CATIE@20
From Community Response to National Responsibility
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Two decades

Twenty years ago, the Canadian AIDS Treatment Information Exchange (CATIE) was incorporated with the visionary mandate to share information about HIV/AIDS treatment. By 1990, CATIE had evolved from its origins as the TIE (Treatment Information Exchange) Committee of the activist organization AIDS ACTION NOW! to a staff of two and a cadre of volunteers in Toronto’s Little Italy. This dedicated group, unable to accept institutional inaction on AIDS, worked in the midst of unrelenting illness, fear, death and grief to realize a community vision of a centralized location where PHAs and those who supported them could pool the emerging scraps of information about possible therapies—most ‘anecdotal’ and outside the realm of ‘proof of efficacy’—that might slow the seemingly inexorable progression to death.

CATIE’s 20th anniversary is a bittersweet occasion. So many of the people who created and provided CATIE’s services, and so many more who looked to these services as a lifeline, are no longer with us. Our anniversary gives us pause to remember the contributions of all who aligned themselves with this fundamentally community-based venture to conquer HIV through treatment.

HIV has dealt a crushing blow to global health and to the health of Canadians. CATIE’s role in the HIV epidemic through the years has, nonetheless, demonstrated the foresight and the inestimable force that can be brought to bear against adversity once deemed unstoppable. Certainly this is reason to celebrate.

We thank the many people who have contributed so generously to the production of this book. CATIE@20 is really all about the voices of so many who were there to build our organization and influence the course of HIV information sharing. We had the good fortune of being able to connect with a number of those people and we were overwhelmed by their generosity in writing reminiscences. The commentaries provided by our contributors (listed on the inside front cover) speak eloquently of their passion and dedication.

We also thank those who offered us images for our use and consideration, notably Joe Average (for his illustration), Glen Brown, Henry Chan, Bob and Linda Gardner, Brian Huskins, Bruno Lemay, Terry Maurice, Susan Massarella, Donald W. McLeod of the Canadian Lesbian and Gay Archives, Fanta Ongoiba, Jake Peters, Jeff Potts, Trevor Stratton and Ralph Carl Wushke. And for all those who have helped us through the years, we cannot thank you enough.
A bare space on College and an immense task ahead

don’t remember the exact date, but sometime in January, 1990 I opened the door into an empty two-room office at 517 College Street in Toronto (now a condominium building) and the work of laying the organizational foundations of what would become CATIE had begun.

I had been hired as the co-ordinator of AIDS ACTION NOW!’s Treatment Information Exchange Project, an initiative born out of a desperate need for information about this mysterious virus that was killing our friends and lovers.

After two decades and despite many advances in HIV treatment and prevention, HIV is still a major public health challenge. But our current situation pales in comparison to the crisis we faced back in 1990. At that time, HIV/AIDS was, for many, very close to a death sentence. AZT was the only widely available medical treatment to combat the virus in Canada. Institutional mechanisms to test and make experimental treatments available to PHAs were not yet in place. Government response to HIV/AIDS bordered on complete neglect. HIV-related stigma was rampant, and people living with HIV – the vast majority of whom were gay men – routinely fell ill with opportunistic infections and died.

Of course, the flip side was that the urgency we faced helped fuel a period of incredible political activism centered on HIV/AIDS. This was a time before the AIDS response.

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1981

- The US Centers for Disease Control (CDC) in Atlanta receives reports of unusually high rates of the rare diseases Pneumocystis carinii pneumonia (PCP) and Kaposi’s sarcoma (KS) in young gay men
- Reports on the first U.S. cases are published in the medical and popular press – 20 gay men in the New York area, six in Los Angeles
- Disease is initially called Gay-Related Immune Deficiency (GRID) because it is thought it only affects gay men
- Reports on AIDS begin to appear in The Body Politic, Toronto’s major gay newspaper
- Cases of the disease reported among injection drug users
in Canada had become crystallized into a network of AIDS service organizations, when grassroots activism was in its heyday. It was a time when the identity of a “person living with HIV/AIDS” emerged as a vibrant political, cultural and social reality. It was also a time when structures of power that created problems for PHAs, from science to government to the health professions, were contested and transformed.

In Canada, AIDS ACTION NOW! (AAN!) led the way. The group, which drew largely on gay liberation politics and feminist health activism, followed a strategy of “documents and demonstrations,” a term coined by George Smith, one of CATIE’s founders. That strategy involved publishing critiques and analyses of key issues supported by creative street actions and demonstrations, with the goal of making effective treatments widely available to PHAs.

AAN! used these approaches to criticize how the response to HIV/AIDS – including the activities of early community-based AIDS organizations – emphasized HIV prevention to the neglect of PHAs’ treatment needs. By the late 1980s, the group decided that a new kind of community-based AIDS organization was needed, one that focused exclusively on health and treatment information. After much effort, a successful grant application from the Ontario Trillium Foundation, which funded my position, helped make that vision possible.

So while the Treatment Information Exchange (TIE) Project office may have been physically empty in January, 1990, it was full of the vision of an organization that would exchange treatment information in order to enhance the health of PHAs. But what that would look like, and how to make it happen, were wide-open questions. Luckily, I had a lot of help, particularly from an advisory committee formed of AAN! members and others.

I would like to say that we approached our work in a rational and step-wise manner. But that’s not exactly how it happened. Of course, we weren’t completely slapdash. In the early months we commissioned an assessment of treatment information needs among PHAs and ASOs, conducted by Ron Foley. It showed us the extent to which our communities wanted and needed clear and up-to-date information on treating HIV infection. But much of what we ended up doing seemed to arise out of circumstances of exigency and crisis. We didn’t always have the luxury of careful planning; we often had to jump in and think on our feet.
The early days of AIDS ACTION NOW! and the beginning of CATIE seem to come from another lifetime. I remember George and Sean and Eric. I also remember Max Allen and working with him to write the original funding application. We could choose either three years or five years in the proposal. We chose three, thinking that AIDS would be all over by then, that the cure was only around the corner. I believed (as I still believe) that if we worked and fought hard enough it would all really end. I believed (as I still believe) that if we worked and fought hard enough it would all really end. In 2011-2012, we start the third decade of the HIV era. Who could have imagined in the 1980s all that it would become?

I occasionally share some of my early experiences with my colleagues here in Africa. I tell them about driving to Buffalo to buy vials of pentamidine. I can still see the brown paper bags on the seat beside me. Who even remembers that whole process now with the portable aerosolizers? And what about the early days of AZT and the fancy pill boxes with the electronic alarms? It was before all of us had cell phones even. I still have a photo from the big visit to Ottawa where people took their different drugs that weren’t available in Canada. I am in a far corner of the photo with a megaphone. Was that really me? All of the ‘panelists’ who are sitting at a table in front of the Centennial Flame with the Peace Tower looming behind are dead now. The feeling of breaking out with open resistance was so intoxicating. There was such hope, then, that we could turn this disaster around...

