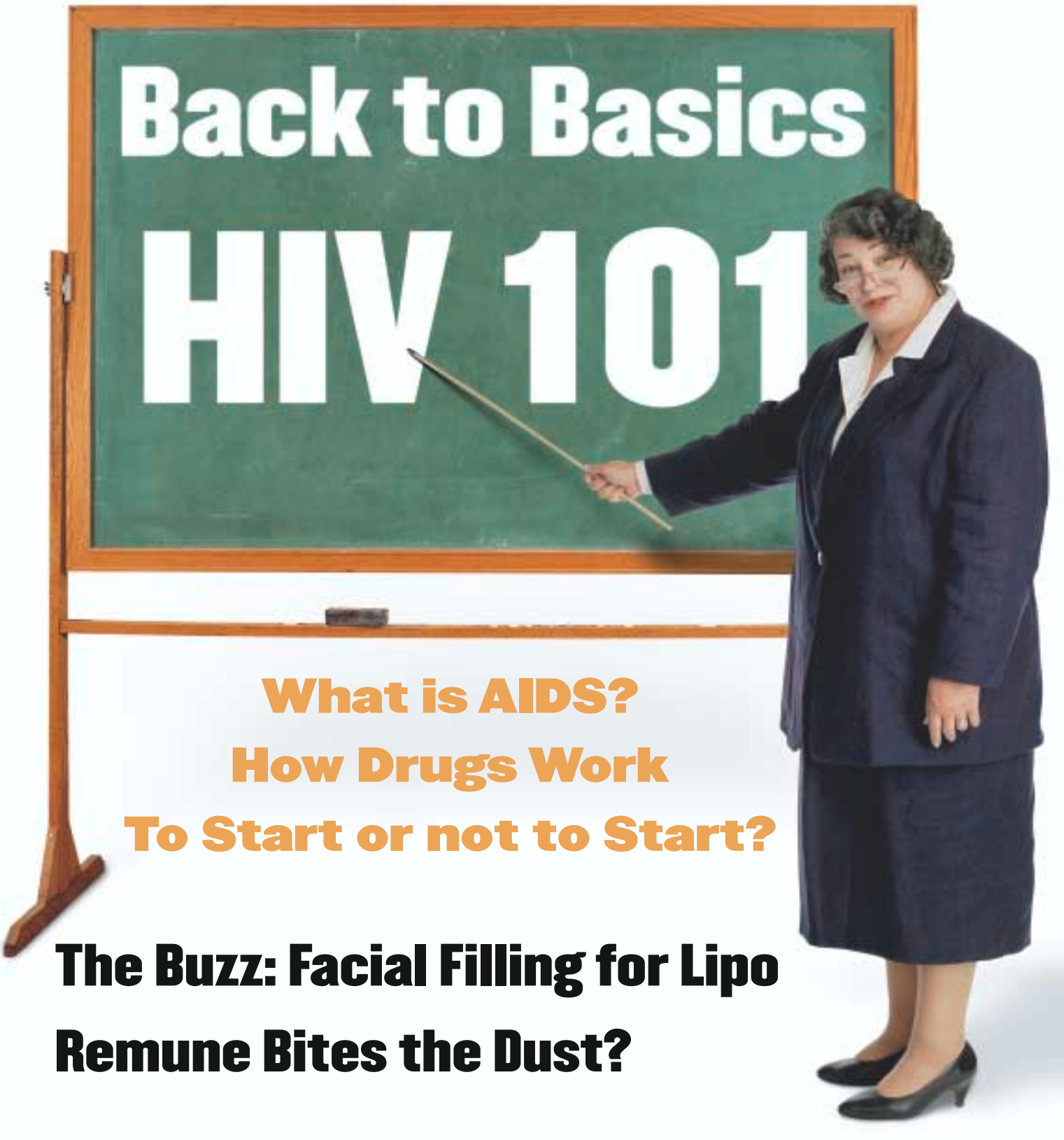
September / October 2001

Positively Aware

The Journal of Test Positive Aware Network



What is AIDS?

How Drugs Work

To Start or not to Start?

The Buzz: Facial Filling for Lipo

Remune Bites the Dust?

Table of Contents

September / October 2001 • Volume 12 Number 5

Departments

Articles

A model, photograph, or author's HIV status should not be assumed based on their appearance in *Positively Aware*.

You can view these (and other stories from previous issues) online at http://www.tpan.com

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Editor's Note

Going Clinical?

Earlier this year I had my third colonoscopy in three years. A colonoscopy is a procedure that detects and prevents colon cancer. In all three procedures my physician had removed pre-cancerous polyps. If these polyps had gone undetected they could have developed into cancerous tumors. Following this last colonoscopy I was asked to join a three-year research study intended to investigate if a certain experimental drug can decrease or prevent the recurrence of polyps.

Today cancer of the colon, like AIDS, is one of the worst killers in the United States. This is mainly because of stigmas attached to disease and discomfort in dealing with treatment. I decided to join this study because if this experimental drug is successful it may reduce the risk of colon cancer in individuals like myself.

People take part in clinical trials for a number of reasons. You may want to help in the development of medical therapies and vaccines that may help treat or even cure life-threatening and chronic diseases. You may suffer from a disease for which good treatments do not presently exist, and decide to join a study hoping to obtain improved medical care. Or you may not have health insurance, and clinical trials provide study related medical care.

A clinical trial is a study that is carefully monitored by a physician or a research professional. They are usually conducted in four phases (I, II, III, IV). Each phase requires a larger number of participants. They require people like you and me to volunteer to receive investigational treatments. All clinical trials are reviewed by the U.S. government's Food and Drug Administration (FDA) and by Institutional Review Boards (IRBs). The IRB ensures that your rights and privacy are protected, that you aren't exposed to any unnecessary risks, and that you have signed a consent form prior to entering a trial.

Once accepted into a study group you will receive a physical examination. Your physician or research professional will review your medical history. A detailed description of your specific clinical trial, what's expected, duration and expected outcomes will be outlined. You will then be placed into a study group.

In order to make your experience in a clinical trial a safe one, it is important that medication is taken as prescribed, that you keep all scheduled appointments, and that you keep a log of how you are feeling between appointments. The information you provide in regards to any symptoms or side effects you may experience is valuable.

There are a number of valuable resources available if you are considering entering an AIDS clinical trial. The AIDS Clinical Trial Information Service is confidential, maintains a trained staff and provides a list of new drugs being tested, where studies are being conducted and who is running the studies (available Monday-Friday 9 am to 7 pm EST, 1-800-TRIALS-A [874-2572]). In addition, the American Foundation for AIDS Research (amfAR) provides information on both basic-biomedical and clinical AIDS research (1-212-806-1600, txdir@amfar.org and www.amfar.org).

For whatever reasons that you might choose for taking part in a clinical trial, it's ultimately important that you make an informed choice and have all of your questions about the trial and study drug answered. And remember you have the right to leave a study at any time and for any reason.

Charles E. Clifton

Charles E. Clifton
Editor
Send comments and reactions to
posaware@aol.com

photo by Russell McGonagle

Don't Toss Out Your Condoms... Do Write to Your Elected Officials

photo by Russell McGonagle

The effects of last November's election are becoming clearer. For HIV prevention and education and for sex education in general the signs are not good. The Bush II administration is making clear that they believe the only approach to sex education and HIV prevention are abstinence-only programs.

According to a report in the *Washington Post* (07.30.01, Ceci Connolly), the administration, while aggressively pushing for expansion of abstinence-only programs, has refused to allow states to expand family planning services to poor women, re-imposed a ban on abortion counseling in overseas health clinics, proposed eliminating mandatory contraceptive coverage for federal employees, and released a controversial report on the effectiveness of condoms for stopping HIV and other STDs. In addition, when Surgeon General David Satcher issued a report calling for sex education that included discussions on both abstinence and contraception, the administration quickly distanced itself from it.

Potentially the most damaging incident to date is the recent report from the National Institutes of Health (NIH) on the effectiveness of condoms for preventing STDs, including HIV. The study concluded that condoms were effective in stopping HIV and gonorrhea infections, but that the effectiveness for other STDs is uncertain. The CDC immediately backed away from the report, reiterating that condoms are effective against STDs.

The potential damage from this report is twofold. First, many healthcare providers and HIV service providers fear that this report will be used by a public already reluctant to use condoms as proof that there is no good reason to "cover up." The second major fallout can be seen in a letter from conservative former U.S. Rep. Tom Coburn (R-Okla.). Mr. Coburn wrote to the secretary of Health and Human Services saying, "This report means that when condom use is discussed it is no longer medically accurate or legal for the CDC to refer to sex as 'safe' or 'protected.'"

Twenty years into the battle against HIV/AIDS we have an administration that does not support sex education teaching anything other than abstinence. There are no credible studies that abstinence-only education reduces teen pregnancies or STDs, yet government leaders want a "just say no" approach to sex. "If you ain't married don't do it." (Remember, masturbation is not an option, as former Surgeon General Joycelyn Elders found out under a different Bush administration.)

Let's be clear about condoms, HIV and STDs. Condoms do reduce the risk of contracting (or passing on) HIV. Condoms do reduce other sexually transmitted diseases. Condoms do reduce teen pregnancies. HIV is still a serious issue in the U.S., more than 40,000 individuals become infected annually. A disproportionate number of these people are under the age of 25. The vast majority of people are infected through sexual intercourse (either vaginal or anal). Consistent condom use would prevent the majority of these cases.

I ask all of you to write your representatives and the President. Let them know that outside of their "think tanks" and conservative focus groups, outside of their cabinet meetings and their offices, beyond the realm of the conservative lobbyists populating their world, there are people having sex. And (gasp!) it is not all occurring in "long-term, committed, monogamous marriages" (or relationships if you are homosexual, since this same administration will not allow you to marry). Let your elected officials know that sex education must be more than abstinence-only. Educate them to the fact that condoms do prevent the spread of HIV and other STDs.

Dennis Hartke

Dennis Hartke
Executive Director
Thoughts, comments, reactions? Write me at tpaned@aol.com

Readers' Forum

Our mail box runneth over! An extended version of Readers' Forum appears online at www.tpan.com.
Thank you for your comments.

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Fear of Disclosure

I am the mother of two HIV-positive children. Many people already know the status of my children, but it is still mostly a big secret. If I was the only one to feel any repercussions I think I would let the world know and face whatever was thrown my way. I worry about the children suffering. I think living the secret does nothing to help those infected. There is no emotional support, no understanding to receive. The secret promotes the disease as being distant in people's lives. They have little reason to think of it. I sometimes feel guilty when they have a playmate, wondering how their parent would react if they knew. Sometimes I wonder what to tell the new babysitter. When the children were a year old we were tossed out of our playgroup. When I wanted to go back to work I had a difficult time finding daycare for them. The children needed to be given meds. Now my children are in school. I worry complaints that my son touches kids too often have a hidden meaning. My children are doing very well with their disease and that's a relief. I wish I could do more about making this illness less frightening and ugly for others.

Via the Internet

From a mom

I read your article with many tears [article not identified]. I am always looking for info for my son. He is beginning to suffer from dementia and it's very hard to keep his spirits up. To all of you out there who suffer, please don't have unprotected sex. It isn't just you who carry the disease. Your loved ones carry it with you.

Via the Internet

Juice meal

In "Complementary Therapies for People Living with HIV," adapted from *CATIE* (January/February), it is irresponsible to close with "Think of juice as a meal." Of course nutrition has both objective and subjective components as does anything else. However, I absolutely do not want any of my patients thinking they can consume juiced foods as a meal. Food and water safety and the basics of nutrition are not to be dismissed. Show me some scientific basis for your claims. I do indeed use a juicer myself, but your excerpt is far from providing adequate information.

Jeannene Davis, dietitian
via the Internet

Editor's Note: Ms. Davis's comments were forwarded to CATIE (Community AIDS Treatment Information Exchange). However, we can say that juice packs more sugar and less fiber than fruit. It also has more calories. While juice provides vitamins and minerals, you need to be careful because of the concentrated fruit sugars in it.

Prison Pen Pals

Yes, we still have Prison Pen Pals, at P.O. Box 1217, Cincinnati, OH 45201. We list the names and addresses of all prisoners who write to us, but we are not able to reply to them ourselves, or acknowledge their letter. Nor are we able to include any descriptive information, just their name and address. We list an average of 5,000 prisoners a year and can't keep up with the volume enough to do anything further!

Joy Perry
Freedom Through Christ Prison Ministry
via the Internet

Thumbs Up on *Positively Aware*

I always enjoy every issue of your well-informed magazine. On behalf of my positive peers here at Central California Women's Facility, I thank you for printing articles about women living with HIV/AIDS and HBV/HCV in prison. Since I'm one of the women who spoke at the hearing in October 2000 in front of [California State] Senator Polanco's committee, seeing some of our testimonies in *Positively Aware* brought tears to my eyes. Thank you.

Beverly Henry
W72830 510.23.02L
CCWF
P.O. Box 1508
Chowchilla, CA 93610-1508

Thank you for running my article (July/August). I loved it. You made my dream come true. Now I can die in peace 'cause I chipped in for the AIDS cause—I put my pebble in.

Kevin Lisboa
Cayuga Correctional Facility, New York

The prison issue is amazing. Really great information layered with sad and horrifying stories. I sent an all-staff e-mail out recommending that everyone pick up a copy.

Bob Huff
Gay Men's Health Crisis, New York City

I recently decided to let go of the HIV stigma and get some much needed help for my health. I read your article (November/December 2000) on women and HIV and it's as if you have been watching me for the last nine years. Thank you for the

wonderful directory and all of the great services that you make public to the community! I am glad to know that I really don't have to face this alone, and I would like to begin anew. Thank you for writing down all of the things that "we" are ashamed to say aloud. I plan to repay my debt to all of the people who are dedicated to AIDS and HIV as a way of life by using my talents to make a difference in some small way. I believe life throws these curves to test our spirituality and your agency has helped me to see (after a long time) that it's not only about me. I was the one who needed to get in the game. Thank you!

Veronica E. Howard-Sims
Chicago (Look, Ma, I came out!)

I receive PA as an indigent HIV-positive inmate of African descent who is very active in prison issues affecting PWAs [people with AIDS]. There is a dearth of information available to the inmate population here and the medical staff is not "inmate-friendly." This is a total "lock down" prison which has a death row as well. Needless to say, PWAs receive only the most basic medical attention. Positive doctor-patient relationships are all but non-existent. Were it not for your magazine I would not have the insights that I do now. The May/June issue was filled with updated information and compelling stories and interviews that are sure to empower your readers. Thank you so much—your labors are not in vain.

Willie Green, 558618
P.O. Box 181
Florida State Prison, Q1304
Starke, FL 32091

Thumbs Down on *Positively Aware*

I read some of your articles on TheBody.com from time to time about living with HIV, if they are not too depressing, that is. It would be nice if you would write about ordinary couples (my wife and I in my case) and their lives. Everything is not gloom and doom. I married my wife knowing that she was pos. We live in Europe. I am American and she is Czech. She gets all her treatment paid for by the state, thank God. We don't spend a lot of time talking about it. We don't belong to any support groups. We just go about living and she considers it just another disease that she happened to get. It is getting old only reading about gays or former drug users and HIV. She is none of those and really is a very upbeat and happy person despite everything. I wish I could be as positive about life as she is.

Via the Internet

Positively Aware continues to disappoint me. Jim Pickett's "A Crisis Obscured" (July/August) is merely one more example. After 16 years of living with HIV, I am tired of hearing how "HIV is a vicious ugly…and always fatal contagious disease…" Many people with HIV have lived strong, healthy lives, some infected greater than 20 years. HIV has not ever been shown to be universally fatal. I do not intend to minimize the struggle and pain nor the horrible deaths that many people with HIV have experienced and will experience. One of my greatest struggles with HIV has been with the stereotypes and assumptions from friends, family and strangers that I am sick and dying. I look to TPAN as a source of hope and inspiration and support. Unfortunately, *Positively Aware* continues to remind me that I have an "always fatal contagious disease." I hear and deal with enough of that in my day to day life. I don't need it from TPAN.

Name Withheld, via the Internet

Editor's Note: First, please accept my sincere apologies for the mistake. HIV is a communicable disease, not a contagious one. Secondly, I agree with your statement about survivors. Many HIVers have lived well over 15 years, some on antiretroviral therapy and others without ever taking meds. Jim Pickett's column is an editorial opinion included in Positively Aware *because for the most part he provides a light-hearted, tongue-in-cheek perspective on living with HIV, but mainly because Jim's struggles with HIV touch people, in positive and negative ways. He makes people think and react.*

Kaletra trial

In response to Dr. Daniel Berger's article, "The Importance of Sequencing Treatment Options" (May/June), Dr. Berger referenced a study by Abbott Laboratories… The PLATO study is designed to determine the impact of changing from a poorly-tolerated therapy to Kaletra based on a patient's quality of life… With our objectives focused on the patient's perception of medication side effects, we have set the study duration at eight weeks. We feel this timeframe will enable us to capture data regarding the patient's experience of side effects relative to a therapy change….

