the centers interested in HIV-positive transplants and that you ask for referrals to other centers if you’re rejected.

He also points out that a center closer to home is important, because post-operative care might require daily visits for a time, and because being far from home puts an extra burden on family members and other support people.

Time—and research—will tell

“Experimental” procedures leave the realm of the experimental after a significant amount of work takes place—with the help of solid research.

It’s in this area that HIV-specialists from the University of California at San Francisco (UCSF) are leading the way. Doctors at UCSF successfully struggled to establish a large, multi-center study on transplants in HIV-positive people. This trial opens 17 centers around the country to people with HIV (see box). As with the trial at Northwestern and at other centers, this research seeks to determine the best way to make transplants successful for people with HIV.

This does not mean that people with HIV will be able to receive an organ any faster than anyone else. What is does mean is that this rigorously designed trial will look at the transplants from A to Z, collecting the information needed to make transplants work best for people with HIV. If it turns out that these transplants are safe and effective, such data should also help put to rest battles for reimbursement from Medicare and private insurance. Also, without a study, transplants can be done in HIV-positive people, but the knowledge gained is either lost or reported after the fact such as with a case report or a chart review—not the best way to advance scientific information.

Study co-chair Dr. Michelle Roland, an assistant professor of medicine at UCSF at the Positive Health Program at San Francisco General Hospital, points out that there are other studies being conducted as well, and that people with HIV should investigate all of their options. She notes, however, that some of the centers in this study have the most experience in this work. “This is a new area...
and there are a lot of things to learn. It could be that a center doing this for the first time can do it perfectly. Most people, however, can expect to do better with a center that has a high volume vs. one with a low volume of any particular procedure, such as a bypass.

Dr. Roland and her colleagues have published several papers and presented reports on their work. In their papers, the researchers note that transplants may be a good option for HIV-positive people who are “relatively healthy.” This is an important distinction. “End-stage liver disease is different from end-stage HIV disease in the context of transplants. We don’t include people with advanced HIV disease in our study,” she explains. Dr. Roland stressed that people with HIV “do everything they can to prevent a transplant.”

A few suggestions: get screened for hepatitis B and C, and have your doctor monitor your liver enzymes and other blood work on a regular basis. Says Dr. Roland, “Transplantation is a very serious endeavor. While it’s very exciting that this option is available, you would rather not have to exercise this option and take all these meds with all these toxicities for life.”

If you do need a transplant, she advises that you get evaluated for one early after you receive that diagnosis, not wait until you’re very sick.

* Urge your friends and family to sign up to be an organ donor (contact UNOS for more information). Even people with hepatitis A, B or C can donate organs (but not people with HIV—although that may change in the future). According to DHHS, “One organ and tissue donor can help save or enhance the lives of as many as 50 people.”

* Some people think they are unable to donate because of advanced age, disease (such as diabetes) or other reasons. This may not be true. People are urged to sign up to become donors and let medical providers determine later whether their organs and tissue are usable or not.

* Stay as healthy as you can. A transplant is rigorous and requires lifelong care. The transplant center needs to see that you are willing to do what you can to maintain your health—such as taking your HIV medications correctly.

* The National Transplant Assistance Fund provides challenge grants and fundraising ideas for people who are uninsured. Call 1-800-642-8399 or visit www.transplantfund.org. The American Liver Foundation may also be able to help through its Transplant Fund Program. Call 1-800-GO-LIVER (465-4837).

* Before you let fear of rejection over your HIV keep you from seeking a transplant, remember that other groups have been denied transplants. Obese patients were often denied a transplant organ because of their higher surgical risks and poorer outcome. Times change and technology advances. As they say, you are not alone!
Waiting For a Transplant—

One Man's Story

by George S. Martinez, as told to Enid Vázquez

I was diagnosed with hepatitis B in December 1969. About 25% of people with hepatitis B become chronic carriers, and a smaller percentage of those develop severe liver disease—cirrhosis. So I’m one of the rare ones. From this smaller group, some may develop liver cancer.

I’ve had HIV since 1987. I know that because I tested negative the year before.

Disability
My hepatitis has been monitored on a regular basis. In 1999 my liver enzymes were elevated and I was diagnosed with cirrhosis. I went on disability as a result, that and my high [HIV] viral load. Later that year I was also diagnosed with AIDS.

Three years after going on disability my doctor told me I needed a liver transplant. A year later I was put on a transplant list. In 2001, Larry Kramer had gotten a transplant [as a result of hepatitis B]. He and other patients opened the door for transplants in people with HIV.

The Transplant List
I’ve been on the list now for one year. I’m monitored quarterly by the Kovlar Transplant Center and the HIV clinic at Northwestern Memorial Hospital.

Last year I decided to seek a second opinion, so I contacted the University of Pittsburgh Medical Center. The decision to go to a second center is your choice. You can get a second opinion as to the severity of your condition. There’s a numerical score, the Model for End-Stage Liver Disease—MELD. It’s objective, the higher your score, the more critical you are. Forty is the highest. At the first center [Northwestern], I was 19, and I’m now 24. At the second center [University of Pittsburgh], I had no score. They determined that I didn’t meet their criteria.

So now we just wait… for my condition to worsen.

Near Death
In 2000 to 2001, I had encephalopathy [any of various diseases that affect the functioning of the brain]. I had acites—water retention, with weight loss from loss of muscle mass. I was constantly tired, depressed, lacking an appetite and suffering with neuropathy.
Those were bad years for me. I was a mess. I had two liters of water taken out of me when I got the ascites [abdominal swelling due to an accumulation of fluid caused by the obstruction of blood flow through the liver].

With the encephalopathy, you become confused and the simplest thing to do becomes difficult. With encephalopathy you become like a child.

I’ve come close to dying several times. A friend of mine says, “My God! He’s just like the phoenix! Like the phoenix, he rises from the ashes.”

Today

My health is good. My viral load is undetectable. My CD4 was 179, but the latest count is 129. They prefer it to be 200 and above. It’s been three or four years since I’ve had 200 T-cells.

I recently found out through an MRI [magnetic resonance image, a procedure similar to an X-ray] that a lesion in my liver has grown from .8 cm to 1.8 cm. As a result, I will be getting a liver biopsy and bone scan to check for possible signs or spread of cancer.