When I reflect on those days of activism, I realize they changed my life. Sometimes, I think of myself sitting in a room of empty chairs – spaces where friends, colleagues, lovers, once sat. I can’t work out why AIDS took all of them and skipped me. After trying to ‘retire’ from HIV work a few times, I am back in the thick of it, working at the epicenter with a new family of activists around me. My style is changed, though. Rather than motivate people with megaphones and clever slogans, I work more closely with individuals, trying to inspire vision, trying to build courage that things can still be different.

I have seen what I could never have imagined in those days in Toronto about what HIV could do. While the price I have paid is an inconsolable sadness, I don’t anymore wish that I had chosen a different path. HIV has revealed so many things to me, to all of us. It has brought us closer to the complexity and, ultimately, the mystery of who we are, and what we are about. So, I am grown old and wise now. The ‘lessons’ through time of witnessing the devastation of HIV are now my strength. To you, and to all the others, who drew me into activism around HIV, I can only say thanks. I hope that I have lived up to the expectations of everyone from that incredible time. My memory is alive for all of you; my sadness is always with me for everyone who can’t share this moment of reflection with us.

Molimo, aku boloke bakhotsi baka. [Sethos language: ‘God bless my friends and keep them safe from harm.’]
One of the first things we did after we opened the office was take over the publishing of TreatmentUpdate. Sean Hosein had been writing TreatmentUpdate for some time. Issue 12 was the first published out of the TIE office. I created a subscription database on an old WordPerfect program, learned how to desktop, started to help with co-ordinating the French translation, trained a group of volunteers, and in no time we were stuffing envelopes and distributing the publication across Canada and beyond. It was some time before Sean was hired as a CATIE staff member, but he had already laid the foundation for establishing TreatmentUpdate as CATIE’s flagship publication.

At about the same time, PHAs, frontline workers and others began calling the TIE Project office with questions about HIV treatments. We hadn’t formally planned to start up a treatment information “hotline,” but as a new organization committed to exchanging HIV-related health information we needed to be able to respond to people’s questions. At first, we thought about establishing treatment-information “buddies” by adapting the model of the successful Casey House buddy program to treatment information but, for liability reasons, we decided against it. In the end, a small team of volunteers rescued me. They began assembling files of treatment information for me to use when answering telephone requests. I learned about HIV treatment as fast as I could, advertised specific times for people to call, and the telephone inquiry service was born.

It was a good thing, too, because the treatment hotline was the main way that the TIE Project had direct contact with PHAs. Over months of taking calls, I not only learned about HIV treatments, but about how complex people’s needs were and how their questions about treatments were embedded in broader health and life concerns. Soon it became clear that we needed to think of ourselves not simply as providing discrete answers to discrete questions, but in a more holistic manner.

As an HIV researcher who ‘grew up’ in the early stages of the AIDS epidemic, CATIE gave me purpose and held researchers like me accountable to PLWHAs in everything we did. CATIE played a critical role in bridging the divide between activism and evidence, and gave a valid, respected voice to the HIV-affected community.

— Steffanie Strathdee

“Killing Time, Killing People”

Protesting AAN! members Tim McCaskell (on mic) and Glen Brown (megaphone)
but as providing a more holistic and sustained form of information and advice that addressed HIV, treatment and health in broad terms.

One immediate response to that insight was the establishment of The Positive Side. Created by a group of CATIE volunteers in 1991, the publication responded to a demand for information about complementary and alternative therapies that expressed the real-life experiences of PHAs, at a time when there were few medical options and little information about the use of complementary therapies in the context of HIV.

The idea of working with your doctor, being at the table making decisions and being heard, was still a distant dream. We were a bunch of frightened gay men trying to come together and trying to survive. We felt alienated from the medical establishment and there was a lot of mistrust, primarily because our friends and lovers were dying and nothing seemed to be working. The early established medical therapies did more harm than good. Sean Hosein was one of our lifelines and we were calling him regularly for information and also to share ideas. He was always very supportive and encouraging in the midst of this darkness. He had his finger on what was going on and was very patient and caring. Sean was one of our trusted allies. We did not have much in terms of good therapies but we were determined to survive. Sean Hosein and CATIE were a lifeline for us and a haven of hope in a dark time.

As one of the founding members of the Treatment Information Program at BCPWA in Vancouver almost 20 years ago, I recall the early years of HIV as ‘the dark ages’ because there was very little in terms of therapy and support. The depth and breadth of treatment information and materials that CATIE has available for people living with HIV and the organizations that serve them is amazing. Your work makes our work locally much easier.

– Debra Jakubec
One of my proudest moments at CATIE was securing a grant that helped put the vision of a more holistic approach to treatment information into place by providing funds to create the first version of Managing Your Health. The application went to the AIDS Prevention Program of the City of Toronto Department of Public Health in early 1991. By that time, it was clear that AAN! needed to remain at arms length from government funding, so the TIE Project became incorporated as a distinct organization with a new name: the Community AIDS Treatment Information Exchange.

In the past, the AIDS Prevention Program had only funded HIV prevention projects. To get around that problem, we argued that secondary prevention – preventing the progression of HIV to AIDS – was part of the Public Health Department’s mandate. Long before funders began to require research evidence to support funding requests, we cited research that showed that the most common reason for not testing for HIV amongst urban gay and bisexual men was the belief that there was no effective treatment. We argued that the HIV Health Handbook, as we called it then, would encourage voluntary HIV testing by describing health-management strategies for PHAs. The funding we received helped us hire CATIE’s second staff person, Brent Patterson, to oversee the creation of the publication. In 1993, Managing Your Health was published.

I left my position as co-ordinator of CATIE toward the end of 1991 but remained involved with the organization and joined the board in 1993. I remember the years that followed as a period of major transition for the organization. Shortly after the TIE Project had been established, George Smith and other AAN! members began to lobby the federal government to establish a national treatment registry for HIV. After national consultations held in 1992, the federal government committed to establishing a national AIDS Treatment Information Service (ATIS) as part of its National AIDS Strategy (Phase II). The vision was of a service that would provide reliable, up-to-date treatment information for PHAs and service providers across the country. ATIS was plagued with a series of false starts and mishaps, including a rather public scandal over a failed attempt to establish it at the University

For ten years, the Federal government failed miserably in setting up its national AIDS treatment registry. Finally (and thankfully) it gave the job to an activist-created Toronto group, CATIE.

– Tim McCaskell

1984

The discovery of HTLV III (later named HIV) is formally announced and is seen as the probable cause of AIDS. A test is soon established to detect antibodies to the virus

1985

First AIDS Awareness Week held in Toronto, and the first in Canada declared by a public official (Toronto Mayor Art Eggleton)
of Toronto. I remember how those of us at CATIE were angry at the failure of established, well-resourced institutions to launch ATIS. We convinced ourselves we could do a better job and under the leadership of Wayne Hellard, CATIE’s executive director at the time, we submitted a successful bid. Things were never the same.

There were the obvious changes and challenges: new hirings, a technological ramp-up, expanded French-language capabilities, and planning out what ATIS, which was

"Grown out of a grassroots movement of affected communities striving for an informed and empowered response to choose and access HIV treatment, CATIE has matured into an important resource to many diverse community efforts throughout the country, including the Toronto Ethnoracial Treatment Support Network. Congratulations and thanks!"

