March / April 2002

Positively Aware

The Journal of Test Positive Aware Network

An HIV Treatment the World May Never See

More News from ICAAC

Mixing and Matching Meds

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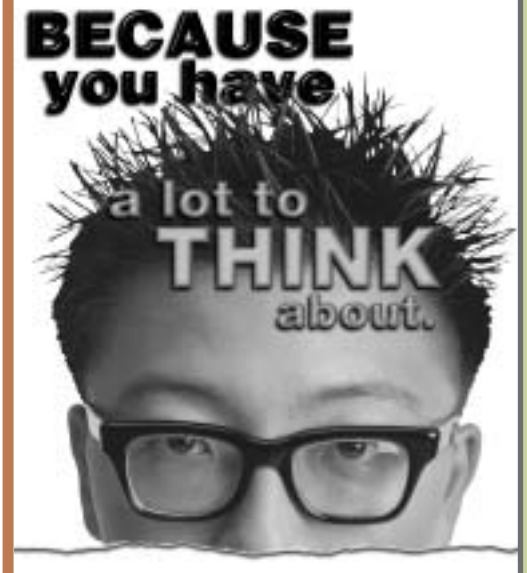

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Editor's Note

HIV Activism, it's Necessary

Over the weekend of February 23-24, 2002 a large group of HIV activists, treatment advocates and people living with HIV met in Seattle under the umbrella of the AIDS Treatment Advocates Coalition (ATAC) and the Coalition for Salvage Therapy (CST) to discuss the past, present and future of activism.

ATAC is a national coalition of people living with HIV/AIDS and advocates working together to end the AIDS epidemic by improving HIV research and treatment access. ATAC, like the Black Treatment Activist Network (BTAN), is driven by a core group of activists committed to building a national coalition to improve AIDS research, treatment access, and empowerment of new activists in communities most affected by the epidemic. These groups seek to encourage greater and more effective involvement of all people with HIV in the decisions that affect their lives by identifying, mentoring and empowering new treatment activists in all communities affected by the epidemic. The goals are very ambitious, but basically revolve around enabling people with HIV/AIDS and their advocates to provide meaningful input into HIV disease (visit www.atac-usa.org and www.blackaids.org).

Now, it would be much easier to sit on the sidelines and throw daggers like, "Not another HIV coalition." "Those people who have been in control for so long they will never share their power." "What's the sense in wasting my energy and time?" However, we are at a critical point in the HIV/AIDS struggle given the current political, social and economic climate in the U.S. We can no longer afford to sit on the sidelines and bitch and moan about what's not being done, or how it's being done wrong.

If you are living with HIV, if you are a service provider, if you work for or volunteer for a community based organization, or if you're a member of a local HIV planning group the reality is that doing business as usual is not going to cut it any longer. Being apolitical and fixing blame is no longer an option. Nothing is guaranteed any longer. The very future of HIV drug development, ADAP and HOPWA programs are all up for grabs. And if you believe that slogan "use a condom every time" is outdated, try to imagine a future where the distribution of condoms (as a risk reduction tool) is no longer an option. It's possible.

What power do we have against the pharmaceutical industry and government? One answer voiced at the meeting was that our power is housed in the ability to make change. Our charge is to overcome the urge to resist collaboration. To assume good faith in each other when conflict and tension arises; to communicate without condemnation. And as activist Julie Davids of Philadelphia reminded us, as a coalition we should "strive for power among, not over, each other."

Everything changes. Leadership changes. Administrations change. Public policy changes. Drug development changes. Relationships change. It's a fact of life and it's a good thing. But the facts are that when processes don't reflect change, they become stale, people become frustrated and bitter, while others take flight.

However, the reality of change is that all change includes loss. And because loss is involved in the process of change, many people are resistant to change. So how should we navigate in these troubled times?

I believe that the indicator of a vibrant movement or strong leadership is knowing when it is time to shake things up, when it is time to share knowledge, when it is time to pass the torch, and encourage the "next generation" to assume leadership and responsibility, for better or worse. It's not an easy task, but ATAC and BTAN have demonstrated an initial commitment to this process.

Continued on page 16

photo by Russell McGonagle

Why Are There New Cases of HIV?

Why are men and women in this country continuing to become infected with HIV at the rate of 40,000+ per year? Why, after nearly two decades of prevention and education efforts are individuals still engaging in activity that places them at risk?

Is it the "sexy" advertising from the drug companies? Do pictures of buff women and men climbing mountains and sailing, thanks to the anti-HIV medication they are taking, encourage people to become infected? Does a muscled arm holding a rose encourage risky behavior?

Is it because communities heavily impacted by HIV are not seeing large numbers of people dying? Is it because infected men and women no longer look as sick as their counterparts of a decade ago?

Is it because children and young adults are not being given sufficient education about safer sex and the dangers of sharing needles? Does sex education that teaches only abstinence or that doesn't discuss condom use leave teenagers uninformed on simple methods to reduce their risks?

Is it because people engage in risky behavior to be "accepted"? Is it because the need for someone to show some interest, some caring, is so strong that we are willing to place ourselves at risk for HIV infection?

Is it because people no longer fear HIV? Do people think that HIV is not around? Or do they think the medicines are a cure—that "having HIV" is no big deal?

It is all of the above in some combination. That is why prevention is so difficult. That is why we continue to see new infections in numbers that seem completely preventable.

The underlying reasons behind continued HIV infections are many and complex. They are individual in nature (the need for acceptance, low self-esteem, etc.). And they are broader societal norms and beliefs (incomplete sex education, "second class citizens", etc.). Some are easily addressed (broader access to condoms and clean syringes) and some are very difficult to address (improving self-esteem).

But at the heart of it all, at the very core, lies responsibility for yourself. Take away all the glitzy drug ads, the hype about how much better sexual intercourse is without a condom, the delusion (or misunderstanding) that HIV is not a threat or is treatable; take away the many other reasons surveys uncover for risky behavior and you get to the single critical factor—responsibility.

Each of us must understand that ultimately we are responsible for our own health and safety. Each of us, especially those who are not HIV positive, must understand that nearly all HIV infections in this country are the result of freely chosen acts. This is not an attempt to blame the person who becomes infected. Rather, it is a call for all of us to accept that we are responsible for our own actions. If factors in our lives, from peer pressure to low self-esteem to excessive drug and alcohol use are permitting us to engage in risky behavior, we need to look at addressing those factors.

It is also a call for us, as a society, to help address the underlying factors. We need to create an environment, through discussion and peer pressure, that discourages risky behavior while encouraging more complete education about HIV and its prevention. We need to support each other in abstaining from risky behaviors, while at the same time reinforcing the idea that such behavior is the result of self-choice. And we need to do this in a supportive manner, not one that places blame.

Dennis Hartke

Dennis Hartke
Executive Director
Thoughts, comments, reactions? Write me at ed@tpan.com

photo by Russell McGonagle

Readers' Forum

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What about vaccines?

Vaccine, vaccine, vaccine. I'm disappointed with your recent 2002 Drug Guide. Not for its information, but for its cheery, consumer, sales-brochure appearance and the message which it continues to send. Yes, I use some of these drugs, and they have probably saved my life, but at the cost of almost constant nausea, diarrhea, anemia and lipodystrophy, with even more drugs piled on to combat these conditions. Twenty years of HIV research—enough is enough. The 2001 index shows only two articles related to vaccines. There is not a single listing for immune system reconstitution! I am tired of being a guinea pig and a cash cow for your sponsors. Where is the incentive to cure this disease and ironically, to put *Positively Aware* out of business? Obviously, nowhere on the drug companies' balance sheets. Will we find vaccines at the top of *Positively Aware's* advocacy agenda in 2002? Whose side are you on?

Timothy Craig,
McMinnville, Oregon

I read your "I'm tired" editorial in the November/December issue, when I went in to get my HIV test results—negative, thank goodness. I'll tell you what I'm tired of—insulin potentiation therapy (IPT) being ignored by the medical establishment. And by HIV/AIDS patients, too. In IPT, insulin makes regular drugs act like super drugs. For HIV/AIDS treatment, it may help deliver antiviral drugs better into hidden compartments of the body, where viruses can hide, like the brain or spinal cord. This transport ability of insulin has been known since Donato Perez Garcia discovered it in 1926, but no one is doing anything about it. He was the only doctor who could cure tertiary (neuro) syphilis, the AIDS of the day, before antibiotics, and should have gotten a Nobel Prize.

Dr. Perez's son and grandson treated several AIDS patients in the late 80s with IPT, and got incredibly good results, quickly clearing up all symptoms and secondary infections. But no one did anything about it. All the billions of dollars spent on research, and nothing spent on IPT research. I hope that you will look into this, and that you would publish this information. I wonder if you would, because your publication is clearly supported in a major way by lucrative ads from drug companies. But I felt that I just have to give you the chance.

Chris Duffield, Ph.D.,
Stanford, CA

Editor's Note: It is true that the ads of drug companies "support" the publication of Positively Aware *and* Positively Aware en Español. *These ads also make it possible for TPAN to print and distribute 100,000 copies at low cost or no cost to our readers and agencies across the U.S. We would truly love to cover more topics of interest and importance, however, the reality, for this not-for-profit publication, is that space and financial restrictions are real, and limit what we can do. The ad revenues have never and will never dictate content of the journal. I'm sure there are some companies who don't advertise with us because of content. I acknowledge those drug companies who support the unbiased treatment information we provide and all the writers who contribute their knowledge and work at no charge. Without these two groups and the dedication of Enid Vázquez and Jeff Berry there would be no* Positively Aware.*—Charles E. Clifton*

So tired

Yes, I'm also tired. Having tested positive 16 years ago, I've lost too many friends to count (or cry anymore). I've had so many opportunistic infections, I can't remember them all. And today, with the world thinking that AIDS is over, I'm tired of explaining to people, even other PWAs [people with AIDS], why I'm still dealing with CMV retinitis, microsporidiosis, and esophogeal thrush, when they all think these miracle drugs have healed everybody. And I'm tired of going online only to find guys ready and willing to bareback. Have they all forgotten what it was like, or don't they have any dead friends? Or have the light bulbs in their heads gone out? But I still get an occasional "How do you stay so upbeat?" I guess it's just that after seeing it all, the only thing I can do is be a little piece of positive energy in this whole mess. Maybe in some way, I might make a difference in one person's life. So I volunteer on a hotline, listening without judging, as tough as it is sometimes, hoping to make a small difference in the world. Am I dreaming? Maybe I was getting so tired, I fell asleep, and it is all a dream. Keep up the good work.

John Lesnick,
via the internet

I'm grateful for editors such as you, Charles Clifton, whose personal values, professionalism and strength make an already excellent publication even better. For men and women of passion who aren't afraid to express their deepest feelings and for executive directors of those organizations who sanction and provide freedom of expression. For publications such as *Positively Aware* that give us the real information and not the fluff of other "HIV journals." I don't really care

how Shirley McLaine deals with HIV in her world. What I care about is knowledge that can save lives, and I find that in your journal. I'm grateful that after 20 years or more of this epidemic that there are organizations and people within them that care on the level you do. No, it's not easy to keep the pace and no it's not always easy to slap on that condom, and no it's not easy to talk to our children about safe sex practices, especially when we don't always follow the guidelines we promote. However, it is always good to be reminded of the consequences of our behavior. I'm grateful for articles from Jim Pickett (all you need is love) and Enid Vázquez. I'm grateful for these people because they are on the front lines. I'm grateful that this particular issue of *Positively Aware* was exceptional, and Charles, since you have become editor every issue just gets better. I'm grateful for my children, I'm grateful that we have a dialogue on sex and safe sex practices. I'd welcome any one of you into my life and my home and my community to share your experiences and knowledge. I'm grateful for having lived in Chicago when TPA Network first started and grateful that even at a modest level I can still support you. I'm grateful for having known my friends, those who have succumbed to HIV/AIDS and those positive still alive, because from them I learned about life. I'm grateful that even in some small way, even if it's just the AIDS Walk, that I can contribute to the cause. I'm grateful every time I see a panel of the Quilt. It always moves me to tears and up until I came out to my children they could never understand why. I'm grateful you recognize and grieve Antonio's death some 15 years ago, I would expect nothing less from a man of your caliber. Don't only wonder what could have been...wonder about what is to come! I'm grateful that we are still alive and vibrant human beings capable of sharing with each other our pain, love and the majesty of life. I'm grateful that even in the face of HIV/AIDS we can still love and be loved. Yes, I'm tired of the games we play with each other but I'm grateful that I still believe at some point even the most hardened of us will begin to live our lives in honesty and dignity, and with love and compassion. It's the hope I cling to. I'm grateful that you all are doing what it is you know how to do best. I'm sure you're tired, stressed, depressed and overwhelmed, but remember that there are thousands of people like me who gain experience, strength and hope from what you're doing, and for that I'm not tired. I am grateful. Keep on fighting the fight.

Brent Reid,
via the internet

Sustiva syndrome

I want to thank you for your speedy reply on my letter asking for help in regard to the false positive Sustiva syndrome. Mucho thank you for the copies of the article, "Sustiva Dirty Drops Put Prisoners in Solitary." If I never would have come across your magazine, I would have thought that the Sustiva false positive syndrome was just another rumor. It is important to us to know this fact since many inmates are being placed on "keep locked" status or placed in the "box" for positive urinalysis while they are on Sustiva. Other magazines wouldn't dare print any information that may reflect some negative aspect of a pharmaceutical corporation's medication for fear that they will lose advertising revenue. So it is only fair that I thank *Positively Aware* for being on the front line of a very serious fight. The work you do is very much appreciated.