In December 2000 I got a stent from my portal vein to my hepatic vein, what’s called the TIPS procedure [transjugular intrahepatic portosystemic shunt]. All our blood goes through our liver, so this allows a lot of my blood to bypass my liver so that it doesn’t have to work as hard. I don’t feel it. Normally they do a TIPS procedure as a last step before a transplant. You can have this for five or more years before you need a transplant. I’ve had it for four.

The past couple of years have been good. I was on a rollercoaster, but now I’m looking forward to the future. Two years ago I was planning my funeral—getting my will done, finding a place to be buried and leaving instructions for my wake—that was my state of mind.

With my conditions came added stress and basically a change in life. I often find myself in a position of being “not in control” of my life due to having lots of questions and having no answers, and trying to have a positive outlook in life.

It’s taken two years to accept the idea that maybe there is more time for me. And if there is, why don’t I enjoy it, while I can. Still, you always have in the back of your mind the idea that one day it’s not going to be as good as it is today. But I guess you can say that about anything.

Now I’m in a position of wanting to live. Not that I didn’t want to live before, but I’m less fearful, I guess, of waiting for the inevitable. I decided, “Well, I may as well enjoy life and enjoy those around me, my family and friends.” That’s why I like coming here [to Test Positive Aware Network], because of the good atmosphere.

Support groups

Having a support group for people who are co-infected is important to me because when I was put on the transplant list, I became aware of the gravity of my situation. I not only have HIV, but I’m battling with liver disease, which ultimately could kill me, and be even worse than HIV.

There’s a support group [in Chicago] for straight people waiting for a transplant and one for people with hepatitis C who are in recovery. I started a support group because I wanted to talk with someone about co-infection and transplants. Maybe they have questions too. I wonder, how long have they had co-infection? What experiences are they going through? Do they have difficulties with their meds? That’s what I see a support group doing for others—answering questions.

I know that liver transplantation for HIV patients is very new, however, I felt a need to start addressing new support systems as we continue to live longer.

Now I feel like I want to help others. It’s something to look forward to.

George Martinez formed and facilitates HEALTH (HIV Empowerment and Living Together with Hepatitis), which meets Mondays at 7:30 p.m. at Test Positive Aware Network (TPAN). He can be reached at aztec5545@aol.com.
Anal health is not necessarily something most people want to think about let alone be proactive about. But in recent years more gay men with HIV have been diagnosed with anal cancer. I can count at least five men that I know of that have had to deal with the disease. One close friend in Berkeley has just celebrated one-year post surgery to remove a cancerous tumor in his anus. It was not a pleasant experience for him or his partner to say the least. His story is representative of the perplexity of anal cancer and issues around screening and treatment. Surviving with HIV is a reason to be proactive about all health concerns, one of those being anal health and sexually transmitted diseases.

My friend Bill is originally from the Bay Area and is in the process of moving again after having lived there since 1991. He is a very dedicated AIDS activist and works on national AIDS vaccine issues with the AIDS Vaccine Advocacy Coalition. Bill was diagnosed with HIV in 1989 and began antiviral therapy in 1992 when not many anti-HIV treatments were available. He didn’t have much success with therapy until Fuzeon (T-20) came along. Like many other friends of mine including myself, he enrolled in a University of California at San Francisco (UCSF) anal cancer study in 1992. After 10 years of exams every three months Bill was diagnosed with moderate dysplasia (an abnormal cellular change that can signal cancer). During the study, he also had been diagnosed with high-grade dysplasia. In 2002 the study closed and he stopped being monitored. Shortly thereafter he experienced symptoms of bleeding. He was later diagnosed with anal cancer due to an egg shaped tumor in his anus. It was removed through surgery and he later went on to experience a painful recovery period, radiation treatments and chemotherapy. Bill stated, “my most important failing was not continuing to get the [anal] exams after ending the study. I had symptoms I hadn’t been taught to recognize—especially bleeding, and what I believed were hemorrhoids. And I was misdiagnosed by the first proctologist I saw.” Bill’s story highlights the complexity and confusion about anal cancer.

**Human Papilloma Virus (HPV)**

HPV is a common virus that causes warts and dysplasia on the skin, mouth and the genitals and can lead to anal cancer. It is one of the most common sexually transmitted diseases among men who have sex with men. According to the Center for Disease Control, there are 20 million people living with HPV compared to 900,000 people living with HIV. In 1994 Joel Palefsky from UCSF found that anal HPV infection is extremely common in gay men, and as CD4 counts decline the prevalence of high-level infection increases. Another of his studies in gay men showed that HIV-positives were more likely to develop the high-grade lesions than HIV-negative men. HAART (highly active antiretroviral therapy) seems to have little to no effect on regression of lesions suggesting that immune reconstitution due to anti-HIV therapy has little effect on HPV. Also, because anal cancer is slow to develop the risk may increase...
now that people are living longer with HIV. It is another unfortunate paradox of surviving with HIV.

Over 100 types of the human papilloma virus exist that lead to a spectrum of disease from genital warts to pre-cancerous lesions to anal or cervical cancer. Thirty HPV types infect the genital tract. Five of those types have been linked to dysplasia that can cause cervical cancer in women and anal cancer in men and women. HPV can be detected by sight if there are warts, or through pap smears. Yes, gay men can and should receive anal pap smears despite the fact that some doctors and patients are squeamish about performing the procedure.

Sometimes a biopsy is taken with a process known as “high resolution anoscopy” where a scope is inserted into the anus, magnification and a type of acid is used to detect the abnormal cells. Tissue is sent to a laboratory to be analyzed and the graded on severity. This technique of screening is not in widespread use due to lack of clinicians skilled in HPV diagnosis and treatment, and the lack of effective medical alternatives to removal of lesions. Most physicians go by visible signs if they go “down there” at all or they refer patients to proctologists or a surgeon. Unfortunately, some doctors don’t consider HPV screening a routine part of HIV follow-up and care. And often surgeons just want to cut without the knowledge of HPV disease progression and follow-up.