Margo Heath Chiozzi, MD,
Senior Medical Director,
Global Marketed Product Development,
Abbott Laboratories, IL

Editor's Note: The point of Dr. Berger's comment is that eight weeks is not long enough to uncover some side effects, such as the body shape changes seen with Norvir (ritonavir, one of the two protease inhibitors in Kaletra) and other HIV medications.

Drug ads

After reading your magazine and the ads by the pharmaceutical companies, I am convinced that two phrases would have an immediate and lasting prevention effect. The phrases must be displayed prominently in all pharmaceutical HIV and HIV-related ads: "Always use a condom when having sex" and "If you've had sex without a condom, contact a health care provider today." Why? Because condoms before and prophylaxis [preventative medicine] after exposure is proving to be an effective way to help prevent HIV and its spread. It's the same message, but when added to the pharmaceutical disclosure "HIV drugs do not cure HIV infection or prevent you from spreading the virus," it becomes a powerful message that people will act upon now.

Keith Smith,
Aurora, IL

Privacy issue

In regards to HIV test kits sold online, I have encountered at least one website company that advertises that the packaging that arrives at your home is not marked with any obvious words describing the contents. However, my credit card charge was billed very blatantly as "HIV test." Isn't this a gross breach of privacy? Just thought others would be interested to know that this doesn't exactly protect one's privacy, which is why people order these things online to begin with.

Anonymous,
Via the Internet

News Briefs

by Enid Vázquez

photo by Russell McGonagle

Cesarean complications

A comparison of 86 HIV-positive women and 86 HIV-negative women undergoing cesareans showed that positive women had more minor complications, such as fevers, following surgery than negative women. However, women with HIV viral loads between 1,000 to 10,000 were eight times more likely to experience complications than were women with undetectable viral loads.

In reporting these new findings in the *American Journal of Obstetrics and Gynecology*, Dr. Elisa Josefina Rodriguez and colleagues note that caution is still needed in making a decision to deliver by cesarean in positive women when not medically necessary. Elective cesareans are shown to decrease the risk of transmission, but not any greater than the use of potent HIV medications which significantly decrease a mother's viral load. Of course, HIV infection for a child is in itself a major complication that should be considered in making a decision.

HIV drugs in pregnancy: updated guidelines

The following is taken with permission from a recent newsletter of WORLD, Women Organized to Resist Life-threatening Diseases, in Oakland, CA.

On May 4, 2001 a Public Health Service Task Force published updated guidelines on how HIV drugs should be used in pregnant women with HIV. Other aspects of health care for HIV-positive pregnant women—such as preconception (before pregnancy) counseling, C-section, and monitoring tests—are also discussed. Here are some of the things in the guidelines and information about how to get them:

- Treat (give drugs to) all pregnant women… to reduce the risk of passing HIV to the baby.

- HIV-positive pregnant women should avoid or be extra cautious about certain drugs or drug combinations. These include: ddI + d4T (in combination) [Videx and Zerit]; the oral solution of amprenavir [Agenerase] (capsule form is okay); hydroxyurea and efavirenz [Sustiva] should be strictly avoided during pregnancy, and AZT + d4T [Retrovir and Zerit] should not be used together in any HIV patient, not just the pregnant ones.

- C-sections, done at 38 weeks gestation, should be considered for women with viral loads over 1,000 at 36 weeks. For women with viral counts under 1,000 it is unlikely that C-section would provide any added protection, though there's not enough information to be sure yet. Providers should get the mother's full informed consent before doing a C-section, because a C-section is major surgery and poses risks to the mother's health. [*Editor's Note: A substantial review of elective—emphasis on elective—C-sections in positive women found few major complications.*—EV]

For more information,

- You can obtain the full text of the new perinatal guidelines at http://www.hivatis.org or by calling the HIV/AIDS Treatment Information Service (ATIS) at 1-800-448-0440.

- You can also get the most recently published report from the Antiretroviral Pregnancy Registry (or have your doc report complications to them, especially if you suspect your child has problems related to your taking HIV drugs during pregnancy) from: The Antiretroviral Pregnancy Registry, Research Park, 1011 Ashes Drive, Wilmington, NC 28405. Call 1-800-258-4263 (free for US and Canada), international telephone 1-910-256-

0238. Fax 1-800-800-1052, international 1-910-256-0637 or +44 1895 825 005.

Lactic acid and liver problems

Prominent HIV specialist Dr. Andrew Carr of Australia and colleagues warned that people with HIV may suffer liver damage without the usual symptoms. They wrote a case study in *The Lancet* medical journal in May about a positive man who had taken Retrovir (AZT, zidovudine) by itself in the early '90s, stopped for three years, then took a combination of Zerit (d4T, stavudine) and Videx (ddI, didanosine). About a year after that he had weight loss, fatigue, nausea, a distended stomach and difficulty breathing. Lab work indicated that he had hepatitis (liver disease) and lactic acidemia, both of which reversed after stopping meds. Later, however, even though he had only slightly elevated liver function tests and lactate levels were normal in his blood, the lactate level in his urine was high. He soon died of internal bleeding. The doctors noted that low-level lactic acidemia may be the cause of ongoing liver damage that could be hard to detect. They noted that the class of HIV drugs called nucleoside analogues, from which all three of the drugs noted are taken, are associated with lactic acidemia and mitochrondial toxicity, as found in this patient.

More lactic acid, with bone problems

Dr. Carr and two of his colleagues also made a separate report linking lactic acid to osteopenia. They reported that osteopenia (reduction of bone tissue to below normal levels, which can weaken them and eventually lead to fractures) is common in HIV-positive men, but that men tend not to show symptoms of the condition. The osteopenia was also associated with lower weight prior to HIV therapy and with lactic acidemia due to treatment with nucleoside analogs. The findings were published in the April 13th issue of *AIDS*.

Hep C

The Food and Drug Administration (FDA) has approved an "unbundled" version of Rebetron. The combination hepatitis C treatment consists of Intron-A (interferon alfa-2b) and Rebetol capsules (ribavirin), both made by Schering-Plough. Rebetol capsules will now be available by themselves. The Hepatitis C Action and Advocacy Coalition (HAAC) contends that the capsules will be priced so high that doctors will be discouraged from combining them with interferons from other companies. These combinations may be more effective for some patients. Compounded ribavirin is still available at a lower price. Contact HAAC at HAAC_SF@hotmail.com.

UN session on AIDS

The United Nations in June held a special session on HIV/AIDS. An exhaustive list of priorities were presented, among them the need for prevention efforts for young people, ensuring rights for people living with the virus and stronger commitments for fighting HIV—including treatment—from all governments. For transcripts, video search, and complete archived webcast from the special session, visit http://www.kaisernetwork.org/healthcast/un/aids/jun01.

HIV drugs and insulin resistance

An association has been seen between HIV therapy and insulin resistance, a condition whereby the body is unable to adequately use its supply of insulin. This hormone helps regulate sugar in the body. Insulin resistance is in turn associated with all kinds of problems, including diabetes and heart disease. Doctors giving the HIV protease inhibitor Crixivan (indinavir) to 10 healthy people without HIV observed that they developed insulin resistance after four weeks on therapy. The men took 800 mg of Crixivan twice a day. Dr. Mustafa A. Noor and colleagues reported their results in *AIDS*. They noted that genetic factors need to be examined and, of course, the other HIV drugs should be examined for this effect. The reason why insulin resistance is being seen is still unknown.

Circuit party transmission

Circuit parties are large-scale, razzle-dazzle dance parties and party marathons for gay men, held around the country to raise money for HIV-service organizations. The parties have drawn strong criticism for high incidence of sex and drug use that potentially contribute to HIV transmission. However, defenders say that transmission can occur anywhere, not just at circuit parties. Kudos to researchers writing in the *American Journal of Public Health* for reminding people that unprotected anal sex may lead to transmission owing to "a lack of knowledge about—or incorrect disclosure of—current HIV status." Gordon Mansergh and colleagues surveyed 295 men to document the sexual activity and drug use of the circuit.

Methadone cuts mortality

In the May issue of the *American Journal of Public Health*, other researchers reported that injection drug users who drop out of a methadone program are more than four times likely to die of an overdose. They looked at 827 participants of the Amsterdam Cohort Study. The researchers stated that "harm reduction-based methadone treatment, in which the use of illicit drugs is tolerated, is strongly related to decreased mortality from natural causes and from overdose. Provision of methadone in itself, together with social-medical care, appears more important than the actual methadone dosage." They also noted that while HIV has increased deaths among injection drug users, overdose remains a more common cause of death for IDUs in most countries.

Gay and lesbian healthcare not up to snuff

An online survey of lesbians and gay men taken by GayHealth.com found that 40% of the men had not been vaccinated against hepatitis A and B. The potentially fatal infections are spread through sexual contact and are more common among men who have sex with men than among other groups. GayHealth.com associate medical director Susan Ball said, "Every gay and bisexual man should be vaccinated against hepatitis A and B. They are serious conditions, especially for patients co-infected with HIV." As for the women, almost 18% report having never visited a gynecologist and 23% report having not seen one in more than two years. The report noted that yearly Pap smears are the best defense against cervical cancer. The majority of cervical cancer cases are caused by the human papilloma virus (HPV), which can be transmitted by woman-to-woman contact.

New Facial Filling Treatment for Lipodystrophy

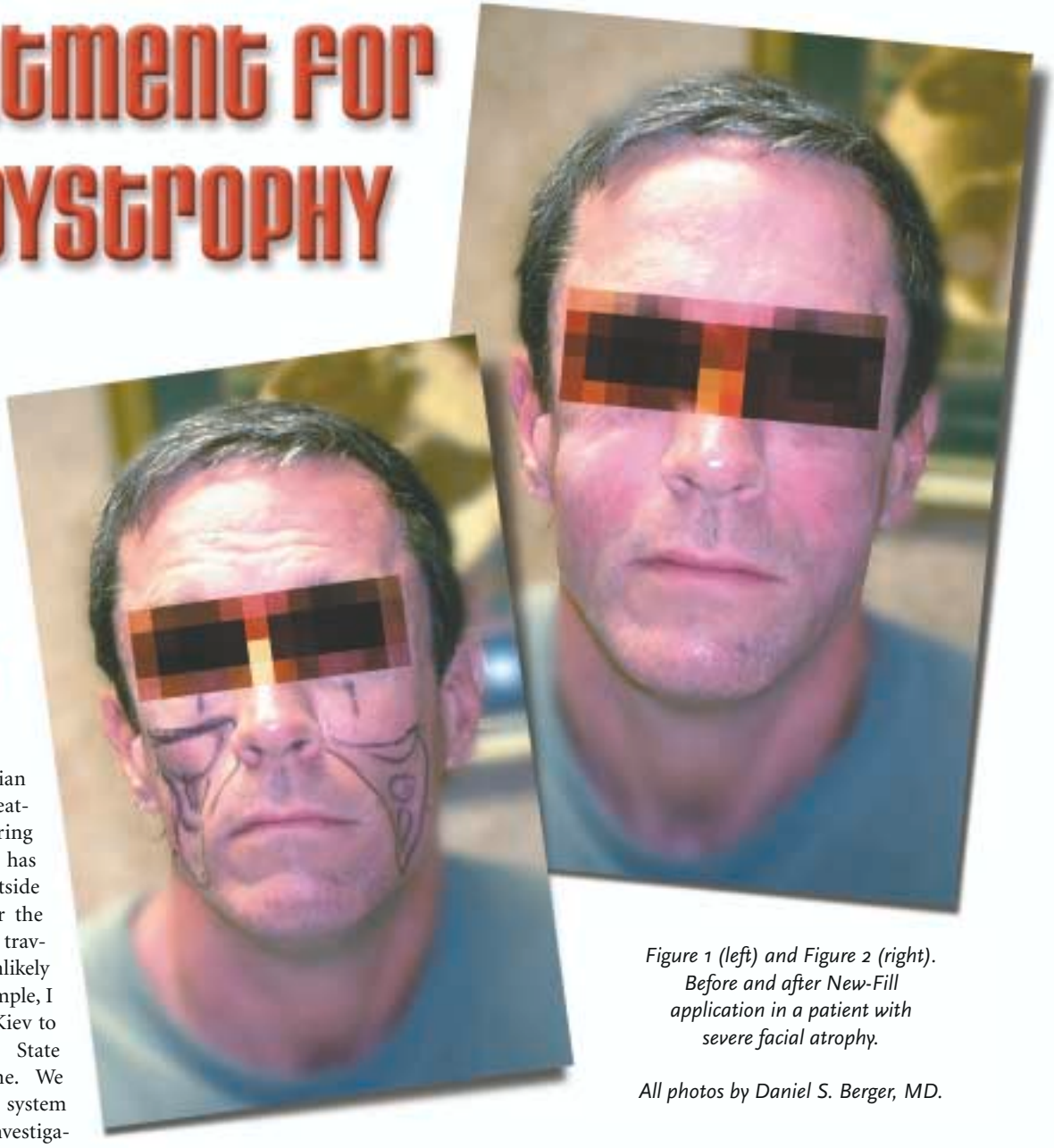


Figure 1 (left) and Figure 2 (right). Before and after New-Fill application in a patient with severe facial atrophy.

All photos by Daniel S. Berger, MD.

BY
Daniel S. Berger, MD

Introduction

As a physician engrossed in HIV treatment and often exploring new treatments, work has taken me to places outside the United States over the years. Sometimes these travels have been to very unlikely places. In 1994 for example, I made several trips to Kiev to collaborate with the State University of Ukraine. We attempted immune system regeneration by an investigational project to infuse fetal stem cells into many of our patients (in Kiev). Some of our patients gladly participated in this venture at that time. This was before protease inhibitors were available and fetal stem cell research for HIV infection was not available in the U.S. at that time. Recently, my interest in new treatments led me to Tijuana, Mexico. I traveled past the southern U.S. border to investigate, and be trained in, the use of a new treatment for facial wasting.

Polylactic Acid (New-Fill)

New-Fill is the product name for the polylactic acid treatment. I first became interested in New-Fill after attending the 2nd International Workshop on Adverse Reactions and Lipodystrophy in HIV conference held in Toronto in September of 2000. I spoke with Patrick Amard, MD, a plastic surgeon from France, who presented his results of using polylactic acid injections for facial wasting.

New-Fill was approved for use in Europe in November 1999 and in Mexico during June of 2000. Polylactic acid is a synthetic polymer polyester chemical; it is immunologically inactive, biocompatible and absorbable. This product has undergone many toxicology studies and is currently being sold as New-Fill in France and Mexico.

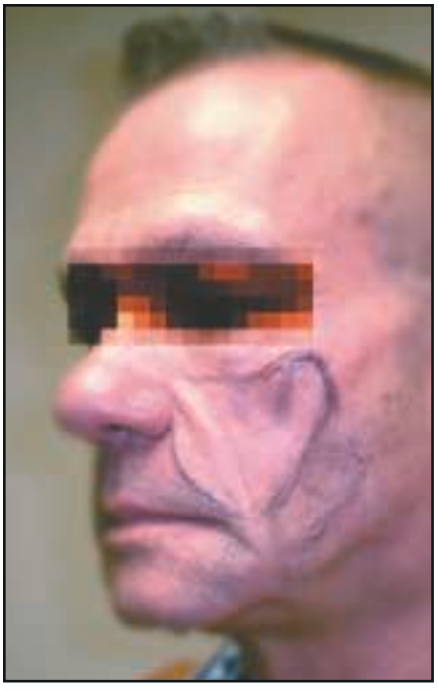


Figure 3. Side profile of a patient with facial drawings outlining areas of needed filling, prior to procedure.

Demand for New-Fill is increasing rapidly, because of its versatility. The mechanism of action of New-Fill is to stimulate collagen production as the filling agent. A U.S. based pharmaceutical company is rumored to be in negotiations to acquire the distributorship in the United States and a study is being undertaken at a Texas university for cosmetic application for healthy (non-HIV-positive) individuals.

Dr. Jorge Tagle

Tijuana is the home of plastic surgeon Jorge Tagle. I landed in San Diego, then took a cab to the border, crossed over by foot into Mexico, and taxied to Hospitale del Prado, the location of Dr. Jorge Tagle's clinic. Dr. Tagle seemed down to earth and an easy-going friendly person who enjoys many of the good things in life, such as golf and a good beef steak. But on further acquaintance, Dr. Tagle, or Jorge as I call him, is quite a unique person. He studied medicine at the Universidad Autonoma de Guadalajara (Autonomous University of Guadalajara), a school that many Americans have also graduated from. He started residency in plastic surgery in Mexico City, in a program that emphasized reconstructive surgery for burns and other injuries. Jorge, more interested in cosmetics, moved to Madrid, Spain to study and train in his chosen field. After completing four years in Madrid, Dr. Tagle enrolled in a special program to attain an International Masters Degree in plastic surgery. This unique degree allows him to practice plastic surgery in almost any country of Europe. Moreover, Jorge teaches in many European countries and maintains a plastic surgery practice in Madrid, for which he travels to from Tijuana three times, yearly.