Name withheld,
Comstock, New York

Editor's note: Kevin Lisboa, an ex-prisoner from New York state who has written for Positively Aware*, says you need to write to your Deputy Superintendent of Security and ask him or her to contact the medical staff for a letter regarding Sustiva's potenial for causing false positive results on drug tests. Kevin was able to keep himself out of solitary while other inmates weren't as lucky. He suggests including any literature you can, such as our article. He also states that prisoners should bring this matter to the attention of their security supervisor right away, before it becomes an issue.—EV*

AIDS and prison

I have read a lot of stories about people doing time and having to deal with an ignorant system when it comes to getting health care. Back in June of 1994 I was sent to a county jail in Massachusetts for assault and battery on a police officer. I received a one year sentence just two weeks later. Justice is fat for the poor. When I went in the house of correction I was on the methadone program. I was on 120 mg, plus I was doing 30 bags a day. I had just gotten five credit cards in the mail about four months before I went to jail, so I was on a roll. At the time of my booking, I was 180 lbs. Within two days I was in withdrawl. I was sick as a dog for months. It took me at least four months before I could get a few hours of sleep per day. Right after the holidays I started to lose a lot of weight. I had a hard time breathing, going up stairs, etc. I went to medical. I was told I was just complaining and to take Sudafed and vitamin C. By March of 1995 I was down to 100 lbs. When the other cons told the medical people I could not eat or walk, they got off their asses and gave me a chest X-ray. It was PCP [*Pneumocystis carinii* pneumonia]. They sent an ambulance into the jail to take me out. I never knew before that I had AIDS. My T-cells were 46. Back then they did not have the viral load test. Anyway, I did 22 days in and outside the hospital, chained to a bed, IV's hooked up to me. I couldn't take three steps without being out of breath. But I was just complaining. That's what I was told months before. The dogs almost killed me. When I went back to the jail, it was a Friday. All the people in charge of me were gone until Monday. I gave the med orders to the nurse in charge that 2nd shift. The next morning I asked the guy who brought the med cart around where my meds were. He told me I was not on any list. I told him how I just did 22 days in the hospital. I was on AZT, and all the other meds. He told me he would get back to me. He never did for the whole weekend. Plus I was on oxygen. These lazy county workers could get me sick all over again. I wrapped up my sentence 12 days later. Thank God I got away from them. A year before that two AIDS patients died in the same Pod. I would love to give them the health care they gave me. There are good people who care. But there are not enough to protect us from the lazy dogs who couldn't care less about the junkies. Every dog gets his day. I hope they get theirs.

Via the internet

News Briefs

by Enid Vázquez

photo by Russell McGonagle

New Sustiva pill

The popular once-a-day Sustiva (efavirenz), potent and easy to take without too many side effects (but in some cases a little problematic—see *Sustiva Electric Dreams* on page 23), is now available as a one-tablet dose. You can now take a 600 mg tablet instead of three 200 mg capsules. The tablet is roughly the same size as one of the capsules. There's also a 300 mg tablet now available for the people who take Sustiva twice a day (not recommended for most because of its potential for a sedative effect). The cost of the new formulation is the same. The capsules are still available.

Not actual size.

African American HIV drama wins award

The Black Filmmakers Hall of Fame awarded first-place prizes for television special and health education to the Chicago Department of Public Health for its one-hour drama "Kevin's Room." The television pilot follows the stories of young African American gay men as they come to terms with their sexual orientation and a positive HIV status. The outstanding program was originally broadcast April 18, 2001 on Chicago's UPN station. Kudos to CDPH for an important and innovative work for reaching the masses in a highly effective style.

South Africa ordered to provide HIV med

Thanks to a lawsuit brought by HIV treatment advocates, the South African High Court ruled in December that the country's government must provide positive pregnant women with the drug Viramune (nevirapine) to prevent transmission to their infant. The medication has proven to greatly reduce transmission to infants at a low cost, easily, with minimal side effects, around the time of birth. Clinical trial sites include South African cities. The court ordered the government to produce a plan for implementation in three months. Manufacturer Boehringer-Ingelheim has offered the drug free to South Africa for use in pregnancy, but the government has stalled the process.

Larry Kramer gets liver transplant

Prominent playwright Larry Kramer, an HIV-positive gay man and founder of both ACT UP (AIDS Coalition to Unleash Power) and Gay Men's Health Crisis, received a liver transplant in December. Transplants for positive people—many of whom suffer severely from liver disease—are still controversial. But times are changing and medical centers realize that the transplant survival rate for people with AIDS or HIV is much greater now than might have been possible before. Kramer has hepatitis B and had been close to death. The surgery was conducted at the University of Pittsburgh Medical Center, which now has 10 transplants for HIV-positive people to its credit.

Adherence survey

It's for a good cause. The AIDS Action Committee, in Boston, and Florida State University have posted an adherence survey on the internet. AIDS Action tells us that, "The adherence survey is a short set of questions designed to help you learn more about taking HIV medications.…There will be no way for anyone to connect your answers to you. This site does not use internet 'cookies' to track you or to find out any other information about you. We do not sell or share our lists." Visit http://www.aac.org/hivhealth_adherence_survey.html or go to www.tpan.com and click on adherence survey link. Questions can be sent to study coordinator Neil Abell, nabell@mailer.fsu.edu.

Prison tales

Amazing. The HIV/AIDS Awareness Program (HAAP), a non-profit organization located within Oregon State Penitentiary, has published a book,

Voices from Within: An Anthology of Prisoners' Expressions on HIV & AIDS, to raise money for their program. How innovative. And perhaps the writers came to know the powerful emotional release and the insights that can be gained by writing down personal experiences. That alone makes the book worthwhile. Many of the more than 50 pieces suffer from sentimentality, but others get to the core of what living with HIV is about.

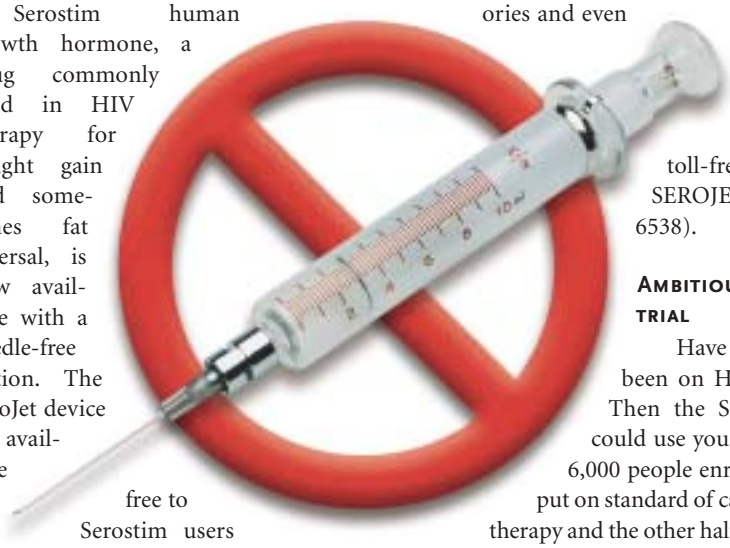
In "One Last Smoke," Anthony Rozzell says, "How painful when he had a rash on him that looked like some kind of psoriasis and he would ask me to apply his medication in places he couldn't reach. Or the time his toenail just came off, the whole nail, and he showed it to me. Then the conversation about death and dying. He would tell me, 'Tony, I'm ready to die. I'm just tired of being sick and taking all the pills.' What do you say when your friend, someone you love and cared about, has come to this stage in life, when death is more welcomed than life."

In "My Friend, Steven," Darrell DeMotte says, "One of the last things Steven told me is that life is so short. It's meant to be shared with someone, and that no matter the heartache one goes through in life, never let bitterness or anger consume what is good."

For a copy of the 100-page, 8 1/2 by 11 book, send $10 plus $3 for postage and handling to CIC Inc. ATTN: HAAP, 1108 N. E. Going St., Portland, OR 97211.

Needle-free Serostim

Serostim human growth hormone, a drug commonly used in HIV therapy for weight gain and sometimes fat reversal, is now available with a needle-free option. The SeroJet device is available free to Serostim users (the drug itself is extremely expensive). "[Using] a coiled spring mechanism, SeroJet delivers a finely dispersed, high-pressure stream of Serostim through a point of entry in the skin that is five times smaller in area than that of a standard 28-gauge needle injection," says a company press release. The device should be attractive to needle-shy people, including those in recovery from injection drug use (the sight of an injecting needle can trigger bad memories and even relapse). For more information, call toll-free 1-866-SEROJET (737-6538).



Ambitious clinical trial

Have you never been on HIV therapy? Then the SMART trial could use you. Half of the 6,000 people enrolled will be put on standard of care anti-HIV therapy and the other half will only be put on therapy when their T-cells drop below 200. These folks will be taken back off therapy if their T-cells go back above 350. Positive people over the age of 13 are eligible. This is a huge trial. It seeks to overcome the nagging doubts of the common short-term studies that are basically used to bring drugs to market. Here, research will be looking at Strategies for Management of Anti-Retroviral Therapy (SMART). To start or to wait? That is the question. The study is being conducted by the Community Programs for Clinical Research on AIDS (CPCRA) under the sponsorship of the National Institute of Allergy and Infectious Diseases (NIAID), a part of the National Institutes of Health.

"This approach of not using antiretroviral medications when CD4+ T-cell counts are higher and when the risks of complications of HIV are low could have the advantage of reducing side effects, drug resistance and cost, while saving antiretroviral medication options for a time when the risk of complications from HIV begins to increase," said Dr. Wafaa El-Sadr, principal investigator at Harlem Hospital and Columbia University in New York City and co-chair of the study. Study sites include Philadelphia FIGHT, the Community Consortium of San Francisco, the VA of Greater Los Angeles, and the AIDS Research Alliance here in Chicago. Visit www.smart-trial.org and www.cpcra.org.

Editor's Note *continued*

Continued from page 7

A core group of national HIV activists have been very successful at working the "insider" and "outsider" strategy to effectively improve HIV research and treatment access during the last 20 years. However, this group of highly experienced activists is overcommitted. Therefore, they are dead-serious about their efforts to encourage more people living with and impacted by HIV to engage in the decision-making process on the level of drug development, clinical research and public policy.

We are at a critical point in the fight against AIDS. A change is upon us. How will you, your organization, and the groups in your area respond at this moment? Will you be part of the problem or part of the solution?

If you don't become political about HIV/AIDS now, you may have nothing at all to be political about.

Charles E. Clifton
Editor
Send comments and reactions to publications@tpan.com

More News from ICAAC

by Charles E. Clifton and Enid Vázquez

Switching studies

In the SWATCH study (Netherlands), 69% of participants who switched between two different regimens every three months attained viral loads under 400, as compared to 57% of individuals who remained on the same regimen for 48 weeks. One group of 52 participants took Zerit, Videx and Sustiva. A second group of 54 took Epivir, Retrovir and Viracept. The third group of 55, the switching group, alternated between the two regimens. T-cells were not statistically different among the three groups, however, cholesterol increased significantly among all three groups, when compared to baseline. Participants on Sustiva had an increase in HDL cholesterol levels, and Viracept treated individuals had an increase in LDL cholesterol.

At 48 weeks, the 106 participants who switched to Trizivir (Ziagen, Epivir, and Retrovir) from HAART (highly active antiretroviral therapy) regimens, continued to have the same rate of success (78%) of maintaining a viral load less than 400 as the 103 participants who remained on the same HAART regimen. In order to enter the study, participants had to have a viral load less than 50 and to have been on their current regimen for more than six months. The study also reported a sharper decline in fasting cholesterol and triglyceride levels in the participants who took Trizivir.

PI mutations

In a study designed to observe protease mutation patterns associated with lopinavir, data at 96 weeks shows no drug resistance in treatment naïve participants who were given a Kaletra-based regimen. Of the 326 individuals taking Kaletra in combination with Zerit and Epivir, 40 experienced a viral load rebound (greater than 400), but none had a protease inhibitor resistant HIV by genotypic testing.

Resistance rampant?

Data from the HIV Cost and Services Utilization Study (HCSUS) indicated that 78% of HIV-positive adults, treated in early 1996, who had detectable viral load showed some form of drug resistance. A total of 1906 samples were collected from participants using ViroLogic's PhenoSense test. The HCSUS is a longitudinal study representing some 209,000 HIV-positive adults in the U.S. who were in treatment in 1996. The levels of resistance differed by drug class, with 42% for protease inhibitors (PIs), 70% for nucleoside reverse transcriptase inhibitors (NRTIs), and 31% for non-nucleoside reverse transcriptase inhibitors (NNRTIs). Male sex, lower CD4 T-cell count, and higher viral load were identified as key indicators of higher risk of drug resistance.

The report got treatment advocates to raise charges of media and research hype. As stated here before, the issue of resistance—when the virus learns to resist the drugs thrown at it—is very complicated. Sometimes the virus mutates before people go on meds, which means that their HIV may develop resistance to one or more of the HIV meds. One study found that even with a near-perfect adherence level of 95%, one out of five people will develop detectable viral load (one indication of drug resistance). And generally, if you go on HIV drugs, you develop HIV drug resistance. Maybe only a very little and maybe not even detectable by drug resistance tests. On top of that, it's not very clear what all the mutation patterns of the virus mean for clinical care.

Longtime activist and advocate Matt Sharp said the results of the survey are not surprising, and only indicate that HIV medications are too "mediocre" to control the virus. Another advocate pointed out that you can often still do well and be healthy with resistant virus—absolutely true. Another important point: the majority of the people looked at in this analysis started out with suboptimal therapy, which contributes to the development of resistance. People taking HIV medications today start out with stronger therapy.

In his longtime, highly respected newsletter, *AIDS Treatment News*, John James concludes that, "…generally it is best to have HIV fully suppressed whenever antiretrovirals are used, so that there is little or no viral replication, and resistant virus cannot evolve. But for many patients this goal is not feasible. For these patients and for everyone else with HIV, we need new drugs that are more effective, less toxic, and less susceptible to viral resistance. We especially need new classes of treatments, including new targets for antiretrovirals, and immune-based therapies to help the body itself control HIV."

New drug on the block: Viread

Viread (tenofovir disoproxil fumarate, TDF) is a nucleotide reverse transcriptase inhibitor that was approved by the FDA last fall (see 2002 *Positively Aware* HIV Drug Guide). It is taken as a single 300 mg tablet once a day with food.

