Early to Mid-'80s: Igniting Hope

IN THE EARLY 1980s, the nightmare of AIDS broke like a tsunami over gay communities in Canada’s major cities. Young, healthy men were suddenly and inexplicably dying across the country. No one knew the cause of the epidemic, and even after the identification of HIV in 1984, there was ongoing controversy over the role of the virus in the syndrome. No cure existed for the underlying immune dysfunction, and treatments for the opportunistic infections that came in its wake were largely ineffective.

With medical science impotent and in disarray, gay communities were largely thrown back on their own resources. They established organizations offering support and counselling, set up hospices to care for the dying and, once HIV had been identified, launched prevention campaigns urging safer sex. But with “only” marginalized groups such as gay men dying, government efforts, what little there were, tended to be restricted to preventing the virus from spreading to the “general population.”

Some 25 years later, it’s illuminating to trace the course of events that ensued — the outcry, struggles and victories of early AIDS activists in their efforts to force key changes within the medical establishment, the pharmaceutical industry, the government and the health care system — and to look at the role that treatment information played in those struggles.

In 1987, impatience with government inaction and lack of research for treatments and a cure finally erupted in the U.S. The AIDS Coalition to Unleash Power in New York (ACT UP NY) emerged, quickly leading to the formation of chapters across the U.S. Canadians soon followed ACT UP NY’s example of in-your-face activism, drawing on the women’s health movement’s healthy skepticism of the medical establishment and the strategies and tactics of lesbian and gay liberation, with its demonstrations and street theatre.

That same year, Kevin Brown, a founder of the B.C. Persons With AIDS Society (now Positive Living BC), began lobbying the federal government for speedy access to AZT, which had just been approved as the first treatment for HIV infection in the U.S. And in early 1988, inspired by the example of American activists, AIDS ACTION NOW! formed in Toronto. Most of AAN!’s activists were HIV positive. Treatment quickly emerged as a key issue, as did criticism of the Public Health approach, which was so focused on prevention that it ignored the needs of those already infected.

When AAN! published its first treatment information broadsheet, Treatment AIDS, and distributed thousands of copies at Toronto’s Lesbian and Gay Pride day in June 1988, there was little distinction between “alternative” and mainstream approaches, and minimal scientific rigour. The medical establishment might have warned against raising “false hopes,” but to activists, trying anything made more sense than waiting around to die.

Information and Access

In this context, treatment information was the foundational element of treatment activism. If they were going to mobilize and fight back, people needed hope. The idea that treatment, or even a cure, might be within reach helped
combat the resignation and despair that had seized many people living with HIV/AIDS (PHAs), convinced that they faced an imminent death sentence. It also raised expectations and focused attention on the barriers to treatment — government red tape and inaction, and lack of research and information. The virus might be incurable but, according to treatment activists, people were not so much dying of a virus as they were dying of neglect and indifference. That, we could do something about. The goal was to empower PHAs to make demands on the health care system, the government and the pharmaceutical industry.

At this point, activists confronted the incomprehension of most people in positions of authority. It took time for doctors to recognize that their patients often knew as much as they did about the new and mysterious disease, and that a much more collaborative approach was necessary. Governments were blind to the fact that the glacial pace of standard drug approval and a laissez-faire approach to research were inappropriate in the face of crisis. The pharmaceutical industry was befuddled by unprecedented demands for immediate access to experimental treatments and trial designs that didn’t use PHAs as expendable guinea pigs. They were all oblivious to what BC Civil Liberties Association President John Dixon began to call the “catastrophic rights” to treatment for those facing major illness.

Pentamidine was a case in point. When the drug was used in a nebulizer that turned it into a fine mist breathed directly into the lungs, pentamidine trials in the U.S. had shown dramatic results in preventing PCP (Pneumocystis pneumonia), at the time the major AIDS-related killer. But the drug, although available in most hospital pharmacies, had not been approved for aerosolized use in Canada and Canadians could not get access. Activists demanded the opening up of the federal Emergency Drug Release Program (EDRP) to allow PHAs access to a range of experimental treatments from around the globe.

Also, in the face of increasing demand for action, a placebo-controlled trial of aerosolized pentamidine was finally set up in Canada in 1988. It would enroll 750 participants, all of whom had had at least one bout of PCP and who were therefore at high risk for a second attack. But half the group, in a placebo arm, would receive nothing. The deaths in that group would be the measure of success of the drug among those who received treatment. AAN!’s first public action was a demonstration that marched on Toronto General Hospital, site of the trial in that city. The demonstrators demanded that the trial be halted and the treatment be made available to those who needed it. To hell with the regulations, lives were at stake.

The fall of 1988 saw a federal election. AIDS activists across the country dogged the ruling Progressive Conservatives for their lacklustre efforts against the epidemic. The message got through. Although the Conservatives were re-elected, one of the first announcements made by the new Health Minister, Perrin Beatty, was that Canadians would be able to access experimental AIDS treatments, including pentamidine, through EDRP (now renamed the Special Access Program, SAP). The unethical pentamidine trial was halted and a whole range of new treatments became available.