Jorge's office is pleasing. There I met another physician, Dr. Pedro Cervantes, who serves as an anesthesiologist and surgical assistant for Dr. Tagle. The afternoon was spent with both physicians discussing polylactic acid and other plastic surgery methodology for HIV-positive patients who have facial wasting and lipodystrophy. We talked some in Spanish and some in English. Being fluent in Spanish came in handy (I had spent a few years in Mexico during my student days). It was obviously easier for Dr. Tagle to explain in his native Spanish his technique and passion for the work. He passionately described the technique that he employs with this particular product as being different than other plastic surgery products. Jorge has extensive experience in facial cosmetic surgery and now with HIV-associated facial atrophy. Also, the method of instillation of New-Fill has been modified for HIV-associated facial wasting and then perfected by Jorge, based on results he observed using different techniques.

The Procedures

On Saturday morning, Dr. Cervantes, who lives a hop from my hotel in San Diego, picked me up for an early breakfast. We then proceeded to the clinic in Tijuana, where we met with several HIV-positive American patients from New York, Baltimore, San Diego and Hawaii. All of these individuals had severe facial lipodystrophy, or facial wasting. In addition, two plastic surgeons from California were also on hand for training.

From about 10 in the morning till 3 p.m., six patients were brought in, one at a time. Lunch never happened. Each patient was examined for facial wasting and then had their faces drawn on with magic markers by a surgeon (*see figures 1 and 3*). The face is divided up into several quadrants and each area is given special attention. The purpose of drawing on the surface of the face is to mark places where New-Fill is applied. Emphasis in areas of deeper deficiency is also made. Areas that need filling are marked carefully with the anticipation of what that individual's normal facial contour should be. If the pre-surgical drawings are not accurately performed, the final outcome of the treatment can be jeopardized. Therefore, the surgeon must give proper attention to detail while envisioning the outcome.

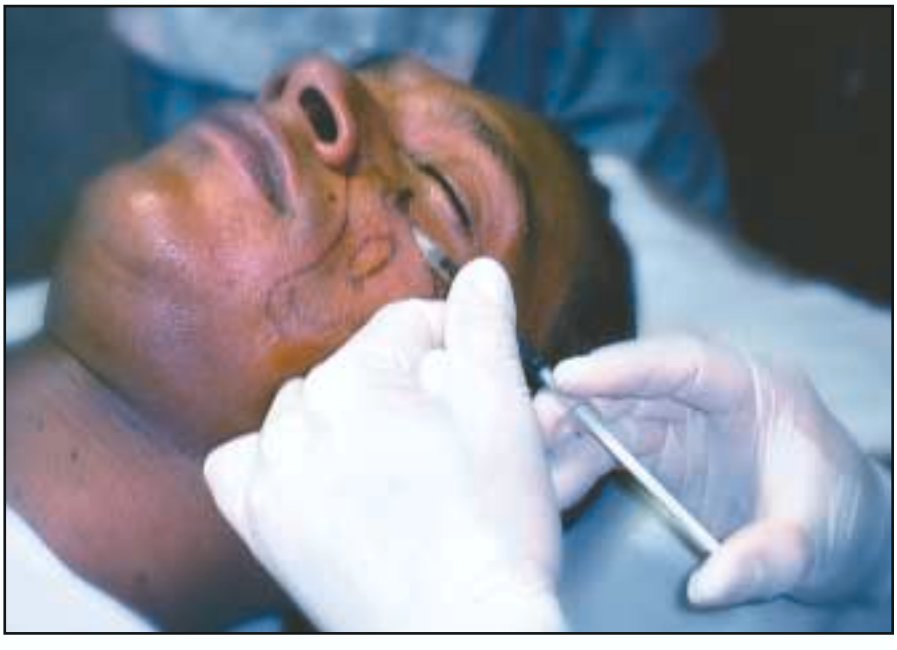


Figure 4. Local anesthesia with nerve block applied by Dr. Pedro Cervantes.

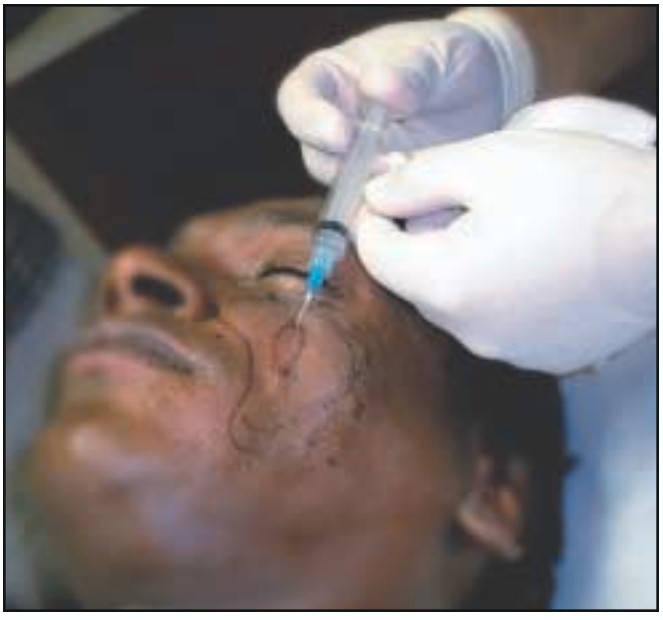


Figure 5. New-Fill being applied into facial wasted areas.

Patients then had ice applied to their face for five minutes. This procedure helps the anesthesia, while causing vasoconstriction (blood vessel shrinking) so that bleeding is minimized. Following this step, Dr. Cervantes proceeded to skillfully apply nerve-block anesthesia and other smaller injections of xyloacaine to the facial areas (*see figure 4*) of each patient. Care to the individual anatomy of the face is important so that blood vessels are avoided with each injection. None of the patients experienced bleeding problems, nor complained of being uncomfortable during the procedure.

Finally, Dr. Jorge Tagle is ready to perform his magic. Unlike other products or other surgeons' practices, Dr. Tagle applies the polylactic acid in three different planes using needle injections. In fact, he goes deep to the periosteum (above the bones of the face). He starts with a method called tunneling under the skin (*see figures 5 and 6*) and covers the entire area of facial wasting in each individual. Dr. Tagle is careful to note that in each HIV-positive patient with lipodystrophy, the abnormalities are not always symmetric. Often one side of the face is worse or different than the other (*see figure 1*). Eventually Jorge proceeds to the second and third deeper planes to instill the product. Only a total of three cc's is administered to each side of the face. With such small amounts, Jorge needs to apportion the product to the various parts of the face, so as to derive at the most benefit for each patient. Patients did not show any discomfort during the procedures, nor were there any complications. All the patients were happy with the results, and I thought their appearance was dramatically improved. However, as in any surgical procedure, bruising, bleeding and infection are always possible side effects.

Personal Observations and Details

Some of the patients have had similar procedures done by other surgeons; some with failed outcomes. This is often not necessarily due to poor surgical skill, nor faulty product. These procedures require the surgeon to be experienced with the application of various products and to use them based on their track record for specific problems. Different products are useful for specific treatment situations.

I think it's important to note that patients need to feel at ease with their doctor or surgeon. These physicians exercised patience and compassion with each of the patients present during my visit.

Physicians performing the procedure should have extensive experience in facial cosmetic surgery. A medical doctor not fully trained or adept at facial plastic surgery can potentially cause harm or the results may not be the most optimal. I believe it is questionable whether an internal medicine or infectious disease physician can use facial reconstruction techniques, having not been trained in such. An internist doing the procedure, not fully trained, might apply the product under the skin only. This superficial application restricts the potential benefit and durability of effect. It appears useful for plastic surgeons to educate themselves regarding the product itself and the techniques used with New-Fill, developed by Dr. Tagle, Dr. Amard and others.

For the procedure to be successful it is suggested to have New-Fill applied a total of three times (for most patients with HIV-associated lipoatrophy of the face). There should be 3-5 weeks between each treatment. The first treatment establishes a base of treatment. Subsequent applications are done to continue the stimulation of further collagen production. The durability of the treatment is expected to be approximately 12 to 18 months. Dr. Tagle has seen patients one year post-treatment and notes that with his technique the effects are still holding.

Conclusion and Future Plans

Many attempts have been made to help HIV-positive individuals with the disfiguring manifestations of HIV. It is not the purpose of this article to list or discuss alternative surgical therapies. While not all patients on HAART (antiviral therapy) develop facial complications, for the significant numbers of persons with facial atrophy, a new treatment, albeit surgically based, can be applied. Patients should have the right to seek this option, if they so desire. However, Patients should also be wary of medical doctors willing to apply the treatment without the proper surgical training and skill. Additionally, DAAIR (Direct AIDS Alternative Information Resources), a New York-based

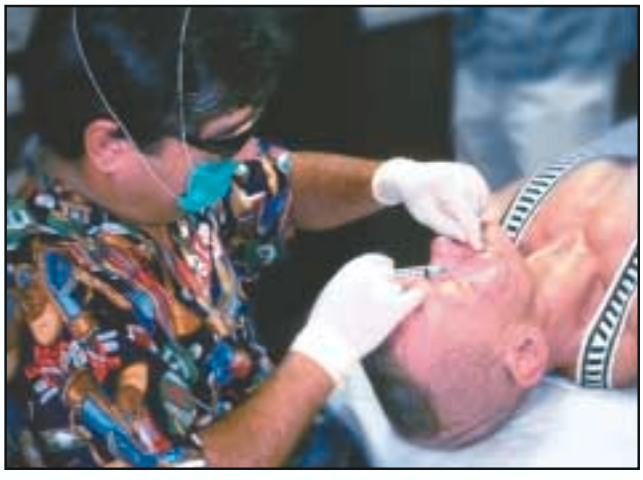
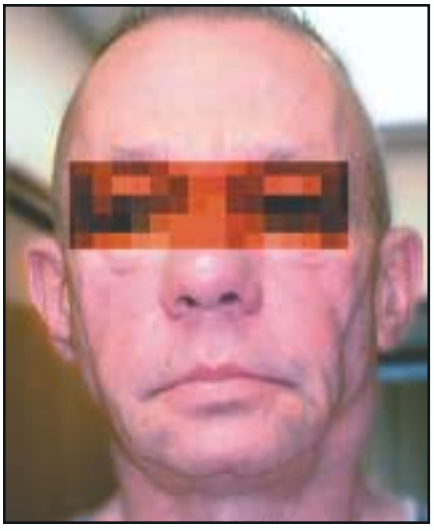
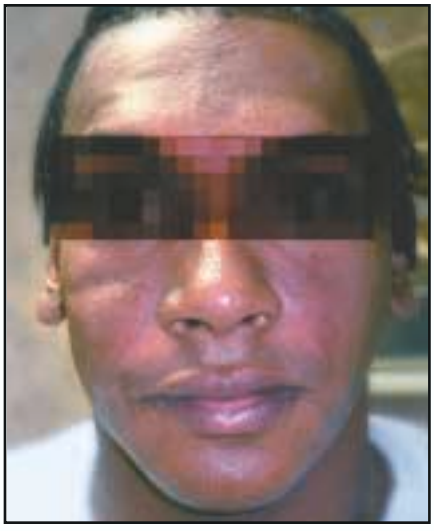


Figure 6. Dr. Tagle applying New-Fill with the "tunneling" technique under the skin surface.





Figures 7 (left) and 8 (right).
Figures 2, 7 and 8 demonstrate the change in three individuals' appearance immediately following the procedure.

buyers club, is committed to assist patients through attaining New-Fill product, while responsibly advising on its use (www.daair.org).

I have been impressed with the treatment. We are formulating a program at NorthStar Healthcare in Chicago. In time, the use of this not-yet-licensed product in the United States may become more widespread. HIV-related research has led me into some personal research projects and controversial investigations. I continue to conduct many clinical trials for antiviral drugs, immune system response modifiers, and alternative treatment with less conventional agents. Now we are probing into the mechanical application of a polylactic acid product. If treatment with this product is successful, it will improve the morale, quality of life and sense of well-being for many HIV-positive individuals affected by HIV-related facial lipodystrophy. I welcome further inquiries and comments.

Daniel S. Berger, MD is Medical Director of NorthStar Healthcare and Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and editor of AIDSInfosource (www.aidsinfosource.com). He also serves as medical consultant and columnist of Positively Aware. *For further inquiries, Dr. Berger can be reached at DSBergerMD@aol.com or 1-773-296-2400.*

Where to go

DAAIR has compiled a list of plastic surgeons now using New-Fill. Prices do not include the cost of New-Fill unless indicated. One kit of two vials of New-Fill currently costs $250.00 plus shipping charges. Each administration usually takes one kit (two vials). The estimated number of kits needed to restore normal appearance varies from two to six kits, depending on severity. Call toll-free 1-888-951-5433.—Enid Vázquez

Dr. Jorge Tagle
Tijuana, Mexico Clinic
011-526-681-3626

$500 per administration of two vials (Note: this price includes the $250 cost of the New-Fill). Dr. Tagle has extensive experience and conducted the Mexican trials of New-Fill.

Dr. Gervais Frechette
30 Fifth Avenue, Suite 1-G
New York, NY 10011
1-212-388-1441

$500 per administration of two vials. Dr. Frechette trained with Elizabeth LaGlanne, the developer of New-Fill, in Paris.

Dr. Michael Echavez
490 Post Street, Suite 542
San Francisco, CA 94102
1-415-392-9800

$500 per administration of two vials. Dr. Echavez has extensive experience in treating HIV-related facial atrophy.

Dr. Douglas Mest and Dr. Gail Humble
1301 Manhattan Avenue, Suite 201
Hermosa Beach, CA 90254
1-310-374-0347

$500 per administration of two vials.

Dr. Peter Engelhard
446 Arthur Godfrey Road
Miami Beach, FL 33140
1-305-534-7255

$650 per administration of two vials. Dr. Engelhard trained with Dr. LaGlanne in Paris.

Dr. Daniel S. Berger and Dr. Kenneth Stein
NorthStar Healthcare
2835 North Sheffield, Suite 104
Chicago, IL 60657
1-773-296-2400

Dr. Stein is board certified in plastic surgery with extensive experience in treating lipodystrophy. Dr. Stein has trained with Dr. Jorge Tagle. He is participating in a program at NorthStar Healthcare.

Remune Bites the Dust... Again

by Enid Vázquez

This is what happens when you get into bed with the devil, says Martin Delaney. The founding director of Project Inform, a well-respected HIV service organization based in San Francisco, says the demise of the experimental HIV treatment called Remune is long overdue. The therapeutic vaccine for HIV (meant to control disease progression, not to prevent infection) has shown disappointing results from its beginning.

Now, in a move that could leave people with HIV and researchers hanging, Pfizer Inc. announced that it would end its partnership with the Immune Response Corporation (IRC) to develop Remune (generic name HIV-1 immunogen). The giant Pfizer recently purchased Agouron Pharmaceuticals, which a couple of years ago had teamed up with IRC to pursue Remune. Agouron is a small company that produces Viracept (nelfinavir), an HIV protease inhibitor. The Pfizer pullout may effectively end Remune's development, since IRC is a small firm with little money of its own.

But doctors had already warned people not to enroll in any Remune trials that may still be open. As the new Remune crisis unfolded, another HIV specialist contacted *Positively Aware* asking that readers be warned not to be "duped" into enrolling in the vaccine's trials.

"Aside from showing a lack of benefit, what was worse is the spin that IRC put on its vaccine," says Delaney. Even when Remune was introduced at the Ninth International AIDS Conference, held in Berlin in 1993, scientists jumped all over a company presentation, contending that the data did not justify the conclusions that this particular product was a good one to pursue. That was followed over the years by actions that infuriated advocates of people with HIV, including a meeting with the Food and Drug Administration (FDA) that was misrepresented by the company to get people to come, Delaney said.

A more recent controversy was the lawsuit IRC filed seeking millions of dollars in damages against a group of Remune researchers. Daniel Berger, MD., reported on the findings of a large-scale clinical trial involving Remune in the March/April issue of *Positively Aware*. The researchers published a report in the prestigious *Journal of the American Medical Association (JAMA)* stating that clinical trial results failed to demonstrate that the vaccine had any effect on HIV progression-free survival or clinical improvement (actual good health). In fact, that trial was stopped early because it failed to show beneficial results. It was largely believed that the introduction of potent anti-HIV combination therapy made the vaccine unable to muster outstanding results above and beyond what the trial participants were already taking. (Either Remune or a placebo—fake medicine—was being added to people's HIV therapy.)

IRC claimed that data not presented in the *JAMA* report would show some efficacy from Remune. The researchers said that the data omitted was inconsequential and that the company refused to turn over other data that they had requested. The University of California, home of the *JAMA* report's lead researcher, in turn filed its own lawsuit against IRC.