If you do get screened and a biopsy is taken you then get a diagnosis with various stages of HPV-associated lesions and cellular changes that are: normal, mild, moderate, and severe to carcinoma. Dysplasia is sometimes referred to as pre-cancer. Cervical or anal intraepithelial neoplasia (CIN or AIN) refers to an abnormal growth within the cells lining the cervix or anus and is graded as warts (condyloma), grade 1, grade 2 or grade 3. Squamous intraepithelial lesion (SIL) also refers to abnormal cell growth in the same areas, classified as low or high grade (HSIL). If left untreated these HSIL growths may lead to cancer that can sometimes be life threatening. However sometimes the HSIL can be stable and not progress to cancer. Many physicians feel this is the reason to simply monitor patients and not treat them. In men if cancer does develop it will progress similarly to cervical cancer in women. The lesions grow very slowly and take years to develop.

Studies have shown clinical and cost effectiveness in HPV screening. It doesn’t take a rocket scientist to understand that early detection for cancer should be the standard of care especially in people with HIV. It’s a message we’ve been hearing for years from women with breast cancer and individuals with other cancers. Why should it be any different for anal cancer, especially in a population of people at higher risk?

**TREATMENT FOR HPV**

Treatment for HPV can be as problematic as screening and diagnosis. HPV related warts are easy to remove with cryotherapy, laser removal or special chemicals such as trichloroacetic acid, podophyllin resin or 5-FU. Treatment for dysplasia is trickier because it may be difficult to detect with current tests, someone treated with diffuse (scattered) dysplasia may suffer from long term side effects of removal. Recovery from these treatments can be severe and last several weeks.

The standard treatment for anal and cervical cancer is often surgery followed by radiation and chemotherapy. Anal surgery is, as you can imagine, very painful with a lengthy recovery period. Combination treatments such as radiation, chemotherapy and cidofovir are used in combination with surgery in clinical trials to a positive effect. Reoccurrence with HPV is common, however whether it develops to cancer depends on good follow up and screening. Bill commented on his surgery, “Anal cancer is very treatable if it has not progressed beyond a local tumor. It is basically like skin cancer. The treatments are nasty however and prognosis is only about half as good for HIV-positives as it is for HIV-negatives.” Again, early detection and early treatment are highly recommended.

The good news about HPV is there are vaccines being studied for prevention and treatment. The treatment vaccines are based on the proteins that cause cancer in HPV. So far all the vaccines studied are safe, well tolerated and most data so far shows they are clinically effective. Larger studies are underway and more information is forthcoming.

In the absence of an effective vaccine Bill told me, “The final word should be if you have any doubts, don’t hesitate to ask [your doctor] because if you bring up the idea of cancer, doctors are obligated to follow up for their own protection.”

Gay men need to be more informed and proactive with anal screening for HPV as they have been with the syphilis campaigns around the country, including Chicago. Although anal cancer is relatively rare we may be sitting on a time bomb unless doctors are willing to make anal pap smears a part of routine medical care, and patients are willing to speak out about their own anal health, despite the unease and awkwardness of this area of health care. Besides, no one wants to go through cancer and surgery, especially if they are surviving with HIV. Ask for a pap smear!
Across the country, AIDS Drug Assistance Programs (ADAPs) are running out of money, rationing care, or simply turning away people who need assistance. The situation is worsening as the number of people with HIV/AIDS continues to grow but public resources for programs to help them do not.

Nationally, ADAP needs an increase of $217 million to help the additional 24,000 individuals estimated to need anti-HIV therapies and no way to pay for them. The program already provides life-extending medications to some 100,000 individuals annually. Failure to adequately fund ADAP will only escalate the AIDS crisis in America by forcing thousands of low-income and uninsured people with HIV to forgo therapy until they become severely immune compromised. These individuals will develop higher viral loads than people on therapy, increasing the risk of HIV transmission to their partners. Ultimately, failure to expand ADAP will result in more people becoming HIV infected and more people dying of AIDS-related causes.

Created in 1987 to assist states in paying for AZT—the only anti-HIV medication available at the time—ADAPs currently operate in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, Northern Mariana Islands, American Samoa, and the Marshall Islands. Congress incorporated ADAP into the Ryan White CARE Act in 1990 to provide access to AIDS-related prescription drugs for low-income individuals who have no other source to obtain them.

ADAP was instrumental in achieving the historic decline in AIDS-related deaths after protease inhibitors became available in 1996. The nearly 70% drop in AIDS-related death in the U.S. in the late 1990s is largely a result of CARE Act services, including ADAP, made available to deliver life-saving medications and essential health and social services to the individuals who most needed them.

Despite its record of success, ADAP is facing an uncertain future. As of April, nearly 1,300 people nationwide were on ADAP waiting lists, 15 states had closed enrollments or limited access to antiretrovirals, and eight states anticipated program restrictions in the coming months.

Chronic under-funding by the federal government and inadequate state contributions, combined with escalating drug prices, more people needing HIV medications, and needing them for longer, has ignited the crisis.

Despite an unprecedented call to action on AIDS in his 2003 State of the Union address, President George W. Bush sought only a $20 million increase for ADAP in FY04, and no increases for vital medical and social services through the programs of the CARE Act. Senator Charles Schumer (D-NY) offered an amendment in

Will Lawmakers Save ADAP?

by David Munar and Sara Schmitt
September to boost ADAP funding beyond the president’s request, but the effort failed in a vote cast along party lines. Lawmakers finally agreed on an ADAP appropriation of $748 million—a full $180 million less than is needed to meet current needs—for the fiscal year ending October 2004.

Concerned that insufficient funding would force additional states to cap enrollments, reduce services, or start waiting lists, a group of 100 ADAP advocates from 30 different states traveled to Washington, DC in February to ask lawmakers to consider a $180 million emergency supplemental appropriation for ADAP. The group included individuals on waiting lists and those representing states with program restrictions. Organizers agreed that, while the effort increased awareness of ADAP on Capitol Hill, passage of a supplemental appropriation is unlikely.

In addition to the battle in Congress, ADAP advocates are also fighting for adequate state funding. While two-thirds of states augment federal ADAP contribution with state funding, not all states do, or do so at sufficient amounts. These variances have created significant differences between the states in terms of eligibility and the number of medications covered.

Advocates from California and Texas waged successful battles against draconian restrictions proposed by their legislatures. This year, Illinois advocates are asking state lawmakers to approve the governor’s proposal to increase state ADAP funding by $3.1 million to meeting new needs and add anti-cholesterol and mental health drugs to the formulary.

