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summer  
2003

## Starting, Switching, Stopping: Personal Perspectives on Making Treatment Decisions

by James Learned

For this issue of *ACRIA Update*, we wanted to explore the different ways that people make decisions to start, switch, or stop antiretroviral treatment. We invited individuals to share their personal experiences and deeply appreciate the contributors' willingness to offer their stories so thoughtfully and honestly. Although a few of the pieces share some similar themes, what is most striking is how differently each individual approached the decision-making process and how very different their decisions tended to be.

As an HIV treatment educator, I work under the comfortable delusion that if people learn about HIV, the immune system, and current treatment options, they'll be better able to make informed decisions that will extend their lives and increase their quality of life. In my most optimistic moments, I believe that education is key to addressing the pervasively inequitable access to good medical care and treatment. So I try to help people better understand the relationship between CD4 counts and viral load, current treatment strategies, the individual antiretrovirals and their attendant dosing schedules and side effects, even the mistakes we've made throughout the history of the epidemic. To that end, I provide one-on-one counseling and group workshops for people with HIV, train non-medical providers to incorporate treatment considerations into the provision of social services, and help create written materials that offer information to people with HIV, hoping to help them make decisions about treatment that are right for them.

I'm certainly not alone in my belief that education leads to better personal treatment decisions. Community-based educators throughout the country work tirelessly to explain the results of recent studies, discuss strategies for self-empowerment, and try to help people better communi-

cate with their healthcare providers. Flipping through community newsletters or visiting the websites of HIV treatment advocacy and education organizations reveals articles with such promisingly informative titles as *How HIV Damages the Immune System*, *Keeping Your Liver Healthy*, and *Blood Work: A Useful Tool for Monitoring HIV*.

The experiences shared in this issue of *ACRIA Update* make me wonder if the seemingly paradoxical adages "Knowledge is Power" and "Ignorance is Bliss" may be equally true. Some of the contributors have done everything the "right" way according to the prevailing wisdom for maximizing the likelihood of HIV treatment success – they read everything they could get their hands on, sought out experienced doctors, developed personal treatment plans, and made decisions to start, switch, or stop therapy based on a solid base of self-education and empowerment. Others have done everything the "wrong" way – they threw up their hands in varying degrees of denial, ignorance, intimidation and, perhaps, common sense and followed the advice of whoever spoke first or loudest. Yet if we were to separate the stories into categories of those who did things the "right" and "wrong" ways, the results in terms of treatment success and failure aren't very different. Some of the individuals who have most embraced the precepts of taking control, educating yourself, and making informed treatment decisions haven't done so well, while others who accepted the first advice to come along are doing just fine.

As a relatively knowledgeable educator, I have no easy explanation for this seeming incongruity. Except, perhaps, to return to the frustrating bottom line – every individual is different, with very different responses to HIV and anti-

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ACRIA is an independent, non-profit, community-based AIDS medical research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. Bulk copies of *ACRIA Update* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call 212-924-3934 ext. 121.

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**Standard of Care Treatment vs. ZEST Once-Daily Regimen**  
This trial will study whether people on their first HAART regimen who take their drugs two or more times a day can switch to a once-daily regimen. People in the trial will either remain on their current medications, or switch to Zerit XR, Epivir and Sustiva (ZEST) taken once daily. They will visit ACRIA 9 times over 11 months. All blood tests, study visits, and study medications (Zerit XR, Epivir & Sustiva), as well as medications from the Standard Of Care arm that are manufactured by the sponsor, will be provided at no charge to the participants. Prescriptions will be written for any other anti-HIV drug. You are eligible if you are HIV-positive, age 18 or over, and on an initial HAART regimen (one or more NRTIs, at least one agent must have a twice-daily dosing schedule, and no NNRTI in the past or in current regimen) with a viral load below 50. Study participants will be reimbursed \$25 for each visit.

**RESIST 1: Tipranavir in Multi-Drug Resistant Patients**  
This trial will study the safety and efficacy of tipranavir (a protease inhibitor) boosted with low-dose ritonavir in people who have taken multiple antiretrovirals. This study lasts about 11 months, with 10-12 visits to ACRIA. All blood tests, study visits, and study medications will be provided by the sponsor. All patients must have taken drugs from each of the three antiretroviral classes, have taken at least two protease inhibitors, have a viral load over 1,000, and must currently be taking a protease inhibitor. Patients who do not qualify will be screened for RESIST II, another trial of tipranavir. Participants will be reimbursed \$25 for each visit.

**For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at 212-924-3934 ext. 124**

**Social Networks Study**  
We have completed the first phase of enrollment for this study. Results from this study will be available soon on our website. If you want to participate in future HIV Over 50 studies, contact Salone Howard at 212-924-3934 x105 or email [showard@acria.org](mailto:showard@acria.org).

**Using Complementary Treatments to Manage HIV/AIDS**  
People in this study will be interviewed and complete a brief survey about treatments other than antiretrovirals, such as supplements, exercise, acupuncture, herbal remedies, as well as who provides the treatments, how often they use them, and if they feel they are helpful. Participation will require approximately 90 minutes, and people receive \$25 for their time. To qualify, people must be HIV+, using HAART for at least a year, and be using other treatments for HIV/AIDS. To enroll, call Philana Rowell at 212-924-3934 x125 or email [prowell@acria.org](mailto:prowell@acria.org).

**HIV Over 50 Database** ACRIA is currently establishing a large cohort to conduct research on HIV+ people over 50. If you would like to be included in this database, please contact Salone Howard at 212-924-3934 x105 or email [showard@acria.org](mailto:showard@acria.org).

**Web Research Study** This internet survey studies the extent to which HIV service providers may benefit from HIV prevention programs or programs designed to assist them in other areas of their job. Visit [www.acria.org](http://www.acria.org) to participate.

## Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIA Update* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

## Starting, Switching, Stopping *(continued from first page)*

retroviral treatment. I see this regularly in my counseling work. How else to explain the guy who cuts his twice-a-day regimen in half to lessen the side effects, only to see his viral load remain undetectable and his CD4 count continue to rise? I dutifully explain drug resistance, trough levels, why drugs are dosed the way they are, and the possibility that he might be blowing one or more class of drugs. The part of me that wants things to make sense patiently waits to see how long it takes for him to develop resistance to his meds – so how do I make sense of his repeated genotype results that show no resistance has developed? And what of the other guy who’s strictly adherent to the same combination, struggling through the side effects, only to see his viral load rise, his CD4 count decrease, and the rapid development of resistance? Differing absorption, maybe. That would be comforting. But it’s probably much more complicated than that.

As educators, when we talk about making treatment decisions, we often begin by discussing an individual’s relationship with their doctor or other healthcare provider. The kind of relationship someone has with their healthcare provider is often indicative of their connection with their personal treatment decisions. We sometimes make the mistaken assumption that everyone wants – and needs – a truly collaborative relationship in which the patient and the healthcare provider work together to make treatment decisions. We envision a more or less equal relationship, with you being as responsible for your care as your provider is. Sounds ideal, but it may not be right, or even possible, for everyone. Some people feel far more comfortable with a provider who is directive and in complete control, telling the patient exactly what to do. You follow orders, trusting your provider completely, relying on him or her to know what’s best for you. Relinquishing all control can be enormously comforting when there are so many other concerns that require you to take responsibility. And then there’s a third possibility, one in which the patient is in control and makes all the decisions. The doctor is your consultant – a consultant who can write prescriptions and order

diagnostics – but a consultant just the same. In this relationship, you have to be very well educated about available treatments and current strategies. This isn’t for everyone either.

Whether we’re talking about HIV or any other health condition, many of us feel most comfortable somewhere between these extremes. And our needs may change over time. The relationship with a healthcare provider that works best for any one individual is likely to be based on many factors, including culture, previous experiences with the healthcare system, and personality. As with sex or any inti-

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***“...sometimes we want to feel in complete control, sometimes we want to relinquish all control, and sometimes we want the give-and-take...”***

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mate relationship, sometimes we want to feel in complete control, sometimes we want to relinquish all control, and sometimes we want the give-and-take that offers us at least the illusion of equality. The personal experiences shared by the contributors to this issue of *ACRIA Update* attest to the fact that different provider relationships work equally well depending on the individual. As with treatment decisions, there are no “right” answers.

The collection of personal stories included in this issue doesn’t pretend to be a scientifically accurate representation of the current epidemic. Many of them describe stopping therapy, not as structured treatment interruptions in research settings, but

as drug holidays taken for various reasons with or without their doctor’s approval. The number of drug holidays described may at least partly be a result of self-selection – people who have successfully stopped therapy may be more willing to share their experiences. Or it may reflect an experience that is more widespread than many people realize or want to acknowledge. Most of the contributors also have an advantage over almost everyone with whom we conduct treatment education at ACRIA – private insurance, which generally affords patients better care and treatment than people on Medicaid. It’s also important to acknowledge that some individuals who wanted to share their personal experiences chose not to for fear of reprisal if their status were revealed. They were afraid that, even if they used a pseudonym, there might be enough identifying details in their stories to threaten their jobs, their families, their relationships, and their homes. That concern may not be surprising to most of our readers, but it’s an important reality check for all of us. It’s critical to keep in mind that the voices represented in these pieces don’t necessarily represent everyone – or even most people – making treatment decisions today.