Data was presented on Gilead 907 study, a phase III trial with 552 participants (viral load between 400-10,000 copies/mL) on a stable antiretroviral regimen. TDF was added to the regimen of 368 participants, and 184 were given a placebo (sugar tablet). At 24 weeks, the viral load of participants who added TDF had dropped 0.61 log; the viral load of 42% of the TDF recipients was less than 400 copies/mL; and less than 50 copies/mL in 22%.

The potential of cross-resistance between TDF and nucleoside analogs suggests that this is not a salvage drug. However, it has shown promise as a nucleoside alternative in the NRTI-experienced or for intensification in individuals with low-level viral load. Gilead's ongoing study 903 will provide much needed data on the effectiveness of this drug for treatment naïve individuals.

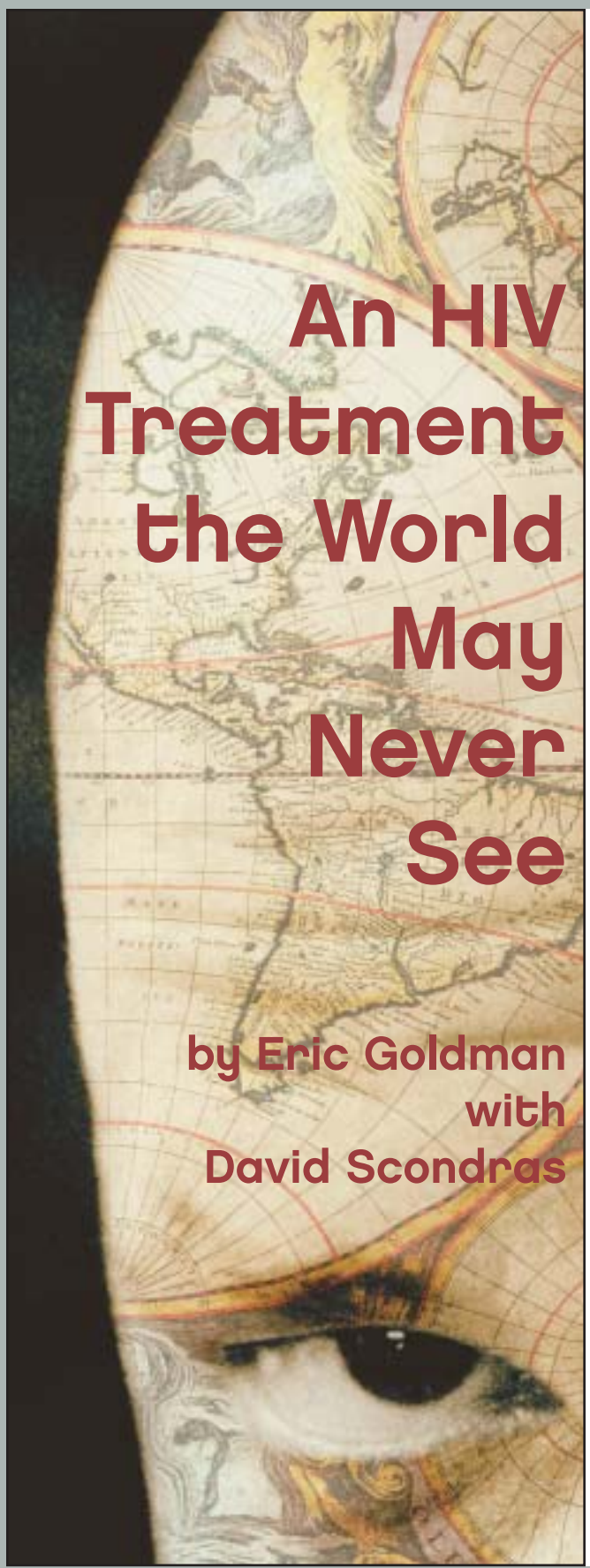
Drugs on the horizon

TMC 125 is a second generation NNRTI in the same class of drug as Sustiva and Viramune, that is being tested by Tibotec-Virco. It has shown promise in vitro against highly NNRTI-resistant virus. The results of a small phase II trial were presented. Twelve treatment naïve participants received seven days of direct-observation monotherapy with TMC 125, at a dose of 900 mg twice a day, and were compared with six participants who received a placebo. Those who took TMC 125 experienced a very impressive 2 log drop (1.13-3.30 log) in viral load over the one-week treatment period. "As far as we know, no drug has shown this large of a viral load drop in this short of a time," said presenter Dr. G. Van 'T Klooster, who works for Tibotec-Virco. "This spells hope." Eight participants achieved viral loads less than 400 copies/mL and two achieved viral loads less than 50 copies/mL in seven days. However, participants taking TMC 125 in this trial had to swallow 18 pills twice a day! This means that some serious formulation issues will have to be resolved before TMC 125 can be expanded to larger clinical trials. Afterwards, they received standard of care therapy. The primary side effect was mild somnolence (sleepiness). Study participants were taking HIV medication for the first time. Doctors at the conference expressed enthusiasm for the drug's potential.

Tipranavir (TPV) is a non-peptidic protease inhibitor that has demonstrated potential against a wide range of PI-resistant strains, is being developed by Boehringer-Ingelheim. Data was presented from 16-weeks of an open-label trial comparing two doses of TPV/Norvir (ritonavir) [500/100 mg twice a day and 1250/100 mg twice a day] with Fortovase (saquinavir soft-gel)/Norvir [400/400 mg twice a day] in participants who had failed a single PI (viral load greater than 1000 c/mL) and who still had at least two NRTIs available. The data indicates that participants who received a higher dose of TPV/Norvir (55%) achieved viral loads less than 400 c/mL than those who received the lower dose TPV/Norvir or the Fortovase/Norvir based regimen. Nearly 42% of the participants in this study did not demonstrate PI resistance, despite failing a PI-based regimen. This would seem to indicate that more testing is called for with more PI-resistance participants.

If all goes well atazanavir, the once a day protease inhibitor, being developed by Bristol-Myers Squibb, will most likely be the next PI approved by the FDA. Results from BMS 008 were presented, in which treatment naïve participants were randomized to receive either: atazanavir (400 or 600 mg once a day) or Viracept (nelfinavir, 1250 mg twice-a-day) plus d4T/3TC (Zerit/Epivir). The observed reduction in viral load was similar in all three arms of the study. Most notable was the increased cholesterol level in 5-7% of those receiving atazanavir, compared to 20-25% receiving Viracept, and diarrhea was less common in participants taking atazanavir. Like Norvir, atazanavir increases the level of other PIs. However, atazanavir seems less likely to cause hyperlipidemia (heart disease) than Norvir. Atazanavir or "Taz" (as some doctors call it) also appears to have little if any adverse effect on lipid profiles. An expanded access program is expected to startsoon; call toll free (877) 726–7327.

T-1249, the "Son of T-20" (as doctors call it), showed a good drop in viral load after two weeks, despite baseline resistance in the people using it. You would expect this fusion inhibitor to work for people with HIV drug resistance, since it's in a new class of anti-virals. Nevertheless, the influence of resistance patterns needed to be examined. Half of the people in this tiny, early trial had relevant mutations to all three HIV drug classes now on the market. Like the people in T-20 trials (expected to be on the market this year), these participants had taken many other HIV drug combinations. Viral load drop varied according to the dose of the injections: an insignificant drop for people on the 6.25 mg dose per day vs. an excellent result in people taking 50 mg per day (–1.40 log).



An HIV Treatment the World May Never See

by Eric Goldman with David Scondras

There's a class of cancer drugs that could be a very effective treatment for HIV infection. But we may never know.

Three published laboratory studies, dating back to 1992, show the potential effectiveness of these drugs against HIV replication. The NIH holds two patents for using these cancer drugs on retroviruses, such as HIV. Some of the drugs have been approved by the Food and Drug Administration (FDA) for use in humans, and at least three major drug companies are actively testing, developing and marketing these drugs, but only for use against cancer.

No major drug company that is currently testing, developing or marketing these drugs has any intention of turning them into HIV drugs. The NIH has never tested these drugs in people as a potential treatment for HIV, and without that basic research none of the major drug companies involved will invest any money on further development and testing.

It has long been thought that inhibiting an enzyme called topoisomerase would help both cancer and HIV patients. It has long been known that a substance derived from the camptotheca tree indigenous to China operates as an inhibitor of topoisomerase I, and inhibiting topoisomerase might limit the growth of cancer and the advance of HIV infection. However, this derivative was considered too toxic for use in humans, until recent advances. Now, topoisomerase I inhibitors are FDA approved for the treatment of certain cancers.

For example, topotecan is currently marketed by SmithKline Beecham under the trade name Hycamtin and FDA approved for the treatment of ovarian cancer. Irinotecan is an FDA approved treatment for colorectal cancer currently marketed by Pharmacia & Upjohn under the trade name Camptosar. Rubitecan is currently awaiting FDA approval as a treatment for pancreatic cancer, and exclusive distribution rights have been acquired by Abbott Laboratories. It is worthwhile to note that Rubitecan is a pill and is taken daily. Several more topoisomerase I inhibitors are currently in development.

In two studies completed in 1997, Dr. Arthur Pardee of the prestigious Dana Farber-Cancer Institute has shown that it might take only a small amount of Hycamtin to treat HIV. According to Dr. Pardee, further study in the use of Hycamtin as an antiretroviral is needed.

Dr. Pardee's work on topoisomerase has not gone unnoticed in the AIDS community. In a 1994 memo to the National Task Force on AIDS, John James of *AIDS Treatment News* recommended the study of topoisomerase I inhibitors. What James found particularly exciting was that topoisomerase I inhibitors targeted cellular, not viral, proteins. This, and the fact that topoisomerase I inhibitors appear to be broadly effective against retroviruses, suggests that patients may not develop resistance to such inhibitors as rapidly as they do to other HIV drugs. Further, patients who are already resistant to other HIV drugs may still be able to benefit from topoisomerase I inhibitors. Simply put, these drugs could save lives.

In 1997, the NIH found itself in possession of some pretty compelling evidence that topoisomerase I inhibitors could be developed into HIV drugs, as well as the patents on the process of treating retroviruses such as HIV with those drugs. Historically, then, the appropriate next step was for the NIH to conduct the necessary basic research—test the drugs in people. However, rather than conduct the basic research itself, the NIH exclusively licensed its patents to a third party, a small drug company named Virologix. The decision to license these patents was made in accordance with a government policy, initiated early in the Reagan administration and continued through the Clinton administration to the present day, of granting exclusive licenses of government patents to private companies.

The logic behind this policy is that granting exclusive licenses to the private sector provides an incentive for private industry to conduct the necessary basic research, in exchange for realizing reasonable profits from the drug when it is developed. These exclusive licenses are generally acquired by smaller drug companies looking to break into a larger market.

However, at least in this instance, this government policy has not yielded results. In 1999, Virologix was acquired by a company named Access Pharmaceuticals, largely to gain access to Virologix's HIV treatment technology, that is, the patents in question. Access Pharmaceuticals is a company which acquires rights to drugs, and then looks for other companies to partner in the financing of drug development.

Access never expected to develop topoisomerase I inhibitors as an HIV treatment entirely on its own. However, the company is now in a Catch-22. It cannot interest major drug companies in helping to develop the drug without first conducting the basic research, and it is finding it difficult to finance the basic research without outside assistance. Therefore, more than four years after the exclusive licenses were granted by the NIH, topoisomerase I inhibitors are nowhere on the HIV drug development map.

In the face of such an apparent breakdown in the drug development process, it's tempting to try to find someone to blame. The major drug companies have made themselves easy targets to blame by never definitively stating why they will make no investment in the basic research necessary to develop topoisomerase I inhibitors for use against HIV.

For example, there has been some suggestion that, as a matter of marketing policy, GlaxoSmithKline (GSK) did not want to undermine its marketing of Hycamtin as a cancer drug by indicating that the drug may have use against HIV. Representatives from GSK were unavailable for comment. Pharmacia & Upjohn took the position that Camptosar did not warrant study as an AIDS drug because there could be a significant side effect—neutropenia, painful sensations in the extremities. Apparently, Pharmacia made an educated guess that trials in humans would be unsuccessful based on the drug profile. However, what Pharmacia cannot know is whether Camptosar will cause worse side effects than other HIV drugs, and what Pharmacia has not explained is how this drug which is deemed too toxic for HIV patients is tolerable for cancer patients. The doctor who made this determination, Dr. Langdon Miller, was also unavailable for comment. Abbott Laboratories has been the most forthcoming on this issue, stating that it will not develop Rubitecan as an HIV treatment because the NIH has exclusively licensed its patents and because the research to date is inconclusive, in other words, the basic human research has not been done.

Perhaps blame should be laid at the NIH's door. The NIH licensed its patents, and has taken no subsequent steps to ensure the timely development of topoisomerase I inhibitors as an HIV treatment. At what point does the NIH become responsible for spearheading these drugs through the required basic research?

Some AIDS activists say that now is the time for the NIH to step back in. The NIH could fund an investigator initiated research grant, a so-called "R01" to directly test these drugs for use against HIV. Or, a retrospective study could be done quickly, asking every doctor who has treated an HIV positive cancer patient with a topoisomerase I inhibitor to send any information regarding the effect of these drugs on HIV viral load to a central location for analysis. In addition, the NIH could finance a community-based test, where willing HIV positive patients agree to take the drugs to see if they are effective against HIV in humans.

There may even be some responsibility to be shared by the AIDS community, including activists, doctors and patients. In the early days of the AIDS epidemic, doctors experimented with topoisomerase I inhibitors and other drugs such as papavarin, tobramycin and certain anti-fungals. Many showed an ability to reduce HIV viral load. With the advent of protease inhibitors and triple drug regimens in the mid-1990s, many of these promising treatments were simply abandoned. Now, with drug resistance as an ever present danger and the knowledge that the drugs don't work for everyone, these abandoned treatments should be pursued anew. Yet there is little call for such a course of action.