While grassroots activism is gaining small, state victories, achieving significant victories at the federal level will take our best efforts. In addition to ADAP, adequate funding is needed for other critical programs including Medicaid, HIV prevention programs, AIDS research, the Housing Opportunities for People with AIDS program, global AIDS programs, and the entire Ryan White CARE Act. Strong grassroots pressure can influence the future of ADAP funding, particularly during the election year as all candidates and elected officials must answer to their constituents.

In addition, AIDS service organizations are encouraged to designate a staff person, volunteer, or board member as a representative to Save ADAP. To join Save ADAP or to get more information, go to www.atac-usa.org/adap.html.

Educate your elected officials about ADAP. Find out who represents you in Congress and in your state’s legislature and make sure they know that ADAP saves lives and money. Join Save ADAP’s “Message in an Empty Pill Bottle” campaign and send empty pill bottles to your U.S. senators and representative, urging them to provide a “refill” of funding for ADAP. (Visit www.atdn.org/save8.html)

Make HIV/AIDS, and the ADAP crisis, an issue in this year’s elections. Go to www.AIDSVote.org and endorse its platform calling for treatment access for people living with HIV/AIDS in the U.S. and around the world. Read Senator Kerry’s platform on HIV/AIDS issues, and send an email to President Bush to ask his campaign to share its plan to combat the epidemic. Finally, ask local candidates how they will solve the ADAP crisis. Check out the website’s “rally in a can” and use the materials to draw attention to HIV/AIDS during the next campaign event in your town.

David Munar and Sara Schmitt monitor federal AIDS issues for the AIDS Foundation of Chicago, visit www.aidschicago.org.

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Failure to adequately fund ADAP will only escalate the AIDS crisis in America by forcing thousands of low-income and uninsured people with HIV to forgo therapy until they become severely immune compromised.

Take Action to Support ADAP:

Join a network. Individuals and organizations can play an important role in solving the ADAP crisis. Save ADAP and numerous national and regional AIDS organizations monitor Congress and state legislatures on ADAP and other HIV-related issues. By joining one of these groups, you can keep up-to-date on national, state, and local ADAP advocacy issues. In Illinois, call the AIDS Foundation of Chicago at (312) 922-2322 or go to www.aidschicago.org to join the Statewide Advocacy Network. Project Inform’s Treatment Action Network is a national grassroots network for individuals concerned about ADAP and other HIV-related issues (www.projectinform.org).

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t's rare that members of the HIV community and its activists have an opportunity, or a reason for that matter, to pause from their work in the ongoing struggle just to say thank you to their legislators for progress made and a job well done. With so many cuts in both state and federal budgets in HIV/AIDS-related services, and a constant rise in new infections across the board, we realize that even though this virus has devastated our community for over 20 years now, the reality of the matter is that we must continue to fight, or die.

In Illinois, however, on March 31st, 2004, members of the HIV community, led by the AIDS Foundation of Chicago (AFC), gathered at the state capitol of Springfield to show support and to say “thank you” to Governor Rob Blagojevich for his proposed budget for fiscal year 2005. This new budget includes a $1 million increase for HIV prevention services in communities of color and a $3.1 million increase for the AIDS Drug Assistance Program (ADAP). In a time when ADAPs across the country desperately lack critical funding, and most states are seeing drastic cuts being made to their budgets for HIV/AIDS services, Illinois is one of few that recognizes and appears ready to act on the need for increases in funding.

At the same time, however, the struggle in Illinois continues. While at the state’s capitol, lobbyists also spoke with State Senators and Representatives concerning other important bills that are critical to the lives of the 35,000 Illinoisans living with HIV/AIDS. These bills include HB 4439, which will protect low-income renters with public assistance from housing discrimination; HB 4622, which will standardize the definition of “disability” among all state agencies so that disabled people living with HIV/AIDS can gain access to important public benefits including Medicaid; HB 6563, which will help to ensure that children of terminally ill parents will be raised by the guardians of their choice; and HB 3857, which will allow HIV-positive individuals to become organ donors, increasing access to life-saving organ transplants for people living with HIV/AIDS. The fate of these bills are yet to be determined, however, the presence of hundreds of people with HIV at the state capitol is bound to leave a lasting impression upon the hearts and minds of legislators as they make their voting decisions.

Having been born and raised in Illinois, I was one of those who lobbied at the state capitol, grateful to be a resident and for my life. For a brief while, a couple of years back, I was a resident of the state of North Carolina. It was in that state that I received an AIDS diagnosis and became extremely ill with no health insurance. I was taken to a local emergency room with chronic diarrhea and severe wasting, only to be turned away and given a phone number to call so that I could make an appointment at a free clinic that provided treatment for residents of the city of Charlotte without health insurance.

I was instructed to call this number between 8 and 9 a.m. only, Monday through Friday, and pray that I would reach someone. With only one phone number for everyone in the city without health insurance to call at the same time of day, you can imagine that a busy signal was all that I received. If I did happen to get through, there were only a certain number of appointments available to be given out on any given day, and if those were already taken then I had to try all over again the next day. When I was finally able to get an appointment (which took almost two weeks using this system), it was not scheduled for another 3 1/2 weeks.

While waiting for the appointment, I was instructed to apply for the ADAP program, which at that time was bankrupt, so that once I received health care I would at least be already medications that would be prescribed. Needless to say, due to the seriousness of my health situation, I could not wait through all of this. I was forced to move back to my hometown, Chicago, and was able to receive the care that I needed immediately, minus the phone calls and the waiting lists. It is believed by many, my physicians included, that had I stayed in Charlotte, North Carolina much longer, I probably would not have lived to share this horrifying experience.

North Carolina is not the only state that operates in this manner. Several states within the U.S. do not provide adequate, timely health care to those in need who, for whatever reason, are without health insurance. The power for change, however, lies in the voice of the constituents of those states and in the votes that they cast. Lawmakers are selected by the people. Just as the HIV community in Illinois has lobbied for years so that all can have equal access to health care, residents of those states must unite and do the same. The lives of millions who are infected with HIV and other health care issues desperately depend on it.