The seeming contradiction between our belief in the importance of education in making informed treatment decisions and the fact that lots of people do just fine by blindly following doctors’ orders or making decisions based exclusively on emotion and faith may not be as antithetical as it first appears to be. Sometimes maybe knowledge *is* power and ignorance *is* bliss. Conversely, maybe ignorance is sometimes enormously powerful and knowledge is luxuriously blissful. As we work in our communities as peers, educators, case managers, and friends, sometimes it may be best to toss aside our handy lists of questions designed to help people develop treatment strategies and prepare to start, switch, or stop therapy. Sometimes it may be best just to listen and support them on their journeys.

*James Learned is Director of Treatment Education at ACRIA and Editor of ACRIA Update.*

## My Sordid Antiviral Past

*Carlton Hogan works for the Statistical and Data Management Center of the Community Programs for Clinical Programs on AIDS (CPCRA), and is active in the Coalition for Salvage Therapy and the AIDS Treatment Activist Coalition.*

In retrospect, I probably started AZT too early, although I have survived when many people I knew with higher T-cell counts back then are gone. Who knows why? From 1985 to 1988, I had a pretty severe case of what used to be called ARC (AIDS-Related Complex) – swollen glands, night sweats, shingles, etc. In 1988, AZT had just received FDA approval, but since the pivotal trial was done in persons with AIDS (or more precisely, men who had already had PCP pneumonia), it was not approved for people with HIV who didn't have AIDS, and I didn't have insurance anyway. So I entered a clinical trial (ACTG 016), which was comparing AZT to placebo in people with ARC.

I entered the trial to get AZT. I am almost ashamed to say it now, but if I had been given the placebo, I would have gotten the AZT some other way. The trial was supposed to be blinded: neither the researchers nor the patients were supposed to know who was getting AZT or the placebo. That was wishful thinking with an experienced substance abuser like me. I checked out the AZT as though I was testing coke. I put my study med and AZT side by side on a piece of aluminum foil and heated it with a lighter. While pharmaceutical companies have gotten pretty good at making "taste-alike" placebos, these tend to melt at lower or higher temperatures than "the real thing," to smell different when they burn, and to leave different-appearing residue. My study medication melted at the same instant as the real AZT and gave off the same foul smell. I had the real stuff. I hereby apologize to my research colleagues, in advance, for disseminating this easy method of unblinding.

Back then, my strong conviction was that HIV's reverse transcriptase enzyme could only endure so many mutations before it became ineffective.

So as soon as the ddl expanded access program opened up in 1989, I added ddl to my AZT. There was a thriving "gray market" in "alternative treatments" back then. Now that we have effective antiviral therapy, that seems to have waned greatly. But isoprinosine, ribavirin, Dextran Sulfate, Peptide-T, AL-721 and others were big sellers back then. As soon as ddC was proven safe in humans in 1990, it appeared on the gray market in an "underground" version available through activists.

Since then, I have never been on less than three drugs, and sometimes four. Sadly, we have learned that reverse transcriptase has an unbelievable amount of flex, so my theory that HIV couldn't reproduce in the face of multiple mutations didn't pan out. But my T-cells were 6 in 1991, and I'm still here. My T-cells have never been much above 200 since then, generally below, but I am here and relatively healthy. I have no regrets, but I wonder what

would have happened if I had started antiviral treatment later.

When I gave presentations in my professional role as a statistician, it was uncomfortable to say that combination treatment was unproven, since I was using it. But it seemed to be working for me. Was it genetics, combination treatment, or a weak strain of virus? I'll never know. But I suspect 15 years of almost perfect adherence did the trick. I missed three days for the first time last year - within a month, I had my first detectable viral load in years, and my T-cells fell to half of what they were. So I probably did the right thing starting treatment so many years ago.

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*"I have no regrets, but I wonder what would have happened if I had started antiviral treatment later."*

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# Crossing the Line

*Jennifer McGaugh calls San Francisco home. She's been active in the HIV community for over ten years and currently works as the Women's Services Coordinator for Shanti, an HIV and breast cancer organization. Some of her biggest passions are riding her 1978 BMW motorcycle, cooking, and going to see loud, live music.*

In one of the most difficult decisions I've ever made, I started taking HIV medications recently. I crossed a line I said I'd never cross. I remember a conversation I had 13 years ago with a former roommate named Brian. We had both just turned 22 and moved to San Francisco. He feared he'd been infected with HIV because he was having symptoms that looked like sero-conversion. We talked a lot about what he'd do if he were HIV-positive; he said he'd never take AZT, the only available treatment at the time, but would use Traditional Chinese Medicine instead. In solidarity with Brian, I announced that if I became HIV-positive, I, too, would never take AZT but would only use Traditional Chinese Medicine. How ironic that my gay roommate, like a kid in a candy store when it came to unprotected sex, didn't get HIV, but his straight, female roommate eventually did. (Honestly, I was like a kid in a candy store.)

On January 1, 1991, I was infected with HIV and I was diagnosed on January 9, 1993. Even though HIV medications weren't offered to me at the time, I knew I would have refused them. Within two weeks of my diagnosis, I found an acupuncturist/herbalist who I began to see three times a week. I felt like she and I were allies in the fight against HIV and the Western medicine establishment. As new HIV treatments came out, I dug my heels in even deeper – I wasn't convinced that pharmaceuticals would be helpful to me or anybody else with this disease.

I became an activist and helped start an agency called Bay Area Young Positives, providing support to HIV-positive youth like myself. Many of the members of BAY Positives held views similar to mine about AZT and emerg-

ing HIV medications. For the first time in my life, I was part of a community. But, one by one, many of them joined protease inhibitor trials and started to see drugs as their only option. As more and more of my peers started to take the new HIV medications and discontinue natural therapies, it felt like my com-

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***“...I announced that if I became HIV-positive, I would never take AZT but would only use Traditional Chinese Medicine.”***

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munity was abandoning me. Hoping that I would be convinced of their benefits, I learned as much as I could about the medications. Because a big part of my job has been to provide treatment education and advocacy, I have become articulate about the virtues of antiretroviral therapy (ART), but somehow have held on to my negative views about the Western approach to treating HIV.

Before I started taking meds, I deliberated about what it would take for me to use ART. My medical providers had advised and even pestered me to take them for several years. I created an imaginary line in my mind about what it would take for me to begin ART. Whenever I approached that line – my

T-cells dropping to a certain level, my viral load increasing to a certain level, experiencing certain symptoms – I moved the line farther away. This went on for four years, and I started to feel like an anomaly in the HIV community. The peer pressure was immense. The HIV community at large – HIV-positive people, activists, treatment educators, researchers, conferences, medical and service providers, friends, colleagues, clients, the media, newsletters, and magazines – are now all geared towards treatment. When people asked me what medications I was taking and I said that I'd never taken them, the responses ranged from shock to being told that I was irresponsible regarding my health by not being on medications.

I'm definitely not a non-progressor. Until the past couple of years, I'd been relatively asymptomatic, but have always had a very sensitive constitution. My T-cells steadily declined from a high of 500 when I was diagnosed to a recent low of 225. My viral load fluctuated between 6,000 and 70,000, but crossed that 100,000 line in the past year. The most troubling thing was my CD4 percentage. Last year it dropped to 9%, which officially gave me an AIDS diagnosis even though my T-cells were above 200 and I had never had an opportunistic illness. I started to experience troubling symptoms and decided to take a PCP prophylaxis. I developed oral hairy leukoplakia and struggled with persistent vaginal infections, which forced me to resort to using major pharmaceuticals to treat them. I had fatigue, depression, night sweats, chronic sinusitis, allergies, and gastrointestinal problems. Nothing was life threatening, but my quality of life was declining along with my T-cells.

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## Crossing the Line *(continued from previous page)*

Last year I had an epiphany that allowed me to more seriously consider medications. I admitted to myself, then to my Nurse Practitioner, that a lot of my identity was tied up in being “an HIV-positive female activist who has never taken ART.” So many people had told me how lucky I was for being so healthy and not having to take medications. I’d never felt like a lucky person before. A second epiphany I had was that I was afraid to admit to my parents, my acupuncturist and my HIV-negative partner that I was considering treatment. I was afraid my family and partner would see me as sick rather than as a healthy person who can have a long life. I was afraid my acupuncturist would feel betrayed by me for “giving in.” My medical provider validated my feelings around my identity and encouraged me to tell the people closest to me that I was considering starting medications. She said it would be good practice for me to hear myself say it and to test the waters. I took her advice, and the responses were positive and encouraging, which took a lot of the pressure off. My acupuncturist surprised me by saying she was upset that I hadn’t shared with her how I was feeling sooner, that she was supportive of my decision and would work with me around any side-effects I might experience.

