



To the Editor

July 1, 1998

Learning Channel

The portrayal of the HIV positive physician's assistant, Jeanie Boulet, on the TV show ER is very unrealistic (POZ Picks, April 1998). She is on Crixivan, the protease inhibitor hardest to take, but has only ever taken one dose on the show. A more realistic picture of Jeanie's day: Wake up at 5 am. Take Crixivan, take a shower, withstand the nausea for at least one hour, take other meds at 6 am. Eat breakfast. Get to work around 7 am. Once there, spend a lot of time at the water fountain or carry around a bottle of water. Lunch at 11 am (barring any emergencies), then take other meds and finish by noon so that at 2 pm she can take her next dose of Crixivan. Jeanie had better hope none of the good-looking residents asks her out to lunch, as she'd have to explain that she has to be finished eating by noon or her dosing for the day will be messed up. The same goes for any dinner dates. When not drinking water, eating meals or taking her reverse transcriptase inhibitors or Crixivan, Jeanie would be on her way to the rest room. Where would she find the time to see patients?

Name Withheld

Meg's 15 Minutes

Catholic University demonstrated an insanely homophobic posture by rescinding actor Joseph Sicari's Distinguished Alumni Award ("The Award Goes To...", March 1998). Once again, Susan Sarandon graciously used her celebrity status to draw public attention to a grave injustice. However, behind-the-scenes activists are often responsible for bringing these things to light. In this case, it was CU alumna Meg McSweeney, who immediately contacted Ms. Sarandon and other celebrity alumni upon hearing of CU's decision. It was Meg's humble campaign that helped ensure that CU's prejudiced action would not go unnoticed.

Stuart Litchfield
Dallas

But What Did He Say?

Sean Strub's editorial on the current sad state of affairs of AIDS service organizations was both timely and accurate (S.O.S., March 1998). One of our local ASOs recently retaliated against a PWA client who is an outspoken critic of the agency. He was slapped with a restraining order prohibiting him from criticizing the ASO, was sued for libel and slander, was denied case-management service and was left to fend for himself. The "service" organization asked for monetary and punitive damages.

The ACLU had the restraining order overturned. The court held that it was an illegal prior restraint

on freedom of speech, and the agency temporarily suspended the lawsuit. This ASO's actions gave it a black eye in our community, and proved that if others speak out against injustice, secrecy and uncaring attitudes, they too may be punished.

Thanks for pointing out what many ASOs would like to keep a secret: They're not fighting AIDS, only people with AIDS.

Roscoe E. Parker
Asheville, North Carolina

Good for Nothing

Stephen Gendin's beautifully written essay ("At the End of My Hope," February 1998) perfectly describes the impending disaster facing highly treatment-experienced individuals. Alarm bells should be sounding regarding the growing phenomenon of drug resistance, yet the popper-like high of the protease party has drummed out the common sense of most ASOs and punch-drunk PWAs wallowing in their "undetectable" status. The second-generation drugs are a useless rehash of the originals, showing similar resistance patterns across the board. Absolutely nothing is being done to research new drugs for the tens of thousands of individuals now resistant to all available meds or the hundreds of thousands soon to be resistant.

Doctors prescribe one new drug after another in an effort to shore up a failing drug regimen, thus creating the fatal cycle of serial monotherapy and ever-increasing resistance. Isn't it ironic that these individuals are up shit's creek not because they weren't compliant, but because they were? The very term salvage therapy is an admission of mistakes—perhaps unintentional, but fatal nonetheless.

Loran Rodewald
Scottsdale, Arizona

I am grateful for the Stephen Gendins of the AIDS epidemic. And I thank POZ for stating what I think is the obvious: If you can, wait.

I was infected three and a half years ago and, in spite of the advice of many activists, I have yet to take any anti-HIV medication. It just hasn't felt like the right thing to do. Fortunately, my doctors have supported my decision to wait. My CD4 cells have remained high, and my viral load is low. I've never been accused of being a pessimist or crazy, but I have wondered if I was in denial about my infection when such supposed experts were so insistent that I begin combination therapy. It seemed like they wanted their decisions affirmed by masses of people joining them. Have they learned nothing from AZT? I remember activist Michael Callen's early observation that taking AZT was like pouring Drano down your throat. I wonder what he'd tell us today.

Thank you, POZ, for guiding us to use not skepticism, but caution. This is truly where my hope lies. And thank you, Stephen, for sharing your struggles and demons of regret with us.

Christopher Morrison
New York City

Wart a Guy!

“Warts and All” was the first informative article I have read about molluscum (February 1998). My first wart appeared on my elbow in August 1992. By December 1993, I was wearing a trimmed beard. By December 1994, I no longer recognized myself in the mirror. The warts covered my entire face, neck and a few other parts of my body.

Psychologically, the effects were worse. I went from having model looks to being a recluse. I wouldn't let friends and family see me, or allow anyone to photograph me. I went grocery shopping late at night and hardly left my home. I could not see my reflection without crying, so I stopped looking in the mirror. It changed me forever—more so than having AIDS.

I used cryotherapy and Retin-A unsuccessfully, and once tried laser surgery, which left two large scars. Finally, I was prescribed Efudex. It helped. Then I started saquinavir, which boosted the Efudex, and after six months the molluscum was almost completely gone. I still occasionally get a wart, but a few days of applying Efudex immediately stops it, often with no return.

However, I'm heavily scarred from the Efudex, but it is still better than the molluscum. I recognize myself again. I see my family and friends, I've returned to work, and have even gone on a few dates.