~ Dr. Alan Li

"Always the Big Picture"

We always saw CATIE as part of a bigger picture -- as part of the radical, progressive HIV/AIDS movement. CATIE arose out of PHAs’ need to understand and manage available treatments in a very desperate period: there were few treatments and so many were dying.

Collecting and mobilizing information on treatment was vital to enabling people to win some control over their health and lives. From the start, CATIE worked to be accessible to as many people as possible, including the most marginalized. And this empowerment became a vital principle of the overall movement. Mobilizing around treatment highlighted the desperate need for better research and treatment.

Out of AIDS ACTION NOW! and other groups and affiliations, we joined together to build a broad movement not just for better treatment, but for all the other social and policy changes needed to address the crisis. CATIE was dedicated to serve and support the health and empowerment of PHAs, and in its support for policy change, it was also, always, deeply political.
Wayne Hellard submitted a successful bid for federal funding to manage a national treatment information service for people living with HIV/AIDS.

eventually absorbed into the newly named Canadian AIDS Treatment Information Exchange, would look like. But the most vexing issue I recall was about governance. CATIE had long been directed by a hands-on local board of PHAs, and community members intimately involved in the day-to-day running of the organization. With the transition to a national organization, that approach came into question. I remember endless discussions into the wee evening hours at board meetings where we debated different governance models. In the end, it became clear that a policy model of board governance with national representation would be required and that we could no longer imagine or relate to CATIE as a small, local, community-based organization.

That January day in 1990 when I walked into that bare office space on College Street, I had no idea how much CATIE would accomplish and how much it would define the trajectory of my own work life. When I look back at the early years of CATIE, I am amazed at how much we were able to do with so little. Many of the initiatives that we worked on in the early 1990s – TreatmentUpdate, the telephone inquiry service, Managing Your Health, and The Positive Side – have continued in one form or another to this day.

It seems to me that many of the key debates we had as part of establishing these initiatives continue to be explored even as CATIE moves forward with new challenges and an expanded mandate. CATIE staff and volunteers are still thinking creatively about how to link experiential knowledge with scientific information, and about how to present HIV as a chronic, manageable infection without erasing the reality of illness. They are still working through questions about the relationship between HIV prevention and treatment and about how to respond to the broad social context of people’s health and treatment information needs. I’ve learned and benefitted from these discussions tremendously. I hope that they continue to unfold, to raise new challenges, topics, and questions as CATIE changes and develops in the years to come. Congratulations on 20 fine years.

The need for a publication like Managing Your Health based both on medical knowledge and the personal experiences of people with HIV seems obvious, but no one before its publication had collected and written down all this information. We wanted people with HIV to know that there were things they could do in order to live longer and healthier lives. We may take this for granted today but it was an important message when Managing Your Health was first published in the early 1990s.

— Brent Patterson

1986
First Canadian AIDS Research Conference held in Toronto

1987
CPHA first funded to do education and awareness work and the National AIDS Clearinghouse is established in April
Canada’s first AIDS Walk organized by the Vancouver PWA Coalition on the Stanley Park Seawall
Ontario AIDS Network (OAN) is formed
FDA approves first anti-retroviral drug, AZT
George Smith
May 7, 1935 – Nov. 6, 1994

If I could put it all into a sentence, I would say that George Smith was one of the most brilliant people that I have ever met and that he was always a supporter of the oppressed. But even that sentence could not do justice to George’s massive legacy, not just to the struggle against AIDS but to human dignity.

George graduated with distinction from McGill University and he was encouraged to apply to Harvard University and to McGill’s medical school by his professors. Instead, he chose a life of political and sociological enquiry. He used his training as an ethnographer to make visible the hidden world of agencies that controlled people’s lives. George put his skills and findings in the service of despised minorities – initially these were gay men in the late 1970s and early 1980s, later to be followed by HIV-positive people.

In the mid-1980s as the AIDS epidemic blossomed across Canada, governments of the day were largely indifferent to the suffering. If they paid any attention to what was called ‘the gay plague,’ it was to make sure that HIV did not break out of its initial ‘risk groups’ and infect the ‘innocent.’

To shift the focus to helping people with HIV, George used his training and knowledge to form a remedial and grand strategy. He brought diverse activists together and, with community activist and intellectual Tim McCaskell, formed Canada’s first AIDS activist group – AIDS ACTION NOW! Their demonstrations, street theatre and guerilla press conferences were always successful in garnering sympathetic media attention and, ultimately, public support.

Next, George, together with other activists such as McCaskell and University of Toronto professor Michael Lynch, pressured the Federal bureaucracy into allowing promising experimental HIV therapies into Canada so that doctors could treat their patients. George helped to draft policy papers that would contest and rewrite the rules for conducting clinical trials with HIV-positive people in Canada, making them fairer by discouraging the use of placebos.

Being an ethnographer allowed him to penetrate the inner sanctum of bureaucracies, medical associations, universities and corporations. He was able to take advantage of their competing interests to make them serve the treatment needs of PHAs.

One of George’s legacies is CATIE, which together with lawyer Alan Cornwall, he co-founded to help meet the complex and changing information requirements of HIV-positive people. George did all of this work while doing the research necessary for two PhDs at the University of Toronto. We can only marvel at such drive and vision.

In addition to all of this work, somehow George found time to be my mentor, tutoring me on a wide range of subjects from the principles of adult education to politics, media analysis, mathematics and philosophy. He would always be interested in making sense of the research papers that I brought home almost every night from my foraging in the University’s Science library. He described this work as “Going to medical school at night.” Our medical allies nodded in mirth and wonder.

My partner George passed away in November 1994, before HAART was available. But thanks to the nutritional expertise of Chester Myers, PhD, the Traditional Chinese Medicine of Dr. David Bray, the experimental therapies made available by Doug MacFadden, MD, PhD, and the knowledge that I had accumulated over the years, we were able to preserve his intellectual functions and give him good quality of life until the very end.

We have lost so many gracious, talented, brilliant and beautiful souls to AIDS. They would be proud of what has been achieved and accomplished. The memory of their struggle in the face of so much adversity is a testament to the resiliency of the human spirit. It inspires me to this day.

– Sean R. Hosein
HAART and the Evolution of Therapies

1996 was, to put it mildly, an interesting year to launch a national HIV treatment information service. I came on board as CATIE’s Director of Programs and Services at the beginning of 1996. By that point, most of the hard slogging had been done to get the national service ready to launch. The national consultations had been done and the results analyzed. Infrastructure – phones, computers, desks, a photocopier the size of a freight train – was in place. An information management system had been meticulously designed and developed, along with state-of-the-art information technology. Staffing was mostly in place, and the Treatment Information Counsellors (TICs) had gone through a rigorous training program.

Progress had been tracked with marathon weekly team meetings with board and staff involvement (one of my first managerial decisions was to abolish those meetings; many were grateful!).

By the beginning of February, we were as ready as we were ever going to be. We threw the switch. The HIV/AIDS Treatment Information Network (as it was then called, one of many nomenclatures through the years) was open for business.