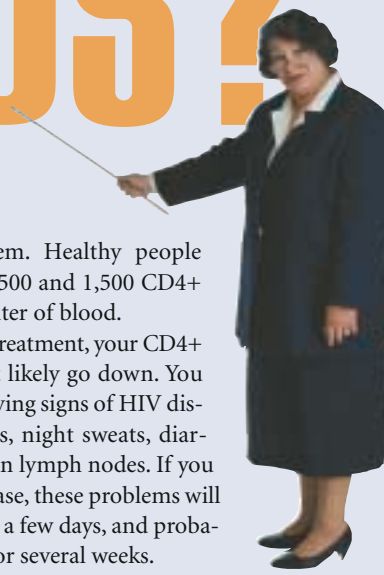
Soon after Pfizer's announcement on July 6, the Weiss & Yourman law firm in Los Angeles announced it had filed a class action complaint on behalf of all people who acquired IRC securities between May 17, 1999 and July 6, 2001. The complaint charges IRC and Agouron with violations of federal securities laws. According to a press release from the firm, "The complaint charges that Immune and Agouron withheld the results of Remune's major clinical trial, and instead hyped the prospects of Remune, even though defendants knew during the Class Period that Remune had no effect upon people with HIV and AIDS. The complaint further alleges defendants' false misrepresentations worked to artificially inflate the price of Immune stock." (Visit www.wyca.com.)

The *New York Times* on July 9 reported that IRC shares dropped 44% the day of the Pfizer announcement, down $2.01 to $2.58. According to the report, IRC planned to continue its Remune trials, but with only enough money for about six months. Company executives told the *Times* that money from investors may be hard to come by following Pfizer's decision.

HIV treatment advocate and longtime Remune supporter David Scondras, founder of Search for a Cure, in Boston, is struggling to either get Agouron to state a scientific reason for dropping out of the Remune trials, or to continue funding trials looking for another potential role for the therapy. These trials seek to determine whether using Remune during a Strategic Treatment Interruption (STI) can increase the amount of time that a person can be off drug and remain below a predetermined HIV viral load (the amount of HIV in the blood). Scondras' own partner is in a clinical trial looking at this issue. According to Reuters Health news service, Agouron based its decision on data from several studies.

The thought of a pharmaceutical company callously stopping a trial midway outraged many advocates. But Delaney claims that the truth is, the STIs trial were still in preliminary stages and have not actually started, and that the 10 people in Boston signed up have not yet been given Remune. (Scondras says his partner *did* receive a Remune injection already.) Delaney says one of the big dangers now would be a public perception that immune-based therapies—the stimulation of people's own immune system to fight HIV—don't work, rather than that Remune doesn't work.

What is AIDS?



What Does "AIDS" Mean?

AIDS stands for Acquired Immune Deficiency Syndrome:

- Acquired means you can catch it;
- Immune Deficiency means a weakness in the body's system that fights diseases.
- Syndrome means a group of health problems that make up a disease.

AIDS is caused by a virus called HIV: Human Immunodeficiency Virus. If you get infected with HIV, your body will try to fight the infection. It will make "antibodies", special molecules that are supposed to fight HIV.

When you get a blood test for HIV, the test is really looking for these antibodies. If you have them in your blood, it means that you have HIV infection. People who have the HIV antibodies are called "HIV-Positive."

Being HIV-positive, or having HIV disease, is not the same as having AIDS. Many people are HIV-positive but don't get sick for many years. As HIV disease continues, it slowly wears down the immune system. Viruses, parasites, fungi and bacteria that usually don't cause any problems can make you very sick if your immune system is damaged. These are called "opportunistic infections." [*See "The Stalker Awaits" on page 34*]

How do you get AIDS?

The blood, vaginal fluid, semen, and breast milk of people infected with HIV has enough of the virus in it to infect other people. You can get HIV from anyone who's infected, even if they don't look sick, even if they haven't tested positive (yet). Most people get the HIV virus by:

- Having sex with an infected person.
- Sharing a needle (shooting drugs) with someone who's infected.
- Being born when the mother is infected, or drinking the breast milk of an infected woman.

Getting a transfusion of blood from an infected blood donor used to be a way people got AIDS, but now the blood supply is screened very carefully and the risk is extremely low.

There are no documented cases of HIV being transmitted by tears or saliva, but it is possible to catch HIV through oral sex, especially if you have open sores in your mouth or bleeding gums.

In the United States, there are about 800,000 to 900,000 people who are HIV-positive. Over 300,000 people are living with AIDS. Each year, there are about 40,000 new infections. In the mid-1990s, AIDS was a leading cause of death. However, newer treatments have cut the AIDS death rate significantly.

What happens if I'm HIV-positive?

You might not know if you get infected by HIV. Some people get fever, headache, sore muscles and joints, stomach ache, swollen lymph glands, or a skin rash for one or two weeks. Most people think it's the flu. Some people have no symptoms.

The virus will multiply in your body for a few weeks or even months before your immune system responds. During this time, you won't test positive for HIV, but you can infect other people.

When your immune system responds, it starts to make antibodies. When you start making antibodies, you will test positive for HIV.

After the first flu-like symptoms, some people with HIV stay healthy for ten years or longer. But during this time, HIV is damaging your immune system.

One way to measure the damage to your immune system is to see how many CD4+ cells you have. These cells, also called "T-helper" cells, are an important part of the immune system. Healthy people have between 500 and 1,500 CD4+ cells per milliliter of blood.

Without treatment, your CD4+ cells will most likely go down. You might start having signs of HIV disease like fevers, night sweats, diarrhea, or swollen lymph nodes. If you have HIV disease, these problems will last more than a few days, and probably continue for several weeks.

How do I know if I have AIDS?

HIV disease becomes AIDS when your immune system is so damaged that you have less than 200 CD4+ cells or you get an opportunistic infection. There is an "official" list of these infections, put out by the Centers for Disease Control. The most common ones are:

- PCP (*Pneumocystis carinii* pneumonia), a lung infection
- KS (Kaposi's sarcoma), a skin cancer
- CMV (cytomegalovirus), an infection that usually affects the eyes, and
- Candida, a fungal infection that can cause thrush (a white film in your mouth) or infections in your throat or vagina.

AIDS also includes serious weight loss, brain tumors, and other health problems. Without treatment, these opportunistic infections can kill you.

AIDS is different in every infected person. Some people die soon after getting infected, while others live fairly normal lives for many years, even after they "officially" have AIDS.

Is there a cure for AIDS?

There is no cure for AIDS. There are drugs that can slow down the HIV virus, and slow down the damage to your immune system. But there is no way to get all the HIV out of your body.

How HIV Drugs Work 101

by Glen Pietrandoni, R.Ph.

Adapted from the 1998 edition of HIV 101 Positively Aware *by Enid Vázquez*

Quick tips

Doctors are often difficult to get a hold of. A pharmacist who is knowledgeable in HIV/AIDS can help you take your medications correctly. Take a list of current medications with you to the doctor's office and to the pharmacy. This helps avoid potential drug interactions when getting new meds. Also tell the pharmacist about medications that you take over-the-counter, vitamins and herbal supplements, and drugs you may receive from other pharmacies. Those folded-up, tiny-lettered package inserts that come with medications explain many issues affecting therapy, such as how that particular drug works, its known interactions with other drugs, and results from clinical trials. Save those inserts for future reference (such as when serious side effects start to hit). Know the names of your drugs and the correct doses. This will help you understand the doctor and pharmacist when discussing your treatment.

There are three categories of HIV antiviral drugs that have FDA approval. (Because HIV is a retrovirus, these drugs are also called antiretrovirals.) Nucleosides and non-nucleosides work to stop HIV from infecting cells and protease inhibitors stop infected cells, from reproducing the virus. In addition, new classes of drugs to treat HIV/AIDS are on the horizon. Fusion inhibitors, nucleotide inhibitors and immune modulators may be available in the near future.

Nucleosides

Nucleoside reverse transcriptase inhibitors (NRTIs) are also known as nucleoside analogs, or nukes for short. As their name says, these drugs inhibit reverse transcriptase, which is an enzyme that HIV needs in order to infect cells. Retroviruses like HIV use reverse transcriptase to convert their RNA into DNA. Without the ability to create its DNA inside the nucleus (core) of a cell, HIV cannot infect that cell. (An enzyme is a cell protein that causes chemical reactions in other substances). The HIV DNA then integrates with the DNA of certain cells in the body. DNA is the structure containing all of a person's genes.

Once proviral DNA has integrated into the body's natural DNA, HIV becomes a lifelong infection. (No virus has ever been cured with medicine. Some are naturally eliminated by Mother Nature, while others—like HIV and herpes viruses—are forever. Science continues to work on this.) Generally, HIV successfully converts into proviral DNA within 72 hours after infection. Once inside the cell's DNA, HIV awaits activation by cytokines and chemokines. In simple terms, these are chemical substances that tell cells what to do (thus, activating them).

NRTIs are analogs (think of the word "analogous," which means "similar") because they are imitations of the body's own nucleosides, which HIV uses to infect cells. The nukes trick HIV reverse transcriptase into using the worthless fake nucleosides, thus preventing the spread of infection to more cells. The virus thinks it is inserting a natural nucleoside into its DNA chain, but it's inserting the drug. This breaks the chain.

The HIV nucleoside analogs are not as potent as the other antivirals. The nukes interfere with other enzymes in the body that perform similarly to the HIV reverse transcriptase enzyme. As with the other drugs, serious side effects are rare, but need to be closely monitored. They can, rarely, be fatal. Retrovir (AZT) and Zerit (d4T, stavudine) cross the blood-brain barrier (*see sidebar The Brain*).

The brain

While not proven, it is hoped that medications which cross the blood-brain barrier will help prevent or even treat neurological disorders such as ADC (AIDS Dementia Complex). AZT has been shown to prevent and treat dementia, while Ziagen, Sustiva, Epivir, Viramune, Zerit and Crixivan may also help. The body protects the brain—its command center—by making it difficult for various chemicals to enter this barrier. To date, the usefulness of using an antiviral drug that can enter the central nervous system (composed of the brain and the spinal cord) is based more on clinical experience than proven fact. Drug therapy from all three classes of drugs have been found to decrease neurocognitive impairment and has even increased survival for people with serious neural disorders.

Non-nucleosides

Like the nukes, the non-nucleoside reverse transcriptase inhibitors (NNRTIs, or non-nukes) also keep HIV from infecting cells by interfering with the virus' reverse transcriptase. However, they do it in a different way. The non-nukes bind directly to reverse transcriptase, preventing further replication of the virus. The non-nukes are highly cross-resistant to one another. They are metabolized in the liver, so therapy needs to take special consideration of potential interactions with other drugs that are also processed hepatically (through the liver).

Rescriptor (delavirdine) is an inhibitor of the cytochrome P450 system (see box), while Viramune (nevirapine) and Sustiva (efavirenz) are inducers. Inducers increase drug metabolism, which in some cases results in lower levels of protease inhibitors. Thus the need for increased protease inhibitor doses. Sustiva has been placed in the strongly recommended category of the DHHS guidelines for treatment of drug

naïve patients, along with most of the protease inhibitors, in combination with two nucleosides.

The non-nukes provide a choice for people who are intolerant of protease inhibitors, those who want to save the protease class for the future, or whose PI therapy failed them. Chances are, if you've never had a non-nuke, you would get beneficial results from adding one if you're on your third or fourth regimen. Some of the non-nukes might be considered a superior choice in that they are easier to take than the protease inhibitors. Viramune requires two tablets daily, with or without food. Sustiva requires three capsules once a day, also without food requirements. Soon, a single 600 mg Sustiva tablet will be available to simplify regimens even further. The non-nukes also have fewer short-term side effects and are generally effective in crossing the blood-brain barrier (*see sidebar Liver Metabolism*). Again, careful monitoring of severe reactions (such as rash) can prevent illness and even death.

Protease inhibitors

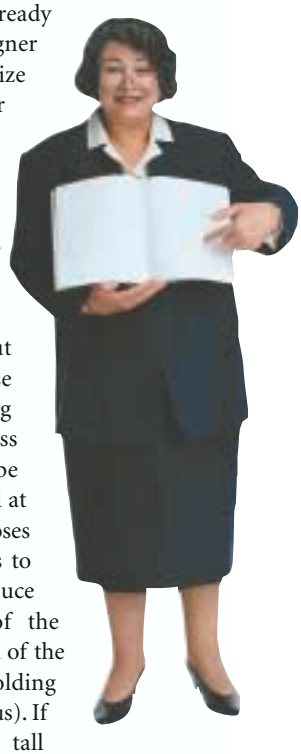
Protease inhibitors, like the name says, inhibit protease. Almost every living cell has a form of protease, a digestive enzyme that breaks down protein. HIV protease is only one of several enzymes the virus uses to reproduce itself. The HIV protease works by cutting up long chains of the virus' proteins and enzymes into smaller pieces that go on to infect new cells. By blocking HIV protease—or as some people say, by gumming up the HIV protease scissors—these drugs keep the virus from making copies that can infect cells. Thus the drugs keep immature non-infectious virus particles from becoming mature infectious particles. HIV protease works near the end of the replication cycle of the virus. As shown by the way in which antiviral drugs work, the HIV protease inhibitors can slow virus production in both newly infected cells and cells that have been infected for a long time, compared to the nukes and non-nukes which do not work on longtime infected cells.

The protease inhibitors are for the most part very powerful in relation to the nucleosides and have received major public attention. The protease inhibitors also do not generally have overlapping toxicities with the other two classes. However, they may be difficult to tolerate because of side effects like gastrointestinal symptoms. As with the nukes and non-nukes, some long-term side effects are still not understood. Researchers are working to understand the obvious relationship between protease inhibitors and very serious long-term side effects such as hypercholesterolemia and fat redistribution. Other abnormalities include the development of heart disease and diabetes in people who are predisposed to these conditions. The nukes and non-nukes are also potentially involved in the development of these problems.

Liver metabolism

The cytochrome P450 (CYP) system, a family of enzymes, breaks down drugs in the liver. All of the non-nukes and the protease inhibitors go through these enzymes. Some of them are inhibitors of P450 enzymes. Inhibitors impair the liver's ability to break down other drugs. As a result, the blood levels of these other drugs may increase (with increased toxicities and side effects).

As with the non-nukes, there is a lot of cross-resistance among the protease inhibitors despite different patterns of drug resistance among them. For this reason many specialists once believed that people with HIV may have only one shot at taking a protease inhibitor. With the introduction of Kaletra (lopinavir/ritonavir) and the increased usage of dual protease combinations, this may no longer be true. The protease inhibitors also have poor penetration into the cerebral spinal fluid (CSF), although again, the clinical benefits of this are unclear. Crixivan (indinavir) has the highest penetration of CSF of all the protease inhibitors. The PIs are highly protein bound. This means they are attached to proteins in the bloodstream. It is unbound drug that is active (gets absorbed), so the higher the protein binding the less drug is available to work. This creates a bioavailability problem. Protein binding, bioavailability, and metabolism in the liver (which can cause drug interactions with other drugs metabolized in the liver) all can lower the concentration of protease inhibitors in the body. However, most people achieve adequate drug levels at the doses prescribed. Some clinics are now using Therapeutic Drug Monitoring (TDM) to measure how much drug is available in *your* blood. At some time in the future, we may be ready to prescribe "Designer Drugs" and customize doses of drugs for each individual.



A note about adherence:

A discussion of "How Drugs Work" must include a mention about adherence. Because the amount of drug needed to suppress the virus must be above a certain level at all times, missing doses will allow the virus to fight back and reduce the effectiveness of the drug therapy. Think of the drugs as a dam holding back a river (the virus). If the dam is not tall enough (not enough drug), the water will just pour right over the wall (viral replication). Food is also important in making sure there is enough drug to fight the virus. Most protease inhibitors (except Crixivan) must be taken with food to be absorbed into the blood. Other drugs like Videx and Crixivan require an empty stomach because stomach acid destroys the medication before it is absorbed into the bloodstream. [*See "Adherence 101" on page 30 and "To start or not start?" on page 28.*]

Some HIV drugs will require closer monitoring, and sometimes dose reductions, to decrease the risk of side effects or toxic levels of drugs in the blood. Other HIV drugs can have the opposite effect, and may require increase in dosage in order to achieve adequate blood levels. Liver disease such as hepatitis, inherited deficiencies in the CYP genes, and multiple medications can cause problems with drug metabolism. Doctors use information on how drugs affect the different CYP450 enzymes (there are more than three hundred of them) to help determine which drugs to use in combination therapy and the doses to be used.

See Positively Aware 2001 Drug Guide *for a complete listing of currently available HIV antivirals.*

To Start or not to Start?

The question of when it's best to begin antiretroviral therapy may be as controversial and frustrating as any of the many HIV treatment questions to which we have no clear answers. The US Department of Health and Human Services (DHHS) HIV treatment guidelines were revised in February, and the biggest change in the guidelines addresses this question.

Since their first appearance in 1997, the guidelines have been relatively aggressive in their recommendations about when people with no symptoms should consider starting treatment. They've recommended that treatment be considered once CD4 counts fall below 500 or viral load [the amount of HIV in the blood] rise above 20,000 copies/mL by PCR [Amplicor], the most commonly used test. The newly revised guidelines lean more toward delaying therapy in people without symptoms—they now recommend considering therapy if CD4s fall below 350 or viral load rises above 55,000. Many people living with HIV and their healthcare providers have been delaying treatment despite the guidelines' previous recommendations, but this is still a big change.