Keith R. Green (27), Distribution Coordinator at Test Positive Aware Network, is a young poet, student, activist and lover who is dedicated to making a difference in his world. A sharp thinker with a positive attitude, Keith willingly shares his knowledge and talent with all.
Coping with Depression

by Ross Slotten, MD

Depression is the most common psychiatric disorder in the United States. According to the National Institute of Mental Health, 10% of American adults, or nineteen million people over the age of eighteen, suffers from some sort of depression every year and a third of the adult population will experience a major depressive episode in their lifetimes. The incidence of depression in individuals living with HIV is twice as high. This is not surprising, since depression occurs at higher rates in all groups of people with chronic illnesses. The economic costs of depression in terms of lost time at work and medical care are considerable; but the greatest effects are on health. In patients with HIV disease, severity of depression correlates with rapidity of decline in CD4 counts, suggesting that a failure to treat depression may accelerate HIV disease progression and impact survival. Thus, depression can be as serious as certain co-infections, like hepatitis B and C.

Although there has been considerable progress in our understanding of the brain, the ultimate cause of depression is unknown. Even the role of certain neurotransmitters like serotonin is still unclear, despite intense marketing by the pharmaceutical industry. The hallmark of depression is an alteration in mood, but there are physical symptoms as well. Psychiatrists have identified ten symptoms of depression, which include the following:

- persistent sad, anxious or empty moods;
- feelings of hopelessness or pessimism;
- feelings of guilt, worthlessness or helplessness;
loss of interest in pleasurable activities like sex or hobbies;
decreased energy, fatigue or feeling "slowed down;"
difficulty concentrating, remembering or making decisions;
sleep disturbances (insomnia, frequent awakenings or oversleeping);
appetite and/or unintentional weight changes;
thoughts of death or suicide or suicide attempts; and
restlessness and irritability.

If five or more of these symptoms are present every day for at least two weeks, then a person is suffering from a major depressive episode. If the depressed moods and two or more of the above symptoms persist for at least two years, then the person is diagnosed with a dysthymic disorder (an antiquated term derived from the Greek, meaning diseased mind—in this case, representing mild, chronic depression). If in addition to one or more major depressive episodes, the person experiences wild mood swings in the opposite direction—that is, inflated self-esteem, grandiosity, pressured speech and so-called “flight of ideas,” and abnormally high energy—then he or she is said to be bipolar.

**DIAGNOSIS**

Complicating the diagnosis of any mood disorder is substance abuse, which not only can mask underlying mental illness but can also mimic one mood disorder or another. Crystal methamphetamine, for example, elevates a person’s moods to the height of mania, until the person crashes and appears profoundly depressed. Chronic use can lead to depletion of serotonin, which may result in permanent depression unresponsive to antidepressant medications. Crystal methamphetamine attracts depressed individuals because it creates a temporary sense of well-being and high energy, counterbalancing the low self-esteem and other debilitating somatic and cognitive symptoms of depression. After ingestion, this drug can also produce intense anxiety and palpitations or chest pain; patients frequently request antianxiety medications like Xanax or Valium to calm their nerves. Frequent requests for such medication should raise suspicions of substance abuse. In some studies, nearly three quarters of HIV-infected individuals who abuse drugs and alcohol suffer from some sort of psychiatric disorder, including depression.

Despite clear-cut criteria for diagnosing depression, depression is not always easy to diagnose or manage. Patients present with headaches, fatigue and weight loss, just as people do with other illnesses. If depression is suggested as a cause, they may insist that something else is wrong. In HIV-positive patients, the diagnosis of depression is especially tricky because they may indeed have serious underlying disease. But unless a person has end-stage AIDS or is on the downward slope of uncontrolled HIV infection, most HIV-positive people are relatively healthy—the various nonspecific symptoms that they are suffering from may be due not to a deadly opportunistic infection but to depression. Yet ruling out other causes may be greeted with resistance or skepticism. It is ironic that, because of the stigma attached to mental illness in our country, people would rather be told that they have some dreaded disease than depression.

The public still does not equate psychiatric disorders with organic disease—diseases of the mind seem less legitimate than pneumonia or lymphoma. A blood test, CT scan, MRI or an X-ray will not diagnose depression; it remains a clinical diagnosis, after other diseases have been ruled out. And treatment is no easier. The prevailing belief is that depression can be solved by a change in attitude, finding a new job, moving to a new city, or ending a relationship—all of which may happen without improvement in symptoms before the true problem is addressed. In the meantime, the patient is lonely, unhappy and living in strange surroundings without adequate emotional support. Moreover, the notion of psychotherapy or antidepressants repels most people, even though depression is a treatable condition, unlike the dreaded disease the patient thinks he or she has.

As mentioned, other diseases should be ruled out before diagnosing depression. First and foremost is advancing HIV infection. Patients with declining CD4 counts and rising viral loads may exhibit a few of the characteristics of depression, such as fatigue and weight loss. If the patient has never been treated for his or her HIV infection, or the patient with resistant disease has remaining treatment options, then highly active antiretroviral therapy (HAART) should improve symptoms in a few weeks. AIDS-dementia, now rare, may also present as a depression-like illness. In more subtle cases, neuropsychiatric testing—a battery of written and oral testing by a specially trained psychologist—must be conducted in order to distinguish between organic brain diseases like HIV encephalopathy and a mood disorder. Unlike depression, dementia progresses over time, with profound impairment of men-
The management of depression in HIV infection is usually multidisciplinary… The primary health care provider rarely has the time or expertise to provide the full scope of services to the depressed person.

tal processes, radical personality changes, and eventual alterations in levels of consciousness before death.

Two other medical conditions should be considered before treating depression: hypogonadism and hypo- or hyperthyroidism. Hypogonadism, or abnormally low testosterone levels, may cause fatigue, weight loss and depressed moods. For reasons that are unclear, impairment of testosterone production is common in HIV-infected men. Testosterone deficiency is defined as a total serum testosterone < 300 ng/dL or a serum free testosterone < 5-7 pg/mL. Replacement of testosterone by injection, topical patches or gel restores a sense of well being. Both low (hypo) and high (hyper) thyroid levels can affect mood, which improves when the thyroid problem is treated.

Finally, a number of anti-HIV medications have so-called neuropsychiatric side effects. The most infamous in the category of antiretroviral agents is efavirenz (Sustiva in the U.S. and Stocrin in some other countries), which can cause an array of symptoms, from vivid dreams to mood-altering states mimicking depression. AZT (Retrovir) and abacavir (Ziagen) can produce extreme fatigue, loss of energy, and depression. Cause and effect are usually obvious, occurring within days or weeks of initiation of therapy. When the patient finds these side effects intolerable, stopping the medication resolves the problem; persistence suggests another reason for alterations in mood. Many other agents used to treat a variety of non-HIV related problems can also depress mood or induce somatic complaints, but the list is too long to enumerate in this article.

