

FACING THE AIDS CRISIS:

PART TWO

By Paul Armstrong

The PWA Foundation
--"We Stand and Fight"

In late August, 1986, Jim St. James and a few of his friends got together to form the People With AIDS Coalition. The coalition (later re-named the PWA Foundation) grew out of a need that was not being recognized by hospital staff and others working with PWAs; that, says St. James, "PWAs are still alive." Strictly put, the purpose of the organization is to assist those afflicted with AIDS to live as fully as possible while they still can.

It is a response to the death diagnosis that reaffirms life. Hence, the story of their logo. The muscle-bound archer is a symbol of hope, strength and fighting back. It points to AIDS as the enemy, not bureaucracies or individuals, but the disease itself. The logo aims to remove the stigmatization of PWAs as victims and re-label them as not only still among the living, but also still fighting. James St. James is the former president of the foundation and sometime spokesperson. He considers himself a fortunate man: this winter his diagnosis is already four years old. He has some strong opinions about why he has lived longer than most with full-fledged-AIDS. "The key is to remove stress. Half the battle against AIDS is mental."

Much of that stress results from the lack of money - for drugs, nursing care and even to pay the rent or buy groceries. Most PWAs find themselves out of a job very quickly. Income suddenly plummets and savings are soon depleted. So above and beyond the disease itself you may find yourself fighting just to be able to keep a roof over your head. The PWA Foundation recognized the importance of lifting some of that burden so part of their mandate is to provide financial assistance.

Another motive for the formation of this service was to provide a social network of support and caring for those with AIDS by PWAs themselves. "People didn't understand what it was like to have AIDS", says St. James.

So, it is this social network of caring and concerned individuals, all of whom have AIDS, that provides the outreach to those in need. Again, the services range from advocacy to financial aid, but like all the AIDS organizations now available the PWA Foundation has its own specific mandate; "to bring hope."

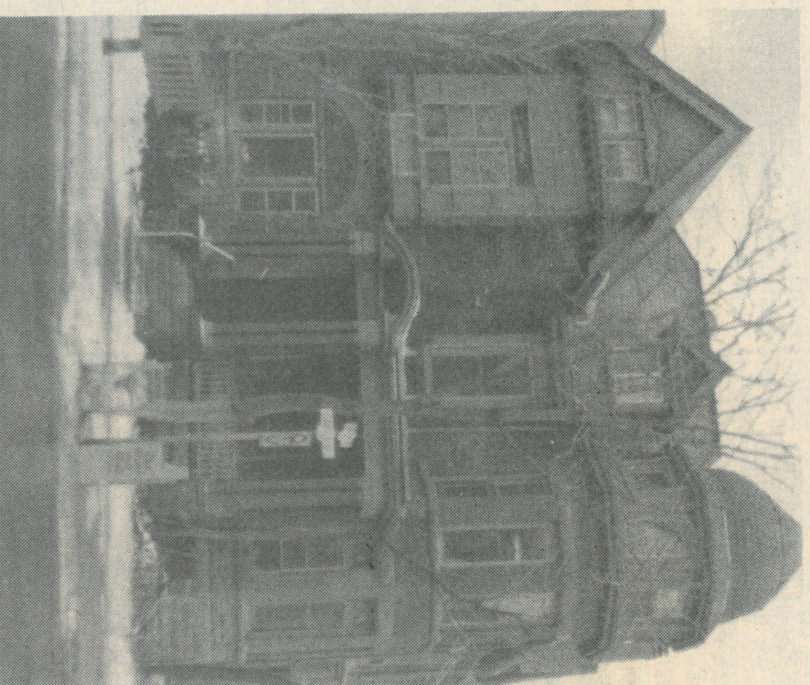
Casey House
--"You matter because you are you. You matter to the last moment of your life and we will do all that we can, not only to help you die peacefully, but also to live until you die." - Cicely Saunders, founder of the hospice movement.

Casey House, at the corner of Huntley and Isabella is expected to open its doors sometime early this year. Extensive renovations have pushed back the proposed opening date. When I arrived to interview then - Project Coordinator, Jim Shea, the house was abuzz with activity. Stripped walls, bare floors and several people scurrying about gave an impression of work well under way.

When it opens, Casey House will be able to accommodate up to 12 people with AIDS in a long-term palliative care set-

ting. Affiliated with St. Michael's Hospital, Casey House will provide direct physical, emotional and pastoral care to AIDS patients, their families and loved ones. There will be 24 hour nursing coverage, medical consultation as well as emotional and psychological support. This will be accomplished by a staff of 30, including full time RNs, a nursing co-ordinator, a part-time MD who will serve as Medical Director, a full-time Counsellor, Volunteer Coordinator, food service and maintenance workers and a number of unpaid volunteers who will work directly with AIDS patients and their loved ones.

The concept of a hospice implies providing humane palliative care in a home-like setting. To that end Casey House will ensure that the interior of the hospice will be as comfortable and non-institutional as possible. There will be rooms to accommodate out-of-town visitors, as well as roll-out beds for the lovers of patients who wish to sleep next to them.