If the government had begun to move, the pharmaceutical industry was still slow to respond. It took a month-long picket of the Bristol-Myers offices in Toronto by a mother demanding access to ddI for her seriously ill son, international news coverage and the arrest of AAN! activists occupying its offices in the summer of 1989 before the company gave in and agreed to make the drug available on a compassionate basis.

Foundations of an Infrastructure

Treatment information had proved itself a powerful weapon in mobilizing PHAs to demand change, and in the spring of 1989 AAN! set up the local Treatment Information Exchange (TIE) in Toronto to make scientifically reliable information on cutting-edge treatments available. TIE took on the publication of AAN!’s TreatmentUpdate / TraitementSida, a low-budget summary of breaking treatment information written by Sean Hosein.

But activists also recognized the limitations of grassroots, local efforts in spreading the word. With what’s now called the Special Access Program open for business, AAN! joined the Canadian AIDS Society to demand that the federal government establish a national treatment registry to provide information about treatment options and strategies for PHAs and their doctors across the country. When Health Minister Beatty announced funding for the country’s first national AIDS strategy in April 1990, he also included funding to set up the registry.

But announcements and implementation are quite different animals. A year later, after several false starts, there was still no national treatment registry in sight. Rather than wait on the government, activists decided to do it
themselves. In February 1991, AAN!’s TIE project became the Community AIDS Treatment Information Exchange (CATIE). As an independent, charitable organization, CATIE would be able to raise funds to put in place a credible infrastructure to gather, evaluate and distribute treatment information, at least on a local level.

By now the government, the research establishment and the pharmaceutical industry could no longer ignore the voices of PHAs. When the Canadian HIV Trials Network (CTN) began functioning in 1991, it included a Community Advisory Committee made up of activists from across the country. The Committee has veto power over any research protocol considered by the CTN. One of the great legacies of treatment activists was that they successfully pushed for the involvement of PHAs at all levels: public policy, research design, hospital advisory boards, AIDS service organizations (ASOs) and more.

New Access Issues

By 1992, the face of AIDS was changing and so, too, were the strategies employed by treatment activists. The epidemic was no longer confined to the gay community. More women were now infected. Treatment activists, many of them women themselves, struggled with understanding how the new therapies coming on line were affecting women’s bodies since most had only been tested on men.

As well, as scientific understanding of AIDS deepened and more drugs and treatments were tested, enrollment in clinical trials of new antivirals became a major mode of access to treatment for PHAs. Suddenly, the design and ethics of clinical trials became a serious concern. In early 1992, AAN! published the information booklet AIDS and HIV Drug Trials in Canada: What you need to know. A major AAN! demand was that all trials include a compassionate arm so that those seeking treatment could participate in trials knowing that they were receiving the drug and not a placebo.

Increasingly, cost was also becoming a factor. Most provinces had originally established programs to pay for the early antivirals, but as time went on, the growing number of newer antivirals and treatments for opportunistic infections were not covered. In Ontario and Quebec, for example, more and more PHAs without adequate private drug coverage were forced to stop work and go on welfare in order to be eligible for a provincial drug card to pay for their medications. In a dramatic video broadcast shortly after his death in January 1993, AAN! Chair James Thatcher indicted the Ontario government, whose failure to establish a catastrophic drug program had prevented him from accessing treatments he needed to stay alive. The following year, in the face of persistent pressure, the government finally relented and established Ontario’s Trillium Drug Program.

The role of treatment information continued to be an integral part of the struggle for access throughout the first half of the 1990s. Knowledge that options existed empowered PHAs to demand more from their doctors. It increased pressure on governments to cover the cost of expensive therapies and mobilized PHAs to demand that the pharmaceutical industry take their interests into account in the design of clinical trials.

Mid-’90s to 2005: Managing Service

In the summer of 1995, CATIE received the federal government contract to implement the national AIDS treatment information service [formerly called the national treatment registry], which had been floundering in successive agencies since its announcement in 1990. Much had changed since AAN! had made its first proposal for a national treatment registry in 1989. As CATIE struggled with transforming itself from a local to a national, bilingual organization over the next year, AIDS treatment in Canada was being transformed by the introduction of the first protease inhibitors. For the first time, effective combination therapies — highly active antiretroviral therapy (HAART) — and the dream of AIDS as a “chronic manageable infection,” a concept popularized by AAN!’s George Smith in 1988, were real possibilities.

But the emergence of new therapies also had unexpected results. As the dying diminished, so did the perception of AIDS as a crisis. One of the major activist fights at the International AIDS Conference in Vancouver in July 1996, was to demand that the government renew the National AIDS Strategy with its dedicated funds for prevention, services and research. The Chretien government had previously announced its intention to let the strategy lapse.