When combination therapy first went into widespread use in 1996, people increasingly needed help figuring out how to best use the drugs. The DHHS guidelines, often simply referred to as the federal treatment guidelines, were created to offer people a roadmap to help them navigate their way through their options. Developed by a group of researchers, physicians and community members, the guidelines can help in the process of determining if and when to start therapy, what drugs to start with, when to stop or switch, and how best to use available diagnostic tests. They reflect our current understanding of HIV progression and treatment and are periodically revised as ongoing research increases our understanding of HIV.

Clearly, current anti-HIV drugs can't rid the body of HIV. Even when viral load is undetectable, HIV is still reproducing at low levels. The realization that treatment with current drugs will probably be lifelong is the impetus behind the change in the guidelines. The change also reflects an appreciation of long-term drug side effects, the recognition that these drugs require a difficult level of adherence, and the likely development of drug-resistant virus while on lifelong therapy. If we had drugs that completely suppressed HIV, caused no short or long-term side effects, and were easy to take, everyone would start them soon after infection. But that's unfortunately not the case.

As much as we'd like a clear answer about when to start treatment, the debate continues. In the rush to get to the tables and charts, it can be easy to overlook the guidelines' thoughtful discussion of some of the benefits and risks of starting treatment later rather than earlier. Possible benefits of delaying treatment include better quality of life, no drug-related side effects, putting off the development of drug-resistant virus, and having more drug options later on, when you might need them more. On the other hand, the risks of delaying treatment include the possibility that your immune system might have suffered irreversible damage and it might be harder to achieve an undetectable viral load [below the level able to be measured by your test—].

But starting treatment early requires a consideration of risks and benefits, too. The stronger your immune system is when you start, the easier it is to achieve and maintain an undetectable viral load—and drug resistance is less likely to develop when your viral load is undetectable. Earlier treatment might also delay or even prevent damage to the immune system. Conversely, possible risks of starting treatment early include a reduced quality of life due to short and long-term side effects, the development of drug resistance if viral load doesn't stay undetectable, and limited treatment options in the future.

The information we have to help us answer the question of when to start comes from retrospective studies based on patients' medical records, rather than from prospective studies designed specifically to answer the question. Such a prospective trial is extremely difficult to design. It would have to run for years and enroll thousands of people. And a trial that started now would, at best, answer the question of when to start therapy in 2001, with the treatments available in 2001. By the time the trial ended years from now, new, hopefully better drugs and strategies would be available and our understanding of HIV disease would be more complete.

At the 8th Conference on Retroviruses and Opportunistic Infections (CROI) in February, there were many reports on retrospective studies that looked at the relationship between disease progression and CD4 counts and/or viral load levels of people when they first started combination therapy. A retrospective study from Johns Hopkins University looked at what happened to 1,014

by James Learned

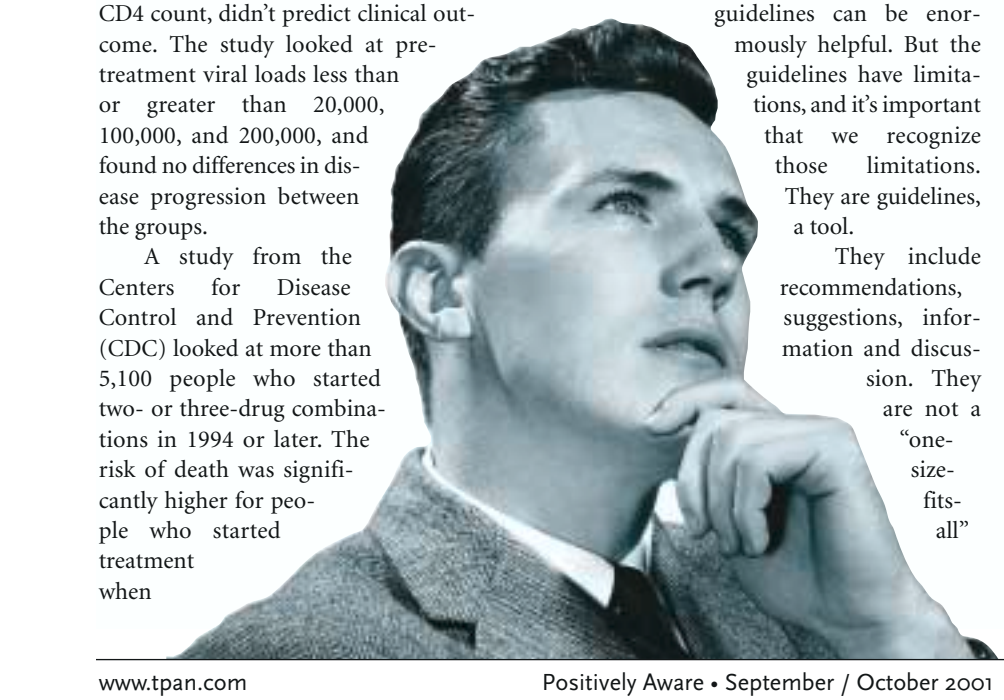
patients who began two- or three-drug combinations after July 1, 1999. There was a strong correlation between disease progression and starting therapy with CD4 counts below 200. The higher rate of disease progression in these patients may be at least partly explained by observations made by the Johns Hopkins group (and other studies) that people are less likely to achieve undetectable viral load if they start treatment with a CD4 count below 200. Progression rates in people who started therapy with CD4 counts between 200 and 350 didn't differ substantially from those who started when their CD4s were above 350. Interestingly, pretreatment viral load levels, independent of CD4 count, didn't predict clinical outcome. The study looked at pretreatment viral loads less than or greater than 20,000, 100,000, and 200,000, and found no differences in disease progression between the groups.

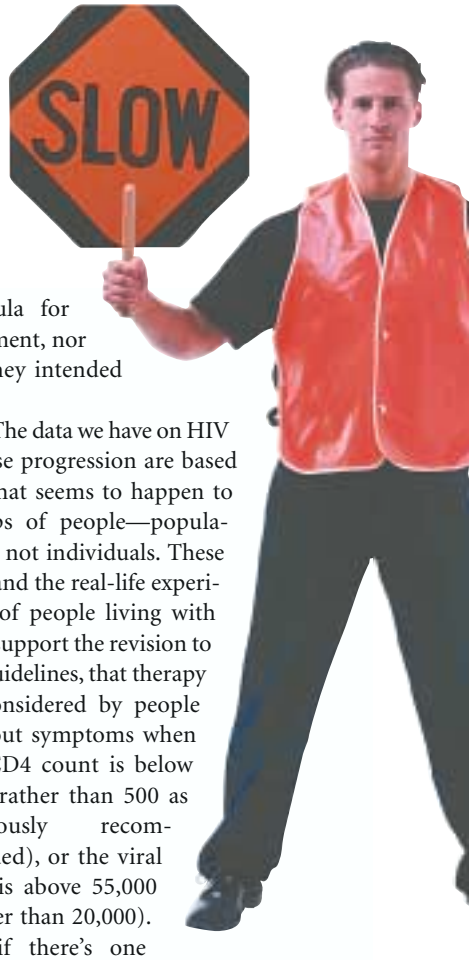
A study from the Centers for Disease Control and Prevention (CDC) looked at more than 5,100 people who started two- or three-drug combinations in 1994 or later. The risk of death was significantly higher for people who started treatment when their CD4s were below 200 compared to those who started treatment when their CD4s were above 200. The study showed a trend for better clinical outcomes in people who started treatment with CD4 counts between 200 and 350, but the difference wasn't statistically significant. And people who started treatment with CD4 counts above 350 showed no clear benefit.

These and other studies show pretty convincingly that people who begin therapy before their CD4s dip below 200 do better clinically. So is it best to consider treatment before you reach that point? Probably. But what's the cutoff? Somewhere between 200 and 350, perhaps. But even then, there are so many factors to consider. Is someone whose CD4 count has dropped from 700 to 300 in a year in the same situation as someone whose CD4s have remained steady at 300 for five years? Clearly not. This is where the individual flexibility called for within the text of the guidelines comes into play.

As people living with HIV and their healthcare providers make complicated treatment decisions—including the decision about when to start therapy—the federal guidelines can be enormously helpful. But the guidelines have limitations, and it's important that we recognize those limitations. They are guidelines, a tool.

They include recommendations, suggestions, information and discussion. They are not a "one-size-fits-all" formula for treatment, nor are they intended to be.





The data we have on HIV disease progression are based on what seems to happen to groups of people—populations, not individuals. These data and the real-life experience of people living with HIV support the revision to the guidelines, that therapy be considered by people without symptoms when the CD4 count is below 350 (rather than 500 as previously recommended), or the viral load is above 55,000 (rather than 20,000). But if there's one thing we've learned over the last twenty years, it's that HIV disease varies widely from person to person. The percentages and probabilities don't necessarily apply to you, your very particular situation, and the many factors that contribute to who you are—a unique individual.

James Learned is CRIA's Director of Treatment Education Initiative at the Community Research on AIDS (CRIA) in New York and Editor of CRIA Update.

by Glen Pietrandoni, R.Ph.

Adherence 101

Pushing people to adhere to complicated drug regimens may seem to some like intimidation of innocent victims just to maintain high profit margins for multinational pharmaceutical companies. Or, could it be that high levels of adherence may help the medications work effectively and keep people healthier and living longer. In order to get the most benefit out of each drug regimen, people taking the drugs must answer these questions for themselves—Are these medications going to help me? How will these drugs affect my quality of life? Many research dollars have been spent to try to balance drug benefits and quality of life. Understanding drugs and how they work will result in longer durability (how long the drugs will keep viral loads undetectable) for each regimen. If we can string together many regimen combinations to keep the virus from replicating and causing damage, there will surely be better drugs and options for us down the road.

Of course, this will all come at a price. Drugs available today to treat HIV infection have many side effects and problems associated with them. Many of the problems we see today are not understood and continue to be a concern for doctors and patients alike. Not too many years ago, we didn't see a lot of these problems simply because people did not live long enough for the situation to manifest itself. With increased durability of drug regimens, and possible sequencing of interruptions in therapy, everyone's goal is to keep people healthy for longer periods of time. [*See: "To Start or not to Start?" on page 28.*]

It is important that we all understand how adherence plays a role in keeping viral loads undetectable. It has been shown in many reports that at least 90-95% of all doses must be taken properly to get the maximum benefit from the drugs. Less than perfect adherence teaches the HIV virus to get past the drugs (resistance). For those that take medicine twice a day, that means that missing one dose a week can put you near the edge. The effect of poor adherence does not always show up right away. You may even get a great viral load test result after poor adherence. Less than perfect adherence will show its nasty head in the durability of the regimen. Your health care provider may have to switch out your drugs sooner than you would like.

In a European study, after two years on therapy, 60% of the people enrolled in the study were undetectable on their first regimen, only 50% got to undetectable on their 2nd regimen and only one out of three could get to undetectable on their third regimen. What this means to you is that the fewer drug changes a provider has to make, the better your chances are getting to undetectable. As we switch around drug regimens, the schedules often become more complicated and the number of tablets usually increases making life with HIV more complicated.

Help your health care provider pick a drug regimen that works best with your lifestyle and schedule. Everybody wants a "one-pill-a-day" regimen, but we are not there just yet. There are some changes that can be made in number of pills and how many doses per day. Communicate with your doctor about any concerns you may have *before* even starting therapy or switching to new drugs. There are only so many drug combinations available, you don't want to waste any options if you don't have to. When an HIV-positive person begins their first drug regimen, this is usually the most potent regimen, often with easier dosing schedules.

We must be clear on what adherence is and what it is not. Adherence is the ability to take each dose of medication at the prescribed time, with or without food when indicated, and without other drugs interacting with the ones used to treat HIV. Adherence is *not* being a couple hours late taking a dose, or forgetting to eat when the RX says to *take with food*, and "*empty stomach*" usually means to take the drug one hour before a meal, or two hours after. Food can either reduce the level of drug in the body (like with Videx) or in another case, having drug without food can also lower drug levels (as with Fortovase). If the drugs you take don't get into the blood, it is almost like not taking the drugs at all. Here are some more tips that may help:

- Your beliefs may help you or hurt you. Do you know how the medications work? Do you believe in Western medicine? Are you an optimistic person? Do you suffer from depression or fatigue? Is the medicine keeping the disease at bay, or are all of those pills just reminders of HIV and therefore bringing down your spirits? Before initiating anti-HIV therapy or switching regimens do a check of your beliefs.

Communicate with your doctor about any concerns you may have before even starting therapy or switching to new drugs. There are only so many drug combinations available, you don't want to waste any options if you don't have to.

- Try to prevent or predict side effects. Your ability to control unwanted side effects will probably result in better adherence. Be prepared to treat diarrhea or nausea with over the counter medication (check with your doctor or pharmacist). Visit jonkaiser.com, larklands.net, daair.org or medibolics.com websites for ideas. Call Project Inform's national HIV treatment hotline toll free at 1-866-448-4636. Ask for a copy of Dealing with Drug Side Effects, or visit www.projectinform.org.

- How about getting a "buddy" to help keep you on schedule. Involve a partner, friend or family member to help you. In Chicago, call TPAN 1-773-404-8726 or call the U.S. Centers for Disease Control and Prevention (CDC) national 24-hour hotline (1-800-342-2437) for referrals to services near you. Make sure that the buddy knows their stuff! You'll want to get accurate information.

- Refill prescriptions before they run out. Sometimes pharmacists have to contact your physician to get prescription refills. This can take a few days in some cases. Plan ahead. For long days at the office, carry your evening dose of meds with you, in case you don't make it home on time. If you are going to be out of town, be sure to have enough medication for your trip. Pack medications in carry-on bags so they don't get lost.

- Use cues as a reminder to take your pills—after a favorite TV show, or after brushing your teeth. Beepers, alarm clocks, and reminder services call all help keep you on schedule. The easiest tool to use is a 7-day pillbox. Line up all your pills for a whole week. Each day's dose of meds is labeled for you. If you are not sure if you took your Wednesday morning dose, look in the pillbox. If they are still in there, you didn't take them!

Do not stop taking your anti-HIV medication, even for a day, without first talking with your health care provider.

HIV Case Management 101

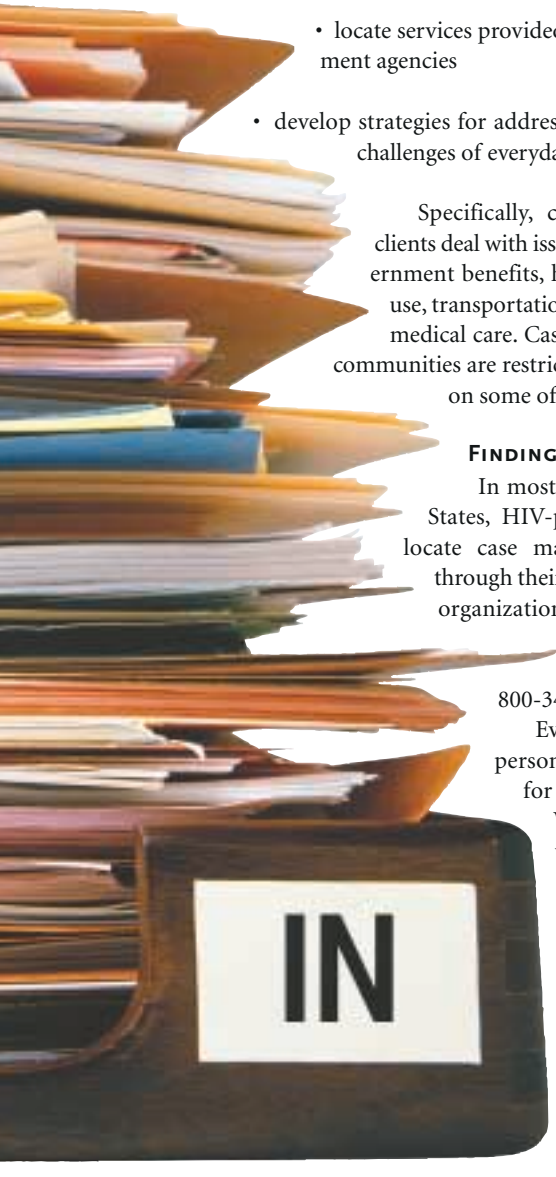
Let's face it—coping with HIV infection can be an enormous job. Some people find that the job becomes easier when they enlist the help of case managers. However, case managers can't always deliver everything clients hope to receive. What exactly is case management, and how can people best utilize this valuable service?

The many roles of case managers

In the most general terms, a case manager's job is to assess a client's needs and assist the client in addressing those needs. Case management systems vary greatly from one location to another, but in general terms, they focus on helping clients:

- navigate government systems
- locate services provided by non-government agencies
- develop strategies for addressing some of the challenges of everyday life

Specifically, case managers help clients deal with issues as diverse as government benefits, housing, illegal drug use, transportation, employment, and medical care. Case managers in some communities are restricted to only working on some of these issues.



Finding a case manager

In most parts of the United States, HIV-positive people can locate case management services through their doctors; local AIDS organizations; local AIDS hotlines; or the national AIDS hotline (1-800-342-2437).