Celest Natale

Casey House Hospice

In addition to in-service care, Casey House also hopes to perform outreach services to PWAs in the community. Provision is also made for bereavement counselling for up to a year after death. And although people who enter Casey House will be those for whom there are few, if any, options there is the possibility of leaving (and perhaps) returning at a later time. The building is wheelchair accessible and has an elevator.

The only sad note to sound on the subject of Casey House is that its 12 bed capacity is vastly insufficient, even before it opens, to adequately meet the needs of PWAs in this city alone. And with an operating cost of 1.2 million dollars per year it is an expensive proposition; though still less than half the cost of identical, but less personal care in a standard chronic care ward in the hospital. Many more hospices will be required to handle the ever-increasing numbers. That, or extensive home-care services together with realistic income support to enable PWAs to stay in their

homes and still receive all the care and love they need.

Other Services for PWAs

If you have AIDS you'll very soon be (if you haven't already) facing some serious life changes. You will suffer a loss of income. If you have little or no savings this could lead to another major problem: loss of accommodation. Thirdly, health care will become an important aspect of your life and this care will need to extend beyond the hospital.

Financial Aid

The Family Benefits Act, more commonly known as welfare, will provide a minimum of \$300 per month (in Ontario). All provinces, including the territories provide some form of welfare assistance to disabled persons. For the purposes of the ACT, PWAs are considered to be disabled. This money is provided on a sliding scale basis according to need, so if you have a private insurance plan, payments will be reduced according to the

AIDS

Update by Sean Hosein

Researchers in Texas have published in *The Lancet* a report of success-rats, discovered that the BBB fully treating a PWA with low doses of tively prevented those drugs oral interferon-alpha. Interferon- is a being taken up by cells in the brain chemical made by the body in response humans, it is known that AZT to a viral infection and it helps to prevent the cerebrospinal fluid (a vent further damage. The PWA was a which surrounds the brain) and i veterinarian whose success in treating assumed that from there it penetr feline leukemia (a disease in cats similar to AIDS) with interferon- led him to brain. No studies of AZT penetrated it on himself. His condition improved dramatically. He then stopped the drug on the advice of his physician, who prescribed Ribavirin the brain acts as a reservoir for the for 8 months. In that time his condition during AZT treatment. This may have become worse and he resumed taking reason why after 17 months of oral interferon- (2.4 units/Kg per day). AZT PWAs are starting once more Over the subsequent eleven months the experience opportunistic infections gained weight, his herpes simplex In the minds of most people, A mouth ulcers disappeared, T4 count a gay disease. However, research increased and he has been able to resume work. Blood tests have revealed that isolated cases of consistent high levels of antibodies North American over the past two against the viral protein p24, a response aids, mostly in heterosexual pe associated with not developing AIDS. according to an article in *Revu* There has been no known toxicity from *Infectious Diseases*. Scientists this therapy which is easy to administer National Cancer Institute and ; and costs only \$600 U.S. per year. Inter- New York State Department of feron- has been used in experiments Health have been inspecting that with PWAs to restore their immune cancer registries and have discovered systems, but results have been mixed. that cases of Kaposi's Sarcoma (a In one small study it had been reported usually rare and benign form o to cause healthy HIV+ men to become HIV-.

Another successful treatment of HIV infection is described in a letter to the *Journal of Clinical Pathology* in England where doctors treated an HIV+ 32 year old man who had severe symptoms -- falling T4 and platelet counts, a swollen spleen and lymph nodes -- who did not respond to antibiotic and antiviral therapy, with a high dose of intravenous globulin (0.4 g/Kg per day). In just two days his fever and lymphnodes decreased and in two weeks his platelet and white blood cell counts rose to acceptable levels. In the past there have been reports of high dose intravenous immunoglobulin used to treat HIV+ haemophiliacs, but these studies have been limited and there was no follow-up data. In the case of this man he showed "striking clinical improvement" and his lab values returned to a normal range. The researchers suggest that the use of high dose immunoglobulin may be useful in similar cases.

Scientists in New Orleans have used the drug amphotericin B to reduce levels of HIV in the blood of 4 PWAs, according to an abstract in *Clinical Research*. After just one dose of the drug (15-25 mg) the levels of virus dropped by between 60-20%. These results are not entirely surprising since it has been shown that amphotericin B can block replication of HIV in test tubes. The drug is commonly used to treat serious fungal infections in PWAs but it has severe side-effects.

While there is no doubt that AZT enables some persons who use it to live longer and experience fewer infections, its use has been associated with severe side-effects which include seizures, according to a letter in *The New England Journal of Medicine*. More alarming however, is an abstract in *Clinical Research* which presents research findings that AZT and actually drugs (DDC, DDA) do not actually cross the "brain capillary wall" or blood-brain barrier (BBB). Scientists at the UCLA School of Medicine have, by

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