

Resurrecting the Body Politic by John Hannah

If you are a person with HIV or AIDS, living in Vermont is a mixed blessing. A socially progressive atmosphere combined with a small population make access to social and medical services much easier here, in many ways, than in most other places. Big cities have greater expertise in dealing with HIV disease and are generally fairly liberal in their application of social services, but they deal with such huge numbers of HIV-positive people that it is difficult to get the personalized attention the condition increasingly demands. By virtue of their size, most small communities are able to deliver highly individualized care. But HIV is generally more stigmatized and treatment strategies less up-to-date in rural areas and small towns.

If Vermont can be said to offer some of the best of both worlds, we must also recognize that it has a unique set of difficulties. The greatest problem with HIV policy and services in this state is related to our small population. One of the driving forces in HIV care in big cities is a larger body of consumers. The critical role organizations like ACT UP and TAG have played in the accelerated development of medical and social services in large cities is a positive example of how much influence people with HIV and AIDS can have, *need* to have, on the effective management of their condition.

Here in Vermont, we simply haven't had an adequate number of consumers with HIV to establish a serious political or social presence. We have necessarily relied on our ASO's (AIDS Service Organizations) and medical providers to keep us current medically and to maximize our chances of survival. The administrative and political savvy of a few individuals, notably Mary Pierce, who manages the AIDS Medication

Assistance Program (AMAP) at the Department of Health, Keith Goslant, the Governor's liaison for Gay and Lesbian Affairs in Montpelier, and Tim Palmer, the Executive Director of Vermont CARES, has carried us a great distance. But without the visible and vocal support of consumers living with HIV, theirs has been and will continue to be an uphill fight.

As long as we, the PWA's of Vermont, continue to let others do our fighting for us, we will continue to lag behind major urban areas in the quality of care and services we are receiving. We *must* speak up for ourselves and for each other. It is for this reason that the now defunct Vermont AIDS Council formed the Public Policy Steering Committee as its final act. The Council directed that the Steering Committee be entirely composed of people living with HIV or AIDS, thereby giving PWA's genuine and direct influence on policy-making in Montpelier, and enabling us to bring the standard of HIV-related care and services in Vermont up to where it should be.

Though it has been in existence for only a few months, the Public Policy Steering Committee is already in danger of losing its teeth. The composition of the Steering Committee has been altered from that envisioned by the AIDS Council to include ASO's and service providers in its voting body. The rationale of the Committee members who voted for the change was essentially that PWA's can't handle the responsibility. As the only member of the Committee to oppose the change, I felt, and still feel, that no particular effort has been made to include PWA's in policy-direction or to empower them in any way.

Vermont PWA's have accepted too many compromises already under the guidance of organizations that claim to serve and represent us. The formulary of

drugs covered by AMAP is a good indicator of how effective our representation has been in the legislature. The formulary of AIDS medications available to Vermonters is skeletal compared to those of cities like New York and San Francisco. The formularies of these major cities are larger because PWA's have lobbied hard and effectively in their state legislatures to get them expanded to meet their needs.

If the Public Policy Steering Committee is going to serve the function it was created to serve, which is to empower PWA's in the improvement of HIV-related policy and care in Vermont, it desperately needs new blood. As it stands, the Committee is largely composed of individuals who have been involved for many years in the Vermont PWA Coalition. While their commitment is unquestionable, it is clear that the Coalition has not been able to muster adequate involvement of its constituency to keep Vermont up to date with respect to treatment, social services or public policy.

Do not accept the idea that you are represented here. You are not. I have trouble believing that there are no women, no people of color, no one without insurance or, for that matter, no people under the age of 30 living with HIV in this state. You can still make a difference. The Public Policy Steering Committee meets monthly in Montpelier. Come to the meetings. Talk to the Committee about the hardships you face, the expenses you cannot meet, the services you wish you could access. Do not let this potentially powerful voice in Montpelier degenerate into squabbling over insurance deductibles. Don't think that your interests are represented by treatment providers such as the Comprehensive Care Clinic or Dartmouth-Hitchcock. Of the three meetings of the Committee to date, not one has been attended by a provider, though they have repeatedly said that they would come.

The AIDS crisis has entered a new phase — it has become a movement. We are finding more and more ways to live with HIV and, as a result, our needs are becoming increasingly complex. The burden on us to make those needs heard in the legislature, in our AIDS service organizations and in treatment facilities. If we are to have these needs met, we must heed the first commandment of living with HIV, as described by Lark Lands, the PWA Coalition's guru: DO THE WORK. It is not as hard as you think and the benefits are greater than you probably imagine.

Please call Tim Palmer at Vermont CARES for the upcoming Public Policy Steering Committee meeting date, time and location. The number is 1-800-649-AIDS. You are the experts when it comes to living with HIV and your expertise is sorely needed in Montpelier.

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