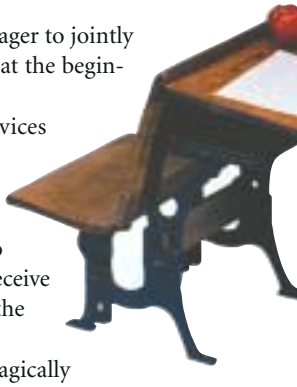
Every HIV-positive person is eligible to apply for case management. When you apply, you will undergo an assessment that determines whether your needs warrant case management or whether your needs can be addressed through referrals to specific services (such as counseling).

Important note: The initial assessment is usually very thorough, and may include questions about private matters such as your finances and your medical history. Be prepared to answer all questions truthfully. You should be able to discuss any concerns about confidentiality with the person giving you the assessment.

If you have a history of addressing your needs independently, then you may not be an appropriate candidate for case management. But keep this important point in mind: some services, particularly those that involve financial assistance, are only available to applicants who have case managers.

When you are preparing to enter a relationship with a case manager, you will probably be asked to sign one or more forms. *Never sign anything without understanding what you are signing.* Don't hesitate to ask for explanations.

Being realistic



It is important for you and your case manager to jointly establish some realistic goals and expectations at the beginning of the relationship.

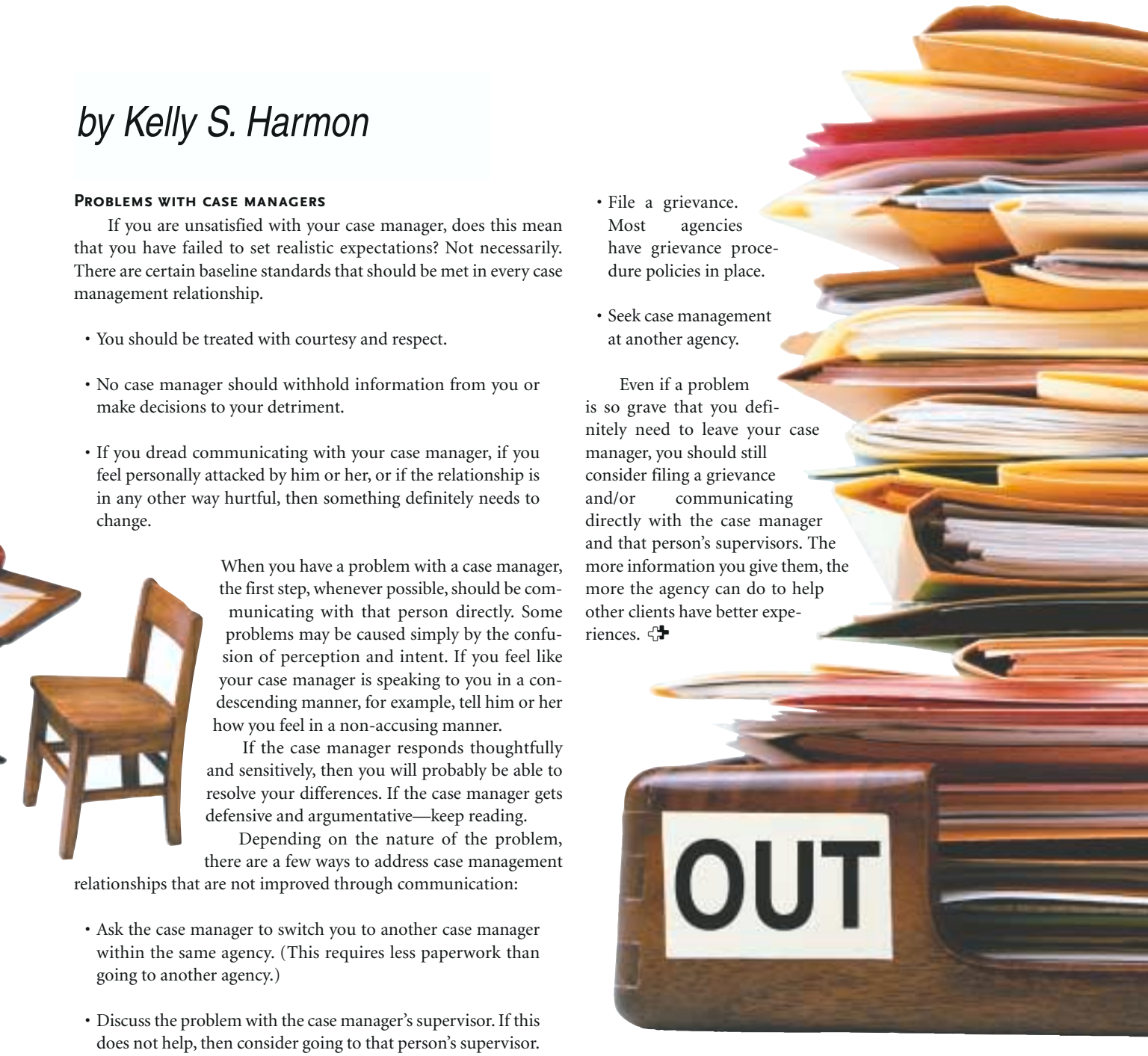
Not everybody realizes that the HIV services community is struggling with a harsh truth: funding in recent years has not kept pace with people's needs. Therefore, both government and non-government programs have been forced to establish strict criteria to determine who can receive their services. You may not qualify for all of the forms of assistance that you seek.

You cannot expect your case manger to magically override eligibility requirements for services. You can, however, expect your case manager to help you keep your expectations in line with the realities of the current funding situation. Some more points to consider:

- You are not necessarily eligible for the same services or benefits that somebody else receives, even if you appear to have similar circumstances.
- Patience is essential—it may take a great deal of time to attain certain objectives.
- The complex systems designed to serve HIV-infected people do not work perfectly. Unfortunately, there may be times when technicalities disqualify you from receiving help that you urgently need.

It is equally important to have realistic expectations of your case manager. Communication is the key to defining these expectations. For example, you might want to ask at the outset how often you should expect to communicate with your case manager, and how long it generally takes the case manager to return phone calls. If your expectations are way out of line with the case manager's, then the two of you should discuss the situation.

by Kelly S. Harmon



Problems with case managers

If you are unsatisfied with your case manager, does this mean that you have failed to set realistic expectations? Not necessarily. There are certain baseline standards that should be met in every case management relationship.

- You should be treated with courtesy and respect.
- No case manager should withhold information from you or make decisions to your detriment.
- If you dread communicating with your case manager, if you feel personally attacked by him or her, or if the relationship is in any other way hurtful, then something definitely needs to change.

When you have a problem with a case manager, the first step, whenever possible, should be communicating with that person directly. Some problems may be caused simply by the confusion of perception and intent. If you feel like your case manager is speaking to you in a condescending manner, for example, tell him or her how you feel in a non-accusing manner.

If the case manager responds thoughtfully and sensitively, then you will probably be able to resolve your differences. If the case manager gets defensive and argumentative—keep reading.

Depending on the nature of the problem, there are a few ways to address case management relationships that are not improved through communication:

- Ask the case manager to switch you to another case manager within the same agency. (This requires less paperwork than going to another agency.)
- Discuss the problem with the case manager's supervisor. If this does not help, then consider going to that person's supervisor.
- File a grievance. Most agencies have grievance procedure policies in place.
- Seek case management at another agency.

Even if a problem is so grave that you definitely need to leave your case manager, you should still consider filing a grievance and/or communicating directly with the case manager and that person's supervisors. The more information you give them, the more the agency can do to help other clients have better experiences.

Tips for getting the most out of case management

- Keep your case manager up to date about what's happening. If you think there might be a problem developing, tell the case manager immediately—don't wait until you've reached a state of crisis.
- Don't assume that your case manager will take care of everything. Explicitly ask what your responsibilities are.
- Arm yourself with information about resources. Your case manager will do everything possible to help you, but you must still be prepared to act as your own advocate.
- Write down questions in preparation for appointments with your case manager so that you will remember them all.
- Avoid the pitfall of relying solely on the case manager—develop a good support network with other HIV-positive people.

An opportunist: someone who takes advantage of you. Well, that's what an opportunistic infection is—one that waits until your immune system is weak so it can prey on you. Specific microorganisms that normally live in a peaceful co-existence can potentially overcome the body when the immune system is failing. In fact, getting some of these illnesses gives you an AIDS diagnosis.

The problem today with opportunistic infections (OIs) is that so many people, especially people of color, are unaware of their HIV infection until they are hit with a serious disease. The U.S. Centers for Disease Control and Prevention (CDC) estimates that one out of four people with HIV in this country are unaware of their infection. The good news is that many OIs can be averted with prevention medicines, also called "prophylaxis."

PCP (*Pneumocystis carinii* pneumonia)

Formally thought to be caused by a parasite, but *Pneumocystis carinii* is now recognized as a fungus. It's present in almost all people since childhood. PCP generally occurs when T-cells fall below 200.

Transmission: None. Exposure to someone with PCP will not trigger PCP in you.

Symptoms: Persistent dry cough (more than two weeks), shortness of breath or difficulty breathing on exertion, fevers, chills, sweats, and increasing fatigue. Cough may produce thin, clear mucus.

Prevention: Everyone with less than 200 T-cells should take prophylaxis (preventative medicine), as well as people with a prior history of PCP and those with thrush and persistent fevers. Fortunately, prevention medications are very inexpensive. Taken at night, prophylaxis can help with the sun sensitivity often caused by TMP-SMX (brand names Bactrim, Septra). The daily double-strength medication also protects against toxoplasmosis and some common respiratory bacterial infections. People with severe reactions can discontinue until they get better, then go back on at lower doses until their tolerance builds up. People who once had less than 200 T-cells may discontinue prophylaxis if they now have more than 200 T-cells for three to six months with HIV therapy.

Take home point

Continue to monitor your T-cells, even if you're not on therapy. You're more at risk for certain infections when your T-cells at are certain levels. If you can't, or don't want to take HIV meds, you can still take OI prevention medications (prophylaxis) to keep you healthier and out of the hospital.

Candidasis (thrush)

Usually the first OI to appear, and certainly the most common. Although there's a very low mortality rate for thrush, its often painful oral presence can lead to a decrease in eating and therefore, nutritional intake, with the potential for escalating complications such as wasting, which is life-threatening. Lots of sugar, alcohol, caffeine and carbohydrates (like bread and pasta) promote thrush. Stress and lack of rest encourages fungus growth.

Transmission: None, although very rare cases of person-to-person transmission have been documented.

Symptoms: Causes fuzzy white or pinkish-red patches in the mouth and esophagus (feeding tube down the throat). Burning, altered taste sensation (especially when eating spicy or sweet food), and difficulty swallowing and eating. Also, because food can get stuck in the esophagus, people with candida esophagitis have chest discomfort with eating. Thick white discharge in the vagina, plus itchiness, rash, and burning sensation.

Prevention: Not recommended due to the low mortality rate of the disease, the cost of prophylaxis and the potential for developing resistance to it. Also, treatment is usually effective if thrush does develop. Interventions include smoking cessation, good oral hygiene, and avoiding both unnecessary antibiotics and use of corticosteroids. Additionally, diabetics tend to have thrush because of its tendency to live off sugar, so if you're diabetic, watch your sugar intake and keep blood glucose (sugar) levels under control. Vagina thrush is associated with high-estrogen oral contraceptives, pregnancy, diabetes, tight-fitting pants, deodorant tampons and deodorant sprays, douches, intestinal parasites, sexually transmitted diseases, and antibiotics (ironically, some of which are used to treat other vaginal conditions).

Opportunistic Infections 101

by Enid Vázquez

Hepatitis C Virus (HCV)

A virus that infects the liver. Now considered an OI because people with HIV are seven times more likely to die from it than people who are HIV-negative. [*See "HCV/HIV co-infection" on page 40.*]

Transmission: Blood-to-blood contact, including the sharing of straws for snorting cocaine, and sexual contact. Injection drug users should avoid sharing equipment, including water and cookers, or sterilize the equipment that they can clean. Estimated to be present in 85% of current or former injection drug users. Can be transmitted at birth from an infected mother. May possibly be transmitted through unprotected sex, infected instruments during tattooing or body piercing, and by using the razor or toothbrush of an infected person.

Symptoms: May cause no symptoms until liver damage occurs. Then causes flu-like symptoms such as nausea, fatigue, and headache.

Prevention: Infusion during labor. Bleaching syringes. Syringe exchange programs. Use of either new needles or of an autoclave for sterilizing needles by tattoo artists and body piercers. People with HCV should be vaccinated against hepatitis A. They should also avoid "excessive amounts of alcohol" to prevent serious liver damage, although it is unclear if even 12 ounces of beer a week can increase the risk of cirrhosis (scarring of the liver).

Tuberculosis (TB)

A disease of the lungs that can spread to other organs. Risk of TB increases 100 times with HIV infection. It generally occurs in HIV-positive people when they have between 200 and 300 T-cells. Also, heavy drinkers, injection drug users and people who are very underweight are at higher risk.

Transmission: Through the air by coughing and sneezing.

Symptoms: Productive coughing (producing phlegm), chest pain, fever, fatigue, night sweats, weight loss and the spitting of blood.

What's HAART got to do with it?

Opportunistic infections have gone down as much as 85% in the developed countries following the introduction of HAART (highly active anti-retroviral therapy, the so-called "drug regimen"). According to the OI guidelines, "HAART [highly active antiretroviral therapy] is the most effective approach to preventing OIs and should be considered for all HIV-infected person who qualify for such therapy. . . . In addition, [prevention] against specific OIs continues to provide survival benefits even among person who are receiving HAART." [*See: "Adherence 101" on page 30 and "To Start or not to Start?" on page 28.*]

Prevention: Upon HIV diagnosis, undergo a tuberculin skin test (TST). If positive, or if you have symptoms, undergo a chest radiography and doctor's evaluation to look for active TB. If no TB is found but the TST was positive, take preventative medicine for either two months or nine months. (See the OI guidelines for TB drugs that cannot be taken with HIV antivirals.) Also avoid places thought to be high-risk, such as volunteer work or employment in prisons, homeless shelters and health clinics (believe it or not), but always consult your healthcare provider.

Human herpesvirus 8 (HHV-8)

The virus associated with Kaposi's sarcoma (KS). Kaposi's sarcoma is a rare cancer that is generally benign but sometimes disfiguring. It can cause purplish or brownish marks on the skin and sometimes spreads to cause disease in the organs. Most commonly occurs in men.

Transmission: Seems to be sexually transmitted, including during deep kissing. Research has found greater amounts of the virus in saliva than in semen.

Prevention: HAART that successfully lowers viral load has been shown to reduce progression of KS, including development of new lesions. People who've used either Cytovene (ganciclovir) or Famvir (famciclovir) to treat CMV (cytomegalovirus) also show less cases of KS, but these drugs are not be recommended for prevention and treatment at this time.

Cryptosporidiosis

Caused by the parasite cryptosporidium. Difficult to control. May lead to rapid weight loss and severe weakness. There is no standard treatment. Drugs being tested for treatment include paromomycin (Humatin),

azithromycin (Zithromax), latrazuril and atovaquone (Mepron). Research with the promising drug nitazoxanide was stopped after the drug failed to win FDA approval. Also, bovine colostrum concentrate (Sporidin-G) is being tested for controlling diarrhea caused by crypto.

Transmission: Contaminated water. Oral/anal contact. Raw oysters. Failure to wash hands (after gardening, playing with pets, changing diapers, using the bathroom, etc.).

Symptoms: Severe persistent diarrhea. Also, nausea, vomiting, and stomach cramps.

Prevention: Bringing tap water to a rolling boil for three minutes kills the parasite. Water filters should be those that use distillation or reverse osmosis, those labeled as absolute (not "nominal") 1-µm filters, and those labeled as meeting NSF #53 for cyst removal. Not all bottled waters meet these standards; call the tollfree number on the bottle to check. Don't forget to use safe water for ice cubes and be careful with drinks made with tap water when you go out.

Cytomegalovirus (CMV)

Cytomegalovirus infection can be acquired throughout life by direct contact with bodily fluids. It is spread throughout childhood and later in adults through sexual activity. Approximately 40 to 100% of the U.S. adult population has been exposed to CMV. It primarily damages eyesight (CMV retinitis) and can lead to blindness. May affect other organs. CMV is a herpes virus, and thus lingers in your body forever.

Transmission: Sexually transmitted. Found in saliva, semen, respiratory excretions and urine. Presence is higher among positive men who have sex with men than in other groups. Also, CMV can remain dormant in the body (latent) and in immunocompromised people, CMV can be reactivated, producing disease in various organs, such as the eye.

Symptoms: Look out for floaters (spots in your vision), especially if increasing over time. Also watch for blurring when reading.