Phone call volume was at first slower than we had anticipated, but it grew steadily. At the same time we increased our print resources, especially fact sheets, to respond to the most common inquiries coming in on the phone lines.
Beyond its immense and immediate contribution to keeping people alive, CATIE has been part of two lasting changes to health and healthcare. By being part of a movement demanding research to find treatment when there was none, we transformed the nature of research. No longer were research priorities defined solely by financial or intellectual concerns — no longer defined by professionals in white coats and isolated labs. People living with the condition became part of driving the research agenda.

PHAs and AIDS activists also redefined healthcare: building on the legacy of the women’s health and other movements, PHAs mobilized to empower themselves individually and collectively, with the latest knowledge to be able to negotiate and manage their own care. This totally transformed the relationship between provider and the person needing care. It also made the idea of the passive patient and the omniscient doctor an outmoded notion.

These transformations have made an impact far beyond HIV/AIDS, and that is a huge legacy about which CATIE and other AIDS activists can be justly proud.

Transforming Health

Then came Vancouver. In the summer of 1996, the International AIDS Conference changed the game. Fragments of hope over previous months (each reported by Treatment-Update) reached the tipping point at the conference. Highly Active Antiretroviral Therapy (HAART) was working far better than previously thought. People with HIV were retaining their health. More miraculously, people with AIDS were regaining their health. Could the elusive goal of a chronic manageable illness be in sight? Could a cure be in sight?

The shift that began with Vancouver would have implications for CATIE and for treatment information for the months and years to come. Treatment information was no longer about extending lives; it was about saving them. At CATIE, this was not just about the people who used our services. It was about us. People living with HIV on staff, →

Back in 1990 when I was diagnosed with HIV, it was reassuring and heartening to know that CATIE, incorporated in the same year, was there as a kind of “lifeline.” CATIE was one of the very few entities I was aware of that made me feel remotely connected to the living world. When we dared to hope, CATIE was there to answer our questions and share our experiences.

Trevor Stratton

REMINISCENCE

BY BOB GARDNER

1988

AIDS Community Care Montreal (ACCM)/ Sida bénévoles Montréal is formed by members of the English Services Committee of CSAM and is incorporated in February

First AIDS Candlelight Memorial is organized in Vancouver

AIDS ACTION NOW! founded in Toronto; publishes Pride Day broadsheet on possible treatments

World Summit of health ministers from 148 countries held in London, England to develop an AIDS Strategy

Federal Minister of Health and Welfare Jake Epp is burned in effigy in an AAN! demonstration, held during a national conference on AIDS, protesting treatment issues and a lack of overall policy commitment on AIDS

1988
on our Board, our advisory committees, and among our personal friends and families were facing a future far different than that imagined just a year before.

With every new addition to the treatment arsenal, the complexity of information increased exponentially. Callers and web visitors now wanted to know which combinations were most effective at which stages, what side effects were involved, what sequencing possibilities were available, what was coming next in the pipeline, and many other challenging questions.

And, at least temporarily, the focus of treatment information would be located almost exclusively within the medical and pharmaceutical model.

The other game-changer surrounding the Vancouver conference was political. Earlier that year, the ruling Liberal government had announced that the National AIDS Strategy would not be renewed when it expired in March of 1997. Instead, HIV/AIDS would be folded into Health Canada’s “population health” strategy. The government would make no commitments for dedicated AIDS funding beyond the coming year.

The Vancouver conference became a magnet for activists’ response to this decision. Activists across the country – initiated by AIDS ACTION NOW! – rounded up funding and signatures for a full-page ad in The Globe and Mail on the opening day of the conference condemning the government’s abandonment of the fight against AIDS. Prime Minister

I immigrated to Canada in 1990, but it was only after I joined CATIE seven years later that I started to feel that Canada was my second home. While working at CATIE for 11 years, I not only improved my understanding of Western culture, but also, more importantly, I came to understand a true Canadian value – that everyone has the responsibility to care for the community.

– Lin Ai

Congratulations, CATIE, for 20 years of commitment, growth and vision. The Aboriginal AIDS movement acknowledges the respectful manner in which you include Aboriginal people living with HIV/AIDS, understanding and supporting Aboriginal ways, knowledge, traditions and culture. CATIE brings hope to the people and is a strong foundation in the HIV and hepatitis C movement.

– Margaret Akan

1988

- The National Coalition of People Living with HIV is formed
- Casey House hospice in Toronto opens
- WHO announces that December 1 will be the first World AIDS Day
- AAN! publishes first issue of AIDS Update (later renamed Treatment Update) by Sean Hosein

1989

- AIDS activists seize centre stage at the International AIDS Conference in Montreal: AAN! calls for the federal government to establish a national treatment registry
Now that I’ve been living with the HIV virus for five years, I look back at the journey and can see that I hit the ground running. Getting educated was a personal quest, and that propelled me to get involved with my local AIDS Service Organization, which in turn offered opportunities to connect with CATIE in their delivery of capacity-building workshops, ‘train the trainer’ programs, and body mapping facilitator training.

The information delivered was trustworthy and reliable – and relevant to my own experience living with HIV. I took advantage of these opportunities which became integral to my growing knowledge and understanding of the viral replication cycle, HAART medications and, most important, managing my illness. The accessibility of CATIE’s services and resources to their membership has benefited the PHA community in Canada and beyond its borders. Through CATIE, I have networked with amazing individuals from across the country. I now view CATIE as a reliable friend… an organization I can turn to for information, support and a gentle push to accept new challenges and take advantage of the opportunities that lie ahead.

CATIE’s move to include a broader range of services as a national Knowledge Exchange Broker, including addressing hepatitis C information, was a natural one. CATIE has always been in the forefront of change, quickly adapting to meet new needs.

— Terry Pigeon

Jean Chrétien declined to attend the conference, so activists vented their anger at Health Minister David Dingwall. When Dingwall rose to speak, all of us on the main floor of the convention centre turned our backs on him and chanted “shame.”

It was not a well-kept secret that I and other CATIE staff attending the conference (on Health Canada’s dime) played key roles in supporting the activism at the conference. I, along with a brilliant colleague from AIDS Vancouver, facilitated daily activist meetings, produced leaflets and media materials, and provided other logistical support. Several other CATIE staff participated in daily activist strategy sessions, helped organize demonstrations and took on other roles as needed.

The advocacy campaign eventually resulted in the government reversing its decision (just prior to the 1997 election) and launching consultations to determine the shape of the new Canadian Strategy on HIV/AIDS (CSHA). That
In the early days of the Viral Load Testing Program, there were concerns about testing uptake. After the first six months of testing, the number of PHAs getting a viral load test was only about half of what had been expected. The Viral Load Evaluation Committee called on CATIE to help.

Quickly and very collaboratively, the CATIE staff developed a client-friendly brochure that described the test and its benefits for HIV care. It was included with all HIV positive test results. We also developed a travelling road show for community organizations to promote viral load testing for those living with HIV. I recall several occasions when Craig McClure and I would do our presentations and then do Q&As for community members. It was a great way to get out and meet the very people who we hoped would access the service.

Slowly but surely, the message spread, so that the number of PHAs accessing testing was closer to 80 per cent of the eligible population. This was a great success and showed that increasing PHA awareness of services could increase uptake of testing. It was a real pleasure to work with the CATIE staff, whether developing educational material, sharing a presentation or celebrating our successes.

