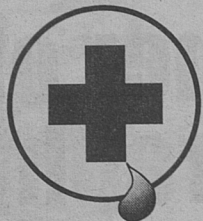


RESURRECTING



THE BODY POLITIC

BY JOHN HANNAH

Living with HIV is incredibly difficult. It takes discipline to stick to medication schedules. It takes grit to put up with the side effects of highly toxic AIDS drugs and the symptoms of the virus itself — fatigue,

health & wellbeing

depression, nausea — day after day, year after year. It takes courage to face the future with no cure in sight. The fortunate few of us who benefit from protease inhibitors and other recent medical breakthroughs are locked in a deadly waiting game.

Bear in mind that I am an HIV success story.

Around Thanksgiving, after watching my viral load rise steadily over a period of nine months, my doctor and I decided to switch my HIV medications. I had been on the last combination for a year and it had effectively suppressed the virus for most of that time, but my particular strain of HIV was clearly developing resistance to those drugs.

So I said good-bye to Viracept and Viramune and said hello to Saquinavir, Ritonavir and DD1. Big deal, right? Wrong. Huge deal. The change was very tough, mainly because of the corresponding bouts of side effects that kicked in shortly after taking my new pills.

Huge chunks of my day were routinely wiped out by nausea, dyspepsia, and pervasive drops in energy. For the first few weeks I was vomiting every day, so desperate was my system to purge itself of these new toxins. I've experienced non-stop muscle weakness and I've all but lost my equilibrium. My eyes have become sensitive to bright light and my field of vision is cluttered most nights with flashing shapes and hallucinogenic trails. Even my taste buds have flipped out. My feet are tortured with shooting pains that nothing seems to relieve. Most people tell me that this is par for the course with this particular combination and that I should expect my side effects to subside in a few months. (Remember — this is a success story.)

Bear in mind that there are only a handful of HIV medications on the market and that those of us for whom they're working know that they will only work for a limited time, whether long or

# Ignoble Initiatives Would Be Destructive to HIV Care

short, no one knows. No one in my position switches medications before they absolutely have to, and we are obviously willing to put up with a lot in our effort to tolerate these chemicals. The violence, unemployment, and racism, among others." Just think about that for five seconds and tremble over the scale of ignorance it belies. I've known all kinds of people with

aggressively addressed by Vermont CARES on many fronts. CARES has developed programs for all people at high risk for HIV infection: women, IV drug users, young gay men, and people of color. They are striving to deliver counseling and services to the populations that need them most, however remote or isolated these people are. Recent grants and awards from national AIDS organizations have recognized CARES as a leader in providing a model for AIDS service delivery in rural communities.

What could possibly justify Noble's efforts to hamper AIDS funding in Vermont? Sadly, he is also involved in another sinister and unnecessary directive at the Department of Health: the push to establish "names reporting" in Vermont. Under this system, should it be instituted, anyone receiving treatment for HIV will be identified by name on a list at the Center for Disease Control in Washington and on a computer at the Department of Health. You may still be tested anonymously, but if you seek treatment, your doctor will be forced to disregard doctor-patient confidentiality and report you, by name, to the feds.

There have been several instances of names reporting abuse in other states. Last year, in Florida, a Department of Health employee walked into a gay bar and publicly identified several men present as being HIV-positive. The potential for violations of privacy and civil rights inherent in names reporting is enormous — and unnecessary.

California, soon to be the front-line state in the war on AIDS due to its large population, has adopted an excellent alternative to names reporting: a "unique identifier" system. Unique identifiers deliver the sta-

tistics needed to track the epidemic, but they do not in any way jeopardize the privacy or well-being of those struggling with the disease. Nor do they deter untested individuals from getting tested. Confidentiality is absolutely integral to HIV case management. Nothing, and no one, should be allowed to compromise it.

Write to Noble's superiors at the Department of Health to protest these dangerous new

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virus pulls us greedily, relentlessly down a slippery slope to sickness, infirmity, and death. It takes money to resist the pull. My HIV drugs and the drugs I take to counteract their side-effects cost well over \$1,000 a month and I have only enough energy to work about 20 hours a week.

This is the reality of HIV at the beginning of 1999. It is a massive killer, it is expensive to combat, and it is a long-term proposition for those of us who are lucky enough to get treatment for it.

So imagine my shock when I read a letter that Joshua Noble, the AIDS Program Chief at the Vermont Department of Health, sent to community service organizations throughout the state late in November, encouraging non-HIV-related agencies to take a slice of the AIDS funding pie.

In a spectacular departure from reality, Mr. Noble declared that "new drug treatments have prolonged people's lives and HIV has, in many cases, become a secondary concern to other issues, whether substance abuse, mental illness, poverty, domestic

HIV. Blacks, whites, men, women, straight, gay, working, not working. HIV is the driving force in their lives without exception. Don't imagine for a second that anything upstages HIV if you've got it. Being black or gay or a woman or out of work may be hard, but AIDS is lethal.

The \$750,000 to which Noble is encouraging social service agencies with no expertise in HIV case management to help themselves is already inadequate to fund the battle against the epidemic waged by established AIDS service organizations like Vermont CARES. To give this money, which is appropriated specifically for HIV prevention and services, to any service agencies that are not already set up for HIV case management amounts to taking it out of the hands of those who need it.

Noble goes on to say that "access to HIV-specific case management is not an issue." This is simply not true. Access to services and case management most certainly is an issue in Vermont. It is an issue being

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directives. Write Bernie Sanders, write Howard Dean. Only through active and organized public outcry can confidentiality violations and still more suffering be avoided.▼

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