My medical provider gently suggested that now was the time to seriously consider starting meds, but she wanted to address my depression first. She was concerned that I wouldn’t be adherent with my depression as bad as it was. We went through a couple of antidepressants before finding one that worked, but within two weeks of starting the second one, I found myself whistling and starting to feel emotionally stable. Two weeks later, I marched into her office and announced that I was ready to start HIV medications and felt that I could stick to a regimen.

During the trial and error of stabilizing my mood, I consulted a close friend who is also HIV-positive about which regimen would be right for me. My friend is a treatment advocate and educator, and we went through the pros and cons of each of the antiretrovirals. I had criteria for choosing my combination: I didn’t want to start off with a protease inhibitor for concern of devel-

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***“I was afraid to admit to my parents, my acupuncturist and my HIV-negative partner that I was considering treatment.”***

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oping high triglycerides, lipodystrophy and gastrointestinal problems; I was not going to take Sustiva for fear of exacerbating my depression and because of the central nervous system side effects; I wanted to avoid the “D” drugs – d4T, ddI – because of their implication in mitochondrial toxicity, lipoatrophy and neuropathy; I wanted to take pills two times a day at most and the least number of pills possible (I have difficulty swallowing pills); AZT scared me because of its mythology and its tendency to cause bone marrow suppression; Viread was brand new and my friend encouraged me to “keep

it in my back pocket for future use”; 3TC was looking really good; and Viramune was starting to look good, although the possibility of developing a life-threatening rash and hepatic failure scared me.

Taking all of this into consideration, the combination I came up with was Viramune and Combivir, just two pills in the morning and two at night. I decided I would get over my attitude about AZT. My Nurse Practitioner said she would monitor me very closely during the first three to six months on the medications, and we would immediately address any side effects I might experience. Between her and my extended support system, I had a safety net.

On Monday, January 13th at 8:30 am, I took my first dose of Viramune and Combivir and, instead of fear, I felt excitement about the possibilities of my future.

During that first week, I was increasingly nauseous and by day seven was throwing up. I ended up taking five weeks off from work to adjust to the medications. I’ve always been a fan of marijuana, but I got to put the “medicinal” in front of “marijuana” and, honestly, that’s what made it all bearable. Although the nausea was unlike anything I had ever experienced, it was all worth it when only a month and a half after crossing that line, my T-cells shot up to 510 and my viral load dropped to 1,400. Three months after starting the meds, my T-cells were at 592, my viral load was at 800, and my CD4 percentage rose to 17%. I’ve never had lab results this good or as much energy the entire time I’ve been HIV-positive. I’m so glad I went through this process. I’ve learned a lot about myself and I’m totally invested in maintaining my health – and I’ve not missed a single dose. ●

# Letting Someone Else Drive

*Christopher Murray is a member of ACRIA's Community Advisory Board.*

Like many HIV community activists, I became involved after my own diagnosis. My work in the field has become my profession, training people with HIV to become community advocates and represent themselves and others with HIV on local advisory boards and planning groups. It's a privilege to talk to other people with HIV about the process of empowerment and how vital it is to both individual and community responses to such a devastating disease. It's work I love and believe in.

That makes it all the more confusing to consider my own role as a patient struggling to make decisions about my healthcare. I'm not sure how empowered I actually am when it comes to medical decisions, and my history with antiviral therapy bears that out. It's hard enough to sort through all the individual drugs, let alone the complicated regimens, contraindications, and possible side effects. The life and death import of these decisions has sometimes led me to avoid responsibility and adopt a close-your-eyes-and-aim-in-the-direction-of-the-dartboard strategy. Upon reflection, it's clear that I've most often relied on the advice of people that I saw as authority figures, for better or worse. Mostly for better, luckily.

I was diagnosed in 1990 when I was in my early twenties. By 1995, I was working in public policy at Gay Men's Health Crisis, and a treatment educator friend told me about the combination therapy trials being conducted by David Ho at the Aaron Diamond AIDS Research Center here in New York City. I was treatment naïve, meaning that I had never taken any anti-HIV medication – and I was certainly naïve about treatment.

My T-cell counts had been slowly declining and were dipping below 500. I figured what the hell. There was excited buzz around the work Ho was doing, and I thought I'd be at the center of what was cutting edge in HIV. Frankly, that fed my ego and sense of myself as an in-the-know, sophisticated New York homo with HIV. I looked up to my treatment educator friend for his encyclopedic treatment knowledge and his commitment to educating people about their options. I viewed him

as a mentor. I never considered myself a treatment wonk. I still don't. While every drug approved by the FDA was a victory for access and care, each also complicated things and increased my sense that it was all beyond me. On some level, I think I entered the trial to please my friend by following his advice. Not a very scientific motivation, but there it is. I think he was a good person to trust in that he was very well informed and had my best interests in mind. So my choice of him as a resource was well founded even if the decision to participate in the trial was based in part on emotional considerations.

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***“Upon reflection, it’s clear that I’ve most often relied on the advice of people that I saw as authority figures, for better or worse. Mostly for better, luckily.”***

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I was in the trial for several months and experienced excellent clinical benefit, although I had to deal with difficult side effects, mostly diarrhea, which necessitated bringing clean underwear with me everywhere I went. I was “intermittently compliant,” as the investigators reported at the International Conference on AIDS in Vancouver in the summer of 1996. Eventually, I was dropped from the trial. I felt like a bad patient, but also harbored resentment against the study doctors. I felt that their allegiance was more to the trial than to me as a patient. As with my treatment educator friend, they were renowned in their field and seemed appropriate persons to trust for medical advice, so I don't regret the trial experience. But the ignominy of

being dropped still stings a little.

A few years later, having switched treatments a few times, I was seeing a new doctor at a clinic because I was unemployed and relying on my ADAP (AIDS Drug Assistance Program) coverage for primary care. New York State ADAP, then and for the present, provides primary care, a roster of medications, and home care if needed, but not hospital stays. The clinic doctor was nice, but I wasn't sure he'd know my name if I met him on the street. Advised to completely switch regimens, I was put on Ziagen, Sustiva, and maybe something else (I can't remember). I was a fool to make any treatment changes without insurance. Within a week, I had a severe allergic reaction to the Ziagen, puffed up like a balloon, and was in the hospital on steroids for three or four days. And I have the \$8,000 medical bill to prove it.

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## Letting Someone Else Drive *(continued from previous page)*

I was mad at the doctor for not considering my lack of insurance in switching my treatment. And I was mad that he hadn't underscored the possibility of an allergic reaction. Maybe he *did* go over the possible side effects, but I don't remember that happening. I was furious with myself, too – not for the allergic reaction, but for not making sure I was covered for hospitalization and for not clearly examining the drugs' side effect profiles and being alert for signs of a reaction. I had figured that I was an old pro at AIDS meds. I was wrong. I had taken several of them, but hadn't invested a lot in studying them.

I don't want to oversell the *mea culpa* aspect in describing my experience with HIV medications. My intention is to describe the impact of my emotions on taking medical advice and to validate, at least for myself, how overwhelming and scary dealing with treatment decisions can be. I've noticed in myself that there is a strong desire to sit back as a patient and let someone else drive. I pick adequate, even excellent people to advise me because I recognize that, emotionally, I'm easily overwhelmed by treatment issues. But I'm still uncomfortable with the idea that I'm evading taking control of medical decisions.

There's a sense that people with HIV should become super-consumers, know all about every aspect of HIV, and be rabid activists. That's a lot of pressure and a lot of responsibility. Beneath my behavior is a skewed belief that if I allow someone else to make the decisions for me, then I get to blame them if something goes wrong. That equation is what also troubles me. It's hard enough to take personal responsibility for contracting HIV and hard again to take responsibility for what happens to my body.

Of course, people with HIV aren't the only ones who struggle with issues of personal responsibility. Everyone who smokes cigarettes or eats fatty foods makes decisions that may negatively affect their health. For me, tolerating my impulse to let someone else drive my medical decision-making is the first step in acknowledging, and eventually challenging, my passivity as a patient.

Currently, I have the luxury of not needing too much advice, which is great. I was having a lot of trouble on Sustiva and went off everything in 2000. I've been able to maintain satisfactory T-cell and viral load counts since then without being on combination treatment. It's really nice not to be taking drugs. I figure I'll have to go back on some regimen eventually, and I know that my previous experiences will stand me in good stead. Experience is a powerful teacher, and I now know things to watch for, questions to ask, and more complex ways to analyze the advice I'm given and the regimens I'm considering.