One of the highlights was taking the Viral Load Brochure to a national level. This occurred long after I retired from the public health unit and began working at the Ontario HIV Treatment Network, but was still involved in national HIV issues. Based on the success of improving uptake in Ontario, the Canadian Association of Clinical HIV Laboratories Specialists (CACHLS) invited CATIE to modify the Ontario brochure so it could be used in all provinces. This was the beginning of a new relationship for CATIE, one that continues and ensures that diagnostic and monitoring information reaches those who need it in a user-friendly format.
Strategy guided the federal response to HIV until 2004 (when it was succeeded by the “Federal Initiative on HIV/AIDS”). CATIE played a central role in those consultations – the first phase in CATIE’s ongoing role as a “national partner.” All national partners – organizations or networks with a national mandate related to HIV/AIDS – have continued to meet regularly and provide a collective voice to the government.

Another phenomenon was unfolding around the same time. This passing fad called the Internet (the “information super-highway”) was beginning to look like it might be around for awhile. Fortunately, CATIE was blessed by a number of prescient staff and Board members who recognized the potential this emerging format could have for information delivery and information sharing. CATIE’s head IT guy at the time, Paul Merriam, deserves particular mention for building the platform that was to make CATIE a world leader in Internet-based HIV service provision.

Over the months and years that followed, CATIE experienced major successes but also faced growing pains...
CATIE played an important role in identifying that harm reduction had to be integrated into HIV treatment and care. Work was also done to understand the needs of HIV-positive drug users and to help increase their access to healthcare and HIV treatment. Collective action on the part of a number of associations and individuals was required, and what we learned from users was shared with other health care providers and used to demand government services.

— Brent Patterson

and challenges. We expanded our range of print and Internet resources and engaged more with health care professions. We were lauded for the quantity and quality of our French language materials. Our website traffic hit levels we could not have predicted – both in Canada and internationally.

One significant debate was what we meant by the “Exchange” in CATIE’s title. What role does lived experience play in providing “evidence-based” reliable information? If lived experience is evidence, how does an information management system reflect that? As CATIE became better known for its skills in assembling and translating scientific data, would PHAs also look to CATIE to facilitate exchange with their peers?
Life-Saving Intervention

This story is about an Aboriginal woman who lived with HIV for many years before passing away some years ago. I don’t recall the exact date that this story took place but I think it was four or five years ago, perhaps even earlier. It was around the time when Abacavir was new on the scene. Brenda Loyie had just started a new treatment regime which included Abacavir. Her local family physician was/is one of the doctors in Prince George that we know we can rely on. He is a strong advocate for Aboriginal people, for injection drug users, for people living with HIV/HCV, and for the population we worked with. He goes above and beyond for patients. He even visited Brenda at her home.

When she began the treatment with Abacavir, it was pretty much her last regime to try; she had been on the HIV/AIDS rollercoaster for many years. In and out of the hospital, she was now at home, and if I recall correctly, it was a Friday, late afternoon. She had been getting progressively weaker, very tired and listless but adamant that she didn’t want to go back to the hospital. Brenda figured she just needed to be on her new meds long enough for them to make some headway. I cannot recall whether or not I had a conversation with her doctor at that point. What I will never forget, though, is the conversation I had with someone at the other end of the phone when I called CATIE.

I called CATIE because, for whatever reason, things weren’t being figured out here in PG and I was trying whatever means I could to help Brenda. The person (a male) I spoke with was very thorough in listening to me; he was researching while we spoke and he was consulting someone else at CATIE. I felt so supported and when the person at CATIE said that he was very sure she was having an allergic reaction to Abacavir, I believed him. He was adamant that I needed to stop Brenda from taking her next dose, telling me that the next dose may prove fatal for her, given what was already happening.

I immediately went to her place and spoke with her partner. There was a lot of fear in not taking her next dose – that it would jeopardize this possible last treatment option. It was a very difficult decision to make but in the end, she did not take the next dose of Abacavir, telling me that the next dose may prove fatal for her, given what was already happening.

Brenda did end up taking a different combination of meds that did not include Abacavir. She continued to fight for her health up until she passed away a year or so after this incident. The fact that she lived through the Abacavir experience is due to the knowledge, the skill, the availability and the compassion of folks at CATIE, and we are all grateful for the service and the people who provide it.
Indeed, during my era we suspended the peer counselling program because we didn’t have the right tools to ensure quality control. The intensive training, continuing education and supervision that phone line staff required to provide excellent service was not viable for part-time volunteers. I think CATIE has developed some good responses to this challenge – in part by supporting local ASOs where peer exchange is more feasible, and in part by creating greater emphasis on personal narrative in The Positive Side.

As HAART became more successful (and more complex), we were at times challenged by a less-than expected demand for the phone service, despite various attempts at marketing campaigns. I suspect that as HIV treatment came to be understood more exclusively within a medical context, PHAs were increasingly seeking their information from medical professionals rather than community-based models. I wonder whether the increasing effects of aging with HIV and with side effects may shift this dynamic once again. As PHAs encounter a wider range of medical specialists who are unfamiliar with HIV, community supports may be increasingly attractive.

We struggled with how to provide information on complementary therapies. Given the scarcity of “scientific” data on efficacy (both because the research is rarely funded and because some therapies could not be studied with western medical models of research) what does information look like? What do PHAs want and deserve from CATIE? I think CATIE has done a fine job recently of navigating through those tensions with its current range of publications and services.

In my era, I was probably seen as resistant to expanding information on complementary therapy information, and indeed I regret not listening more attentively to those who advocated for it. Part of my resistance lay in a philosophical debate we never really engaged in explicitly: Is CATIE about empowerment or health promotion? Have we met our mandate when people are well informed, or when people go on therapy (pharmaceutical, complementary or otherwise)? I was nervous that some efforts to provide information about complementary therapies would be seen as attempts to promote those therapies.

When I found out in 2002 that I had end-stage cirrhosis due to HIV drugs, I was sure my life was over. CATIE was the first organization to listen to my situation, realize that other PHAs would soon be similarly affected, and to begin gathering treatment information on HIV and transplantation. Their encouragement gave me the support to approach other stakeholders like the OHTN and CTAC, all who have worked consistently and tirelessly on this issue.

– Greg Robinson
Chester Myers had a PhD in biophysics. It sounds like a field of research out of a sci-fi movie, but what it really signified were two things: he was a very smart scientist and he had a deep knowledge of how the invisible cellular machinery that powers the body works. And Chester willingly put his special knowledge and skills in the service of HIV-positive people across Canada.

To anyone who has come of age in the era of HAART, it seems hard to imagine what life was like without it. In those days, the accelerated aging that came with AIDS took hold swiftly. For some people, the knowledge that Chester gave about antioxidants, nutrition and complementary therapies was all that was available to slow the decline of the immune system.

Chester would give talks across Canada to HIV-positive people, teaching them about nutrition, how to get enough protein – a particularly important task in a disease that caused wasting – and which supplements to use. He created brochures on key supplements with amusing graphics. As treatments for HIV became available, he began to focus on ways of reducing their toxicity. His ideas in the late 1990s about preventing some of the complications that now seem commonplace – cardiovascular disease, diabetes, kidney dysfunction – are still relevant today.

