Mailbox

November 1, 2001 By Staff

The STI Blowback

Thanks for Brad Peebles' Publisher's Letter in the August 2001 issue about deciding whether or not to take a structured treatment interruption (STI). I thought I was reading my own life story, except that I have yet to begin my master's degree (it's in the works, though). I can relate to the ever-changing nature of life expectancy -- first with the virus, then with the meds, then without the meds, etc. Thanks also for shedding light on this important topic with Mike Barr's cover story ["Gimme a Break!"]. I have currently been "off'' for two years and am working with my doctor and therapist to get going again. Meanwhile, there is a lot of living to do.

-- Don, Via the Internet

What works well for one may not for others. I started an STI in May 2001. My CD4s were in the mid-300s and my viral load below 500. My reason for going on a drug vacation was my abhorrence of lipodystrophy. Basically, I thought I was more interested in that elusive Pollyanna, quality of life.

So I happily put away my toxic pills and went about my business. All was well...for three weeks. Then I started to have symptoms again. Meanwhile, my CD4s dropped to 90 and my viral load climbed to 100,000. You know that quality of life I was seeking? Well, stopping a bunch of pills did not give it to me. I will never again make such a life decision in such a cavalier manner.

-- Dave LeVin, Via the Internet

P.S. I may have spoken too soon. When I was finally able to restart HAART, I added a new medication for which I had to take part in a Phase III clinical trial. I had my first blood work at 30 days, and much to my gleeful surprise, my CD4 count had almost doubled and my viral load dropped from over 500,000 to 5,800. Now I think that I jumped the gun on dismissing STIs and their benefits.

I read with great interest the article on STIs. I, too, am trying my own and am nine months off meds. Prior to stopping, I had 1,100 CD4 cells and an undetectable viral load. Soon after I quit, my CD4s fell to 625 and my viral load shot up to 4,500. But six months later, my CD4s were back up to 750 and my viral load down to 800. One reason I decided to go on an STI was to see if I have the "long-term nonprogressor" gene.

If we know that there is a gene that makes some people's HIV progress more slowly, why do we not do DNA testing to find out their gene sequencing to see which drugs will work best? It seems

that all this info on STIs is revealing that some HIVers do not benefit from taking drugs at particular stages of disease. It also seems that we are treating HIV in a very general way when, in fact, individuals have such different reactions to HIV and the meds.

-- Daniel McLean, Wilton Manors, Florida

***POZ* responds:** *Testing to see if you have the gene deletion that leads to long-term nonprogression is rare for several reasons: Only a small number of people have the gene; if you have it, you still won't know how much slower disease will progress; and the decision to take meds will still be determined by your CD4 count and viral load. Genotype testing of your virus is altogether different, and done to see if a person has been infected with a mutated virus resistant to certain meds.*

Had all antiretrovirals available today been placed at one drug store without instructions as to how best to use them, would you not expect negative effects? In the same manner, Mike Barr's "Gimme a Break" does not distinguish between the effects of anecdotal self-implementation of STIs *without* proper monitoring and ongoing STI research.

As principal investigators of a randomized clinical trial of short-cycle STIs that was listed in your article -- and due to the concern your article has raised among our patients -- we would like to clarify these points: None of the patients portrayed were participants in our trial. No adverse events or severe drops in CD4 count have been observed in our patients. We provide bi-monthly visits and lab studies to monitor safety outcomes. Early data support that with our approach to STIs, CD4 and CD8 immune responses to HIV can be enhanced without significant drops in CD4-cell percentages.

STIs remain an important area of research that needs the support of the HIV community.

-- Luis J. Montaner, MD, The Wistar Institute, & Jay Kostman, MD, The University of Pennsylvania, Philadelphia

Silence = Evertz

Thank you, Doug Ireland, for saying it like it is ("Missing in Action," August 2001). As a gay man, I am fully aware of what the word *rimming* means. And apparently Scott Evertz has been doing a lot of it to the president. Evertz is a token gay Republican who is officially "out" but refuses interviews. The director of the Office of National AIDS Policy is silent? Well, what a surprise! Evertz is simply a puppet.

We already have a puppet for a president. I do not see why we need another one as "AIDS czar" who is supposed to address the most serious epidemic since the Black Death and instead hides behind the prez's trousers.

-- Randy Sindelar Corturillo, Cleveland

Jail Mail

I have filed a civil-rights action in federal court against the Texas Department of Criminal Justice and the University of Texas Medical Branch, Galveston. Why? Because I was not allowed to take Crixivan (indinavir) as prescribed -- one hour before or two hours after meals. Eventually, Norvir (ritonavir) was added to my regimen. After a while, the side effects made me very ill, and I was too weak to get up and go to the pill line. My system became so toxic that nearly all the hair on my body fell off. Although I brought my situation to the attention of medical personnel, my meds were simply cut off.

The reasonable thing for medical personnel to do would have been to adjust the dosage of Norvir or allow me to take the Crixivan according to federal guidelines. But the criminal justice system doesn't want to provide these expensive meds and intentionally makes it very hard for prisoners to stay on them. This abusive treatment amounts to being put to death.

If you have experienced a similar situation as a prisoner in Texas and wish to take a stand, please write to: Hugh Calloway #881556, 1300 FM 655, Rosharon, Texas 77583.

-- Hugh Calloway, Rosharon, Texas

Send letters, including name, address and daytime phone number, to: The Editor, POZ, *One Little West 12th St., 6th Flr., New York, NY 10014; or e-mail us at: letters@poz.com. Printed letters may be edited for length and clarity. We regret that we cannot answer all mail.*