The management of depression in HIV infection is usually multidisciplinary, involving psychologists, social workers and psychiatrists. The primary health care provider rarely has the time or expertise to provide the full scope of services to the depressed person. When substance abuse is a problem, access to a good treatment program with sensitivity to issues unique to HIV like sexuality is essential. In addition to restoring emotional health, major goals of psychotherapy are the prevention of the transmission of HIV to uninfected individuals or reinfection with a resistant strain of HIV, and adherence to the HIV-treatment regimen.

Most of the DHHS recommendations are common sense. Implementation of these recommendations, however, can be a challenge. The clinician must overcome a number of barriers to ensure proper therapy—social, psychological and medical. Some of these barriers have nothing to do with the patient but everything to do with our health care system, which is fragmentary and driven by third-party payers. Yet until the creation of a comprehensive health care system in this country—whether in the form of a single-payer, government-managed system, or one resembling the mix of government and private payers cobbled together by the Clinton administration—certain barriers, such as access to affordable health care for the working poor, will be impossible to overcome.

First, the patient must be convinced that he or she is depressed, which, as already noted, is not always easy. Second, the patient must agree to see a psychotherapist, at least for an evaluation. For those who lack or have insufficient mental health benefits, access to less expensive or free mental health care varies from community to community. In communities offering such services, quality is not always consistent. Psychotherapy may span weeks or years, which is a significant time commitment; out-of-pocket expenses can be considerable, even for those having the most extensive insurance

### Management of psychiatric illnesses in HIV/AIDS

The U.S. Department of Health and Human Services (DHHS) has published guidelines for the management of psychiatric illnesses in HIV/AIDS patients. Management includes the establishment and maintenance of a therapeutic alliance, or trust, between patient and health care provider; collaboration and coordination of care with other mental health and medical providers; diagnosis and treatment of all associated psychiatric disorders as well as substance abuse disorders; facilitation of adherence to overall treatment plan; risk reduction strategies to minimize the spread of HIV; maximization of psychological and social functioning; harm-reduction counseling to substance abusers to minimize unsafe sexual behavior during drug intoxication and promote adherence to HAART therapy; assessment and support of the role of religion or spirituality; ensuring access to housing and financial assistance; preparation for issues of disability, death and dying; and the education of significant others or family regarding sources of care and support.
coverage. Gay patients often prefer to see a gay therapist, which HMOs and other managed health care plans may not be able to guarantee, though insurers have become increasingly sensitive to sexual orientation in recent years. In some parts of the developing world, psychotherapists do not exist; patients who emigrate from those countries may not be amenable to psychotherapy because they do not accept the Freudian or post-Freudian model of the mind. Thus, there may be cultural barriers that prevent patients from obtaining psychotherapy. Third, the primary care physician or psychiatrist may recommend prescription medication that patients are reluctant to take. Patients often resent the addition of yet another medication to an already burdensome regimen, or they may fear antidepressants, which they equate with mind-altering substances like LSD. They may also worry about side effects, especially the impact on sexual function.

**TREATMENT**

The pharmacological treatment of people with HIV and depression has been studied extensively, though not every drug available has been examined. The oldest class of antidepressants, the tricyclics (amitryptilline, imipramine, desipramine and nor-tryptilline), were the first drugs subjected to a scientific evaluation. Approximately three-quarters of patients given imipramine, for example, responded favorably as compared to 30% on placebo. However, almost a third of the patients stopped imipramine because of side effects, which include constipation, dry mouth, drowsiness, headaches, cognitive problems and sexual dysfunction. This is unfortunate, because tricyclics are inexpensive. Today, their role is limited mainly to the treatment of pain from peripheral neuropathy, which improves with a dose lower than that for depression. More expensive medications, like fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa) and a derivative of citalopram, Lexipro, which belong to the SSRI class (selective serotonin uptake inhibitors), have produced response rates as high as 90% in some studies. Side effects are relatively few, though sexual dysfunction, which is the most common complaint, occurs at rates higher than the pharmaceutical companies like to admit. Rarely are erections a problem; most aggravating is time to ejaculation. In this setting, Viagra, Levitra and Cialis are of no use, since these agents help only those men who have difficulty obtaining or maintaining an erection and do nothing to speed up ejaculation. Venlafaxine (Effexor), nefazodone (Serzone), buproprion (Wellbutrin) and mirtazapine (Remeron)—the non SSRI antidepressants—seem to cause less sexual dysfunction. In fact, bupropion is sometimes added to an SSRI-containing regimen to improve sexual function. Few studies with these agents have been conducted in HIV infected patients—which does not mean they are not effective in this population. Moreover, there may be a significant interaction between these non-SSRI agents and antiretroviral regimens containing Norvir (ritonavir). These drugs should therefore be used with caution in patients on Norvir boosted PIs or Kaletra.

Psychostimulants, like methylphenidate (Ritalin), can also help patients who are suffering from depressed mood, fatigue and cognitive impairment. Their onset of action is more rapid than that of the tricyclics, SSRIs, and other antidepressants, which may take four to six weeks before maximal benefit is observed. Ritalin works in a matter of hours; but its abuse potential is high and tolerance to its effects typical. Annoying side effects include overstimulation and insomnia; and for those who are concerned about maintaining weight or lipodystrophy, amphetamines suppress appetite. This class of drugs works best in patients with end-stage disease or in those whom the clinician suspects adult attention deficit disorder, a syndrome whose symptoms are difficult to distinguish from chronic anxiety disorder as well as depression. Finally, St. John’s wort should be mentioned. Although shown to be effective for mild depression, St. John’s wort negatively interacts with indinavir (Crixivan), making regimens containing indinavir less effective. Its interactions with other protease inhibitors are unknown. St. John's wort should not be used in patients taking HIV medications until further studies support its safety and efficacy.