Chester was CATIE’s scientific advisor and his support and ability to attract volunteers catapulted CATIE into a centre for information on complementary therapies and nutrition in HIV infection. Chester’s hard work laid the foundation for advocacy for the creation of the Natural Health Products Directorate so that the government would take natural health products seriously, regulating them for the safety of Canadians.

Another legacy of Chester’s, together with former CATIE board member Laurette Lévy, was the creation of The Positive Side magazine. In the early 1990s, the magazine was focused mostly on complementary therapies and the lived experiences of PHAs. It was printed on newsprint and published erratically. Now, The Positive Side has morphed into a Canadian, full-colour magazine that speaks to the many needs of PHAs in both English and French.

Chester was from Atlantic Canada and once a month he, several volunteers and I would have a lobster dinner. He used this opportunity to gossip and also teach us about fundamental biochemistry, so Chester was both a friend and tutor. He passed away in 1999 from complications due to lymphoma. If Chester were around today, he would be proud of how much of an impact his legacy has had and how much CATIE has evolved.

– Sean R. Hosein
An expanded, national mandate

When I started as Executive Director at CATIE in 2003, I was excited by the opportunity to work nationally. I had worked in HIV since 1987, initially with street youth at Youthlink – Inner City in Toronto (before treatments were available), and, immediately prior to arriving at CATIE,

at the Toronto People with AIDS Foundation (PWA) where we were fortunate to have a full-time staff dedicated to providing treatment information to PHAs. I had a lot to learn and hoped that my front-line experiences providing practical services to positive adults and marginalized youth would be useful at CATIE. At PWA, CATIE’s website, resources and phoneline services were a first reference point for our treatment information staff when needing treatment information to share with a client – but I was acutely aware that the vast majority of PHAs did not have the benefit of accessing treatment information face-to-face.

CATIE’s first decade was marked by profound change. The last decade has been no exception.

With the launch of the national treatment information service, CATIE quickly grew from a staff of two to more than 30. Talented and enthusiastic staff were hired and systems developed to support the increased activity and deliverables. Unfortunately, this challenging task coincided with tensions between CATIE and the funders at Health Canada.
Prairie Snow Storm

Eighteen years ago, when I was President of the Canadian AIDS Society, I recall CATIE starting to find its way onto the scene. My respect for its work, and interest in watching it evolve from a community-based organization to its emergence as a national supplier of HIV/AIDS information, has never waned. In fact, CATIE played an important role in shaping my professional and personal life.

My history with CATIE really started one January day in 2002 – one that will always stand out in my memory. It was one of those crazy prairie winter days where the snow was piling up on the streets in front of my house, it was -20°C and there was no end in sight. Parked by the curb was my Jetta with the largest U-Haul trailer that they could legally attach to it; packed with my most treasured earthly belongings, ready for my 2,700-kilometer cross-country trek to Toronto!

What precipitated this move? Two weeks before I had interviewed for a job with CATIE and had been offered the position. Toronto was a long way from Calgary but I just knew this was an opportunity that I had to grab. I was determined to make my first day of work no matter what obstacles might be thrown up in front of me.

I looked forward to the opportunity that lay ahead. Working for CATIE as the Outreach and Partnership Coordinator in a new city was going to be a welcome change of both geography and focus.

So, with my car fully loaded, I set out on my trek – one that would be fraught with blinding snow, freezing temperatures, endless rural roadside cafes and near misses with the inevitable transport trucks. The ‘highlight’ of the trip was the day outside of Wawa, Ontario when the OPP ordered me off the road and back to the town to wait out the snowstorm. The snow was so deep that even the large trucks were having problems, let alone my U-Haul.

What a dilemma! It was a Sunday morning and I had to start my new job on Monday morning in Toronto! As it turns out, I did show up at CATIE on time. And I worked at a job I loved for three and a half years before moving on to start a consultancy business once again.

Beyond CATIE being there for the information I have needed over the years, it was an instrumental element of my move east and my starting a new life. For that, I will always be thankful. The good work continues and beyond my personal story, I know without a doubt that CATIE continues to change the lives of many people and communities.
Between Glen Brown’s departure as executive director in 1999 and my arrival in 2003, Anne Swarbrick was at the helm of CATIE. I was fortunate to arrive after she had implemented the majority of the Health Canada-mandated ‘corrective actions,’ and relations with our primary funder were on more stable ground. Additionally, Anne had completed the restructuring of CATIE’s board to reflect its national mandate and membership base. The board adopted its regional representation structure that continues to this day to ensure that CATIE is responsive to, and representative of, all regions of Canada.

I continued my predecessor’s task of managing change. It was clear that in the last decade AIDS Service Organizations (ASOs) were having difficulty staying on top of evolving treatment information and increasingly referring their clients directly to CATIE for their treatment questions. Although we willingly respond to PHAs’ treatment questions over the phone and through e-mail, we are also aware that

When CATIE was founded, the needs were very different from today, with few if any effective drugs, limited access to them, and too much unbalanced, ill-informed and biased information circulating in the community. CATIE has adapted well to change and its hallmark over the years has been scientific integrity and balanced information on contentious issues, along with an obvious compassion in providing advice to clients.  

– Dr. John Gill

As someone who successfully completed hepatitis C treatment before CATIE started its work, I know there was little support in those early days. CATIE has since provided knowledge and hope: two very powerful tools.  

– Harlon Davey

1996

Highly Active Antiretroviral Therapy (HAART) becomes standard treatment for HIV infection: beneficial response to treatment realized, with some showing remarkable progress (the so-called Lazarus Effect of people ‘back from the dead’); some doctors erroneously consider HAART a cure for HIV, and advocate a “Hit Hard, Hit Early” approach with the drug

1997

Canadian Treatment Action Council (CTAC) established  

US reports the number of AIDS-related deaths has dropped substantially for the first time  

UNAIDS estimates the number of people living with HIV is 30 million, much more than previously thought; one in 100 people worldwide are infected, with only one in 10 of those knowing they are infected
CATIE sets the national (and increasingly international) standard for comprehensive, credible, up-to-date plain-language treatment education resources for PHAs in electronic and print formats. ViiV Healthcare-Shire Canada remains committed to our long-standing partnership support of CATIE’s mission to help PHAs improve their quality of life through optimal management of their disease.

– Lorne Fox

PHAs prefer to seek their treatment information support locally. With this in mind, we established dedicated regional Educators who spend much of their time in their designated region, training and building capacity in treatment information in ASOs to better serve their clients and their region. Intensifying our relationship with the regions in this way has also led to partnering with the existing HIV regional networks, supporting the development of regional networks in the Atlantic and Western regions, and holding Regional Educational conferences. In this way, we are able to reach significantly more individuals and focus specifically on regional concerns and priorities.

The most significant change in my seven-year-and-counting tenure at CATIE began in October 2007 when CATIE...
As someone who works internationally, I have always been impressed with how well known CATIE is outside Canada. Especially in Francophone Africa, CATIE’s website is a precious resource.