However, in truth there may be no one to blame. The drug companies are doing exactly what they are supposed to do—maximizing shareholder value by investing in drugs shown possibly effective in humans. The NIH is doing exactly what the government says it should do—outsourcing basic research. Committed AIDS activists and doctors, working with limited resources, do the best they can to ensure access to effective treatments for all HIV-positive patients.

All of which leads to the realization that, even with everyone doing everything they are supposed to do, a potentially promising AIDS treatment has fallen through the cracks in the drug development pipeline because no one will conduct the necessary basic research. And, of course, to the suspicion that topoisomerase I inhibitors are not the only potential AIDS drugs which fell through this particular crack in the pipeline.

Mixing and Matching Meds: ICAAC Update

by Patrick G. Clay, PharmD

At the 41st Interscience Conference of Antimicrobial Agents and Chemotherapy (ICAAC) held in Chicago in December 2001, there were presentations discussing Therapeutic Drug Monitoring (TDM) in HIV. What researchers and some clinicians are doing now is conducting studies, or in some cases select sampling of plasma (the part of the blood that is without cells), of their patient populations. They are doing this to determine if the amount of drug getting into a person's blood is not what is expected nor desired. This may allow the clinician to adjust the dose of the antiretroviral, as in some cases when another drug the patient is taking may be causing the drug level to be an undesirable one.[1]

Many of the ICAAC presentations focused on: 1) how drug-to-drug and drug-to-food interactions may alter plasma levels of various drugs and 2) how plasma levels may relate to viral load suppression or resistance. Only a few focused on the actual monitoring of drug levels, primarily protease inhibitors, and how the process can significantly affect the results. Outcome data are not being discussed in this article and more details on how these persons faired while on these medicines are available at the conference web site: www.icaac.org.

Flaherty, *et al.*, Abstract # 1791, presented much anticipated data on the interaction between Videx (didanosine, ddI) and Viread (tenofovir). Viread is the new kid on the block, and is only taken once a day. So a big question was: how does it function when taken with Videx, the only other nucleoside analog that can also be taken once a day. Together, they might make a good nucleoside base for HIV therapy. It's a tricky question, because Viread can be taken with food, but both Videx and Videx-EC (the newer, non-buffered capsule) must be taken on an empty stomach.

The jury is still out on what is the best way to construct a pill regimen with these two medicines in the same patient, but there are studies being done that may give us this answer. However, this research has yet to be completed. In this pharmacokinetic analysis using non-HIV infected persons, didanosine and tenofovir were given to 15 (8 male/ 7 female) for 7 days. The plasma levels obtained were compared to when the same subjects took each drug individually. The Gilead Science study (makers of Viread) demonstrated an increase in both the total drug exposure (AUC) and the maximal drug level in the plasma (Cmax) of didanosine of about 44% and 20%, respectively, when ddI was taken one hour before tenofovir. All medications were administered in the fasting state. This should not affect the results when applied to the clinical setting, as when tenofovir is administered with food it would not likely cause much greater changes in didanosine pharmacokinetics.[2] This should also not be any different in HIV infected persons as Kearney, *et al.*, presented the effect of demographic variables on the pharmacokinetics of tenofovir in 56 HIV positive persons getting nearly identical tenofovir levels (Abst. 504).

In a related research study, Bristol-Myers Squibb presented data showing that when Videx-EC (didanosine EC) was administered with food (high and low fat) compared to fasting in a total of 99 HIV negative persons (Abst. 499). The authors reported that the extent of absorption was lower when given at the same time with either a low or high fat meal by 27% and 19%, respectively. Additionally, it was reinforced that Videx-EC needs to be taken at least 1 hour prior to any food as a 24% decrease in total drug exposure was seen when it was given only 1 hour before a light meal.

Several combination protease inhibitor pharmacokinetic profiles were presented. Can the popular Fortovase/Norvir combination be taken only once a day? Research presented here suggests that it can—but more research needs to be done to prove that the once-daily dose is actually effective. Montaner, *et al.*, showed data on 20 HIV positive African Americans (11 men/ 9 women) receiving Fortovase (saquinavir soft-gel) 1600 mg with 100 mg of Norvir (ritonavir) once daily (Abst. 1920). After four weeks of therapy, the trough level was drawn (the amount of drug in plasma at the end of a dosing period—in this case it was done at 24 hours after the previous dose). Good news: the average drug plasma level was about 9.4 times greater than what an acceptable trough level would be. Shelton, *et al.*, presented data on 12 (5 male/ 7 female) methadone patients taking 1600 mg saquinavir/100 mg ritonavir once daily (Abst. 492). In this patient population, somewhat lower troughs were seen compared to Montaner's data, yet 83% of these persons still had levels that would be expected to suppress viral replication (lower the viral load).

The optimal Agenerase (amprenavir) dose to be used with ritonavir was being researched by Garraffo, *et al.* (Abst. 489). Here, researchers provided scientific evidence for combination doses that were already widely prescribed by HIV specialists.

Using 10 (9 male/ 1 female) HIV-infected persons, plasma levels of amprenavir were obtained and compared to various dosage regimens. Each patient took amprenavir at full FDA-approved dosage (8 100 mg capsules twice daily), then 600 mg amprenavir with 100 mg of ritonavir twice daily and then finally, 1200 mg amprenavir with 200 mg ritonavir once daily. Each dose was taken for 10 days prior to 8-10 plasma levels being taken. The elimination of amprenavir (APV) from the body was decreased by 50% when given with either dose of ritonavir (RTV). The trough levels of amprenavir were higher when subjects received the 600 mg APV/100 mg RTV compared to 1200 mg APV/200 mg RTV, but both of these were much higher than that seen with 1200 mg APV twice daily. Since this conference, the FDA has approved the 600 mg APV/100 mg RTV dosing regimen.

Correlating the levels of Viracept (nelfinavir) to future regimen failure was the intent of Le Moing, *et al.* (Abst. 1733). These researchers examined single time point plasma levels of 407 patients taking successful regimens (viral load <500 copies/mL) containing indinavir (240 subjects) or nelfinavir (167 subjects) for at least 4 months. As you would expect, the researchers found a correlation between lower than expected plasma concentrations of nelfinavir levels as well as lower levels of its active metabolite (M8) and failure of therapy (at least one viral load >500 copies/mL after the fourth month). (In the past few years research has found that a drug's metabolite—the form it takes inside the body—is often more important than the drug itself, for all diseases. This is one of the earliest studies looking at an HIV drug metabolite.) The authors did point out weaknesses of the study and stress the need for further studies to be done in a controlled, research environment prior to any recommendations being made about monitoring plasma levels of any antiretroviral.

This point was reinforced by DiCenzo *et al.* (Abst. 751 and 487). This collaboration of notable researchers presented two posters that examined what information could be learned from different sampling methods. Basically, they took single time samples (at any point during the day when the patient came into the clinic and was taking the medicine) and compared how accurate and reproducible the results were when compared to a full day's worth of blood draws. The results are important in helping clinicians understand how to best utilize and interpret TDM data. These researchers found that taking less than two blood samples during one dosing period was not informative. The recommendation was that for the most precise and unbiased estimates to be obtained, at least 2 to 3, but seeking 4 to 6 samples would give the best data. The likelihood of a clinic being able to fiscally, physically or emotionally have every patient on antiretrovirals get this intensive sampling procedure done is small.

To summarize, the data presented at ICAAC that displayed research on the use of measuring antiretroviral blood levels do not support this being done as a part of routine clinical practice. This is not meant to dissuade clinicians from measuring plasma levels when legitimate concerns arise regarding absorption, interactions or other clinical scenarios. Obtaining plasma levels of antiretrovirals at this time point should continue to be pursued in prospective, randomized, controlled research environments in order to provide infected and affected persons, clinicians and third-party payors (insurance) with consistent, clear and indisputable results. With upcoming conferences in 2002 (4th International Workshop on Antiretroviral Clinical Pharmacology, World AIDS, 42nd ICAAC, etc.) where more TDM studies are surely to be presented, it is hoped these answers are forthcoming.

These researchers found that taking less than two blood samples during one dosing period was not informative.

[1]Kakuda TN PL, *et al.* Pharmacological basis for concentration-controlled therapy with zidovudine, lamivudine and indinavir. Anti Microb Agent Chemo. 2001;45(1):236-42.

[2]Barditch-Crovo P DS, *et al.* Phase I/II trial of the pharmacokinetics, safety, and antiretroviral activity of tenofovir disoproxil fumarate in human immunodeficiency virus-infected adults. Anti Microb Agent Chemo. 2001;45:2733-9.

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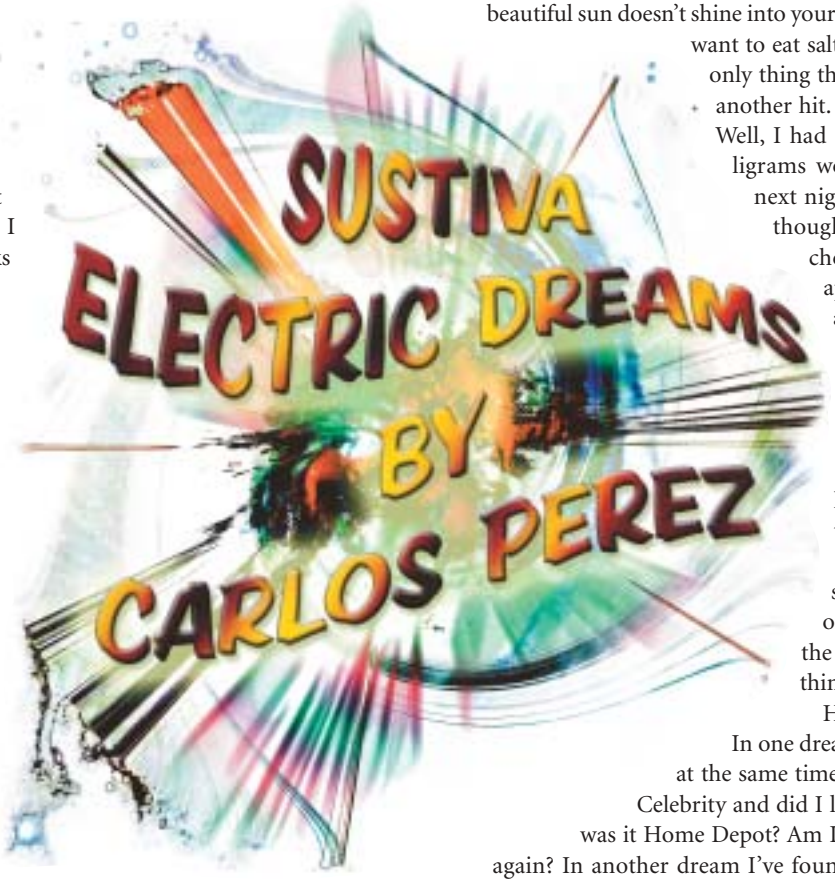
I was driving home, tired from working a long day, yawning, trying to keep my eyes open. I got off of Lake Shore Drive and continued north on Sheridan Road until my turn at Granville Ave. The street looked desolate and was littered with bits of bricks and mortar. I could see the elevated train station but it had structural damage. I peered towards Magnolia St. and it looked like there was a fire. As I approach my next turn there's something terribly wrong. There are fires everywhere. All of a sudden men are pouring out of the buildings, yelling and screaming. I can't make out the exact words, but they're speaking Spanish.



A bomb explodes next to my car and I'm shaken off the road by the explosion. Now I'm sweating and nervous. I almost hit a tree and just as I dodge the tree it looks like I run into the front porch of a house. I look up and see my partner! What is my partner Mickey doing playing the piano on a stranger's front porch? And why does he sound like Patti Lupone? This is ghastly! He is playing his piano and singing "Don't Cry For Me Argentina." He flashes me with a sardonic smile and looks away as if pointing. And there behind him is Argentina and it's in a blaze and indeed those men are screaming epithets at their government. Am I going mad? I feel so anxious now. Why won't Mickey stop playing that music? He keeps repeating the same lines and he just smiles, like he's never smiled before.

SHIT! I just woke up. My pillow is wet and I look over and Mickey is looking normal again, eyes shut, mouth slightly ajar, just sleeping next to me and I realize I've just had another Sustiva Electric Dream.

I can add this one on to the list of horror stories. They started after I quit Sustiva (efavirenz). Yep, I quit her. I couldn't handle her and myself. Going on Sustiva for one week was all I needed to realize a few things. I remembered what it felt like when I copped some bad stuff. I was so nauseated that I couldn't enjoy the party, couldn't focus enough to find that bad dealer and hit him! I also realized that I don't think I can handle getting high anymore. Because, other than the nausea and diarrhea, the rest of the side effects are much like the effects that many of us feel while trying to stay high. Hello! Wake-up call!

I used to fantasize about tripping one more time or doing one more late night-early morning bender. I used to think that perhaps, based on a particularly hyped-up holiday like New Year's or Gay Pride, I could validate the reasoning. Maybe, based on a special occasion it would be OK to get lit one more time. But I seemed to have forgotten about one thing and that's what Sustiva reminded me of: the down side of the high. When you just feel like crap. When all you want to do is stay on the sofa with the shutters closed so that the beautiful sun doesn't shine into your dilated pupils. When you only want to eat salty, fatty, sweet stuff. When the only thing that will make you feel better is another hit. "Hair of the dog" they call it? Well, I had to take another hit, 600 milligrams worth, the next night and the next night, and the next night until I thought I was going to lose it. So I chose freedom, I made another appointment with my doctor and changed my regimen.

I just hope the dreams go away at some point. I know it bothers Mickey. He hears me yelling in fright or cackling in delight. He feels me pushing him or humping him, but in this case he wants to sleep and not hump. He's scared when I scream or jump out of bed only to stand in the middle of the room scratching my head thinking, what was I dreaming?