In conclusion, depression is a common, treatable problem in people with HIV infection. It may be due to a condition long preceding HIV infection or to substance abuse; or it may arise in the course of infection, either as a result of HIV medications, illnesses, or the overwhelming emotional response to HIV itself. If not treated or recognized, it can profoundly affect quality of life and life expectancy. Clinicians, patients, their families and significant others should suspect depression when there is no other explanation for depressed mood, fatigue, or other vague somatic complaints that impair social functioning. Psychotherapy and the appropriate use of antidepressant medications can restore such individuals to normal emotional health, which, by curtailing self-destructive behavior and improving adherence to antiretroviral regimens, will help ensure a long, productive life.

Ross A. Slotten, M.D., M.P.H. is a family physician in Chicago with a large HIV/AIDS practice.
Sometimes the wheel is reinvented and it rolls better. There is a nutritional drink on the market that has redefined the very essence of its nature. Redefined because it is made for the HIV impacted community and others living with chronic diseases like cancer. Unique because it has ingredients way above and beyond your basic A through zinc vitamins. Special because it is specially formulated to help you add body mass and maintain it. Different from others because it fights oxidative stress by helping you eliminate it from your system. Your body gets stressed when free radicals roam around within your cells. HIV medications, smoking, alcohol, food digestion and the omnipresent air pollution can cause these radicals to float around your bloodstream where you don’t need them. And did I mention that it tastes really good?

Millenium Biotechnologies, Inc., has created two formulas Resurgex and Resurgex Plus, which contain a patented ingredient called SOD (Superoxide Dismutase), which helps your body process and eliminate those free radicals. The product also contains an impressive array of essential and non-essential amino acids, vitamins and minerals to help maintain weight, increase energy and strengthen the immune system. This product is superior to other nutritional drinks because it does not start out with any high fructose corn syrup and all that other stuff that, for all we know, may also cause free radicals. It is packaged in neat single serving packages and you get to choose what liquid to shake it up with. I used soy milk with mine and it made the flavor richer and smoother. I could tell you about the impressive profile of all the ingredients but you may find out for yourself by looking it up on the Internet or calling them. Toll free: (888) 412-9179 or go to www.milbiotech.com.

SOD (Superoxide Dismutase) is a metal-containing antioxidant enzyme that reduces potentially harmful free radicals of oxygen formed during normal metabolic cell processes to oxygen and hydrogen peroxide. As mammalians we need oxygen to breathe and survive and as your body lives each day it naturally creates free radicals. Normally, people create SOD on their own which helps the body deal with free radicals by canceling them and returning your cells’ balance to normal. As a natural part of aging the body produces less SOD. Free radicals have been studied and implicated as the main cause of chronic degenerative diseases from HIV/AIDS to cancer to cardiovascular disease and more. HIV-positive individuals taking HAART are at risk of free radical overload as these medications themselves cause free radicals. HIV causes free radicals, now if you also happen to smoke and eat rich foods you are racking up with an overabundance of free radicals.

SOD used to be effective only by injection but Millennium Biotechnologies Inc., has the exclusive rights in the medical markets to use the first orally effective form of SOD—a patented method to cover the SOD with Gliadin, which serves to protect it in the GI tract and help get the SOD into the body. Better yet, the SOD is derived from melon and the Gliadin is derived from wheat, completely vegetarian! Also, there is mitochondrial toxicity that HIV and its medications can induce. Mitochondrial damage has been linked to lipodystrophy, peripheral neuropathy, kidney damage, muscle weakness and liver damage. The mitochondria are the cells power source. HIV-positive people taking nukes for a long time may have poor functioning mitochondria. Along with SOD, Resurgex and Resurgex Plus contain nutrients such as D-Ribose, L-Carnitine and Coenzyme Q10 that have direct and indirect roles in supporting and protecting the mitochondria.

I have been on a Structured Treatment Interruption since October of 2002 and the only thing that I have added to my body in the interim is Resurgex. I prefer the Resurgex because I want to maintain my current body mass. When I first tried it I did not expect much but within minutes I felt more energy. And I have never really felt energy after taking supplemental drinks except for the ones loaded with ephedrine or caffeine. So I could actually feel something immediately. I also felt full and I mean
I Can. I Will.

A two-day bike ride to fight AIDS in the Chicagoland area.

Ride for AIDS Chicago is different. We are completely grassroots & committed to returning 100% of donations received to our beneficiaries: Test Positive Aware Network and BEHIV.

RIDE - CREW - VOLUNTEER

Saturday & Sunday
June 5-6, 2004
Chicago - Lake Geneva

Register online at
RideForAIDS.org
OR CALL (773) 989-9400
extra large, biggie size value meal full. And I felt this way for about three to four hours.

When I returned to my doctor for blood work my viral load was 58,000 and on my next visit my viral load was down to 29,000 and three months after this visit the load was still hovering at 29,000. I expected my viral load to be at least near 100,000, since the last time I went on an STI after only three months my viral load spiked up to 59,000 and within one more month nearly 90,000. So I was ready for a bad report and the inevitable conversation over what meds to start and what side effects to watch out for. I believe the drink boosted and detoxified my immune system. I have been on some type of anti-retroviral medications since approximately 1991 and that does not take into account any antibiotics and other medications to treat specific infections or problems that have occurred. Going back to 1991 I can also add smoking cigarettes daily and a few party favors at least every weekend to my systems' fair share of free radicals.

Naturally, we are all different and everything we ingest works differently on us but these are my results. I have been applying AndroGel for years and I also took a cycle of Deca-Durabolin while I was drinking this product but my weight never went anywhere over 199 pounds. However, during the ingestion of Resurgex, my BIA (Bioelectrical Impedance Analysis) shows that I gained more muscle than ever before to the tune of 205 to 207 pounds. That’s about 6 to 7 pounds of extra muscle that I had never achieved to gain myself.

Representatives from the company were at the United States Conference on AIDS in Atlanta a few years back and a co-worker brought some samples into TPAN and that’s how I was introduced to the product. It is not cheap but we are what we eat and drink aren’t we?

A couple of my buddies said it was too sweet for them, I have a sweet tooth and I like it just fine the way it is. It’s good to know that the sweetness is not from a bunch of processed chemicals or sugars. If it’s too sweet your taste, you can add a bit more of your favorite liquid to lessen the sweetness. You may qualify to have this drink covered under your insurance plan depending on which state you reside in and what insurance plan you have and what kind of rings of fire you can jump through. There are many people impacted by HIV and AIDS that cannot keep any food in them or cannot maintain any weight gains. Then there are people living with cancer and other chronic conditions that require the best nutrition possible. These formulas can be ingested orally or through a feeding tube.