I've been very lucky to be positive in the era when care has been revolutionized, at least in this country, by combination therapy. I'm lucky that I've had the opportunity to explore my impulse towards passivity in the face of a challenging and scary health condition. I continue to develop awareness of my own tendencies so that my actions can be less unconscious reactions and more considered choices. If I've learned anything during my time as an HIV educator, it's that becoming an advocate takes time and fortitude. It's a process, as they say. Little kids think throwing the blanket over their heads will protect them from the monster under the bed. Of course, HIV is a real monster, not an imaginary one, and I'm slowly learning to stare it in the face. ■

### HIV Service Providers: We Want You for an Important Web Research Study

ACRIA is collaborating with researchers from Indiana University on a study of issues facing those who work or volunteer for HIV organizations. If you work in an HIV prevention or HIV care program, we invite you to participate in this exciting study. The purpose of this study is to better understand the extent to which HIV service providers may benefit from HIV prevention programs or programs designed to assist them in other areas of their job.

Participation is completely anonymous and voluntary. Completion of the survey will occur via the internet and will take approximately 20 minutes. Visit the ACRIA website if you want to participate, [www.acria.org](http://www.acria.org).

## Hanging In

*Sue Gibson is an RN and Clinical Trials Coordinator living in Dallas, Texas.*

I began taking antiretrovirals shortly after I tested positive in 1989. My thinking was, "I don't know what happens to people who take AZT (which was already becoming controversial among people with AIDS), but I do know what happens to people who don't!" So I carried AZT around in my pocket and took too much too often, as we did in those days. I took AZT for five years, intensifying it at one point with ddC – until my T-cell count took its first dive, from a baseline of 915 when I started it to a scary 117. Thankfully, ddI was available by then and it put the brakes on my decreasing T-cells. My count floated back up, and I took a parade of "d" drugs as monotherapy – from ddC to ddI to d4T – before combination therapy came into fashion.

When Norvir came out in 1996, I was whisked onto the combination caravan. I then steadily took each protease inhibitor pretty much as each one came onto the market, along with an entourage of nukes and non-nukes. I remember feeling lucky that each new drug showed up just in time to rescue me from what had by then come to be measurable as viral load increases. I hung in there with every regimen until my "numbers" revealed that it had failed me. I hated the smell and the aftertaste of Crixivan and the diarrhea caused by Viracept, but I stuck it out. I was lucky to have a physician with whom I felt a bond of mutual trust. Both of us had taken care of people with HIV at our local county hospital in the days when it was hard to find staff willing to do so.

My first drug holiday in 13 years was unintentional. Simplified regimens were all the rage, and I was sick of Agenerase – eight huge pills twice a day. I wanted to reduce the number of pills I was on, so I decided to change my regimen. In the spring of 2002, though I had an undetectable viral load and 500+ T-cells, I insisted on switching from Agenerase to Viread, stay-

ing on both Viramune and Ziagen. I was able to make the switch with the blessing of my physician.

Within a month, I was stricken with an outrageous pain in my joints. The pain was so strong that, without planning it, I was forced to take a drug holiday. Immediately, my viral load leapt into the tens of thousands, my T-cells plummeted to 170, and thrush spilled out of the corners of my mouth. It was clear that I could not be without antiretroviral drugs. I became terrified and depressed, so much so that I didn't take

care of myself properly. I let more than two weeks go by before I had my first (and only) resistance test, regrettably letting my virus revert to wild type. A month after stopping my medications, the joint pain had gone away, so I restarted my drugs. The joint pain was back within a week. I stopped the drugs again, but the joint pain is still with me to this day. It's pretty clear now that, although the cause of the joint pain is still unknown, its onset after beginning to take Viread was probably a coincidence.

It's been a rough year. Suddenly finding myself again without many options, I signed up to get the new

protease inhibitor, atazanavir, through expanded access. I now take atazanavir and Trizivir. I'm free of side effects on this regimen (though not of the lipodystrophy that lingers from previous ones), and certainly find it easy to take.

Other than that brief holiday last summer, I'm sure I haven't missed even three doses in the last 14 years. I'm very good at adherence; I attribute that to always having understood what resistance means and how to avoid it. Frankly, the market just doesn't have much more to offer me at this point. But this regimen is working well. So I plan on making it last for a long, long time, because I know how lucky I am not to have side effects or much of a pill burden.

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*"Immediately  
... [after my  
drug holiday],  
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# Just Point Me in the Right Direction

*Ellen Hahn lives in Houston and volunteers at the Houston Buyers Club, which provides low cost supplements and nutritional information. She also serves as Treasurer on the Board of Directors of Montrose Clinic. If Texas had mountains, she'd be skiing.*

I've always been healthy. I thought hospitals were places to visit other people and was convinced that doctors were merely human. I did not know the difference between vitamins, minerals, enzymes and amino acids; nor did I care. I didn't need dietary supplements. I took my good health for granted. I once said that if I were a diabetic and needed to give myself a shot, I'd die first. When it came to needles, I was Chicken Big. I had a very strong belief that only foods should be sent down the esophageal slide. I wouldn't even take an aspirin.

In November of 1991, the day after Magic Johnson had announced his HIV status, I got a phone call from a friend in LA asking if I knew that my ex-boyfriend was dying. I assumed he had a brain tumor, judging from his behavior at the time I had left the relationship. My friend told me the truth: "Rick has AIDS." How could this be? I had asked about his health status. Rick had told me he was "clean." I had gotten tested. I knew I was negative. This could not be.

But the next day I got an HIV test – positive. I had no job. I had no insurance. I was scared. Very scared. I began reading and calculating. Calculating how much time I could expect to live.

I immediately entered an early intervention program. I learned that my CD4 cells were 900. Six months later, they had dropped to 500. I'm not altruistic, but I thought that being in a clinical trial might help advance medical science. So in June of 1992, I enrolled in ACTG 175, an early trial to evaluate the benefits of taking two drugs compared to one. The drugs involved were AZT, ddI and ddC and, since this was a double-blind, placebo-controlled trial, I didn't know which drug or drugs I was on. Four months later, I was in a hospital bed with a dangerously low hemoglobin level of 3.8. It was clear that I was on AZT, a drug known to have anemia as a side effect. I was given five units of blood and my AZT dose was cut from 600 to 300 mg per day. On my way home from the hospital the next day, I stopped at the library to read about hemoglobin and what may stimulate the immune system. If I was going to survive this virus, I had to learn what made my body tick.

I remained in the 175 trial for two years, but my blood work continued to decline. My CD4 cells dropped to 300. I had no energy, so I began looking for alternative therapies, and in 1994 I quit the trial, quit the AZT and began IV ozone therapy. The theory was that the virus could be killed if exposed to enough oxygen in the blood. After treatment, my energy level rocketed, but my blood work did not improve much. I learned

about Kombucha tea for detoxification of the body. I began drinking a quart a day. It gave me energy, and I remained free of opportunistic infections even though my blood work still did not improve. I stayed off all medications for two years.

In April 1995, I entered a thymopentin trial. Maybe the stuff would help my thymus make more T-cells. This required injections three times a week with an insulin needle. Since it was a blinded trial, I had my product analyzed to determine if it was the real thing. It was. So I bit the bullet and learned to poke holes in my body. It was later determined that this product showed no promise. My CD4 cells dropped more; I had crawled under the 200 mark, so my disease changed its name from HIV to AIDS.

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***“ I had a very strong belief that only foods should be sent down the esophageal slide. I wouldn't even take an aspirin.”***

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By late 1996, HAART was available. I was basically “drug naïve” (having only taken AZT) and hoped that “the cocktail” would be my salvation. I began triple therapy with Crixivan, Videx, and Epivir in late 1996. My blood work changed little, although my viral load was below detection. So when ACTG 328 opened in April of 1997 to study IL-2, I was the first enrollee. The trial had three arms. Two would get IL-2 (high or low dose) and the third was the “observation” arm – HAART with no IL-2. Unfortunately, I was assigned to the observation arm, taking Crixivan, Videx and Zerit. I began having body changes almost immediately. First my little breasts began a race to catch up with Dolly Parton's. My arms and legs became veiny. The fat left my limbs as rapidly as my belly grew. As time went on, I called this the Tuskegee arm. Sure, I had given “informed consent,” but in the observational arm, I would only be “observed.” What if I couldn't last long enough for the trial to be opened up for everyone to get IL-2? I felt like I was sitting on a powder keg,

waiting for any bug to wipe me out. I was taking tons of nutritional supplements.

I began to have terrible pains in my feet and lower legs. I had headaches that were vice-like. I was going days on end without any sleep. I figured it was the toxins from the drugs. I added herbal tinctures, detox tea and increased antioxidants to my daily protocol. Someone made me a second generation Hulda Clark electrical zapper to destroy parasites. By holding negative and positive rods, a small electrical charge circulates through the body. I figured that if a big jolt would kill the host, it stood to reason that a smaller jolt would kill unwanted poachers. I had to do something before it was too late. I didn't want the next memorial service to be mine.

