

## Voices from the Mountains

### REFLECTIONS ON PROTEASE THERAPY

by Peter Kurth

Last fall, a friend of mine at National Public Radio in New York asked if I would contribute a commentary for "Morning Edition" about the release of protease inhibitors as front-line anti-viral therapy for people with HIV. Since the XIth International Conference On AIDS in Vancouver earlier in the year, the world media had focused immense attention on the dramatic new advances in AIDS treatment and the prospect of a potential cure for the disease— I myself had just begun treatment with one of the famous protease "cocktails," a combination of indinavir (Crixivan) and the nucleoside analogues 3TC and ddC. This is what I wrote for NPR, broadcast nationally on October 21, 1996:

It's only been a few days since I started on a protease inhibitor. Much to my surprise, I find that I'm not greeting the sudden prospect of a long life with untempered enthusiasm.

I became infected with HIV in 1984 and found out about it in 1989. That means that my body has been living with the virus for twelve years and my head has been living with it for seven. Body-wise, I've been doing all right, it you don't count a couple of eleventh-hour rescues from the grave. It's in the head that the virus has taken root most insidiously, by depriving me of any reasonable vision of the future and demanding that I regard it — HIV — as the central fact of my existence. After a ferocious struggle, I had more or less resigned myself to an early death, only to have the rules change now in midstream. For the second time in my life, every assumption I've been working with has been cast into doubt.

There are, in fact, a string of unanswered questions at the back of the protease inhibitor hope and hype. Who's going to pay for them, to start with? Anyone receiving state-of-the-art antiviral therapy for HIV can count on a prescription medication bill of roughly \$15,000 a year. Many of us are unemployed, underemployed or legally disabled, operating in a terrifying atmosphere of inadequate coverage and

vanishing entitlements.

Then there is the prospect of the drugs not working — or anyway, not for me — or of devastating side-effects, or a return of the virus over time.

And, presuming the drugs do work, what do I tell a prospective employer — that I'd taken a leave of absence to consider cosmic issues? That my glimpse into hell turned out to be a mid-life crisis? That I'm not going to be a tragic character after all but I will be costing the company a great deal of money?

For people living with HIV, an element of acute anxiety has entered the picture not equaled since the scientists first developed the sero-conversion test and we took our positions on either side of the line.

One of the hardest things to accept about an HIV diagnosis has always been the well-meaning advice of other people — people who are still walking on the sidewalk, as psychologist Walt Odets has said, while you are walking in three feet of sand. Maybe you're familiar with the conventional wisdom: "Well, none of us knows how long we're going to live. You could be hit by a bus at any time." Like most cliches, this is true as a statement of fact and false in every sense that matters. Most people have a reasonable expectation of not being hit by a bus, and, among the unlucky few, most of them never see it coming. Living with HIV, on the other hand, is like living on the exit ramp at Port Authority, where the busses whiz over you a hundred times a day and you know — you know — that sooner or later one of them is going to crush you to the ground. After a while, you get used to it: the organism can only take so much suspense. It's the tranquility of hopelessness I think I'm going to miss, the special dispensation I was given to live as if there was no tomorrow. Because there wasn't.

Don't be alarmed: I'll be taking the drugs. If nothing else, I look forward to giving the virus the surprise of its life. But I wonder if the line, once crossed, can ever be crossed

again, and, if so, what torments of optimism are waiting on the other side.

In the months since I wrote this piece, I have seen astonishing clinical improvements in the state of my health: a significant rise in immune function and a reduction in viral load to undetectable levels. "Viral load" is the term used for the sophisticated tests now used to measure the level of HIV in the blood; according to my chart, there is no virus remaining, or, if there is, it is so minuscule as to escape detection by current methods.

While this is obviously good news, it is by no means the end of the story. Medical science is as yet unaware whether these clinical benefits can be sustained over the long term; whether the virus will eventually develop resistance to the new drugs; whether HIV may be "hiding" in my lymph tissues, or my testicles, or my brain. The protease inhibitors have been in general use for less than a year. There is an awful lot we do not know about them yet. And for many patients they aren't working at all, throwing up one more wall between the "sick" and the "well" and further isolating people who, six months ago, had just as much reason for hope as I did. For all of us, although newer drugs and newer treatments are continually "in the pipeline," the prospects are still frightening and the treatment options still limited. This is not to mention the staggering cost of the "miracle" pharmaceuticals, currently being borne — or not — by private insurers, public funds, or patients themselves, while multinational drug corporations continue to harvest obscene profits on the backs of the poor and unwell.

For now, and up till now, I'm one of the "lucky" ones. I am under no illusions that my fight with AIDS is over: I'll be dealing with HIV for the rest of my life, and even if I weren't, I don't think I could easily go back to a way of life that seems to me now ridiculously "personal" and carefree. I am alive today, I believe, and healthy, only because I have been tapped in to a wide array of support services. I am well informed, "activated" in a political sense, and never alone in the struggle. I urge everyone to remember that at last count something like 25,000,000 people were infected with HIV around the world. Most of them, the vast majority, have enjoyed nothing like my good fortune. It is imperative that all of us, "sick" or "well," infected or not, remain committed to seeing the day, when AIDS is no longer a terrifying and deadly illness but a memory of something that was, a battle for which many, many, beloved friends gave their effort and their lives. ▼

## Letter to the Editor



Dear Editor:

I write in response to the editorial, *The Contributor's Closet* which appeared in last month's issue of this paper. Certainly the time has come for the g/l/b/t non-profit community to organize ourselves around fundraising. Fortunately, there are many vehicles available in Vermont to facilitate that process. TAP Vermont (Vermont Community Foundation) offers many day long seminars on fundraising, board development and non profit development all of which, at various time, have been taken advantage of by Board Members and the staff at Vermont CARES. Tim Palmer, executive director at CARES has made himself available to several g/l/b/t organizations in the Burlington area as an expert resource on fundraising and Board development. He is very willing to work with Boards on the writing of development plans. These resources wait to be tapped.

Meanwhile, Vermont CARES and its all volunteer Board have worked tirelessly to develop a plan that will meet the demand and need at Vermont CARES for money. We have gone door to door in Chittenden, Rutland, Washington, and Lamoille counties soliciting money and donations for silent auctions. We run a successful phone bank each year when Board members call over 500 contributors asking them to send more money. We have organized a Friend in Business campaign where Board members contact local businesses, meet with them, talk about the work we do at Vermont CARES and ask them for money. The staff at CARES, with volunteer assistance organized the very successful AIDS Walk last fall. Through our ceaseless fundraising efforts, among other activities, we are visible in the community and thus, are the recipient of many non CARES sponsored events. In addition, we have organized events that benefit both Vermont CARES and other organizations. It has taken a great deal of time, energy and commitment to get to where we are today and we have so much further to go.

Sincerely,

Jane A. Van Euren, Chair  
Vermont CARES Board of Directors

## Another Voice from the Mountains!

Dear OITM,

I was thrilled to see Matthew Pinsonneault's article ("A Gay Youth Speaks Out at the State House") in your May issue. I am 16 years old and have been out at high school since January. I also travel around the state speaking on GLBTQ panels and was glad to see that another teenager deeply believes in the same ideals as myself. Although I feel very lucky to be able to attend a very liberal high school, (U-32 Jr./Sr. HS, East Montpelier) and have not suffered harassment to the extent of some other GLBTQ youth, I sympathize greatly with their struggles. Even if I only help one teen come to grips with his or her sexuality, it makes all of my effort worth-while. We only walk this crazy Earth once, and we shouldn't have to be shadowed by fear.

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