I researched the ingredients found in two of the most popular standbys of the nutritional drink arena. It’s incredible that some of these nutritional drinks are covered by most health insurance plans while being loaded with processed ingredients! These are given to the elderly, those with cancer and HIV and anyone in a hospital setting on a liquid diet. Here’s the list of the first three or four ingredients from one can of brand X: water, corn syrup, sugar and sucrose. Further down the list we find canola oil, corn oil, artificial flavors and pyridoxine hydrochloride! While this is only a form of vitamin B6, it is also listed as an eye irritant! I think I’ll stick to something new and truly different that I believe is healthier to ingest. And when it comes to all the sugars and oils, I would rather have these as a treat in the form of pecan pie but not in my nutritional drink.
### TPAN Events Calendar

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

#### May 2004

<table>
<thead>
<tr>
<th>DATE</th>
<th>TIME</th>
<th>EVENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wednesday 5th</td>
<td>7:30-9 pm</td>
<td>Committed to Living Series—New HIV Treatment Options - supported by GlaxoSmithKline Pharmaceuticals</td>
</tr>
<tr>
<td>Monday 17th</td>
<td>8-11 pm</td>
<td>Bar Olympics 2004 Closing Ceremony benefiting TPAN, Metro on Clark, $10.00 Call (773) 989-9400 for tickets</td>
</tr>
<tr>
<td>Tuesday 18th</td>
<td>7-9 pm</td>
<td>Nelson Vergil, author of Built to Survive, speaking on health and body maintenance, Ann Sathers, 929 W. Belmont.</td>
</tr>
<tr>
<td>Thursday 20th</td>
<td>7:30-9 pm</td>
<td>Legal Clinic on insurance and benefits - presented in collaboration with AIDS Legal Council of Chicago</td>
</tr>
<tr>
<td>Thursday 27th</td>
<td>7-10 pm</td>
<td>PULSE, International Mr. Leather weekend Party, Berlin, 954 W. Belmont</td>
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#### June 2004

<table>
<thead>
<tr>
<th>DATE</th>
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<th>EVENT</th>
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<tbody>
<tr>
<td>Wednesday 2nd</td>
<td>7:30-9 pm</td>
<td>Committed to Living Series—HIV and Sexual Health - supported by Bristol-Myers Squibb Pharmaceuticals</td>
</tr>
<tr>
<td>Thursday 17th</td>
<td>7:30-9 pm</td>
<td>Legal Clinic on Wills and Powers of Attorney - presented in collaboration with AIDS Legal Council of Chicago</td>
</tr>
<tr>
<td>Thursday 24th</td>
<td>7-10 pm</td>
<td>PULSE, Pride Party, Berlin, 954 W. Belmont</td>
</tr>
<tr>
<td>Friday 25th</td>
<td>5-8 pm</td>
<td>TPAN Annual Barbecue, The Patio of Buck’s Saloon, 3439 N. Halsted</td>
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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 & STD Testing
- HEP Testing & Vaccination

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

<table>
<thead>
<tr>
<th>Medical Clinic</th>
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<tbody>
<tr>
<td>HIV/STD screenings 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.</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Medical Clinic</th>
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<tbody>
<tr>
<td>See description on Monday. Call for an appointment. From 9 am–12 pm.</td>
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</table>

**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

<table>
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<tr>
<th>Needle Exchange Program</th>
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<tr>
<td>Through a collaborative effort of Chicago Recovery Alliance and TPAN, a free, anonymous, legal syringe exchange and HIV/AIDS prevention is offered Wednesdays from 5–7 pm, or by appointment.</td>
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</tbody>
</table>

**SHE (Strong, Healthy and Empowered)**
HIV-positive women discuss needs, concerns and issues facing women with HIV. Meets from 7:30–9 pm.

<table>
<thead>
<tr>
<th>Yoga</th>
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<tbody>
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<td>All levels of yoga are welcome. Meets from 10–11 am.</td>
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</table>

<table>
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<tr>
<th>Medical Clinic</th>
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<tbody>
<tr>
<td>See description on Monday. HIV/STD screenings and testing is available. Call for an appointment. From 12 pm–8 pm.</td>
</tr>
</tbody>
</table>

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

### Thursday

<table>
<thead>
<tr>
<th>Needle Exchange Program</th>
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<tbody>
<tr>
<td>See description on Wednesday. Thursdays from 2–5 pm, or by appointment.</td>
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</table>

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

<table>
<thead>
<tr>
<th>POZ Leathermen</th>
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<tr>
<td>Support and social group for HIV-positive leathermen and friends. Meets from 7:30–9 pm at Soul Cafe, 1301 West Hollywood, Chicago.</td>
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### Friday

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<thead>
<tr>
<th>Needle Exchange Program</th>
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<tr>
<td>See description on Wednesday. Fridays from 2–5 pm, or by appointment.</td>
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**Scheduled By Appointment**

<table>
<thead>
<tr>
<th>FASN (Family AIDS Support Network)</th>
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<tr>
<td>A group for family, friends and caregivers. Call Betty Stern at (773) 989–9490.</td>
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<tr>
<th>Individual Counseling</th>
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<tr>
<td>AIDS Pastoral Care Network (APCN) professionals provide individuals with one-on-one counseling on Mondays. Ask for Sherry or Betsy at (708) 681–6327.</td>
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<table>
<thead>
<tr>
<th>Peer Support Network/Buddy Program</th>
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<tr>
<td>Trained volunteers provide one-on-one peer, emotional support to individuals living with HIV. Call Jim or Kathleen at (773) 989–9400.</td>
</tr>
</tbody>
</table>

**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)**
This peer-led program integrates 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.

**Reiki**
Energetic healing practice that utilizes hands-on touch and focused visualization. Meets Tuesdays and Thursdays by appointment only from 2–5 pm.

### Miscellaneous

<table>
<thead>
<tr>
<th><a href="mailto:LIVINGPOS18TO24@AOL.COM">LIVINGPOS18TO24@AOL.COM</a></th>
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<tbody>
<tr>
<td>An AOL chat room for young adults (ages 18–24) who are HIV-positive. Monday through Friday from 3–5 pm.</td>
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</table>
5 Million new infections in 2003