I talked to my doctor and he agreed that if IL-2 would help me, I needed it soon. I asked him point blank about the part of the Hippocratic oath that talks about "doing no harm." I think "observing" disease progression in someone qualifies as harm when something really might help. This was not acne, it was my LIFE. It should be my decision. I asked him, "Whose side are you on? The AMA's or mine? Am I going to stay alive in spite of you or are you going to help me?" I remember telling him that he should do nothing to jeopardize his medical license, but damn it, "I'm a smart cookie; point me in the right direction and I'll get the IL-2 myself."

It was July 1998 when I began injections of high dose IL-2 twice a day. Whatever you have heard about IL-2 side effects is true – I actually asked a friend to stop by after she finished work each day to see if I was still alive. I did nine cycles, one every eight weeks. By the third cycle, I had figured out ways to mitigate and/or resolve the side effects. I used everything from Kombucha tea, ginger and high dose antioxidants to Reiki and yoga. The final cycle was in late September 1999. My CD4 had increased to 475 over 18 months. I treated myself with a cruise.

At this point, I had been on medications for four years. Being an accountant, I figured that drug dosing should be based on weight. I eventually cut my dose in half. The night pains in my legs, ankles and feet often reached 15 on a 10-point scale. Worse than the pain was my appearance. My legs had lost all their fat and what were once poster quality gams were now veiny twigs. My pencil arms protruded from a reformatted torso. My face became more and more sunken. The facial fat had disappeared so much that a scary mask for Halloween was not needed. One man told me that my face "repulsed" him. How nice! I may be able to live for years looking like a freak.

Studies indicated that Crixivan and Zerit might accelerate lipodystrophy and lipoatrophy, so in January of 2000 I switched from Zerit to Ziagen. Nothing changed. I heard about a small study of people doing treatment cycles – 7 days on and

## STOP THE PRESSES!

Due to a printer error, some copies of the Spring 2003 issue of *ACRIA Update* were missing some pages and included duplicates of others.

If you received a misprinted copy of *More Than the Virus: OIs, Metabolic Complications & AIDS-Related Cancers*, please call (212) 924-3934 extension 121 or email [treatmented@acria.org](mailto:treatmented@acria.org) and we'll gladly send you a replacement copy.

*ACRIA Update* is a free publication for people living with HIV and service providers. Bulk copies of the newsletter are available free to agencies that provide services to people living with HIV/AIDS. To be added to our mailing list, call us at (212) 924-3934 extension 121 or email: [treatmented@acria.org](mailto:treatmented@acria.org).

7 days off. Sounded good to me. What the heck, it would reduce drug toxicity and maybe slow down whatever was destroying my body. I started slowly, taking a week off every two to three weeks. This reduced the leg pains by half. A year later, I replaced Crixivan with Viread and, with my doctor's approval, began 7 days on and 7 days off, which I'm still doing.

The leg pains got a little better. But the reduction in medications did nothing to reverse the facial atrophy. Believe me, looking like a corpse does nothing to brighten one's spirits. I began researching facial restoration, and nearly got NewFill, but wanted something that would not require constant touch-up. Plus my face was beyond what NewFill could handle. So in December of 2001, I began facial restoration with an Italian product called Bio-Alcamid. If someone had told me 20 years ago that I would pay to have someone stick needles in my face, what do you think I'd have said? I have one more session. In the words of my friend Mike who had the same procedure, "It's the best gift I've ever given myself."

My CD4 cells jumped to 888 - 1,000, here I come. My goal now is to find the right combination of immune stimulants and nutrients so that I can get off medications completely. I think medications are for acute care, but long-term healing needs to come from within. When I brush my teeth, I don't know who I see in the mirror anymore. Inside and out, different person. But life goes on. I plan on mine going on for years and years. And I hope that as my tomorrows get better, my yesterdays will turn into nothing more than a bad dream.

# Heart to HAART

*Devan Nambiar lives in Toronto, Canada and is actively involved in HIV advocacy, research, and integrative health.*

I miss the fiery sun, the torrential rains, and the lush greenery in Kerala, South India. I miss the erotic temple sculptures of Khajuraho, local foods (idly, dosa, and chai), Ayurvedic massages, and sunsets by the Ganges River. Life was so vibrant, intense, and fulfilling there that I hardly ever thought about my HIV status – or the medications and my blood work. But then, I haven't done either of those in nearly two years. You may ask, "Is this denial or passive suicide?" Well, neither, really. I feel great. *Take your meds. Don't skip a dose.* It's enough to give a person a migraine. Then we insist on the importance of quality of life.

## Listening to my body

My non-treatment mode is not for lack of knowledge about such things. I'm quite well informed about treatments, clinical trials, and complementary therapies. I've taken triple-drug combinations and did my fair share of drug holidays before they were in vogue. I managed to achieve clinical efficacy and no drug resistance as I went back on the same combination after four drug holidays. It's not luck. I just listen to what my body needs. This is an innate skill that one must cultivate over time: an eastern cultural belief, a knowing – not something one can easily explain to a person steeped in western culture. I'm not worried about my blood counts.

I stopped making fear-based treatment decisions and following what everyone else was doing a long time ago. Although studies have shown that muscle mass, bone density, height, weight, and body fat are different for women and men as well as for different ethnic populations, 90% of clinical trial participants are Caucasian men. These clinical results are then applied to the general population. I write my own treatment guidelines based on my own clinical trials

on my own body. When the need arises, I'll go back to getting my blood work done and taking meds.

## Mantra initiation

In the west, we're so inundated with the allopathic AIDS mantra, making it seem that the only way to live healthily with HIV is by adhering to a regimen of scientific medicine. However, I believe that when you have made peace with life and death and have trust in creation, everything falls into place. It works for me. I've had HIV for fourteen years. My mantra is: "Health is a state of balance between mind, body, and soul." My recipe combines the best of east and west: practicing yoga (for 21 years now); meditating daily; believing deeply in spirituality; taking vitamins and supplements, as well as my Ayurvedic and Siddha (traditional Indian medicine) immune boosters; exercising regularly; using recreational drugs and alcohol minimally; maintaining a sense of humor; and having good creative sex!

## Karmic callings

Each year my soulful desire beckons me to my parents' birthplace, India (I was born in Malaysia). I've been going to India for close to twelve years. I feel very at home there. My trips to the mystical land have taken me to spiritual centres, where I've met swamis, gurus, and other enlightened beings. I've spent time meditating in caves. I've done research into anti-HIV studies utilizing Ayurvedic and Siddha medicines and have met some of the researchers. This research has helped me discover more holistic treatments. I've incorporated some of the Ayurvedic immune boosters into my health regimen. They are bio-available tonics prepared according to ancient Ayurvedic texts for boosting immunity, increasing muscle mass and energy, and reducing stress. Unfortunately, they're not all available in the west.

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*"I stopped making fear-based treatment decisions and following what everyone else was doing a long time ago."*

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# Had A Great Time, Wish I Was There

*Jim Pickett lives in Chicago and works with the Chicago Department of Public Health coordinating its acclaimed The Faces of AIDS project. He writes a column called "Pickett Fences" for the bimonthly Positively Aware and engages in all sorts of advocacy and activism.*

It's been over a year since I've returned from a two-year holiday from drugs. The break in the war arose through a unilateral decision. I'd had enough. On paper and in my blood, all was well. My T-cells were massing into the 1,000 range and my virus was hiding out in caves, invisible to reconnaissance. The bombing had done its job, the enemy was weak, and, though not necessarily on the run, it was beaten into submission.

But I too was beaten up. I was calling for an unequivocal end to the years of fatigue, the years of catching daily waves of nausea, and the years of "mild to moderate" diarrhea, which had fine-tuned my bathroom radar into a highly sophisticated instinctual response, no thinking required. Who has time to think? No matter where I was, near, far, or yonder, I could locate and advance towards a rest facility within moments. And while moments, crucial nanoseconds, were sometimes more than I had to spare, more times than not I hit the target before a catastrophic bowel movement occurred somewhere inconvenient and embarrassing, like my pantaloons. Of course, sometimes the radar directed me behind an alley dumpster in full view of Chicago elevated trains with only newspapers to freshen up, or to a door-free stall in a gay bar, or to a facility with a toilet that had already been filled to the brim by, no doubt, someone else surviving the joys of protease inhibitors.

So I made the cease-fire decision unilaterally, though it became a bilateral agreement five days later when I showed up at my doctor's for a regular appointment. When I told him I had halted the shock and awe campaign, he listened quietly to my reasons and my complaints, which came out much like the diarrhea, all at once and with an amazing velocity. When I was finished, as I wiped the foam from the corners of my mouth, he calmly laid out three options for me. Two courses of action were of the regimen change variety, to arsenals that promised equal firepower with less gastrointestinal distress. The third was a temporary peace coupled with regular inspections.