A second development was that treatment information had become much more complex. The “exchange” of information among peers originally envisioned was increasingly being superseded by the technical demands of information technology — managing, evaluating and disseminating huge amounts of complex information.
Finally, many of the demands for access by AIDS activists had been met. The Special Access Program was functioning and experimental drugs were available. Most clinical trials now included compassionate arms. And the provinces with the largest numbers of PHAs had programs in place to cover the cost of medications for those who were uninsured. As well, many of the original activists had died and many of those who survived were exhausted. The sense of crisis within the gay community diminished and groups like AAN! were unable to incorporate activists from the newer and often even more marginalized sectors of the population — injection drug users, Aboriginal communities, new immigrants and refugees, youth — now affected by the epidemic.

One group that continued to pressure both government and the pharmaceutical industry on behalf of PHAs on a national level was the Canadian Treatment Action Council (CTAC). Founded in 1996, CTAC worked to orchestrate activists’ participation in pharmaceutical advisory committees and ensure that trial design and management committees were knowledgeable and accountable to the community. Today, CTAC provides policy and research related to treatment access directed at both pharmaceutical companies and government, and conducts related skills-building activities targeting CTAC members and PHAs across Canada.

The growing professionalization required of groups such as CATIE in order to effectively manage and evaluate huge amounts of data was accompanied by a decline in traditional activism. Treatment information became increasingly understood as a service to help patients and doctors deal with a range of confusing choices, rather than an incitement to public action. One group that has bucked this trend, however, still combining treatment information and in-your-face treatment activism, is Montreal’s LIPO-ACTION! Since its launch in 2003, the group has used demonstrations, street theatre and lobbying to raise awareness and demand access to new therapies to combat lipodystrophy.

**Back to the Future**

The growing complexity of AIDS treatment and the increasing marginalization of communities now affected by the virus have meant that power and expertise is once again shifting away from “patients” back to medical professionals and institutions.

In response, many ASOs are deepening the work of providing treatment information to their local communities, usually with electronic links to CATIE. BC Persons With AIDS Society (now Positive Living BC), for example, established its own Treatment Information Project (TIP), and its bimonthly publication Living Positive regularly combines information on treatment issues with practical advice on the challenges of living with HIV, news and political issues.

In Montreal, the Comité des Personnes Atteintes du VIH du Québec (CPAVIH) holds regular forums on treatment issues, as does the Toronto People With AIDS Foundation, which established a treatment resources position as early as the late 1980s. Thanks to the work of the Committee for Accessible AIDS Treatment, that position now includes a component to assist individuals temporarily without access to HIV medications — people with a temporary lapse in coverage, refugees and others. [This program grew from earlier efforts to “recirculate” medications from PHAs who died or weren’t able to tolerate them, to others without access.] As well, a new Ethnoracial Treatment Support Network has been established in Toronto. The network trains peer treatment counsellors from immigrant and refugee communities to work with other HIV-positive community members struggling with cultural, linguistic or legal barriers to accessing treatment.

This last focus illustrates a major challenge facing the treatment information movement in Canada — how to target efforts to make highly complex and technical information about treatment options available to increasingly diverse, marginalized populations from a variety of cultural and linguistic backgrounds. One size can no longer fit all.

The next decade will decide if the treatment information movement, born out of a ferment of patient empowerment and entitlement, will be able to continue to evolve to meet the challenges emerging from the changing face of AIDS. If the resilience that this movement has shown since the first dark days of the epidemic is any indication, however, there are grounds to hope that it will continue to thrive until a cure is found and the AIDS epidemic finally becomes history.

Tim McCaskell is a longtime gay activist in Toronto. He was a founding member of AIDS ACTION NOW! in 1988, and a member of the Ontario Advisory Committee on HIV/AIDS for over a decade.
**Milestones**

**1987**

Vancouver activist Kevin Brown lobbies the federal government for access to AZT.

**1988**

AIDS ACTION NOW! is founded in Toronto and publishes a broadsheet for Gay Pride day on possible treatments.

**1989**

AIDS ACTION NOW! publishes the first issue of *AIDS UPDATE* by Sean Hosein. In subsequent issues the publication becomes bilingual and is renamed *TreatmentUpdate* / *TraitementSida*.

AIDS activists seize the stage at the International AIDS Conference in Montreal. AAN! demands that the federal government establish a national treatment registry.

**1990**

AAN! establishes the Treatment Information Exchange, and Health Minister Perrin Beatty announces funding for a national treatment registry as part of the National AIDS Strategy. The Emergency Drug Release Program opens up to allow access to unapproved treatments for AIDS-related conditions.

**1991**

The [Canadian HIV Trials Network](#) establishes a Community Advisory Committee to vet all its trials.

AAN!’s Treatment Information Exchange project becomes the independent organization CATIE.

**1995**

After years of false starts, the national treatment registry project is taken over by CATIE, which then assumed a national role.

**1996**

International AIDS Conference is held in Vancouver, protease inhibitors are introduced. Canadian Treatment Action Council forms.

**2003**

LIPO-ACTION! forms in Montreal.
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

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