Have I lost both my cars again? In one dream I can't find both of my cars at the same time. Was it the Grand Am or the Celebrity and did I leave them in the Target lot or was it Home Depot? Am I sleeping with my co-workers again? In another dream I've found myself in bed with my co-workers watching a huge television screen and we're all fighting for the remote and in my Vegas dream I'm lost in "casino-land." I can't find my way out of the casinos. I know it's like that for everybody in real life too, but in the dream I never find my way out until I wake up and wipe off the sweat.

Oh, yeah, I got the rash when I switched the Sustiva for viramune, but compared to all the dreaming, a little Benadryl went a long, long way and I only felt drowsy.

Carlos Perez is the editor of the Chicago Area HIV Services Directory *and Information Services Coordinator at Test Positive Aware Network.*

Editor's note: Overall, Sustiva has demonstrated to be highly effective in the treatment of HIV disease, used in combination with other anti-HIV meds. The course of HIV disease and each individual's response to therapy is unique. Therefore, it is important to educate yourself about every possible treatment option—including alternative therapies—and communicate reactions with your primary healthcare provider.—CC

SOCIAL SECURITY BENEFICIARIES RETURNING TO WORK

by John Coburn

The Social Security Administration (SSA) manages two programs that provide cash benefits to persons with disabilities. The two programs are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). For many individuals who are HIV-positive, these programs provide a much-needed source of income at a time when the individual's physical or mental condition makes it very difficult for him or her to work. However, because the monthly benefit amounts are often not high enough to live comfortably, many HIV-positive individuals receiving these benefits are interested in obtaining some sort of employment either to replace or supplement the benefit check. Fortunately, SSA does provide incentives to obtain or return to work, and has recently implemented several new work incentives under the Ticket to Work and Work Incentives Improvement Act of 1999.[1]

In order to take advantage of these work incentives, a Social Security beneficiary must first determine whether they are receiving SSI, SSDI, or both. It is important to determine this because the two programs have different work incentives and rules concerning employment. The easiest way to make this determination is by looking at the amount of a monthly check and the date upon which it is received. SSI recipients always receive their checks on the first of the month, and, in Illinois, the standard SSI payment for a single person living alone in 2002 is $545[2]. However, the amount of an SSI check is dependent on several variables, including, but not limited to, living arrangements, earned income, unearned income and in-kind support. SSDI beneficiaries receive their checks on the third of the month or a later day in the month, depending on their birthdate. The amount of an SSDI check will vary, depending on a person's work history and the amount that the person has contributed under the Federal Insurance Contributions Act (FICA). Dual beneficiaries, persons who receive both an SSI and SSDI check, will receive two separate checks during the month, usually totaling $565 in 2002[3]. Dual beneficiaries can take advantage of the work incentives under both programs.

Below is a brief description of some of the SSA work incentives and employment rules. This description is not exhaustive, and any beneficiary thinking of returning to work should contact the Benefits Planning Assistance and Outreach Project (BPA&O), discussed below. It is important to understand that, in most circumstances, a beneficiary can go back to work and may not lose all of his or her benefits entirely or immediately. In addition, a beneficiary may continue to qualify for some important benefits, like Medicaid or Medicare, for several years even though he or she is working.

Work Rules and Incentives for the SSDI Beneficiary

When an SSDI beneficiary starts working, SSA begins to keep track of the beneficiary's average monthly amount of earnings. Under the SSA rules, when an SSDI recipient returns to work and earns at least $560[4] per month, he or she enters what is referred to as the Trial Work Period (TWP). Each month that a recipient earns at least $560 per month is referred to as a service month. A person is allowed to make any amount of money over $560 for nine service months, which do not have to be consecutive, within a sixty month rolling window. During this time, the individual will still receive SSDI benefits in the full amount and there is no limit on the amount of earnings that a person can make during the TWP. This is a very complicated rule, and a person must keep track of his or her earnings to determine exactly when the Trial Work Period begins and ends. Basically, an SSDI beneficiary who has not earned income while receiving SSDI can return to work and earn any amount of money for nine months and he or she will continue to receive a full SSDI check as long as the disabling condition continues. Once a SSDI beneficiary has accumulated nine months of earnings over the allowed TWP amounts, the TWP ends.

After the TWP ends, a person enters the 36-month Extended Period of Eligibility (EPE). During this period, a beneficiary may or may not receive a SSDI check, depending on their earnings. If, during the EPE, a beneficiary's earnings exceed what SSA calls substantial gainful activity (SGA[5]), then the individual will receive a SSDI check for that month and the next two consecutive months. This is known as the Grace Period. During the remainder of the EPE after the Grace Period, a beneficiary will not receive a check in any month in which his or her earnings exceed the SGA amount ($780 in 2002). However, in the months in which their earnings are below SGA ($780 in 2002), the individual will receive a full SSDI check. This Extended Period of Eligibility assures that a beneficiary has income for a significant time after he or she returns to work.

After the Extended Period of Eligibility ends, a beneficiary earning over the substantial gainful activity amount ($780 per month in 2002) who has exhausted the Grace Period will not receive benefits even if he or she

earns under $780 per month in the future. However, if, within the next five years, the beneficiary can no longer work because of the original disabling condition, that beneficiary can take advantage of the new Expedited Reinstatement of Benefits (EXR). When a former SSDI recipient files under this SSA provision, the former recipient will immediately receive benefits while SSA determines if the person is still disabled. These provisional payments will last for up to six months and if it is determined that the person's disability was not the cause for their reduction or cessation of work, he or she will not have to pay these benefits back, absent fraud.

Under the old SSA rules, when a person completed his or her Trial Work Period, SSA usually performed a medical Continuing Disability Review (CDR). A medical CDR is a review of the disability and determination of whether the beneficiary continues to meet the criteria of an individual with a disability. Many SSDI beneficiaries have been afraid to return to work for fear that if they were successful, they would lose eligibility for benefits when this CDR occurred. Beginning in 2002, there will be no more medical CDR's performed because a SSDI beneficiary is working if that beneficiary has received benefits for at least 24 months. A beneficiary will still be subjected to their regularly scheduled medical reviews, which could occur while he or she is working, and a work review. However, working alone will not trigger a "second look" at the disability.

Most SSDI beneficiaries are eligible for and receive Medicare. The fear of losing health insurance is usually the main reason why beneficiaries do not consider returning to work. However, under SSA rules, almost all SSDI beneficiaries continue to qualify for Medicare for 93 months after their Trial Work Period ends. In addition, after this time, if a person remains disabled, he or she is given the opportunity to buy his or her Medicare coverage for a reasonable price.

Work Rules and Incentives for the SSI Beneficiary

Because SSI is considered to be a means-based welfare program, the rules regarding earned income are different than the rules for SSDI beneficiaries. If a person receives SSI and returns to work, the check does not necessarily stop immediately. Rather, SSA allows for certain deductions from countable income and most SSI beneficiaries who begin earning income do receive a reduced check.

The SSI work formula works as follows. First, SSA disregards the first $65 of earned income. Second, one-half of the remaining earned income is excluded. In addition, there is a general $20 income exclusion that is applied first to unearned income, and then to earned income. These rules allow an SSI recipient to exclude over half of his or her income when determining the deduction from the SSI check.

Simply put, after earning $65, a beneficiary will lose $1.00 of benefits for every $2.00 earned.

An example will make these rules clearer. Jim is an SSI recipient and receives a SSI check in the amount of $545. He gets a job earning $805 per month. SSA will compute his SSI payment amount as follows. First, they will deduct the first $65 of his income, leaving $740. Second, another $20 will be deducted under the general income exclusion, leaving $720. SSA then divides the $720 in half, leaving a countable income of $360. The countable income of $360 is then deducted from his SSI amount of $545. Jim will receive an SSI check of $185 to supplement his earned income of $805. This will give him a total monthly income of $990.

Like SSDI beneficiaries, SSI beneficiaries are often afraid to return to work because they do not want to lose their health insurance. Most SSI beneficiaries rely on the Medicaid program for their health benefits. Fortunately, many SSI beneficiaries can return to work and still receive Medicaid without a spenddown.[6] Under a rule called 1619(b), an Illinois SSI beneficiary will continue to receive Medicaid without a spenddown until he or she earns a countable income of $25,302.[7] Under this rule, a person could no longer be receiving an SSI check due to income but will still qualify for Medicaid. Although there have been some problems in implementing this rule in Illinois in the past, the Illinois Department of Human Service is well aware of this rule now and should not cut a person off of Medicaid simply because they return to work.

SSI recipients can also request reinstatement of their benefits under the provision for Expedited Reinstatement of Benefits (EXR). If an SSI recipient's benefits are terminated because of work, that former recipient can reapply for benefits within 60 months of his or her last check without filling out a new application if the former recipient can no longer work due to the original disability. Under this provision, the SSI beneficiary will receive up to six months of provisional benefits while the reinstatement application is pending. If a determination is made that the person's reduction or cessation of work was not caused by the original disability, the individual will not have to pay these benefits back, absent fraud.

The New Ticket to Work Program

In 1999, the Ticket to Work and Work Incentives Improvement Act of 1999 became law. In addition to the many new work incentives outlined above, this legislation creates a new vocational rehabilitation system for beneficiaries of Social Security. This new system will begin in thirteen states in 2002, and be implemented in all states over the next three years. Illinois is one of the first

thirteen states to implement the new program.

Beginning in February of 2002, most Social Security beneficiaries in the state of Illinois will receive "Tickets" in the mail. These Tickets can be used by Social Security beneficiaries to choose a pre-approved agency, called an Employment Network, from which to obtain vocational rehabilitation services and/or other employment support services. These services could include, but are not limited to, case management, work incentives planning, supported employment, career planning, career plan development, vocational assessment, job training, placement services, and follow-up services. Currently, there are 35 Employment Networks in Illinois.

It is important to understand that this new program is voluntary. A beneficiary can choose whether or not to use the Ticket. This is not a program to force beneficiaries to go to work. In addition, the Employment Networks can accept or reject anyone asking for their services with a Ticket.[8] The new Employment Networks may be listed in the letter sent with the Ticket or can be found at www.yourtickettowork.com. A beneficiary is well advised to shop around to find the Employment Network that is best equipped to meet their individual needs and is willing to take their Ticket.

Support Assistance for SSA Recipients Wanting to Return to Work

Understanding the work rules and incentives of SSA is very difficult. Fortunately, SSA has funded a new nationwide project called Benefits Planning Assistance and Outreach (BPA&O). The BPA&O staff is available to assist Social Security beneficiaries in understanding what will happen to their benefits if they work. A trained Benefits Specialist will sit down with the beneficiary and gather individual information. The Specialist will then do an analysis for the beneficiary to assist him or her in understanding what will happen to each of the beneficiary's government benefits if he or she begins working. It is so important that beneficiaries utilize this service before returning to work. As outlined above, the work incentives are confusing and difficult to understand. By working with a trained Benefits Specialist, a beneficiary can understand exactly how income will affect each of his or her state and federal benefits. Armed with this information, a Social Security beneficiary can make an educated and informed decision about and/or plan for working.

The services of this program are free. In Illinois, three different agencies run these projects, the Mayor's Office for People with Disabilities (1-312-746-5743), the Illinois Department of Human Services-Office of Mental Health (1-866-390-6771) and the Illinois Department of Human Services-Office of Rehabilitation Services (1-800-807-6962). The Mayor's Office for People with Disabilities serves the residents of Chicago, and the other two agencies serve other parts of the State. Benefits planners outside of Illinois are listed at www.ssa.gov/work/ServiceProviders/statebystate.html or with the local Social Security office.

Once a Social Security beneficiary decides to return to work, he or she may need assistance in accessing needed services and supports or requesting a reasonable accommodation for his or her disability. In addition, the beneficiary may encounter other legal barriers to returning to work. Under the Ticket to Work Act, a new project has been developed to advocate on behalf of beneficiaries with their return to work issues. In Illinois, this project is run by Equip for Equality, Inc. and is called Protection and Advocacy for Beneficiaries of Social Security (PABSS).

In Illinois, as in most other states, the PABSS Project has two major components. First, the project will serve as advocates for Social Security beneficiaries with return to work issues. This will include addressing any legal barriers that are preventing the individual from beginning or maintaining employment and assisting beneficiaries with difficulties arising from the use of their *tickets* or in receiving proper and appropriate services from the Employment Networks. Second, the project is available to conduct training seminars on the employment rights of Social Security beneficiaries. These seminars are open to persons with disabilities, their family members, service providers and agencies, or employers. The training provides an overview of the Social Security work rules and incentives and the Americans with Disabilities Act of 1990.

The services of this project are free as well. To contact a PABSS advocate in Illinois, call 1-800-537-2632. All PABSS Projects around the country are listed at www.ssa.gov/work/ServiceProviders/PADirectory.html or can be reached by contacting the local Social Security office.

John Coburn is the PABSS Project Manager and attorney at Equip for Equality, Inc. in Illinois.

[1] It is important to note that many of the incentives and rules explained in this article pertain to non-blind Social Security beneficiaries. For individuals receiving Social Security because of blindness, the rules and incentives differ. Those individuals should consult with their local Benefits Planning Assistance and Outreach Project.

[2] Some states provide a supplement to the standard amount of $545. SSI beneficiaries in those states would receive more than $545 per month.

[3] Again, this is the standard amount, which is given to beneficiaries in Illinois. Some states provide a supplement.

[4] $560 per month is the amount for the year 2002. The amount was $530 in 2001 and $200 prior to 2001.

[5] The substantial gainful activity (SGA) amount for 2002 is $780. The amount will change yearly, based upon the national average wage.

[6] Spenddown is the term used for the monthly amount of medical expenses, billed or paid, that a person or family must accumulate before qualifying for Medicaid during that month.

[7] This amount varies from state to state.

[8] The only exception to this rule is that state vocational agencies that become Employment Networks, including the Illinois Office of Rehabilitation Services, must accept or reject persons seeking services under its previously established rules.