I chose door three. And was so happy I wanted to cry, marry him, and snap the neck of a virgin chicken in his honor. Hail Fine Doctor! Doctor Is Good! Long Live Doctor!

*(continued on page 15)*

A visit to Tambaram Hospital on the outskirts of Chennai completed my last journey. Tambaram is the largest AIDS hospital in South India. A trip to the hospital grounds dispelled any notion of wealth. Patients and families lined the road. Wild pigs, goats, and chickens were scattered about the acreage. This hospital is the best the government can do for the poorest of the poor – the abandoned, widowed, orphaned, illiterate, and marginalized AIDS patients.

When I first visited Tambaram in 1998, I was horrified at the plight of the AIDS patients, the opportunistic infections, wasting disease, and lack of access to things such as medications, food, and bedding. The scene took me back to the epidemic of the early 1980s in North America. I couldn't just walk away and pretend there was nothing I could do. So, upon my return to Canada, I set up the CareShed Project with assistance from a dear friend.

Through the CareShed Project, we raised funds to start a back-to-work program for the patients, hired a nutritionist, and built a room where patients' families can cook food and stay overnight. With my contacts in the AIDS community, I started a drug donations program to the hospital.

I suppose it's ironic that though I choose not to take meds, I'm making sure these patients get theirs. Choice is the operative word here.

My recent trip culminated at the children's AIDS ward in Tambaram Hospital. Seeing all the children was overwhelming, hardened even as I am by my years. I should be accustomed to this. But it angered me to see so much inadequacy. We have so few resources, the doctors explained to me.

## **A little goes a long way**

I left Tambaram knowing that part of my life's mission was cut out for me. With that goal, I know I'll be around for as long as it takes me to do what I must do, irrespective of my HIV status or my blood work. I went to India for the first time in 1989, after I tested positive. I found my roots amidst the wealth, poverty, beauty, dust, silence, chaos, heat, rain, spirituality, compassion, and greed. India welcomed my soul; Tambaram set it free.

# Finding the Right Fit

*Shelley Singer volunteers as an HIV/AIDS educator, public speaker and activist in the San Fernando Valley. She also hosts private karaoke parties whenever she can.*

It was September 1997 and I was a singer, karaoke host, and wife of the owner of the hottest karaoke bar in the San Fernando Valley. I'd been suffering from a deep pain in my chest, making it impossible to swallow. A doctor told me I probably had an ulcer and to see him again in two weeks. By then I had laryngitis and had to stop singing in my show. Now, sitting on the exam table, I practiced the words I would use to tell my husband that it was really AIDS. My "ulcer" was esophageal candidiasis, an AIDS-defining opportunistic infection. I had a 54 CD4 count and 422,900 viral load. All I could think was, "What the hell have I gotten myself into and can I get myself out?"

The first thing I did was go to the library. After reading about CD4 cells, yeast infections, brain disorders, and AIDS dementia, I was numb. Blessed with supportive family and friends, I was encouraged – no, pushed – to fight. The doctor who diagnosed me wrote down the names of two HIV specialists saying, "Make appointments with both and 'shop' them until you find the right fit." I visited each twice and chose the one whose positive and aggressive approach to treating me matched my own attitude to fight hard and turn this around.

My new doctor started me on an antifungal for the candidiasis and Bactrim to prevent PCP. The next day I was blotchy, lobster red, and itching, with a fever so high I could barely sit up. Back in the doctor's office for a steroid shot and a ten-day 'scrip for my newly discovered allergy to sulfa drugs. I switched from Bactrim to Mepron, a diaper-yellow, vile tasting liquid substitute, then retreated into the shade to recover and turn my attention to HAART.

At that time, the US Department of Health and Human Services (DHHS) guidelines advised those of us with less than 500 CD4 cells to be on a three-drug combination. I needed drugs that could dramati-

cally lower viral load as well as cross the blood-brain barrier, and Zerit (d4T) + Epivir (3TC) was a good pair of nukes for both. My doctor liked the double protease inhibitor combination of Norvir + Invirase for its added "kick," citing Norvir as good for "boosting" the weaker Invirase.

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They stared  
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If this didn't  
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Could I manage such a regimen? Being a true night person, I have never followed a standard time schedule. Now I would have to fit three full meals (a heretofore never consumed amount) into a day that started at noon and sometimes ended at 2 am. I told my doctor I would fail if I didn't adapt the timing of meals and pill taking. I mean, who ate breakfast anyway? I wasn't going to set an alarm to eat and pretend I could function at some ungodly hour of the morning. I had one good chance to make this work, and I wasn't about to start with unrealistic expectations. After agreeing to eat by 11 am, 5 pm and 10 pm, we were set.

On October 17, 1997, I sat in my kitchen with my wad of pills in hand. Huge and

slippery, they stuck to each other and to my sweating palm. I stared at them. They stared back at me. This was the rest of my life. If this didn't work, I would die – soon. I no longer had a choice. Now it was time to swallow. Each pill rolled from my palm into my fingers. Each one lodged in my throat before water forced it down. Tears welled as I gagged. Just a month before, I was "normal me" but with each hard swallow I turned into a person living with AIDS. Today I gulp them down in groups of five or six, hardly thinking about it, but on that first day, it took an eternity. Within six weeks, my viral load dropped 2.1 logs and my CD4 count rose to 321. For four years, I swallowed 20 to 30 pills each day, depending on medications for side effects and depression as they came and went.

I have lived with nausea, gas and bloating, a "tinny" taste in my mouth, and facial numbness. My breasts grew and wrapped around my back, which developed a hump of its own. My butt disappeared, along with all the shapely fat in my legs and arms. Within months of starting treatment, not one item of clothing I owned fit me anymore. I had to buy larger sizes of bras, pants, shirts, sweaters – even my shoe size grew by a half. Though my trunk and waist are barrel sized, my thighs and calves are scrawny, forcing me to buy pants large enough to close at the waist with yards of leg material to flap loosely as I walk. I see myself as freakish, and my mood falls and rises as I vacillate between the horror of my body's shape and the miracle that my body still supports life.

In 2001, I developed liver damage, attributed to the protease inhibitors. I stopped taking them, but continued the two nukes by themselves. I lived happily in my half-regimen denial until early this year when my viral load started climbing steadily. Facing this reality check, it was finally time to pick out a whole new regimen.

## Had A Great Time, Wish I Was There *(continued from page 13)*

All I did was cry. No chickens were hurt. Always the bridesmaid...

There was peace in the valley for two glorious years. And then the inspections showed the troops were beginning to mass to threatening levels, and that my defenses were sustaining injuries and taking casualties. For clarity, my T-cells had gone below 350 and my viral load was in the 50 - 60,000 range. I had to acknowledge that it was time to start the smart bombing all over again. I did not want to get sick.

I cried. And PETA be damned, if there had been a chicken nearby I would've throttled him. With bitter pleasure.

In January 2002, the assault was renewed. I decided to join the SMART study (Strategic Management of Anti-Retroviral Therapy) in which I would be randomized into one of two arms. One arm looks at viral suppression, so you stay on meds all the time. The other arm looks at the number of T-cells as a marker, so you cycle on meds when you go below 350 and you cycle off when you go above.

I did 5,000 "nam myoho renge kyo's," knocked wood and threw salt over my shoulder whenever the mood struck, hoping I would be randomized into the cycling arm. I should've tossed in a few million "Hail Mary's" because I was put into the viral suppression side, no interruptions, no breaks, no holidays. Ever!

So I considered throwing a brick through a Kentucky Fried window. Of course, I did have the choice to not be in the study and just do my own thing. But this research is important and I wanted to be a part of it and blah blah blah, shut up already. Put on that burkha and take your pills. Forever!

One of the weapons I chose to utilize was Sustiva, thinking, "hmmmmm, sexy, acid-like dreams? I can do that!" Well, I cer-

A genotype test showed I had probable resistance to quite a few NRTIs and most PIs. I had never taken an NNRTI, so this class was virgin territory and I decided to avoid them in this round. Since all the approved PIs are too toxic for me and the available nukes would need an anchor, I looked at drugs still in the pipeline. I

chose atazanavir, the new PI, to address my high cholesterol and triglycerides. I was lucky to get it through expanded access. Viread and Ziagen combine well and are easy in dosing, so this became my new "cocktail" on April 5, 2003.

I hope this regimen lowers my lipids and

tainly had the freaky dreams, but they were not sexy, and the acid had spoiled. Ever get your hands on some bad acid? "Uff da," we say in Norwegian. "Not good." For almost five months I dreamt incessantly of things like overflowing ashtrays and big, fat, mean Ms. Kronwall from fourth grade. Often violent, the dreaming included collateral yelping and thrashing and lots of it. Every day I woke to my fine cotton with high thread count bed sheets wrapped around my neck, comforter and pillows all askew and akimbo, giving my bedchambers a very "Baghdad post-liberation" look. And gazing into the mirrors on my ceiling, I was a perfect match. I was not getting a whole lot of rest. And

a tired Pickett is a cranky, psychotic, prone to irrational and regrettable behavior Pickett. More so than normal, way above baseline.