I am still self-conscious, though, and am seeking a way to improve the scarring. So far I've seen only one dermatologist, who says nothing can be done. But I believe something can always be done, even if it is a small improvement. After all, I have been fighting AIDS for almost 20 years.

Keith Moore
Mandeville, Louisiana

I am compelled to share with you the approach I took after being diagnosed with molluscum on my thighs, groin and genitals. The dermatologist began treating me with cryotherapy, removing perhaps a dozen noticeable lesions at each visit. I saw him every week for three or four weeks, but I felt I was losing the battle, with six to 12 new lesions weekly.

After careful consideration, I went to a gas-and-air-supply company and leased a five-gallon container of liquid nitrogen for one month. I bought some 12-inch-long Q-Tips at a stereo supplier and began daily molluscum-lesion removal. This aggressive method, something I picked up from watching my dermatologist—coupled with daily changes of bedsheets, a fresh towel after each shower and very frequent underwear changes—resolved the molluscum in about four weeks. Thank-fully, I have not had another outbreak. The entire out-of-pocket cost was less than \$50.

Michael T. Roper
San Francisco

I had a terrible case of molluscum all over my face in 1994. I tried many products and the only one that worked was Canthrone, a blistering agent. After treating myself with it at home (there's very little pain), I am now molluscum-free. But I just ran out of Canthrone, and discovered that it is no

longer available in the United States because the FDA recently withdrew the exemption under which it was sold. But it's available in Canada. Readers should write the FDA urging that this product be sold again. A bottle costs about \$25, and would save you money on doctor visits.

Lisa Rios
Middle Village, New York

The New AIDS Look

Are drug cocktails causing ugly fat deposits? Yes! ("A New Kind of Waisting," February 1998) I've been on Crixivan for six months, and I gained 20 pounds and about three inches on my waistline in the first two months. I can't begin to tell you how upsetting this is. I also can't believe that some doctors think it may be caused by HIV fat maldistribution or "middle age." I was HIV positive for 11 years before I went on therapy. My CD4 cells stayed around 500 for most of that time. I started treatment because the current thinking is to knock the virus to undetectable with a three-drug cocktail. My viral load is there now, but if I'd known about "Crix belly" before starting therapy, I would have had second thoughts about Crixivan.

Mark Donalyn
New Orleans

Cut and Dry

I am dismayed by the credence lent to Dr. Edgar Schoen's push for universal circumcision as effective HIV prevention ("The Cutting Edge," February 1998). The studies cited by Schoen have been subjected to meta-analysis by Dr. Robert Van Howe, who found that after adjusting for their methodological flaws, they demonstrate that circumcised men—not their intact counterparts—are at increased risk of sexually transmitted HIV.

When the media parrots rather than questions specious foreskin/HIV claims, it endangers AIDS education by distracting the public from the task of avoiding risky behaviors. This kind of thing can create a false sense of security among circumcised men and their partners.

From a human-rights perspective, promoting genital cutting of unconsenting children as "disease prevention" encourages violation of their rights to physical integrity and self-determination. This is reminiscent of calls early in the epidemic for quarantine or tattooing of HIV positive people and castration of HIV positive sex offenders.

Tim Hammond
San Francisco

Sage Advice

One issue I haven't noticed gracing your pages is that of age. Are all your readers under 45? Surely some of us affected by HIV must be in the twilight of youth. How do they deal? While I am only 33, with the hope that new developments and increased awareness are bringing, I am looking forward to experiencing gray hairs and dentures in return for just living.

Vincent Fernandez
Honolulu

POZ responds: Look for our upcoming feature on HIV among the elderly this fall. At POZ, everything old truly is new again.

Dear Readers

POZ is more important to me than any other mail besides my SSI check. Those who receive this magazine for free, like I do, should in return do some volunteer work—to help themselves deal with their condition and not feel sorry for themselves, and to do something for someone less fortunate. By the way, I gave POZ to my pharmacist, and she asked if I could give her my copies after I read them. My reply was, “I’ll see, because I read them over and over.”

Gloria Guzman
Brooklyn, New York

I have two strikes against me: I am behind bars and I have HIV. When I discovered I had HIV in November 1997, I freaked out, not knowing much about HIV. I thought my life was over. I met an inmate who showed me books and articles about the virus that were hard to read because of all the difficult terms. So he told me he had something I would enjoy and learn from. He gave me my first POZ, and I was like a kid in a candy store. It was easy to understand and it showed me a new way of thinking. Knowing there are folks out there who have problems and are able to deal made life a little easier for me. Now I push him to hurry with his POZ so I can read it. I’ve learned a lot about myself, my medication and life with HIV. Most of all, I’ve gained respect from my loved ones because not only am I taking care of myself, but I’m able to talk openly and freely about HIV.

Xavier A. Stripling
California State Prison
Vacaville, California

Almost all of what I have learned about HIV and how to care for myself has come from POZ. I wish the Missouri Department of Corrections was as helpful or had up-to-date information for inmates who test positive. Their information is four to five years old and very limited.

Matthew Sullivan
Jefferson City Correctional Center
Jefferson City, Missouri

I would be lost without POZ. I know the ads are what pay for my subscription, and I hope you continue to attract them. I don’t care how many there are as long as the magazine remains timely and informative. I’m sure I speak for many when I say I need you.

Martin Tauber
Kalamazoo, Michigan

Of all the magazines dealing with HIV, yours is the best. I read it cover to cover every month and have passed it on to many friends in denial in one way or another. Your insight, candor and graphics have made some of them open their eyes and minds.

Ronald G. Hague
Via the Internet

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