HCV/HIV Co-infection II: Sobriety and treatment

by Gerald Moreno

Living with HCV (hepatitis C virus)/HIV co-infection can be very challenging. Along with our physicians, we are learning about co-infection and living with it day-today. In addition to living with our dual illnesses, many of us are also dealing with recovery and mental health issues. I personally am living with all four of these conditions. Every day I am challenged to stay clean and sober and mentally fit. I approach life one day at a time, and I try to apply this principle to everything I encounter. So when the difficulties stack up, I deal with them one at a time. I would like to discuss a few of these challenges and my approaches to conquering them.

Maintaining sobriety certainly is a challenge that I encounter on a daily basis. To me, this is invaluable. Without my sobriety I have nothing! I spent many years trying to get clean and sober, and I know that a healthy lifestyle is impossible if I'm using. I remember lying in an alley crying while shooting up because I did not want to do it anymore. Getting arrested was a relief. At least I would have "three hots and a cot." I also wanted to believe that the police cared.

It took me many years to admit, and *understand*, that I was powerless over drugs and alcohol; but once I did, my life took on a different meaning. Today we have many programs, including abstinence-based 12-step programs, harm reduction programs and recovery homes that can assist us in our quest for sobriety and a healthy lifestyle.

Recovery homes can be a valuable asset in establishing a strong foundation, and obtaining the support that a person needs for sobriety. Most recovery homes model themselves after the 12-step program of Alcoholics Anonymous and Narcotics Anonymous, and require that you remain drug and alcohol free. If a relapse occurs, they will simply ask you to leave. This happened to me many times, and at the time I did not understand why. Harm reduction programs were not available to me at this time, so I felt rejected every time I was asked to leave a recovery home because of relapse. I asked the director of one of the many recovery homes that I participated in *why* was I being asked to leave, just because I relapsed. My argument was that if drug abuse and alcoholism is concidered a disease, relapse is a symptom, and should be treated as such (compassion). Her response was simply that within a therapeutic community there needs to be consistency (zero tolerance) both personally and for the rest of the residents.

Harm reduction programs are another option, or lifestyle, for those who choose not to work a 12- step or spiritual program. The harm reduction model upholds that abstinence is the ideal goal for those using illegal drugs. Working with drug users from a harm reduction perspective involves accepting that some people simply are not going to give them up at this time, but nevertheless offering them services to assist them in reducing the harm associated with drug and alcohol abuse. An open door policy can result in a harm reduction snowball effect: small changes can pave the path for further reduction of drug use and an improved lifestyle in other ways. This snowball effect can continue, eventually to the point of abstinence. I believe that everyone must find a program that works for them, and harm reduction certainly is a newer option worth exploring.

Of the many programs available, I choose to work a 12-step program to help me stay clean and sober. Relapse is an everyday reality and I must deal with it one day at a time. When temptation crosses my path, I recall the turmoil I felt while in my addiction and remind myself that I never want to experience the life of drugs and alcohol again. Instead of following temptation, I try to learn from every negative event that enters my life and turn it into something positive.

After living with HIV for approximately 11 years, I was diagnosed with HCV. Soon afterward, I began experiencing feelings that were all too familiar to me from the early days of recovery and HIV: isolation, sadness and fear, plus obsessive tendencies and depression. I never realized how important life was to me, and how much I wanted to live until my life was threat-

ened—threatened with addiction, co-infection, and all the symptoms that accompany it, including depression.

I had always been known as a positive person with an optimistic outlook on life, and I viewed depression as a weakness. But I was willing to do what was recommended, though I did not like the sound of a psychiatric evaluation. My depression had to be stabilized, however, especially before I could start HCV treatment.

The first step in the healing process was to go deep into my soul and apply the steps that I had learned from my recovery process…back to the basics! It is amazing the changes that will occur in your life when you simply shift from a negative attitude to a positive one. Today I do not view depression as a weakness, but more as an element of life that needs the human touch. Along with strengthening my 12-step program, I am also working with a therapist. My positive outlook has returned, and I look at every event in my life as a learning experience, something that I can share with others.

I have followed the scientific advances made in both HIV and HCV treatment in the last 10 years. I began HIV treatment in the early days of AZT in San Francisco, and was very fortunate that I did not develop resistance. I am now benefiting from a HAART (highly active antiretroviral therapy) regimen. Research advances are being made daily, so I live each day the best that I can, one day at a time, so that I can be alive and healthy and able to take advantage of what the future may bring. The future is unknown, but living the best I can one day at a time has brought me much solace and hope.

To treat or not to treat—that has been my dilemma until recently. As with HIV treatment, beginning HCV treatment is an individual decision that should be made with your physician's assistance and as much information about your options and the chances of treatment success as possible. It is important to begin therapy while your immune system is still intact, and your liver is showing minimal signs of liver deterioration. After many hours of research and meditation, I decided to begin treatment in January of 2002. Now that the decision has been made, I am preparing myself in mind, body, and spirit so that I can be 100 percent present to make this experience a success.

Living with co-infection presents many challenges. What keeps me going is the future and what it may bring. In the early days of the HIV epidemic the only hope many of us had was through visualization and meditation. Today we have real hope for long-lasting treatments and eventual cures. Scientists move ahead the same way as the rest of us: one day at a time.

Update: I began treatment for HCV with pegylated interferon and ribavirin (once a week pegylated interferon injection and twice a day single capsule of ribaviron). I did experience the normal course of side effects, flu-like symptoms, and the treatment interacted with my HIV medication. Therefore, I had to temporarily halt all medications for two weeks. I then restarted the interferon, and slowly reintroduced the other mrds. I will discuss my treatment experiences in my next article for *Positively Aware*. Everyone's experience with and response to treatment is unique, by no means do I discourage anyone from begining treatment. I look at this as a learning experience.

I had always been known as a positive person with an optimistic outlook on life, and I viewed depression as a weakness.

Gerald Moreno is a health educator/trials screening coordinator with the University of California San Diego's Anti-viral Research Center (AVRC). This research facility conducts clinical research for people living with HIV and HCV. For more information, please contact Mr. Moreno at (619) 543-8080 ext. 237.

Positive Empowerment

by Shane Doyle

Two and one-half years ago in August of 1999, I received a diagnosis of HIV. The news of my HIV-positive status changed my life forever. I, like many people, almost immediately got sick.

It wasn't so much the knowledge of having HIV, but a combination of events. My health took a steady dive and over the next few months I found myself in hospitals more that I was out of them. I stopped working almost immediately. I was incapable of the daily basic elements of self-care and moved into a support living program in Chicago to assist me with my chores and activities. I was on the edge of life and consciousness and wasn't sure if I would see the millennium.

My illness lasted longer than I had ever anticipated and my knowledge, perspective and body went through many changes. One of which was the decision to leave my home and friends in Chicago, and move to beautiful, warm and sunny San Diego. Thinking back now, I am bewildered and amazed at the strength and will that allowed me to drive myself halfway across the country. By the time my first anniversary of diagnosis rolled around, I was a new resident of San Diego, California.

At first my support circle was extremely limited. I was on disability and as I started to recover both physically and mentally, my awareness, restlessness and isolation grew more and more. That's when I discovered San Diego POZabilities (SDPOZabilities).

SDPOZabilities is a non-political, non-spiritual, non-profit organization dedicated to providing a fun, safe, healthy drug- and alcohol-free social setting for men with HIV/AIDS in the San Diego area, in order to promote and enhance the overall wellness of its members.

In many ways, this group of men has changed my life forever. They provide me with an avenue to meet others in a relaxed environment away from all of the medical jargon and clinics and yet still be around others living with HIV in a comfortable, nurturing environment. They are my extended family of sorts, allowing me to find the strength and desire to not sit around and wallow in self-pity or focus on the negativity that this life sometimes brings. They help me focus on living. The group has opened up an outlet for me to enjoy my newfound health. In all honesty, SDPOZabilities makes all the difference. Like all things, you have to make an effort. It's a two-way street.

We have two coffee hours at the Other Side Coffeehouse and volleyball on Sunday in Balboa Park. It gives us a chance to socialize, chat and feel welcome. I find that I look forward to these times of laughter, camaraderie, and the feeling of belonging that is sometimes rare with the isolation that having HIV can cause.

Additionally, the group schedules low or no-cost events during the week such as bonfires, potlucks, bowling, movie nights at members' homes, and arts and crafts projects. Sometimes we enjoy theater, kayaking, camping and hiking around San Diego County, and on occasion day-trip getaways to Palm Springs or other nearby destinations for the more adventurous. The board even finds a way to pool resources for people on disability or those who have low-incomes so that no one is turned away for lack of money. All activities are conducted with a strong commitment to keep the identity of the members confidential. There is a strictly confidential e-mail list. A calendar of events is distributed to many of the HIV/AIDS organizations in the city, which allows people to pick it up randomly.

As a new board member for the group, I am energized and eager to see the eclectic group of men at each of the numerous events held throughout the year. I'm empowered by the new faces, and find the honesty and integrity of the group refreshing. SDPOZabilities has grown from a great idea to a great number of men reaching out to lift each other's spirit and overall sense of well being. We are being approached by other cities for information on starting a local group, and are eager to help them.

And last, but not least, starting this spring, with the sponsorship of Hillcrest Pharmacy located in the Hillcrest neighborhood, we will have the first self-identified HIV-affected softball team in the America's Finest City Softball League (AFCSL). The league, I am told, is nearly, if not already, the largest gay-identified softball league in the nation.

SDPOZabilities, and all that the group offers, has empowered me with the desire to actively pursue a lifestyle and survive in my newly developing life with HIV. Please visit us at www.sandiegopozabilities.net, with links to HIV-positive social groups around the country.

Shane Doyle is a board member of San Diego POZabilities.

AIDS and HIV Related Research

National Institutes of Health (NIH)

National Institute of Allergy and Infectious Disease (NIAID) Intramural Program

Volunteer Recruitment

NIH houses the nation's most renowned biomedical research institutions. These studies are conducted by the NIAID and the NIH Clinical Center, located in Bethesda, Maryland. For additional information on the specific studies listed here, contact the appropriate coordinator listed below.

HIV

Studies of Lymphocyte Kinetics Using Stable Isotopes (Deuterium - 97-I-0191)

Contact: William Sachau, RN 1-800-772-5464 ext. 5-7940

The purpose of this study is to learn more about how quickly blood cells, especially CD4 lymphocytes, replicate and how long they live. Understanding what happens to CD4 lymphocytes in HIV-infected patients should provide a better understanding of how certain therapies, such as antiretroviral treatments and/or IL-2, affect the immune system. Study requirements include admission to the inpatient unit for a 5-day glucose infusion and apheresis procedures during study visits. Participants will be reimbursed for their time and inconvenience.

Interrupted vs Continuous Anti-viral Thearpy (HAART) in HIV-infected individuals (M77-02-1-0013)

Contact: Diane Rock-Kress, RN 1-800-772-5464 ext. 5-8003

This 72 week study will have 2 groups: one group will continue receiving their current therapy and one group will stop their therapy every other week (7 days). You may be eligible if you are: (1) 18 years or older (2) receiving effective anti-HIV medications with an undetectable viral load for >= 1 month (3) have a CD4 T-cell count of >= 175 cells/mm3 and (4) NOT receiving nevirapine or abacavir containing regimen. Study related medications and clinical care will be provided during the study. Many studies of HIV and the immune response to HIV will also be done.

Study of Lymphocyte Kinetics using Bromodeoxyuridine (BrDu)

Contact: Betsey Herpin, RN, MSN 1-800-772-5464 ext. 5-7630

This study is designed to measure the rate of lymphocyte replication and destruction in persons with HIV infection who have virologic but not immunologic response to HAART. Patients must have a viral load less than 500 copies/ml for greater than one year and less than 50 copies/ml at the NIH, and, (group 1), a CD4 count of less than 300 cells/mm3, or, for comparison, (group 2), a CD4 count of greater than 350 cells/mm3, with a pre-HAART CD4 count of less than 300 cells/mm3. Participants will receive one to two 30-minute infusions of BrDu and will be followed with frequent serial laboratory studies. Additional laboratory studies and a CT scan of the thymus will also be performed. HIV-infected patients with viral loads greater than 20,000 copies/ml will also be evaluated for study participation. Compensation for study participation will be provided.

A Phase III Multicenter Randomized Study of the Biological and Clinical Efficacy of Subcutaneous Recombinant, Human Interleukin-2 in HIV-infected Patients with Low CD4+ Counts Under Active Antiretroviral Therapy (SILCAAT-01-I-0126)

Contact: Linda Coe, RN, MSN 1-800-772-5464 ext. 2-1420

This is an open-label, phase III, multicenter international trial to evaluate and compare the effectiveness of IL-2 combined with antiretroviral therapy, versus antiretroviral therapy alone, on disease progression of people with HIV infection. Patients with CD4 cell counts between 50-299 cells/mm3 will be randomized to receive either subcutaneous IL-2 plus antiretroviral therapy, or antiretroviral therapy alone.

Lymphapheresis (81-I-0164)

Contact: Linda Ehler, RN, MN 1-800-772-5464 ext. 5-7687

This study is seeking HIV-infected volunteers with CD4 counts > 200. Volunteers will participate in a 45-minute apheresis procedure involving removal of some white blood cells from the circulating blood. Study is only recruiting patients residing in the Washington, DC, Maryland, Virginia metropolitan area. Financial compensation is provided for participating in this study.

Pregnancy Pharmacokinetics (00-I-0213)

Contact: Barbara Hahn, RN 1-800-772-5464 ext. 5-8007

This study is seeking pregnant HIV-infected women on HAART therapy. The purpose of this study is to see if the amount of antiretroviral drugs in the blood of pregnant women changes during the different stages of pregnancy. Blood samples will be collected intermittently for 12 hours at two to four different time points, every 6-12 weeks. Financial compensation is provided.

ESPRIT Interleukin-2 (00-I-0071)

Contact: Doreen Chaitt, RN, MPH 1-800-772-5464 ext. 5-8008

This is an open label, phase III, international trial to determine if IL-2, combined with antiretroviral therapy, prolongs the health of people with HIV infection. Patients with CD4 cell counts > 300 cells/mm3 will be randomized to receive either subcutaneous IL-2 plus antiretroviral therapy or antiretroviral therapy alone.