My doctor attempted a couple of times to switch me, but in some sort of demented martyrdom thing I was working, I kept trying to stick it out. I had heard that Sustiva gets better after a month... someone else said after two months... then it was after three months... I wasn't going to wuss out. Plus, it all was working. My viral load was back to undetectable and my T-cells were steadily on the rise.

But it never got better. Poultry was unsafe. And there was no room for yet another set of luggage under my eyes. As much for me as for the people who inhabit my little corner of the universe, I finally switched to something else (Viramune).

Besides the looming threats of neuropathy, lipomatrophy, lipodystrophy, anemia and liver problems, there really are no discernible side effects right now. I feel fabulous. I'm climbing the hills of northern Illinois and kayaking down the rapids of Lake Michigan. I'm high-fiving the lady at my dry cleaners. I'm playing uplifting patriotic music on my tuba. And I'm starring in some billboards with Magic Johnson where he says, "Easy," I say "Breezy," and we both say, "Living with HIV."

viral load and, perhaps, gives me a chance to get my tired body back in shape. I'm really hoping to stop and reverse my lipodystrophy. I haven't had any of the usual side effects yet and am pleased with this regimen. I'll have to check my liver regularly with atazanavir. For now, it's wait and see.

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***“For almost five months I dreamt incessantly of things like overflowing ashtrays and big, fat, mean Ms. Kronwall from fourth grade.”***

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# Taking Control

*Eric Goldman is an entertainment attorney practicing in New York City and living in Nutley, New Jersey. He is also a member of the Transitional Steering Committee for the AIDS Treatment Activists Coalition (ATAC).*

I was diagnosed HIV-positive on October 14, 1999, with T-cells around 170 and a viral load around 70,000. About ten weeks later, my Dad was diagnosed with pancreatic cancer. Although he never knew it, he and I began our experiences with meds at about the same time. Since he never knew I was HIV-positive, he never knew the lessons he taught me about facing illness.

After my initial diagnosis, I was pretty much on autopilot. I just did as I was told. The clinic guy told me to see my doctor; my doctor told me to see a specialist; and within about a month, the specialist was telling me to take these pills – a four-pill protease inhibitor cocktail. I never could remember the names of the drugs, but one had to be refrigerated. Anyway, I took the pills; I threw up. A lot. Six weeks later, the specialist switched me to different pills – Sustiva, Zerit and Epivir. I didn't throw up anymore, but I had outrageous nightmares. Everyone said I had to be on the meds, and I had to take them everyday or I would become resistant to drugs and that would be very, very bad. So I took the pills.

During the thirteen months that my Dad fought his battle, I had little energy to focus on my HIV. My viral load became undetectable within six months, and my T-cells climbed to above 800 after a year. I left well enough alone.

That being said, watching my Dad deal with his terminal illness deeply influenced my feelings and attitudes about being positive – and about treatment. Most importantly, I saw that the chemotherapy weakened my Dad so much that he had little quality of life. It also weakened him so much that, by the end, he was too sick for additional chemotherapy. Equally important to my

Dad was the feeling that he was no longer in control of his life, even the end of it.

After my Dad passed, I had time to pay attention to what was happening to my body. My cholesterol had gone from about 180 to over 300. My body fat had started to migrate from everywhere to

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my gut. My bowels had a mind of their own. So I started to research the drugs I was on. Some great research resources I can recommend are the web sites maintained by The Body, Project Inform and the New Mexico AIDS InfoNet. Body Positive's telephone hotline was a lifesaver.

I found out that Sustiva could be raising my cholesterol and Zerit could be moving my fat around. Then I started to become afraid. What price was I paying to keep my virus in check? What was I doing to my heart, my arteries, my liver, my kidneys?

I was hearing a lot about structured treatment interruptions, and I decided it was something I wanted to explore, just for a while. To give my body a break.

All I really hoped for was a couple of months, and maybe a piece of cheesecake without suffering cholesterol guilt, a bigger paunch the next day and a weekend of quality time with my com-mo-de. Because, after all, everyone said I had to be on meds.

I'll never forget how brief the conversation with my specialist was. I said I was thinking about going off meds. He said “Okay.” And that was that. No discussion of the risks, no explanation as to why he hadn't suggested it before. Just, “Okay”. I figured one of us had to be an idiot.

I knew I needed to have a more informed discussion with someone. So I called around to a few friends and a few hotlines, checked a few web sites. I wanted to know about the risk of becoming drug resistant and if there were other risks I didn't know about. After talking to a bunch of people and reading a lot of articles, none of which had any definite answers, I believed that nothing terrible would happen if I stopped taking my meds. It was kind of a research-based leap of faith. So I stopped my meds. I didn't stop panicking until a few months went by, but eventually I did un-clench.

Twenty-one months later, I'm still off meds and my specialist says I will be for a while yet. My viral load is around 80,000 and rising, but my T-cells are steady at around 300. The specialist is basing his prognosis in part on the ratio between my T-cells and my viral load. Since my T-cells are 300 and my viral load 80,000, the ratio of T-cells to viral load is about .00375. My understanding is that as that ratio gets close to .001 (in other words, as my viral load increases and my T-cells decrease), the likelihood that I'll have to re-start meds becomes greater. Which, when you think about it, is just common sense.

Being off meds has made me feel more in control of my illness. I have found other ways to improve my immune system, including a vegetarian diet, yoga, meditation, and nutritional supplements. I have also become much more educated about the disease and the meds being used to fight it. The web resources I found help keep me up-to-date.

There are some compromises I've had to make – I've developed a skin condition called psoriasis, and I frequently experience fatigue. But it's worth it to me. I think I'm preserving my body's ability to fight the virus in the future.

I know that I'll be back on meds one day. Some people have said that I should go back on if my T-cells stay below 300 for two months, or stay below 250 for two months. No one has really come up with an upper limit for my viral load. In fact, no one has come up with any hard and fast rules at all.

Me, I'm not buying into any pre-set numbers. I think my body will tell me when it's time. The fatigue will become unmanageable, or the psoriasis will advance, or I just won't feel right. These days, I trust myself to know, at least better than someone who does not have the disease.

But it won't be like before. I'll be an educated consumer. Before a drug goes into my body, I'll know its toxicity profile and its side effects. I already know there are some meds I want to avoid, based on their toxicity profile. And I already know of some new drugs that I believe will be more tolerable both in the short run and the long run.

And I know that I won't be relying solely on the meds to fight the disease – I'll have all the resources I've developed over the past twenty-one months to support me. Including the knowledge that my treatment is my choice. ●

## Happy Holidays?

*Nancy Soto lives in Wayne, New Jersey with her two children and husband.*

The city was decorated with holiday glitter. Everywhere you looked there were people smiling and festivities in the air. Christmas was three days away, and I was given the worst news anyone could ever hear. "You are HIV-positive." The words echoed in my head as I left the doctor's office and proceeded back to work to hold the annual holiday party. I was the manager; everyone relied on me to organize the party and mingle with our vendors. I felt like I was having an out of body experience.

It had been almost a year of continuous doctor visits, trying to figure out what was causing my fatigue. I'm a runner. I love to run. When I was healthy, I could run ten miles a day and not feel a thing. But in 1996, I had to muster all my strength just to stay awake. Since I was diagnosed at the end of the year, I wasn't able to start HAART immediately. I only had catastrophic insurance with no prescription plan.

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I was living a nightmare!!! The cost of the medication was stupendous. My husband was able to apply for insurance coverage through his employer. So on January 13, 1997, I began my treatment. I remember this like it was yesterday, and I am now in my sixth year on treatment. My regimen of Viracept, Epivir, and Zerit worked like magic. My energy slowly returned. My hair loss stopped. The coughing that began when I first started the meds improved. Apparently I was very ill when I was diagnosed, and my doctor felt the prognosis was not good. My CD4 count was 2 and my viral load was in the millions. I chose not to know the details at the time. I wanted to be able to focus on the positive and heal.

I had an excellent support system in my immediate family. My mother came in to care for me and provide nutritional meals as only a mom can do.

Years went by and I completely recovered. I was able to resume running. Now I ran to eliminate the toxins from my body. I envisioned all these little viral bugs leaving my body in the form of perspiration. During the first years of my diagnosis, I did whatever the doctor advised without questioning his reasons. I felt that this man had given me back my life. I would go to my appointments and never – not once – did I receive my results. The doctor knew to call my husband or mother with the results. I felt that knowing how sick I was would hinder my physical and mental healing. All I wanted to do was heal.