Prevention: A new drug has become FDA-approved. It is a version of ganciclovir (Cytovene) and is called valganciclovir (Valcyte). It should be considered for people with less than 50 T-cells who are CMV positive. Weigh the possibility of neutropenia (decreased white blood cells), anemia (especially if already taking Retrovir or hydroxyurea), conflicting reports of efficacy, lack of proven survival benefit, and risk of developing resistance to ganciclovir. Also, the drug is expensive and dose is an inconvenient 12 capsules a day (although the oral form of ganciclovir is a vast improvement over the old days of daily intravenous infusions). Do not use acyclovir (Zovirax) or valacyclovir (Valtrex). People whose T-cells have increased to more than 100 for three to six months with therapy, plus have a drop in their viral load, can stop taking CMV prophylaxis, but those with CMV disease should first check with their eye doctor.

Shingles

Caused by the varicella-zoster virus (VZV, varicella means chickenpox and zoster means shingles). Varicella-zoster is a herpes virus, so it's with you forever. Shingles is a painful condition of blisters and sores that run along nerve paths, usually on one side of the body or as a band around your middle. It may occur early in HIV disease. Pain may persist after healing of skin lesions and may be difficult to control. People with HIV experience many more lesions. They are at greater risk of getting bacterial infections on their sores (try to keep them clean and dry as much as possible) and of a life-threatening spread to internal organs.

Transmission: Extremely contagious, through direct contact with skin lesions or through airborne droplets from the lesions getting into mucosal surfaces (nasal sinuses, lining of the mouth, etc.). VZV also seems to enter through the skin surfaces of sensory nerves and then travel down into the nerve fibers. Infectivity usually begins a couple of days before outbreak and continues until all sores are crusted over. For people with HIV, this can take several weeks.

Prevention: No recommendations as yet.

Mycobacterium avium complex (MAC)

Bacterial infection. Organisms of the M. avium complex are common in food, water, and soil. Almost everyone has the bacteria in their body.

Transmission: Not spread person to person.

Symptoms: Recurring fevers, fatigue, swollen glands, night sweats, diarrhea, and severe weight loss.

Prevention: Should be taken by people with less than 50 T-cells. Various medications are available. While it seems that people whose T-cells have increased to more than 100 for three to six months under therapy, with decreased viral loads, can stop prophylaxis without getting MAC, stopping prophylaxis is not yet recommended due to the insufficient number of people having been evaluated.

Lymphoma

Cancers involving white blood cells. AIDS-related lymphoma is also called non-Hodgkin's Lymphoma (NHL).

Transmission: None. Development of NHL is associated with Epstein-Barr virus, longterm HIV infection, and genetic factors.

Symptoms: Swollen lymph nodes, fever, night sweats, and weight loss.

Prevention: None.

Human Papilloma Virus (HPV)

A very common sexually transmitted virus that causes genital warts. Tends to be much more aggressive in people with HIV. Can lead to cancer of the cervix (the lower part of the uterus, leading into the vagina), especially the virus strains HVP-16 and HPV-18. May also cause infertility.

Prevention: As with herpes, condoms do not offer complete protection. To stave off cancer, women should obtain two Pap smears during the first year after infection and if results are normal, a yearly Pap after that. HIV-positive men who have sex with men are at increased risk of anal cancer, but routine screening with an anal Pap smear is not yet recommended by the guidelines. Wouldn't hurt—it's a little cotton swab that can pick up trouble. It's also been found to be cost-effective (medical jargon for "benefits are worth the price"). People with HIV, whether male or female, whether they have anal sex or not, are at greater risk for anal cancer.

For more information

There's more useful information in the OI guidelines, published by the U.S. Public Health Service and the Infectious Diseases Society of America, including additional OIs, as well as information regarding pets, travel, children and pregnancy. Call 1-800-448-0440 for a free copy or visit www.hivatis.org.

Always confer with your healthcare provider before initiating or discontinuing any medication.

How to Be a Player in Federal Decision-making

by Kaethe Morris Hoffer

Every fall, Washington, D.C. buzzes with activity as the U.S. Congress finalizes a spending and taxing plan for the coming year. This year because of the recent tax cut, the slowing economy, and because the Bush administration has proposed spending a ridiculously small amount on the AIDS crisis it is more important than ever for people who care about AIDS to participate in the budget debates. Fortunately, this is easier than you might think, and with one or two phone calls or better yet, one handwritten letter you can have an impact much larger than you might expect.

Do you wonder how one letter or phone call from you could possibly affect the federal budget? The simple explanation is this: small, personal, efforts have a huge impact because most people *never* take the time to communicate with their elected representatives. Think about it. Of all the people you know who have a strong opinion on various government policies, how many have actually written a letter to their Congressperson? Ask your friends, probably fewer than you think ever take the time to communicate with elected officials. Well, this is something that your Representatives *have* thought about, and because they've thought about it, they generally regard one phone call and especially one letter as representing the wishes of a much larger group of people. It is ironic, but true: while every vote counts, every letter and phone call gets counted more, because recipients assume that for each person who takes the time to write, there is a large community of people who feel the same way, but simply don't take the time to express themselves.

So take a minute or two, or ten, and communicate with your elected officials. Tell them what you know about HIV/AIDS, and tell them that you care. Tell them that until there's a cure, and for as long as HIV/AIDS continues to burden already poor and disenfranchised communities, the federal government must make HIV/AIDS prevention, care, treatment, and research significant social and financial priorities. This June marked the twentieth anniversary of AIDS in America, and unless we make the Federal government put significantly more money into the fight against AIDS now, twenty years will quickly turn into fifty, and the worst will be ahead, instead of behind us, where it belongs.

To help your efforts, we have drafted a sample letter for you to use as a model, and if you don't know who represents you, or how to reach them, just go to www.votesmart.org, or call 1-888-VOTE-SMA (1-888-868-3762) and you'll be on your way! Now, let your voice be heard!

Sample letter:

Dear Representative/Senator [their name here]:

I urge you to support increased funding for domestic and international HIV/AIDS prevention, care, housing and research.

HIV is expanding by 40,000 Americans each year, the cost of basic healthcare and prescription drugs is skyrocketing, and the epidemic is growing most quickly among people of color in communities already plagued by poverty and poor access to quality healthcare or affordable housing. AIDS has already grown so enormously around the world that some countries are facing genocide-by-disease.

In my own life and community, I have seen HIV/AIDS wreak enormous harm. [Here is a good place to add some facts from your life or community.]

The budget proposed by the President is not realistic. It does not provide enough money to meet current needs in our country, much less the increasing needs of a growing HIV-positive population. It fails to invest seriously in prevention efforts. It does not contribute enough to the international fight against AIDS especially in comparison to other industrialized nations. The proposed budget would weaken efforts against the HIV/AIDS epidemic in our country and abroad.

We must increase, and not decrease, our efforts against HIV/AIDS. One need only look beyond our borders to see why.

Sincerely,
(Your name and address so they know that they work for *you*)

Kaethe Morris Hoffer is manager of federal affairs at the AIDS Foundation of Chicago (AFC), and can be reached via AFC's website at www.aidschicago.org. She works to help people affected by HIV/AIDS in Illinois work closely and effectively with the men and women who serve them in Congress.

Sloppy Treatm

by Stephen J. Fallon, Ph.D.

Jamie is waving his arms above his head, in a gyrating rhythm that tracks the DJ's beats. I push through sweaty backs and prickly tricep stubble to reach him on the other side of the dance floor. I'm grinning as I approach Jaime, pleased to see him back in the mix. He rarely goes to the clubs. They don't offer him the joy they once did, since he can't dance and can't trick.

The excommunication from the dance floor was issued by his HIV meds, which triggered in him some embarrassing problems with diarrhea. As for tricking out, Jaime once told me that "wearing Depends makes for kind of a let down when the guy pulls your jeans off." Jaime is like that; while other guys might retreat behind bitter resignation, he jokes through the uncomfortable realities of fighting HIV.

So I'm beaming as I wordlessly approach him, and slip into the groove that's directing his motions. He's oblivious to me at first, caught up in the shimmering lights. When he finally spots me, his face explodes in a hearty laugh. "Hey, you!" he shouts, pulling me into a bear hug. We dance a few more sets, then buy champagne-priced bottles of water. I wink and tip my bottle in the direction of the dance floor. "I thought it was *Stella who got her groove back*," I tease.

"Oh, I'm okay," he says, flashing me the waistband of genuine CK briefs to prove his point.

"New regimen?" I ask.

"No, but I'm okay going out. The medicines only mess with my stomach on the days I'm taking them."

Suddenly the music recedes to a hollow echo, and I stare in panic at Jamie. "The days you take them…?" I repeat numbly. "Tell me you're not taking a drug holiday. You've got to know that HIV mutates if you skip your meds."

"For a holiday, yeah, but this is something I plan. I stop all of them for the whole weekend. You know, like a structured treatment interruption."

I glance around at the happy bouncing faces on the dance floor, and realize that this is not the ideal environment for explaining the confusing logistics of Structured Treatment Interruptions, or their new nomenclature, Strategic Interrupted Treatment.

For the record, all of this began with the famous "Berlin patient." This anonymous guy became HIV infected in May of 1996, and started treatment almost immediately. He fell off of his meds twice. First, he developed a testicular infection that left him hospitalized for two weeks. He had forgotten his meds (don't ask me why he didn't ask at the hospital for more). Then after getting back on treatment, he caught hepatitis A, and couldn't hold anything down, so he stopped taking his meds again.

He returned to treatment one more time, but then came to feel that he was somehow better. He decided to stop taking his meds that November, and scientists have since discovered that his intuition was accurate—he shows no detectable HIV in his bloodstream for years. (No, he's not actually cured. Researchers can recover "competent" HIV from deep reservoirs in his tissues. But he is living without the burden of daily treatment or disease progression.)

The "miracle" of the Berlin patient hit the medical journals just as hopes for "eradication theory" were fading. That theory had held that patients who could keep their virus levels undetectable for just a few years would become "cured," because their body's defenses would finish mopping up what little HIV remained below our radar screens. In 1998, Dr. David Ho had to revise his original estimate of the countdown to a cure from 3.1 years to 18-20 years. Later that year, Dr. Robert Siliciano proved it would actually take 60 years of continuously successful therapy to finish pushing HIV out.

So if eradication is impossible, how had the Berlin patient inadvertently accomplished the next-best thing: treatment free health? Clinics all over the world exploded with theories, which they're testing out on a variety of patients. The general belief is that the Berlin patient, by sporadically exposing his body to high levels of HIV, retrained the sights of his immune system (cytotoxic T-lymphocytes) which would otherwise tend to "forget" how to spot HIV when the virus is kept undetectable. In essence, he had vaccinated himself.

In addition, while his immune system was re-targeting HIV, the virus was losing its memory of the medicines that it had once learned to evade. The virus became progressively more "sensitive" to attacks from the meds when it hadn't seen those meds in a while. In other words, it was overcoming drug resistance.

Or maybe not. Dr. Veronica Miller had reported in '99 that the HIV in her patients had indeed become vul-

nerable to the meds again after a structured break. But at last year's conference, she reported that all of those benefits were short-lived, and that some patients were never able to bring their virus back under control again. Far from making HIV less of a threat, imposing a break on treatment may have opened the Pandora's box of drug resistance—just like science used to warn drug holidays could do. Other researchers have concluded that increased Virologic Immunological Response (VIR) does result for ideal patients, but that it's a short-lived benefit.

Who are ideal patients for a possible SIT/STI? Unfortunately, my friend Jamie doesn't seem to be one of them. Most studies with long-term HIV-positive patients show that these treatment interruptions don't help. At the very best, they might provide a reprieve from side effects and leave the patient no worse off than he was before he took the break. At worst, the break may open the same Pandora's box that Miller's patients encountered.

The successes we've seen have almost always centered on treatment-naïve patients—those who are either so newly infected that they were still enjoying the maximal impact of their new meds, or those who have been chronically infected, but never had any trouble at all keeping their virus way down low. Even then, only about one-third of these ideal patients enjoy even a temporary benefit from an SIT/STI.

Most of these studies are also way too small to provide any firm answers on how to stage a successful SIT/STI. Most enrolled only a half dozen or perhaps two dozen patients so far. The biggest study (a Swiss-Spanish group) is on its way to enrolling 122 patients, and thus far has found no benefit to SITs at all.

If any tentative conclusion seems to fall out, it may be this: Jaime's weekend escape is a recipe for disaster. Any benefits in terms of HIV "forgetting" the shape of its medicinal enemies, and the body "remembering" HIV's presence, seem to take at least a couple of weeks to accrue. The NIH's three-tiered study of a more cyclical Strategic Treatment Interruption found that the group that bounced off and on the meds too quickly (5 days on, 2 off) were on their way to treatment failure. That study arm closed, and the one week on/one week off doesn't seem to be faring much better—one patient got worse, and the other six neither improved nor worsened. The only group that seems to have had some success is the one month on/one month off group, for whom viral load is rebounding less dramatically with each successive break.

I've spoken with friends for whom the SIT/STI approach has worked. With each round, they're able to stay off the meds longer, and their HIV peaks to lower levels than during their previous interruption. Yet a recent report in the *Journal of Infectious Diseases* warned that widespread use of STIs could significantly increase the prevalence of drug-resistant HIV throughout the positive population.

Confused yet? So am I, and I do this for a living! That's why I pulled Jaime aside to explain that SITs/STIs are not a "Do It Yourself" course offered at Homo Depot. Even if we do find the exact formula for timing and treatments, this will always have to be a physician-directed plan. If you planned to take one month off, for example, from your Zerit, Sustiva, and Crixivan, you'd better not stop all the meds at the same time. That's because they all clear out of the body at different rates. Your Crixivan would clear out fast, with the Zerit right behind it. That would leave Sustiva acting as a progressively weaker monotherapy, slowly trickling out of your body while HIV plots against it!

SITs/STIs are designed to work like judo; they pull the opposition out of sight just as HIV was trying to attack it. If you do decide to explore this subject, don't take a Sloppy Treatment Interruption like Jaime did. That's more like throwing half-punches at your opponent.

Our hope is that the mysteries of SITs/STIs will be washed away by science, so that every person living with HIV will be able to enjoy some breaks from the costs and side effects of their meds, and maybe even resensitize their virus to the treatments.

If you want to reap those benefits, be sure that you stage a structured treatment interruption.

Stephen Fallon is President of Skills4, Inc., a health-promotion and disease-prevention consulting firm based out of Ft. Lauderdale, offering professional trainings, grant writing services, and community-based workshops. Visit www.Skills4.org.

HCV/HIV Co-infection— A Patient's Perspective

I remember sitting in my doctor's office one day in 1996, feeling great and full of hope. This wasn't the kind of hope that I had been feeling for the last 12 years, but hope that I could actually grab onto instead of visualize. The protease inhibitors were recently approved by the FDA, and I was seeing the dramatic effects they were having on the HIV community, as well as on myself. My doctor asked how I was feeling, and I answered him with a confident "GREAT!" Then he gave me my latest lab results. My T-cells were responding and my viral load was down for the first time in 12 years. I was elated. He then informed me that one lab marker concerned him. This was a marker that measured enzymes produced by the liver.

The liver is an important organ that cleans the blood, makes proteins for muscles, stores energy, helps digestion, boosts the immune system, and is necessary for life. We should all have low levels of liver enzymes in our blood; elevated enzymes may indicate liver injury.

> *Learn everything that you can because knowledge does equal power. Make the effort to explore the options available to you.*

The two most common liver enzymes studied are ALT (SGPT) and AST (SGOT). Mine were elevated. After an extensive history, more lab work was ordered. Two of the tests ordered were a hepatitis C (HCV) antibody test and an HCV viral load (similar to HIV). A week later I received the news. My antibody test came back positive, which meant that I had been exposed to the hepatitis C virus. My viral load came back as greater than 1000, which meant that I had chronic hepatitis C.

Approximately 85% of people who have been exposed to HCV develop chronic infection. Chronic infection means that the body is not able to rid itself of the virus and is continually trying to fight it. It also means that HCV positive individuals can pass on

by Gerald Moreno

> My mission statement in life is empowerment: Empowerment to live, empowerment to grow, and above all, empowerment to give back.

the infection to someone else through a transmission route, predominantly blood-to-blood contact with HCV. I remember asking my doctor what all of this meant. He answered solemnly that hepatitis C is a very serious disease and could be potentially fatal. I recalled familiar memories of receiving another diagnosis…HIV. After a time of self-pity and depression, I called upon the survivor skills that I had learned from HIV: Learn everything that you can because knowledge does equal power. Make the effort to explore the options available to you.

What I learned was that hepatitis C (HCV) is a viral illness that affects the liver. The estimated prevalence of HCV worldwide is approximately 170 million, 3.9 million in the U.S., and 500,000 in California. In 1990 an antibody was identified. Before that, HCV was known as "non-A, non-B hepatitis." The HCV has six genotypes, all with subtypes. A genotype is the specific genetic makeup or "blueprint" of an organism, in this case a virus. Genotype 1 is the most common in the U.S., and is unfortunately the most difficult to treat.