Analysis of HIV Genetic Variation (00-CC-0110)

Contact: Diane M. Rock-Kress, RN 1-800-772-5464 ext. 5-8003

This study will attempt to derive a comprehensive description of HIV population genetics. This study seeks men and women who are HIV positive with CD4+ cell counts in all ranges and viral load of at least 1000 copies/ml at time of screening. Participants must be antiretroviral naïve. All participants will have viral load and CD4 testing of blood as well as genotyping/phenotyping of HIV. Two leukophereses (removal of white cells from the blood) are required. Optional are lumbar puncture and lymph node biopsy procedures and semen donation or genital secretion collection for which participants will be compensated.

Use of Combination Antiretroviral Therapy to Delineate the Persistence of HIV Infection (97-I-0082)

Contact: Betsey Herpin, RN, MSN 1-800-772-5464 ext. 5-7630

This study will attempt to identify and define potential reservoirs (sites in the body) of HIV-1 that permit the maintenance of persistent HIV-1 infection and whether antiviral therapy can reverse the effects of HIV-1 infection. The study is seeking men and women who are HIV positive with CD4+ cell counts less than 500. Participants will receive AZT, 3TC, indinavir, and nevirapine therapy for at least 12 months. All participants will have viral load testing of the blood, up to 4 leukophereses (removal of white cells from the blood), and up to 3 lymph node biopsies.

Vaccine

Evaluation of an HIV-1 DNA Vaccine Encoding a Modified Gag-Pol in Uninfected Adult Volunteers (01-I-0079)

Contact: Grace Kelly, RN 1-800-772-5464 ext. 5-7744

The vaccine in this trial, VRC 4302, is classified as a genetic vaccine. Genetic vaccines contain the genes (hereditary material) which direct the production of the proteins of the HIV virus. VRC 4302 contains the gene for the gag and pol proteins of HIV. It is important to know that you cannot catch HIV or AIDS from this vaccine. Volunteers will be randomized in a blinded manner to receive either active vaccine (at one of 3 doses, 0.5 mg, 1.5 mg or 4.0 mg) or vehicle ("control") alone. Participants will receive VRC 4302 by intramuscular injection once a month for 3 months. The injection is given using a needleless injection device. A total of approximately 21 individuals will be evaluated. Volunteers will be evaluated over the course of one year (approximately 15 visits).

Hepatitis

Study of the Safety and Efficacy of the Addition of Adefovir Dipivoxil to Lamivudine for the Treatment of Chronic Hepatitis B in HIV-infected and HIV-uninfected Patients (01-I-0239)

This is a randomized placebo-controlled study of the safety and efficacy of the addition of ADV to lamivudine for the treatment of hepatitis B in both HIV positive and negative persons who have persistent HBV viremia and active HBV despite at least a year of lamivudine therapy. Subjects will be randomly allocated to receive either adefovir 10 mg daily or matching placebo. The study duration is 48 weeks with possible open-label ADV extension. Some travel costs will be reimbursed.

Adefovir for Hepatitis B in Patients with HIV Infection (01-I-0134)

This is a single-arm, open-label study of the addition of adefovir at 10 mg/day to lamivudine for the treatment of hepatitis B in people who have HIV infection, HBV viremia of at least 1,000,000 copies/mL, and decompensated HBV-associated liver disease. Participants must have been taking lamivudine (Epivir) for at least the past year and may not have hepatitis C or D or other active serious systemic infections.

Visit the web site: www.niaid.nih.gov/hivclinic

Medicine Chest

HCV/HIV Co-infection Therapy

by Glen Pietrandoni R.Ph.

How's your liver? Did you know that about one-third of HIV-positive people are also positive for hepatitis C? Many of the co-infected individuals don't know that there are treatments now for hepatitis C (HCV). Like HIV, hepatitis is a virus transmitted by blood. Behaviors especially at risk for transmission of HCV are the sharing of needles or works for drug use and any other activity that causes blood to be shared through broken skin. Theoretically, this may include the sharing of straws for snorting cocaine. The hepatitis C virus damages the liver over time and causes cirrhosis and possible cancer of the liver. Half of all the liver transplants performed today are done in patients with hepatitis C.

If it may take up to 20 years for a liver to fail in those without HIV, why worry about treatment for HCV now? For starters, there are higher viral loads of HCV in the liver of co-infected people. On average, it only takes seven years for severe liver damage to show in those with HCV and HIV. This is generally true for people with low T-cell counts, but not necessarily true for people with higher T-cells. Hepatitis C virus replicates faster and in greater numbers in HIV positive patients. You need your liver to function at full capacity to handle all of those HIV medications that get processed through the liver (protease inhibitors and non-nucleosides). HAART (highly active anti-retroviral therapy) can keep HIV in check for many years. Many new drugs and combinations require a healthy liver to be effective, therefore, having liver damage will restrict your HIV options in the future. There is also some new evidence that suggests that HIV disease progresses faster in co-infected patients as well.

If HCV therapy is decided upon, standard of care is interferon and ribavirin (combination therapy again), used together to reduce the hepatitis C viral load. The therapy could last for up to one year, but could be discontinued after six months if it is successful at that point. Less than half of patients on this therapy are successful after one year, but it could be tried again. Deciding on therapy includes a look at your genotype for HCV. Treatment is more successful in people with genotypes 2a, 2b, or 3b (perhaps as much as 60%), compared with less than one out of five people (20%) with genotype 1a or 1b.

A new treatment, Peg-Intron brand of pegylated interferon alpha, was approved for use in 2001, and Pegasys pegylated interferon alpha is expected to be approved early next year. These are long-acting injectable drugs given once weekly. The injection is done at home by the patient and is very similar to an insulin injection millions of diabetics do every day. In addition, a single capsule of ribavirin must be taken twice daily. It can be compounded in a pharmacy and thus be less expensive than the brand drug, Rebetol. (See HCV/HIV co-infection, page 27)

If you were thinking there would be no side effects with this therapy, sorry. Severe flu-like symptoms are very common with interferon treatments. Because this new therapy is given once a week, the duration of side effects should be more manageable than prior three times a week doses. As with HAART, proper adherence and management of side effects are important issues to examine before beginning treatment.

Always speak to your healthcare provider if you experience any problems with this or any drug therapies.

Tips for success

Avoid alcohol—Alcohol passes through the liver and will affect the results of therapy of both HIV medications and those used for hepatitis C. Give your liver a break!

Flu-like symptoms—Do the interferon before bedtime, and pre-treat with pain relievers and antihistamines recommended by your healthcare providers. Drink plenty of water and clear fluids each day.

Nausea and vomiting—Try eating smaller meals on injection day. Increase the number of times you brush your teeth. Avoid trigger foods and odors. Sugar-free lozenges and chewing gum helps. Over-the-counter and prescription medicines are also available if needed.

Diarrhea—Over-the-counter and prescription drugs available if needed.

Fatigue—Get plenty of sleep, and make sure you know how tired the medication makes you before driving or performing complex tasks.

Anemia—Anemia is common in co-infected people on dual hepatitis C therapy. Procrit, another injectable drug, may be prescribed.

Irritability, depression and suicidal thoughts—Relaxing techniques can help with irritability. Speak with your healthcare

continued on page 38

Li'l Fucker

by Laura Jones

I started doing this sexual health activism stuff in the early 90's, when I was around twenty. Way back then, when I was young and impressionable, I had a conversation with a man I've mentally named "Li'l Fucker." I hope it's not breaking confidentiality to reproduce it here, because I can still remember it verbatim (and probably always will):

Li'l Fucker: "I got syphilis from this whore I was banging. Is that curable?"

Me: "Yes. Syphilis is a bacterial infection; it's curable if you get it treated with penicillin."

LF: "Yeah, I got that."

Me: "Then you should be cured."

LF: "What about my wife? Should I make her get treated?"

Me: "Did you have sex with your wife while you had syphilis?"

LF: "Well, yeah! Of course I had sex with my wife! And if she doesn't get treated, then she's going to give that shit right back to me, isn't she?"

Um, yeah. Those wives can be awfully inconsiderate when it comes to re-infecting you with infections they don't know you've given them. Bitches. How could they?

I never spoke with Li'l Fucker again, but I've had conversations with many of his brethren over the last ten years. None of the Brethren have been as openly and pathologically sexist as LF, at least not while speaking to me. They've had other names and other stories: Bachelor party. Forest preserve. Business trip. Chat-line hookup. On the down-low. But-I-love-my-children. And while their circumstances vary, they all have these things in common: A) they have HIV or a sexually-transmitted infection, or are having sex that puts them at high risk for such; and B) they're also having sex with a wife or girlfriend who has no idea she's at risk for infection.

Some of them have been stepping outside for years. Others "never, ever thought they would," but did.

Just once. Every weekend. To see what it was like. Because they were drunk. Because they were out of town. Because they can't help themselves. Because their woman won't do "that." Because their woman isn't a man.

When they tell me they're having high-risk sex with one or more people while continuing to have sex with their wife or girlfriend, I ask the pertinent questions. Does their partner know about the other person/people? Do they use condoms with their wife/girlfriend? If not, how are they reducing the chance of passing an infection to their wife/girlfriend? Are they going to tell their wife/girlfriend if or when they pick up an infection, including HIV?

"I can't tell her about this—she'd leave me." "I can't use a condom—she's on the Pill." "I can't avoid having sex with her—she'd wonder what was wrong." "I can't tell her I have (insert infection here). She'd never forgive me."

"I don't want to hurt her." "I don't want to have to move out." "I don't want to lose my kids." "I don't want to see her cry."

I don't want to be "that way." Gay. Bisexual. Not-a-man.

If all you male readers think I'm going to bust out the Whoop-Ass here and paint the wall with these individuals' blood: Think again. I'm not out for vengeance. I'm not the judge or the jury here…I've done a partner wrong before too, so that's not my place.

What I'm out for is Accountability. Responsibility. Whatever "ability" makes men realize their wives' and girlfriends' health—these women's lives—simply matters more than their emotional turmoil or everyday comfort. Whatever will make them act accordingly, whether that means committing to safer sex with outside partners…breaking out the condoms or avoiding sex with the wife/girlfriend until those test results come back…telling a woman you've exposed her to an infection…starting an honest discussion about bisexuality or polyamorous relationships (sometimes you can re-negotiate that monogamy thing—you might be surprised!)…or simply saying "I can't do this anymore. I have to leave."

Most men are not Li'l Fuckers—and yes, yes, women need to take responsibility for protecting themselves from HIV/STDs. But it's a little different when you have a monogamy agreement. One of the best things about a monogamy agreement is the assumption that you don't have to use those damn rubbers anymore (did you think we liked them? BWAAHH!).

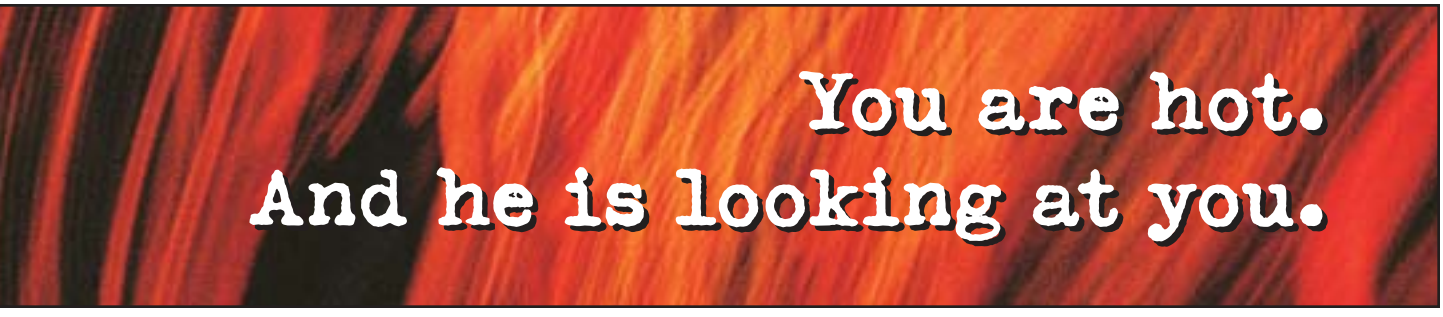
But monogamy isn't masturbation—you can't do it alone. And as women's HIV and STD rates continue to skyrocket, we need men to come to terms with their behavior. Yes, we need to take care of ourselves, but we need our men to take care of us too.

Because if seeing a woman cry is bad, imagine what it's like to see her sick. Or dead.

Land of Oz

Sex, Drugs and HIV

by Michael Barnett



You are in the bar. The music is pumping; your heart is racing. The body that you have worked out all winter is revealing its bulging mass and silky tight skin. You walk towards the back of the bar while noticing that everyone's eyes are on you. A couple of guys smile and give you the quick "once over." They smile more. You know, they like what they see. It's hard to believe that just a couple of months ago you were overweight and out of shape. But the weight has vanished after trips to the gym and with the help of your "little friend." Oh, what you wouldn't do for your little friend.

You walk to the bar and order bottled water. Your friend only likes water. Anything else makes your friend dull, makes your friend feel fat, makes your friend ugly. You can hear your friend screaming in your pocket. But you patiently wait for the music to get better. More drums, more base, more lights. You walk around the bar to see if you can find anyone who sparks your interest. You can feel people's eyes follow you, you can feel their eyes undress you, caress you, love you. You start to smile and then realize that the DJ is playing your song. It's time to get reacquainted with your friend.

You walk to the restroom and wait patiently for a stall. There's a line but you don't care. Soon, you and your friend will be on the floor dancing. You'll be swept away from the childhood you had, from the faggot jokes that you experienced in high school; from the distant parents who told their friends that their son was "different." Yes, soon all of that will go away, and the new you will appear.

The line shortens and you're next. The stall opens next to you and you see *him*. He is the guy you had a crush on for years. He is the guy who would never give the overweight guy you used to be the time of day. The nights you stayed awake and imagined him next to you. The hot sex you fantasized about in your mind. Then you were fat and unworthy. But now things are different. You are buff. You are tight. You are hot. And he is looking at you. He is giving you the "once over." He is smiling. He is the pursuer. You glance at him and move into the stall, locking the door behind you.