By 2001, the middle of my fourth year, I felt I needed to know more – my counts, my prognosis, side effects, where I was when I was diagnosed, and where I was now. I was ready to learn. I dove into books, read periodicals, went on line, and absorbed everything I could about this disease that was consuming my body. In December of that year, I decided I needed a drug holiday. Everything I read indicated the potential for toxicity, liver damage and resistance the longer I stayed on

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## Happy Holidays? *(continued from previous page)*

the meds. I met all the criteria that indicated I had a strong immune system and I was strong! My viral load had been undetectable for two years and my CD4 count was at 800. I was running ten miles a day and lifting weights. My body was in better health than it ever had been in my 37 years.


My doctor advised against stopping the meds. After numerous office visits and lengthy discussions, I was finally able to convince him. I needed his support! He told me I could stop as long as I knew how he felt about it. I was so excited. I looked forward to a life with no pill consumption. No reminders of my illness. Just to be normal again. I know now that it was an attempt to recapture my life before HIV. I believed that once I stopped my meds, I would discover that I was cured, that my own immune system would resume working, and the virus would be completely gone. My body would be mine once again.

I stopped my cocktail on January 1, 2002. A month later, I was in my doctor's office again, a mere shell of the person I was before my holiday. All the literature I had read hadn't prepared me for the reality of the decision. Immediately after I stopped, I experienced severe aches in my bones, night sweats, chills, fever, loss of appetite and terrible fatigue. I could no longer run. By five o'clock each day I was exhausted. I was no longer able to care for my children. For the first two weeks, I kept telling myself these are just withdrawal symptoms. My body had taken these pills for so long, how could I not be experiencing withdrawal? By the fourth week I had missed nine days of work and was barely able to move.

My blood tests in February showed my CD4 cells to be 99 and my viral load was no longer undetectable. I believe it was around 500,000, but I can't say for sure because I was in such disbelief. As I stared at my doctor, I could see the worry in his eyes. He handed my husband four prescriptions – my HAART regimen and Bactrim. My CD4 count was so low that I was in danger of developing PCP. While I had been positive for four years, I had never had an opportunistic infection. And now I was in danger. I had put myself in this dangerous position. I had read all those wonderful articles and I was certain my body would respond favorably. But it didn't. I was devastated. My body had betrayed me. I couldn't get sick – I needed to get better for my children. I promised God and myself that if I got better I would never go against the advice of my doctor again.

My recuperation wasn't easy. My body reacted differently to my medications this time even though I resumed the same treatment. My doctor advised me that I didn't have time to try

a new regimen; I had to go with what worked for me. Thankfully, every month when I went for my check-ups, my CD4 count had increased – some months a 100 at a time, sometimes more. Occasionally, when I caught a bug from my four year old, there would be no increase. I was able to get my CD4 count to 700, my viral load has been undetectable for 14 months now, and my life is back to normal. I've faced some obstacles along the way. My girlish figure is gone – I have lipodystrophy around my mid-section and peripheral wasting. My short-term memory is fading. I developed tumors in my uterus. My face is sunken in, and my cholesterol is very high. With the exception of a thin face, these are all new since my holiday.

Today I think a lot about changing my meds. I have taken them for six years. I am afraid of long-term toxicities and resistance – none of which are present. But when I think back to how ill I became I get scared. Scared that I won't bounce back, scared that resistance might occur. I have been told that my virus is a clean one; I show no resistance to any medication. So I probably won't change. I'll stay with what has proven effective, and I'll remain grateful for their existence. My advice to anyone contemplating a holiday is to do research and find out about how many individuals have tried and failed. It is a gamble we don't need to take. Life with HIV is challenging, but it is life. And everyday I am grateful that I'm here to enjoy it. 

### NATAF 2003

#### December 11-14 in Phoenix, Arizona Registration & Scholarship Information

Again this year, ACRIA is a co-sponsor of the North American AIDS Treatment Action Forum (NATAF), which takes place December 11-14 in Phoenix, Arizona.

The conference, sponsored by the National Minority AIDS Council (NMAC), provides treatment advocates, activists, educators and people living with HIV the opportunity to broaden their knowledge of HIV treatment issues, build advocacy skills, and develop strategies to advocate for people living with HIV/AIDS within their communities, nationally and internationally. A limited number of scholarships to NATAF 2003 are available.

To register for the conference, apply for a scholarship, or for more information, visit the NMAC website ([www.nmac.org](http://www.nmac.org)) or call ACRIA at (212) 924-3934 extension 121 and we'll send you a brochure.

## ACRIA Researcher Presents at Argentine Health Conference

ACRIA Senior Study Coordinator, Douglas Mendez, MD, recently presented on the research community's current understanding of lipodystrophy and HIV at the IV Argentine American Medical Congress.

Dr. Mendez has been a valuable member of ACRIA's research team since 1996. His work here has been pivotal to a great many trials, including over two dozen that have tested promising anti-HIV therapies and treatments to counter side effects of HIV medications like abnormal body fat redistribution. At the same time, Dr. Mendez has been a leading advocate for more effective healthcare for HIV-positive Latinos. He has served as President of the Dominican Medical Association of New York, he is a Board Member of The Latino Health Care Advisory Network, and he is on the planning board for the UNAIDS-sponsored Caribbean HIV/AIDS Conference to be held in Jamaica in October 2003. ACRIA is extremely fortunate to have someone of Dr. Mendez's energy, drive and caring on our staff to help us improve healthcare for those in society who may be overlooked by the mainstream medical establishment. We are also very pleased that the medical community in Argentina could benefit from Dr. Mendez's experience with treating patients who are confronting the challenges of HIV.

## ACRIA Finishes First Over 50 Study

The first in a series of ACRIA research initiatives on the HIV Over 50 population is complete. The study's goal was to conduct much needed research on this growing and neglected group. The over 50 population accounts for one-quarter of all PLWHAs in NYC. ACRIA researchers Andrew Shippy, MA and Stephen Karpiak, PhD recruited 160 individuals aged 50-76. The study population was 66% male and 33% female, and 89% were people of color. We were able to recruit participants from the five boroughs of New York City. Consequently our sample reflects today's epidemic. The study

measured multiple variables that are now being analyzed for publication. Initial findings indicate that age markedly compounds difficulties in accessing services. Formal social support services may be more important for older adults with HIV/AIDS since the study indicates that they have fewer friends and relatives for support compared to younger people.

## In Memory of Laura Payeur

ACRIA recently received a gift from Laura Payeur who was just 24 years old when she died in an automobile accident on March 3rd, 2003. Although we did not know Ms. Payeur, we've subsequently learned of her deep commitment to the care and nurturing of children. It was her wish in life to also in some way support AIDS research, and this is how her parents have decided to honor their daughter's memory with a significant donation to ACRIA. HIV and AIDS has far too frequently caused the untimely death of many thousands of young people in the United States and across the world. We are deeply touched by Ms. Payeur's desire to extend the lives of so many people who live under the threat of also dying so tragically early in life. ACRIA will do everything in our power to honor Ms. Payeur through our research program this year.

## ACRIA Selected To Create Hepatitis C Training Materials

ACRIA has been selected by the New York City Department of Health and Mental Hygiene (DOHMH) to develop comprehensive tools for use in the training of service providers about hepatitis C (HCV). The purpose of this initiative is to help local social service organizations to incorporate HCV prevention information, care and treatment services into existing client programs.

In addition to describing HCV transmission, disease progression and treatment options, the detailed curriculum includes interactive exercises to help training participants develop the tools necessary to successfully integrate HCV issues into existing programs.

ACRIA is also creating a technical assistance guide to help agencies develop appropriate HCV-related counseling messages. Finally, ACRIA is producing a promotional brochure for the DOHMH's use in explaining the new program.

ACRIA is pleased to have been selected for this major project because it demonstrates the city's confidence in our understanding of HCV issues as well as our capacity to create practical tools for educating non-medical care providers about complex medical issues. We expect to have all training and promotional materials for the DOHMH completed by August 2003.



## is looking for new COMMUNITY ADVISORY BOARD members.

ACRIA's Community Advisory Board (CAB) fosters partnership between the education staff and the local community impacted by HIV/AIDS. Involving community members in the development of our education programs ensures that community values and cultural differences are respected in ACRIA's educational work.

Community Advisory Board members meet every other month, review program materials and help us identify education needs.

For more information about the CAB or if you are interested in volunteering at ACRIA, please call Mark Milano at (212) 924-3934, ext. 123.

# generous contributions

*The following persons, corporations and organizations made major donations between April 1, 2003 and June 15, 2003 to support ACRIA's research and education efforts:*

Abbott Laboratories  
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VIAAC

*Thoughtful donations were made in memory of the following individuals:*

Laura Payeur  
Charles Reynolds

*Contributions in support of ACRIA's vital research initiatives were made in honor of the following individuals:*

Kathy Finley & Doug Landy's engagement  
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J Daniel Stricker

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