

AIDS ACTION NEWS!

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A TREATMENT REGISTRY

One more step in managing the delivery of AIDS treatments

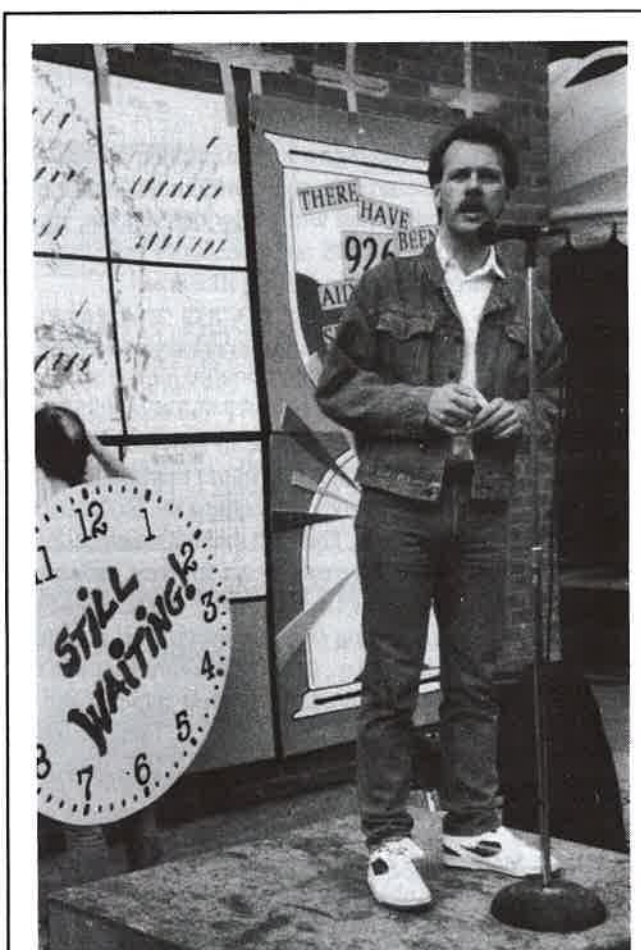
AIDS ACTION NOW!, early on, investigated the serious problem of access to treatment, especially new, experimental treatments for people with HIV infection. Treatment has historically been delivered by a trickle-down arrangement. Treatment discoveries made by researchers were passed on to the specialists working in university teaching hospitals, who in turn passed them on to specialists in private practice, and who then passed them on to family physicians. Very often family physicians only found out about new treatments from pharmaceutical salespeople.

Doctors could have access to experimental treatments using the federal Emergency Drug Release Program (EDRP), but were left, along with the pharmaceutical company, to bear the legal repercussions, such as malpractice suits, that could arise from using unlicensed treatments. They also faced the prospect of having their hospital privileges revoked if they used unapproved treatments.

AAN! realized that it was necessary to put in place a new form of treatment infrastructure. The first step was publishing TreatmentUpdate/TraitementSida to provide family physicians with up-to-date knowledge on AIDS treatment research. The second step was to create the Treatment Information Exchange (TIE) which is undertaking to develop a more elaborate system of treatment information for people with HIV infection.

Two TIE programs under active consideration at the moment are a computer-based system called MedLog for collecting treatment information over time from people living with HIV infection in order to determine what seems to be working for them, and a computer conferencing system for family doctors with HIV patients.

A third part of the treatment delivery system envisaged by AAN! is the creation of an AIDS Treatment Registry. Along with the Canadian AIDS Society and other community-based AIDS organizations, AAN! called on the federal government for the creation of an AIDS treatment registry, which it has now



Yves St-Georges, a PLWA from Sudbury, spoke at AAN's March 15 rally about the absence of a national AIDS strategy on the part of the federal government. St-Georges described the difficulties of getting AIDS treatments outside of Toronto. AAN's proposed treatment registry is designed to solve this kind of a problem. *PHOTO: David Adkin.*