HCV is spread primarily by blood-to-blood contact. Upon learning this, I immediately realized my risk factor. I had been an injection drug abuser, who shared works with people I didn't even know. Other methods of transmission are blood transfusion products, tattooing, body piercing, snorting drugs, multiple sex partners involving contact with bodily fluids, and hemodialysis. The progression of HCV from the acute phase (first six months of infection) to experiencing symptoms is on average 20 years. For persons co-infected with HIV, this time is shortened to 10 to 15 years. Not everyone experiences symptoms, but those who do may notice fatigue, poor appetite, abdominal and muscle pain, itching, dark urine, and jaundice (yellowing of the skin and eyes).

With this information in hand, I decided to seek out a doctor who specialized in both HCV and HIV (another lesson learned from HIV). He ran a few more sophisticated tests and wanted to know all the supplements and medications I was taking. Everything we ingest is filtered through the liver, and many vitamins and minerals are toxic to the liver. Now I never take supplements without informing my physician first, especially because I am on HAART.

Highly Active Anti-viral Treatment (HAART) regimens usually include protease inhibitors (PIs), which undergo extensive hepatic metabolism. This means the medications are processed through the liver. The possibility of liver complications exists for all six of the currently available PIs, especially Norvir and Crixivan. This is why it is imperative to work with a specialist, so that he/she can sort out whether toxicity, if any, is due to medications, to supplements, or to the virus itself. The toxicity that I experienced was indeed due to my HAART regimen, but my specialist recommended that I stay on this combination and be monitored monthly because the toxicity was not very high.

Because I am aggressive about my health, I asked for a liver biopsy. A liver biopsy is a tiny sample taken from the liver (it doesn't hurt) and examined under a microscope. Scientists can see the level of liver damage and make correct diagnoses and suggestions for treatment. The results from my biopsy showed minor inflammation, no scarring or cirrhosis (fibrous tissue, a response to trauma), and no treatment was recommended.

As with HIV, there is great momentum in the development of HCV treatment. Today we have combination therapy with interferon with ribavirin, and in the near future we will have pegylated interferon (a time-released interferon) and pegylated interferon and ribavirin. The response rate to HCV treatment with pegylated interferon and ribavirin in [very small, early] clinical trials is approximately 40% for genotype 1, and 80% for genotypes 2 and 3.

I believe that everybody, with the help of a support team, can find a program that works. Since being co-infected can make HCV or HIV worse, I monitor myself and see my doctor every two months. I am encouraged by the advances we have made and see a bright future. I take care of myself the best that I can, one day at a time, so that I can take advantage of what the future will have to offer. This means that I eat good, healthy food; exercise regularly; and get plenty of rest. I drink lots of water, no caffeine, and definitely no alcohol. (If you want to do one great thing for your liver, stop all alcohol consumption and replace it with water!) As with HIV, living with co-infection has many challenges that may warrant a lifestyle change. I just celebrated 10 years of sobriety/recovery, and if I can meet that challenge, anyone can. My mission statement in life is empowerment: Empowerment to live, empowerment to grow, and above all, empowerment to give back.

Gerald Moreno is a screening coordinator and health educator at the University of California-San Diego Treatment Center. UCSD is a research facility and is currently conducting clinical trials for co-infected individuals (people who are living with HIV and HCV), and some of these studies include pegylated interferon. For more information, contact Gerald Moreno at 619-543-8080 ext. 237.

Editor's note: Thanks to Gerald Moreno for sharing his story and this information, and to James Learned at CRIA for his review and comments on this article.

HIV 101 for Women

by Laura Jones

Trying to write a brief "HIV 101 for Women" article is a pretty big challenge for the Red One here—so many issues, so little space. There's clinical stuff about women's bodies metabolizing medications differently than men's… there's anatomical issues that make it easier for women to become infected…there's always women's health issues, including pregnancy…but that could be a whole article in and of itself.

So, to meet my deadline, I'll say this:

…working with an HIV specialist who is knowledgeable about women's health can help you better navigate…questions …about how HIV disease and antiretroviral therapies work in women's bodies.

Remember: You Are Not Alone

Our friends over at WHO, NIAID and CDC tell us that both the number of women who are becoming infected with HIV and the number of women diagnosed with AIDS are increasing. There was that huge jump in U.S. women's AIDS cases between 1985 (7% of total cases) and 1998 (23% of total cases). Since 1999, we've been hanging steady at 23% here in the U.S., but that may more be due to improved antiretroviral treatments than anything else. New HIV infections continue to increase, especially among adolescent women *and* women over age 45. African-American and Latina women are disproportionately affected: they account for more than 77% of AIDS cases in women, but make up only 25% of the total population of women in the U.S.

Globally, it's a pretty crappy scene for women: an estimated 16.4 million women were living with HIV/AIDS worldwide as of December 2000, making up 47% of the estimated 34.7 million adults living with HIV/AIDS. Since the vast majority of HIV-positive children acquired their infection from their mother during pregnancy or birth, the majority of children's HIV/AIDS cases can be directly attributed to the epidemic among women as well.

I offer these numbers to encourage us, not to drive us deeper into despair—if this many women are living with HIV/AIDS, then HIV-positive women have a lot of company. We can use those numbers as an advantage, if we can all find a way to work together to bring about the changes necessary to improve the lives of positive women and options for HIV-related care.

Find Support

HIV disease isn't something folk should have to deal with on their own—especially women. With all the other work women have to do, they can't afford to drain their health away trying to cope with the stress of living with HIV in a vacuum. Women need (and deserve!) decent healthcare, emotional support, and practical support on days when they feel like shit. They also need an outlet for the emotions that come up while they're struggling to survive and flourish in their daily lives.

If we don't all do this, our heads will explode. It's that simple, and we can't afford that right now.

If you are HIV-positive and trying to do it all on your own, check to see if there's an HIV/AIDS organization or program in your area that focuses specifically on women. Many community organizations, hospitals, and clinics offer such programs, which generally include support groups, forums on practical issues like navigating healthcare and public assistance, and education on health topics specific to HIV-positive women. Some women's jails and prisons are beginning to recognize the need for these services as well, resulting in linkages between medical and community organizations and the facilities—

incarcerated women deserve the same care and support as women on the outside.

If there is not such a program or organization in your area, consider working with an established HIV/AIDS organization or health program to develop women's programming. If you are not a "group" or "program" kinda lady, then please find friends and family members you can talk with and rely on to support you emotionally and practically. Trying to do everything all on your own isn't a show of strength—and it could hurt your health in the long run.

Find A Good Doctor (and a Good Gyne, too)

The obstacles to obtaining decent healthcare are too numerous to detail here, so I don't take that suggestion lightly—it's hard to find a good HIV doctor, especially one who is also knowledgeable about HIV-positive women's specific health issues and concerns. And it's hard to get to all those appointments, and take all the meds, etc. But all of us need to do it if we can, because we're worth it.

Contrary to popular belief, HIV disease doesn't progress more quickly in women than in men—at least, there's nothing about our bodies in and of themselves that makes the disease progress more quickly. However, women are more frequently diagnosed later in HIV disease than are men, which can reduce options for successful treatment and prevention of immune system damage early in infection. Additionally, there are ways in which HIV disease manifests itself differently in women than in men, as well as special concerns that women have and men do not (cervical cancer, pregnancy issues, etc.). Since most HIV research and clinical trials have focused on men during the last 20 years, working with an HIV specialist who is knowledgeable about women's health can help you better navigate the largely unanswered questions we all have about how HIV disease and antiretroviral therapies work in women's bodies.

Here's Stuff For All of Us To Check Out!

Project Inform has great information for HIV-positive women. You can find them at http://www.projectinform.org, or you can call their toll-free Hotline and speak to a real live person: 1-800-822-7422 or 1-415-558-9051 (in the San Francisco Bay Area or internationally), Monday–Friday, 9 am–5 pm and Saturday, 10 am–4 pm Pacific time.

Women Organized to Respond to Life-threatening Diseases (WORLD) publishers a monthly newsletter full of moving personal stories and medical information. Free for HIV-positive women, all others please send a donation. Contact WORLD at 414 13th St., 2nd floor, Oakland, CA 94612. Call 1-510-986-0341.

The Health Resources and Services Administration of the HIV/AIDS Bureau has recently published ***A Guide to the Clinical Care of Women With HIV: 2001—First Edition.*** Free copies are available, and readers are encouraged to send comments and suggestions for the second edition—feel free to add yours! Order forms are available at http://www.hab.hrsa.gov/womencare.htm, email womencare@hrsa.gov fax 1-301-443-0791, or you can send requests and comments to: Womencare, Parklawn Building, Room 11A-33, 5600 Fishers Lane, Rockville, MD 20857.

And, of course, there's *Positively Aware* (you're reading one right now!). *Positively Aware* is dedicated to providing information that's helpful for all HIV-positive people, including women.

So I'll say it again: Women, Love Yourselves! Love yourselves even when it's hard, and even when you don't want to—because at the end of the day, that's the basis of HIV 101 for Women.

Pickett Fences—A Work in Progress

by Jim Pickett

A conversation with a man—

I really really like you... I think I like you a little more than like.

Let's take this slow.

The latest T-cell numbers are in and they're 385. Slowly but surely, down down down they've gone, a steady spiral in slow-mo. However, I stopped taking HIV drugs over a year ago. The viral load stays virtually the same in the 20-70,000 range so the immune system is still doing its job. Good boy! But for how much longer? I didn't always require an afternoon nap, did I? I know I used to have over 1,000 T-cells, back in the day. I have 385 now, and our friends at CDC say its a good idea to start treatment when they're at 350. The train is coming to my stop. Do I get on? Do I let it pass me by, again? Can I pay the fare if I do get on? Can I avoid the stops at Buffalo Hump and Burning Feet, skip Liver Failure, Heart Attack, and Deadly Rash, glide past Gastrointestinal Discomfort and go express to Vivid Dreams—Not the Scary but the Sexy, Trippy Kind?

More than one person—

Have you lost weight? You look great.

A conversation with an activist—

We all know oral sex accounts for next to nada in transmissions. It's fucking. What if we could encourage positive guys to only fuck positive guys? And for negative guys to only fuck negative guys? There are no immaculate infections. What if we promoted segregated fucking?

A conversation with our future—

I'm speaking to a group of junior and senior high school students who are all planning to work in the medical field. Questions. Why would you want to have sex if there's any risk involved? Would you stop having sex? What did your mom say? Do you know how long you may live? Answers. Let's see. I had risky sex knowing full well the risks I was taking because, uhhhhhhhh… I won't stop having sex. Does that make me selfish? Bad? She doesn't know. And, well, I tested positive in August of '95 so that's six years… and I could live maybe 10 or 20 more, maybe into my forties or fifties, I don't know.

News flash!

Circuit parties are big multi-day affairs with lots of boys who come to boogie, bond, drink spring water, and have lots of sex, lots of it unsafe. Unsafe meaning unprotected anal intercourse, top or bottom, with a man of unknown or divergent serostatus. Oooh, and there's lots of drug use too.

Our sexy surgeon general, David Satcher, incites the Administration and other roving bands of misfit boys by daring to say safe sex must be taught as well as abstention. He also says its okay to be a big ole fag or major dyke and that there is no evidence to indicate one can remove or replace one's big fagness or major dykehood. I want to marry this man. At the very least create a cyber fan page or stalk him online. I love you, David!

Fact: The drug companies spent more on advertising than on research and development in the year 2000. Over two times more.

Rumor: The drug companies are pulling out of HIV research and development altogether, or scaling back considerably, cuz they gotta give too much of the shit away now.

The truth hurts… Rumors are sometimes true… Is that the horn from my train approaching?

A CONVERSATION WITH AN AOL FOOL—

An HIV-negative AOL fool. Or so he says.

But it's a risk I'm willing to take.

I'm not willing to be the one you take it with.

But I can't get off with condoms.

Well, then you can't get off with me.

(Good-bye.)

So, hey kids, how's that vaccine research coming along? Where are we at with microbicides?

Question from the same group of teenaged aspiring doctors: Do you think there will be a cure?

No, I don't. I don't think there will be a cure. HIV is too good. We'll never figure it out. There is no profit incentive. I can't even pray for a cure, it's just setting yourself up for a letdown. Like falling in love, or being in that really really like, more than like fog. I like to pray for realistic things, things that I can envision being reality, like reality television, like Fear Factor, like The Real World—Chicago. When I play a buck on the lottery and don't win, I feel sad. So I stay away from the lottery. I feel sad thinking about a cure, because I just don't see it happening, just like I don't see my buck becoming ten million. Sorry… cynical here. I am more hopeful for vaccines and for better methods of protection like microbicides. Both would expand our safer sex choices beyond the shrill one-note of condoms condoms condoms. And I am more hopeful of expanding awareness, improving prevention, decreasing stigma, dismantling barriers to services and addressing health disparities. Super fancy terminology for lofty goals we have a long long long way to reach. But still doable. Still possible. Not too crazy.

A CONVERSATION WITH A MAN—

Let's promise to never use that word. You can think it, just don't say it.

Gotta run. Got a train to catch or not.

TPAN Calendar of Events

All events held at TPAN unless indicated otherwise.
For additional information on these events please contact Keith Waltrip, Program Director, at (773) 404-TPAN (8726)

SEPTEMBER 2001

Date	Time	Event
Friday, 7th	6:00 pm	TPAN Gala 2001 at Germania Place, 108 Germania Place, Chicago, IL Contact Patrick at (773) 404-8726 for tickets.
Tuesday, 11th	6:30 pm	Community Advisory Board Meeting
Tuesday, 18th	7:30 pm	TPAN Board Meeting

OCTOBER 2001

Date	Time	Event
Tuesday, 9th	6:00 pm	Research Update - Adherence
Wednesday, 10th	6:30 pm	Hep A&B Community Forum
Tuesday, 16th	7:30 pm	TPAN Board Meeting
Thursday, 18th	6:30 pm	ICAAC Update - The 41st Interscience Conference on Antimicrobial Agents and Chemotherapy
Thursday, 25th	6:00 pm	Treatments for HIV & Lipodystrophy Community Forum, Speakers discuss late-breaking news and surgical repairs. Guests include: Martin Delany, Dr. Jorge Tagle, Dr. Daniel Berger Call NorthStar Healthcare at 773-296-2400

Programs and Meetings

All meetings held at TPAN offices unless otherwise indicated:
1258 W. Belmont Ave., Chicago.
Office hours: Monday–Thursday, 9 am–8 pm. Friday,
9 am–6 pm phone: (773) 404-TPAN (8726) • fax: (773) 404-1040 •
e-mail: tpanet@aol.com • www.tpan.com

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

Monday

TPAN Daytimers

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

Newly Diagnosed

A group for newly diagnosed individuals. Mondays at 7:30 pm. 2nd and 4th Mondays includes HIV 101 education.

Negative Partners

The Negative Partners of Positive People. 3rd Monday at 7:30 pm.

Tuesday

T.R.I.B.E.

An educational discussion group for Gay Men of Color focused on maintaining a healthy lifestyle. 2nd and 4th Tuesday at 7:00 pm.

Living Positive

HIV-positive gay men discuss how being positive affects relationships and deal with the impact of HIV as single men. Tuesdays at 7:30 pm.

Positive Progress

A group for HIV-positive people in recovery. Tuesdays at 7:30 pm.

Wednesday

Medical Clinic

See description in Friday's listing. Wednesdays 3:30 pm–7:30 pm.

Straight Talk

A group for HIV-positive heterosexuals. Wednesdays at 7:30 pm.

Needle Exchange Program

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

Yoga

Wednesdays at 7:30 pm.

Thursday

TPAN Daytimers

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

Medical Clinic

See description in Friday's listing. Thursdays 2:00 pm–5:00 pm.

Needle Exchange Program

See description in Wednesday's listing. Thursdays 2:00 pm–5:00 pm.

Brothers United in Support (BUS)

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

Berlin HIV-positive Social Hour

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

Friday

Medical Clinic

Free medical care provided by a nurse practitioner. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Fridays 2:00 pm–5:00 pm.

Needle Exchange Program

See description in Wednesday's listing. Fridays 2:00 pm–5:00 pm.

Meditation

Fridays at 7:00 pm

Safe Passage

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

Scheduled By Appointment

Family AIDS Support Network (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 404-1038.

Women's Group

A group for HIV-positive women. Call Sylvia at (773) 404-8726 for more information.

Speakers Bureau

Individuals are available to community groups and organizations to educate on HIV, safer sex, harm reduction and experiences of living with HIV. Call Sylvia or Keith at (773) 404-8726.

Peer Support Network

Provides one-on-one support for recently diagnosed individuals. Volunteers provide support, information and referrals. Call Derek at (773) 404-8726 to get a buddy!

Positive Buddy

Volunteers provide individuals living with HIV/AIDS one-on-one emotional / physical support. Call Derek at (773) 404-8726 to get a buddy!

Chris Clason Resource Center

Find the latest news in the Chris Clason Resource Center. Open Monday through Thursday 9:00 am–8:00 pm., Friday 9:00 am–6:00 pm.

Miscellaneous

ChicagoPos18to24 at aol.com

AOL chat room for young adults (ages 18-24) who are HIV-positive. Hosted by TPAN's Young Adult Program. Go to AOL town square. Monday through Friday 3:00 pm–6:00 pm, except Thursdays 4:00 pm–6:00 pm.