– Dr. Evan Collins

became the National HIV Knowledge Exchange Broker for prevention, care, treatment and support information. We are now responsible for the brokering of HIV prevention information with a significantly wider audience including all frontline agencies working with at-risk populations. Additionally, we were mandated to create a national information Ordering Centre from the Canadian Public Health Association’s HIV clearinghouse service.

Another enhancement to CATIE’s mandate has been the integration of hepatitis C prevention and treatment information, thanks to Ontario’s HCV Secretariat and the Community Acquired Infectious Disease division of the Public Health Agency of Canada. In addition to developing HCV resources and providing HCV training, we’ve established a separate HCV website which includes information from all regions on treatment access and support.

Over its 20 years, CATIE has evolved with the HIV epidemic. The founding Treatment Information Exchange Project

CATIE enhanced its mandate in 2009 to include hepatitis C. A new hep C website was launched and, in 2010, a new CATIE logo (top) reflected the expanded role

In 2007, CATIE became the national HIV knowledge exchange broker for prevention, care, treatment and support information, with a mandate to launch a national Information Ordering Centre.

**1998**
- Canadian Working Group on HIV and Rehabilitation (CWGHR) is formed
- WHO announces that HIV/AIDS is the fourth largest killer worldwide

**1999**
- CATIE renamed the Canadian AIDS Treatment Information Exchange and becomes a partner in the National AIDS Strategy; CATIE structures a national board of directors
- CATIE web site surpasses the one-million-hit threshold and continues to grow
- Discovery that a single dose of nevirapine is effective in reducing mother-to-child transmission during pregnancy

CATIE

Canada’s source for HIV and hepatitis C information
La source canadienne de renseignements sur le VIH et l’hépatite C

www.hepcinfo.ca
1-800-263-1638

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HEPATITIS C

Knowing helps.
committee of AIDS ACTION NOW! developed the Community AIDS Treatment Information Exchange which finally became the Canadian AIDS Treatment Information Exchange. We cherish our history and continue to mourn the loss of our founders and the many individuals who fought for treatment access and organized efforts to establish CATIE and other important HIV organizations.

Unfortunately, there is still much work to do. The continued infection rates among gay men, the fact that young people today are less informed about HIV than they were 15 years ago, and that harm reduction has to be fought for in the face of overwhelming evidence of its efficaciousness, are just a few examples that the HIV sector cannot be complacent, and that as a movement must be sustained and strengthened. CATIE will continue to exercise leadership with our many partners in the years to come.

Bravo CATIE! For 20 years you have been able to not only offer quality services in French, but also successfully establish partnerships with AIDS service organizations in Quebec!

– Laurette Lévy

2000

G8 leaders endorse International Development Targets for HIV/AIDS, Tuberculosis and Malaria, and United Nations creates a Global Fund to fight these viruses

C Health Canada study of HIV treatment emphasizes the importance of working with AIDS Service Organizations (ASOs) and other frontline workers; CATIE begins to develop capacity-building programs for regional organizations

UN General Assembly holds groundbreaking Special Session on HIV/AIDS (UNGASS) during which the Global Strategy Framework on HIV/AIDS is created

The Greater Involvement of People Living with HIV (GIPA) Principle is endorsed by 189 United Nations member countries as part of the Declaration of Commitment on HIV/AIDS
My son Tom has been HIV-positive since birth and for many years went without the need for meds; sadly, his brother who was just one year older, never had that luxury and died at the age of seven. The ‘good’ drugs were not out yet and what little was available for paediatrics was not enough. He had been diagnosed at the age of two with zero T-cells.

When Tom started to take meds – that would have been in 1997 – he was about nine. The ‘wonder meds’ (combination therapy) were out in full force and Tom was one of the first children on them. Compliance was never one of my strong suits and, sadly, I blindly allowed my son to follow suit. By 2004, Tom had done all the meds that were available and built up resistance to the new meds that were coming out. Panicked, we made a last-ditch effort with a drug called Delavirdine; and it almost killed him.

Our HIV doc was unfazed by Tom’s near-death experience and wanted to try that same drug again. I was not having any of that and pulled Tom out of that clinic and called CATIE. I can’t remember whom I spoke to, but in one phone call I found out I could self-refer my son to Sick Kids Hospital in Toronto and also that the Pediatric clinic there was working with children and ‘salvage’ medications. Tom was welcomed into the clinic and put on Fuzeon and within three months, and for the first time in his 15 years of life, he had an undetectable viral load.

Tom remained on Fuzeon for three years and maintained the undetectable viral load until more and easier meds could be introduced. Today, Tom is 21, healthy, undetectable and on his way to Johannesburg South Africa to work at an HIV/AIDS orphanage.
Alan Cornwall was an intelligent, ambitious, hardworking, generous and caring man with a zeal for social justice. Born and raised in Windsor, Ontario, he attended Upper Canada College in Toronto and later received a Bachelor of Arts degree from McGill University in Economics and Labour Relations.

His passion for justice was expressed early on in a rigorous and successful legal career. Completing the joint LL.B./J.D. program at the Universities of Windsor and Detroit where he studied both Canadian and American law, he articled with Borden & Elliot, a large Toronto law firm, where he was later hired in Corporate and Commercial Law when he was called to the Bar in 1988. While working full time, he also passed the prestigious Bar exams of New York State and Massachusetts. Alan was also a member of numerous bar associations, including the Canadian Bar Association and L’Association des Juristes d’Expression Française de L’Ontario.

Alan was far more than an academic. His interests were wide-ranging and they were pursued with equal passion. He was, among other things, an accomplished gymnast and pianist. He also had a love for languages, speaking and writing French, Russian and some German.

It was during the time when he was seconded to be in-house counsel at the Registered Insurance Brokers of Ontario that he got involved in AIDS activism. I met and became friends with Alan at Borden & Elliot when I joined the firm in 1990. It was when we ran into one another at Chuck Grochmal’s memorial at The 519 Community Centre in Toronto that we discovered we had much in common. We were both HIV positive, both involved in the HIV community yet closeted about our serostatus at work. Alan had the added burden of being gay in the relatively homophobic legal profession. He invited me to my first AIDS ACTION NOW! Steering Committee meeting, and we held the first meeting of what was to become the HIV/AIDS Legal Clinic of Ontario (HALCO) in his home which he shared with his partner Paul Meagher.

Alan and I were under a lot of stress working full-time as lawyers during a period of financial instability and layoffs, afraid that we might be fired if the firm found out we were HIV positive and devoting much of our free time to AIDS activism. I remember, for example, working late at night at the firm, together with Bob and Linda Gardner, revising a brief to a provincial standing committee for the next day.

As a member of the Steering Committee of AIDS ACTION NOW!, Alan was a founding member and co-chair of HALCO and CATIE. He was a representative on numerous government and professional advisory bodies on insurance, public health and HIV testing, and before various legislative committees. He was also a member of the Board of Fife House.

Whatever the occasion and whatever the task, Alan had that gift to lighten the mood and make everyone laugh. He always had time for his friends and family. He and Paul hosted friends both at small parties and large, wonderful affairs.

