

VGJV for AIDS

Over the weekend of February 6-7, eight Vermonters helped raise over \$1,500 for AIDS research by playing volleyball in a Boston based tournament. Vermont was the only team not from the Boston area.

Although Vermont's team finished seventh in the seven-team "B" Division, the team reported that it was a worthwhile endeavor, not only helping raise money, but they learned more about playing competitive volleyball.

Vermont Gay Volleyball has been playing on Sunday evenings in Burlington for well over four years. The group's main intent is for gays to gather in a social atmosphere with little emphasis placed on athletic ability and style. Basic rules are followed but the main focus is comradery and the opportunity for a little exercise.

This past January, in preparation for the Boston tournament, a group from the Sunday night outings started playing on Friday evenings to practice skills and rules. However, after the team's first match at the tournament it was evident they still had quite a lot to learn to reach the competitive level.

For confidential AIDS Information



Call

1-800-882-AIDS

Coming out with AIDS in Vermont

by John Rutkowski

In September of 1987, I was diagnosed with AIDS. My immune system was severely suppressed, I was HIV-positive, and the virus was affecting my central nervous system. My initial diagnosis was "AIDS-related dementia," based on problems I had in speaking, memory, and motor coordination. In late October, I developed a cough, shortness of breath and a sudden high spiking fever. I was taken to the emergency room, where it was diagnosed as pneumocystis carinii pneumonia, a common opportunistic infection.

Much of the early period is a total blur to me now. I remember very little of the March on Washington, even though I was there. This "lost month" is not uncommon—it seems that between the combination of medical problems and the emotional impact of diagnosis, a haze develops.

By November, the fog was starting to lift. I had begun taking AZT in mid-October, and it had a noticeable impact I began to deal with the reality of having AIDS. In many ways, the haze was the classic "denial" stage familiar to anyone who has ever read Kubler-Ross's work.

When what was happening began to hit me, my entire life became centered on AIDS. I read everything I could, I talked to everyone about it. It was like coming out all over again.

Despite my fears of negative reactions I have been fortunate. Family and friends have all been positive and supportive, and no one has turned away from me because of the diagnosis. I considered going into an experimental treatment protocol at the National Institute of Health, but became frustrated with the delays and the insensitivity they displayed towards me so I decided to stay in Vermont for treatment.

I also had to face the realization that I was no longer capable of working, and began to deal with the social services bureaucracy. Although I applied in October, my first social security disability check did not arrive until February, and I am still waiting for my SSI checks and my Medi-

caid card (there is supposed to be a waiting period of less than 60 days for these). During that period, I had no income, and depended on loans from family and friends to get me through. For someone who had always been notoriously independent, it was a disheartening turn of events.

I now must take AZT every four hours, getting up in the middle of the night and remembering to take it during the day (a task now made easier with the help of a beeping timer my mother gave me for Christmas). I must also accept my physical limitations. I walk slower than before (friends joke that I am like the traditional "Chinese wife," always ten paces behind). I tire more easily, and need to nap in the afternoon if I want to stay awake at night. I jokingly tell people who ask what I do for a living that I'm retired (at age 28).

My speech is noticeably affected; I am unable to get a sentence out without stammering or slurring my words. At times I need help opening a bottle of pills or buttoning a shirt. My handwriting is practically illegible. All of this is very painful.

I am determined to take power over AIDS, and I am convinced the only way to do this is by becoming a full, active and informed partner in my own health care, not a passive patient who mindlessly follows orders. I am exploring treatment options, following new drugs and therapies in both the general and the technical press. I may start taking AL-721 in addition to AZT. It is promising and as a natural food product, it has no toxicity.

I have decided that it is important to be publicly vocal, to be willing to say publicly that "I am a Vermonter who has AIDS." Vermont has looked at AIDS as somebody else's problem. I want to help give AIDS in Vermont a human face, to make Vermonters understand that AIDS is here, that we must deal with it.

That's why I decided in the fall to become the People With AIDS (PWA) representative on the Vermont CARES board. That's why, slowly, I've been stepping out

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C.A.R.E.S. Plans VT AIDS Conference

Vermont C.A.R.E.S., will sponsor a three day conference. "The Vermont Response to AIDS," April 15, 16, and 17, in Plainfield, Vermont.

The conference will feature a series of workshops, support groups, entertainment, and other events at Goddard College. Overnight accommodations and meals will be included in the conference.

The conference will culminate with the Vermont C.A.R.E.S. annual meeting, where new officers and board members will be elected for the next year.

More details will be available in late March. People with ideas for particular workshops or questions about the conference are encouraged to contact Vermont C.A.R.E.S. at 863-2437.