You reach into your pocket and pull out your little friend. There he is, the friend that you have come to love, the friend with the blue face and countless attributes. You flush the toilet and the next thing you know you are leaving the bathroom in search of *him*. You find him standing next to the bathroom entrance. You can't help but wonder if he is waiting for you. Then you realize that of course he is. You reach into your pocket for a vile of liquid and dump it in your bottled water. This will help your friend kick in. You wait. He walks over to you, his eyes not leaving your chest, still a smile on his face. He starts the conversation with the usual idle chitchat. You can't help notice his square jaw line. His full lips. His strong physique. You hardly hear a word he says. You are captivated by his raw sexuality.

You decide to dance. He leads you to the dance floor, his arm around your waist. You can tell he is doing the "body check." His hands moving up and down your back, then to your side. He turns and says in a sly mumble, "You work out, huh?" You don't answer him. You just smile, reassured that the work at the gym and your little friend have paid off. You start to dance with him.

You dance for a long time. The music takes you away. The touch of his body sends your heart racing. By the way he moves his body, you know he is going to be incredible in bed. You need to get "Tina." You whisper in his ear that you will be right back and you race off to find someone that can hook you up. After a couple of minutes and a trip to the bathroom, you return. You are ready. You are good to go.

In many parts of the U.S., Crystal Meth decides what we actually do in bed as well as the risks that we will take. Ecstasy (MDMA) makes our weekends more enjoyable. Special 'K' (Ketamine hydrochloride) gives us the flight that we need, the ability to lose our identity. The escape. The way it makes us feel. All of us momentarily forgetting about what it really does to us and how it puts us at risk for HIV infection.

We do Ecstasy to get us out on the dance floor and enjoy the music. It makes our heart race and/or blood pressure rise. But it also destroys cells that produce serotonin in the brain. These cells play a direct roll in regulating aggression, mood, sexual activity, sleep, and sensitivity to pain. Scientists have now shown that Ecstasy not only makes the brain's nerve branches and endings degenerate, but also makes them regrow, but abnormally—failing to reconnect with some brain areas and connecting elsewhere with the wrong areas. These reconnections may be permanent, resulting in cognitive impairments, changes in emotion, learning, memory, or hormone-like chemical abnormalities.

We shove our way to the front of the line at the club to enjoy the wonders of drug use. Once we are on the dance floor having a good time we usually need to "kick in" the Ecstasy. We do that with Liquid 'G' (GHB). GHB is an alternative to smoking dope on the comedown, and if you have sex, it's good sex, at least for awhile, until you fall asleep.

After we meet the guy that we want…we go home with him. That's where Crystal Meth joins the party. Crystal enhances whatever you are feeling at that particular time. The touch. If you are at home with the hot guy and want to have sex, then crystal will give you the best sex, even with a guy who doesn't know what to do sexually. It turns the sexually challenged into an Olympic champion, who can last for hours with multiple techniques and gymnastics that would even make Mitch Gaylord blush.

After hours of sex we lose our erections. The sexual Olympics turn into a sick sideshow. We take more to keep up, and maybe even a hit of Viagra. (Is someone keeping track of the drugs that are in our system?) Your judgment is impaired, your heart is racing, you are sweating, it's hard to keep your breath, you are panting, you are horny, and you have no idea if the guy behind you is using a condom, and you don't care. Then you take another hit of Crystal Meth.

And that's the trap of Crystal Meth, you lose your ability to make rational decisions. Users run the risk of getting caught off-guard by the addictiveness of drug. The psychological dependence causes us to need Meth daily to avoid the painful side effects of withdrawal and coming back to reality. The withdrawals can lead to bouts of deep depression, extreme tiredness, possible convulsions, coma or even death.

The drugs today are new. The immediate effects are incredible. The long-term effects are devastating. I have been a prevention specialist for nearly six years now, but I'm still at a loss: What can we say to someone that can compete with the effects of a new era of drugs? We see our friends become distant as they become more and more dependent. What can we say to the person who misuses drugs? Do we go back 15 years and say "Just say no" or "Use a condom"? I think not.

Drugs are just the vehicle. We need to search within ourselves and ask why we choose to ride in a speeding car with no seatbelt, on a dead-end road.

Michael Barnett is the Associate Director of Prevention at Test Positive Aware Network (TPAN). He is the creator of OZ (Outreach Zone), a program committed to behavior change and reducing the rates of HIV infection within Chicago's gay and bisexual community.

Structured Treatment Interruption and Immune Reconstitution

by Daniel S. Berger, MD

Drug holidays, treatment interruptions, and strategic or structured treatment interruptions: many names, many questions but only a few answers. Structured treatment interruptions (STI) were originally investigated due to the hypothesis that stimulation of the immune system would occur with intermittent exposure of the blood to virus. Patients who maintained undetectable viral loads with treatment were thought to have too small a quantity of virus in the blood for the immune system to react to HIV. Immunologic improvements would occur while interrupting treatment due to a cytotoxic T-cell immune response to HIV. In other words, the scheduling of treatments with regular interruptions would provide intermittent exposure to virus and thus repeated stimulation of the immune response (meaning the immune system would attack and keep the virus at bay on its own without the need of antivirals). It was theorized that possible results from these repeated interruptions could lead to eventual discontinuation of antiviral therapy completely. However, several structured treatment interruption studies have failed to demonstrate evidence of this possibility becoming a reality. While treatment of HIV-positive patients with highly active antiretroviral therapy (HAART) has shown to reduce HIV viral loads to below detection in the blood, the significant degrees of immune restoration that followed did not result in eradication of the virus.

At the 41st Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC) held in December of 2001, several studies were presented and several lessons were learned. Data from an 18-month observational study by K. Wolfe, *et al.*, described the outcome of 115 patients with treatment interruptions compared to 186 individuals who did not interrupt therapy. At the start of study, the average CD4 T cell counts were in the 400-500 range and viral loads were less than 50 in 52% of participants undergoing treatment interruption, compared to 43% of the on-treatment control group (not undergoing treatment interruptions). The average length of the first interruption in treatment was 5.4 weeks and interestingly 29% of the participants had more than one interruption. As expected with an interruption of treatment, CD4 count decreased by an average of 72 cells and viral load increased 2.1 logs. However, cholesterol and triglycerides decreased significantly. The significance is that not everyone who underwent interruption had undetectble viral loads.

After 18 months of observation, the patients undergoing treatment interrutions showed no significant change in their CD4 count. Seventy-six percent vs. 47% changed their antiviral regimen, but viral loads remained less than 50 in 66% vs. 73%. Of the remaining patients whose viral loads did not end up under 50, they still had an eventual decrease in viral RNA: -.6 log vs. -.3 log (regimen change and no change respectively).

In another study, Dr. Anthony Fauci from the National Institute of Allergy and Infectious Disease presented results of 10 patients who underwent 32 cycles of seven days on and seven days off treatment (64 weeks). These individuals were on Norvir (ritonavir) + Crixivan (indinavir) + Epivir (3TC) + Zerit (d4T). There was no change in plasma (blood), cellular (within the cells), proviral HIV RNA (building blocks of the virus) or latently infected CD4 cells. There was no evidence of HIV resistance by either genotype nor phenotype testing, and lymph node biopsies done on some of the participants showed no negative changes. Also, there was no change in patients' CD4 T cell counts nor CD4 percentages. However, cholesterol and triglycerides improved steadily during the course of the study, which is ongoing.

Results from STI studies presented at the 13th International AIDS Conference noted the development of resistance in a few patients, but more notably when non-nucleosides were included in their regimen. This can be explained by the fact that non-nukes, especially Sustiva (efavirenz), have long "half-lives," meaning they remain in the blood much longer than the other antiviral agents. Thus when interrupting treatment, unlike most other antivirals which are cleared from the blood faster, non-nukes remain present. Because the drug is acting against the virus alone, the virus can more easily circumvent the effect of non-nukes and develop resistance to this class of antivirals. Thus we can infer that traditional treatment interruptions should be avoided for

those patients on the non-nucleoside class as a backbone for their antiviral regimen.

Interruption situations are found to be useful for patients who have been highly exposed to antiviral agents and resulting multi-drug resistance. These individuals may have little viable options for treatment. Wild type virus, the typical viral population present during initial infection and susceptible to the effects of antiviral drugs, is stronger and domineering over the presence of resistant virus. To invoke the emergence of wild type virus, HIV drug therapy is interrupted for several months. As wild type virus begins to emerge and replicate it suppresses resistant strains, thereby allowing drug treatment to become effective again. This approach is investigative, but is increasingly getting more attention from clinicians and researchers.

At the present time we still do not know enough to boast of a clear understanding about how to best structure treatment interruptions, which patients will benefit most, and what intervals are most optimum. There is the valid concern that patients will stop treatment on their own with little supervision. Due to the risks of the development of resistance and possible opportunistic complications, an STI should not be undertaken without the guidance and care of a trained physician.

However, several essential facts can be abstracted from the valuable studies already done. Firstly, interruptions probably can be performed safely in certain patients within several parameters. Secondly, certain and substantial numbers of patients who have taken treatment holidays for up to a median of five months have had their CD4 T=cells restored and viral loads decrease to undetectable within three months of resumption of treatment (JF Braun, *et al.*, 41st ICAAC). Finally, most studies have shown benefits regarding blood lipids: cholesterol and triglycerides decreased significantly during interruption of therapy.

The fact remains that patients can not be expected to consume fists full of pills forever. As lives are extended, the toxicities of medications have become rather obvious, and pill fatigue has set in. Attention must now focus on dealing with HIV infection in the long-term. Structured treatment interruptions need to be investigated for the good of our patients. Perhaps as the risks of developing lipodystrophy and metabolic abnormalities are minimized, patients may be less likely to develop treatment fatigue and noncompliance. Treatment interruptions can also result in large cost savings. While STIs remain a new avenue for research and hope, it is important to recognize that more studies are needed to examine the many issues discussed in this article. We will continue to explore this approach, patiently.

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

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

TPAN Calendar of Events

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

March 2002

Date	Time	Event
Tuesday, 5th	7:30 PM	Committed to Living Series: Housing
Tuesday, 12th	6:00 PM	Client Advisory Board Meeting
Tuesday, 19th	7:30 PM	TPAN Board Meeting
Wednesday, 27th	6:00 PM	Retrovirus Update Speaker: Dr. Malte Schutz

April 2002

Date	Time	Event
Tuesday, 9th	6:00 PM	Back to Basics: HIV 101
		Presented by the AIDS Research Alliance Community Advisory Board. Food will be served. Speaker: Dr. Malte Schutz
Tuesday, 16th	7:30 PM	TPAN Board Meeting
Mon.–Wed., 22nd–24th, Caring for our Communities: HIV and AIDS in Illinois. Held in Springfield, IL Contact Sara Schmitt at (312) 922-2322 or sschmitt@aidschicago.org		

Medicine Chest *continued*

continued from page 32

provider about your symptoms and possible solutions. Pre-treatment with anti-depressants, a month before going on hepatitis C therapy, is common.

Loss of appetite—Eat regularly even if you have no appetite. Drink clear juices in addition to water. Brushing your teeth can get rid of the metallic taste in your mouth. Zinc supplements may also help with this problem.

Hair loss—It is only temporary! If you lose some hair during therapy, it will grow back.

Most insurance companies and Medicaid plans will pay for the cost of the interferon and ribavirin. These are very expensive drugs. AIDS Drug Assistance Programs (ADAP) vary from state to state, but in general, these drugs are not included in the ADAP formularies. Manufacturer of Peg-Intron interferon alpha (Schering), Rebetol ribavirin (Schering) and Pegasys interferon alpha (Roche) have a compassionate care program available. Manufacturers and pharmacies have support programs available at no cost to help patients manage side effects and ensure continued availability of drug product and insurance coverage.

Glen Pietrandoni is director of Clinical Pharmacy Services for the Walgreen Specialty Pharmacy, focusing on HIV, located in the Howard Brown Health Center of Chicago. Thanks to Ted Terziev for help with this article.

Editor's note: HIV-positive persons enrolled in the Peg-Intron free access program have reported missing doses of the hepatitis C medication. Advocates from the Hepatitis C Action and Advocacy Coalition (HAAC) have sent out a community notice explaining a procedure that Peg-Intron's manufacturer provided to the US Food and Drug Administration (FDA) for avoiding this problem. Enrolled patients who are already on the drug should call toll-free at 1-888-437-2608 and talk to someone about the problem they're having getting their new doses. You should be able to get past voice mail by following the instructions, after a couple of presses of the keypad. If you still have problems, call the customer service number, 1-800-222-7579. HAAC would like your feedback. Contact them via e-mail, HAAC_sf@hotmail.com.—CC

Programs and Meetings

All meetings held at TPAN offices unless otherwise indicated:
5537 North Broadway, Chicago.
Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm
phone: (773) 989-9400 • fax: (773) 989-9494
e-mail: programs@tpan.com • www.tpan.com

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

Monday

TPAN Daytimers

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

Newly Diagnosed

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

Tuesday

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 from 7:00–9:00 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.

Positive Progress II

A group for HIV-positive people in recovery. Fridays 2:00–4:00 pm.

Needle Exchange Program

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

Safe Passage

A group for young adults (ages 18-24) who are HIV-positive. 2nd and 4th Fridays at 7:00 pm.

Scheduled By Appointment

Family AIDS Support Network (FASN)

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

Women's Group

A group for HIV-positive women. Call Sylvia at (773) 989-9400 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 at (773) 989-9400.

Peer Support Network

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

Positive Buddy

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

Miscellaneous

ChicagoPos18to24 at aol.com

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

"HIV scared me...

HCV frightened the hell out of me!"

For additional information and other Internet links visit www.tpan.com

test positive aware NETWORK

For further information about HCV call the CDC National HIV/AIDS, STD Hotline 800-342-2437