He and I both left the firm in 1993 to go on long-term disability with AIDS. Sadly, his partner Paul died shortly thereafter. Borden & Elliot was extremely supportive of us, and a few members of the firm helped out with CATIE’s Board because of Alan. B&E held a gala fundraiser in our honour in 1995, to which Alan took his new partner, Charles Roy.

Alan continued his work in the HIV community as long as his health permitted, including his position as co-chair of CATIE. He and Charles hosted a last party at their home after Gay Pride Day in 1995 but Alan was so ill that he had to sit up in bed with an oxygen mask on to visit with his friends. He died a month later on July 25, 1995, leaving an important legacy to his friends, family and the AIDS movement in Canada.

– Maggie Atkinson
From The Positive Side Files

ON HIV & WOMEN’S ISSUES

At times when things feel like they’re spiraling out of control, I take myself back to remembering the areas where I am exercising control. So, I make sure that I’m taking my meds, doing my exercise and eating and sleeping in a healthy way.

The other thing I do is push through. A therapist once said to me: ‘Sometimes you have to fake it until you can really feel it.’ And that’s what I do. I remind myself of the things over which I’m still exercising control, and then I fake feeling good. It sounds strange, but I carry on as if I’m feeling fine, and then it actually becomes the reality, and I push through and push forward again. – Louise Binder from “The Divine Secrets of the Sisterhood” by Lark Sands, The Positive Side, Spring, 2003

ON HARM REDUCTION

[Injection drug users] Carla and Wayne, like many others, would both like to see more safe injection sites as well as market control and regulation of the drugs they use. “Crime would decrease,” Wayne says. “Death would decrease. A lot of people would get their humanity back, their self-respect… People wouldn't look down on you and you would have a little bit more self-esteem so you might make that change to go over to the other side of the room, to recovery. – from “Out of Harm’s Way” by Elaine Brière, The Positive Side, Spring/Spring, 2006

ON YOUTH

[Alex McClelland, 28]: “[When I tested positive] all I wanted was someone my age, a peer with the same experiences to share, to help me understand how to live through the trauma of the whole experience,” he says. “Instead, I spent a lot of time feeling uncomfortable and out of place. I had quite a few bad experiences… “All I wanted was support but instead I was thrust into a leadership role,” he says. “I was often asked to take part in workshops and presentations as a speaker. I

“People wouldn't look down on you and you would have a little bit more self-esteem so you might make that change to go over to the other side of the room, to recovery. – from “Out of Harm’s Way” by Elaine Brière, The Positive Side, Spring/Spring, 2006

The Positive Side magazine puts out helpful, practical information for people living with HIV and, equally important, puts a human face on HIV in Canada. – Ronnilyn Pustil

BACK PAGES

The Positive Side magazine puts out helpful, practical information for people living with HIV and, equally important, puts a human face on HIV in Canada. – Ronnilyn Pustil

C 2002

HIV becomes the leading cause of death worldwide in people aged 15-59

CATIE introduces the first edition of The Practical Guide to HAART

The Global Fund to fight HIV/AIDS is created

CATIE-News reports on the possible sexual transmission of hepatitis C virus (HCV) among men who have sex with men (MSM). This controversial and initially discounted mode of transmission is now well-established. In-depth factsheets on HCV co-infection and treatments for HCV are produced
I often think how serendipitous it was to attend the CAHR conference in April 2007. On the last day of the conference, I fortunately came across the body mapping display which the CATIE staff had done in Africa. I initially was attracted by the size of the maps and the very colourful artwork, however as I went around the room and read the stories, I found myself profoundly emotionally affected; tears were running down my face. I was struck by the incredible courage and resilience of those who shared their stories and journeys of living with HIV/AIDS. I immediately thought we need to do body mapping at Vancouver Native Health Society (VNHS) for our people to share their stories. This led to a discussion between us resulting in CATIE funding a Body Mapping Workshop at the VNHS, a highly successful event steered by CATIE’s educator Tricia Smith.

Body Mapping Elder and Facilitator Viola Antoine: Following a Body Mapping Workshop in Toronto in October, 2007, VNHS’s Positive Outlook Program ran one in 2008 with six participants, all of whom found it very helpful in their day-to-day living. I found that they opened up and were ready to share with one another. They all were successful in meeting their goals.

I was fortunate to be asked to return to Toronto and present at the AGM and talk about the success of our body mapping workshop. And I have just finished a six-week women’s group aimed at medication compliance, using the body mapping process as an art medium. I found this to be a highly effective way of engaging and teaching marginalized women.
advantage. He says he is not worried because “if one day I become dependent, I can call Casey House. Services are good in a big city. I have had the same doctors for many years and I can talk with them. I feel secure.” That is unfortunately not the case for all PHAs. … New rural facilities need to be created so that PHAs in rural areas can also have access to living environments where they can receive the kind of care they require. – from “Growing Old Gracefully” by Laurette Lévy, The Positive Side, Summer 2007

ON ABORIGINAL HEALING

In order to get her life back on track, Krista developed ties with a few community agencies in Regina. She found a place to stay and got back in touch with her children. “I prayed to God the Creator to help get me through this. I just kept thinking of my kids. I slowly started doing the work to maintain my recovery.” And she succeeded – her children came home in 2008 and 2009. “I reached out for help. The more I tried to move forward, the more help I received. … [Through an All Nations Hope AIDS Network retreat] Krista was put in contact with another Aboriginal PHA. “He really soothed me inside. It diminished the shame, the pain. I wasn’t alone. He lit a fire inside me and I felt that I needed to find a space within the circle. I started to stand up for myself and say, ‘This is me. This is my story’.” – from “Path to Healing: Full Circle on the Prairies” by Kim McKay-McNabb, The Positive Side, Winter, 2010

ON TRANS ISSUES

For many reasons, a substantial number of trans women turn to sex work. For some, it’s a way to make money to live or to put toward surgery. For others, it’s a way of getting off the street at night. Still others choose sex work because they find it empowering. “It’s incredibly powerful when you’ve been called a freak your whole life to then find yourself being desired,” explains Rebecca Hammond, a researcher currently working on TransPULSE, a large community-based project examining the challenges trans people face in accessing health and social services. – from “Trans Canada” by Nora Underwood, The Positive Side, Spring, 2008

ON GAY MEN’S SEXUAL HEALTH

If being HIV positive raises a million questions, being poz and sexually active raises a million more…. Does having an undetectable viral load mean you’re no longer infectious? How do sexually transmitted infections affect people with HIV?

How do you initiate sex if you think your prospective partner may be poz-phobic? HIV-positive gay men may find these questions especially pressing. Gay culture can put a lot of value (and pressure) on having sex. How can a poz gay man feel healthy and horny when sex seems so fraught with potential landmines? First, you can begin by acknowledging that just as your life didn’t end when you were diagnosed with HIV, your sex life doesn’t have to end either. Sexual health is an important part of your overall health; it means taking care of yourself as well as your partner’s well-being — physical, mental and emotional — while still getting hot and heavy. – from “Sex and The Poz Gay Man” by Derek Thaczuk. The Positive Side, Spring/Summer, 2010

From its beginnings as a local treatment information organization to its current national mandate, CATIE is well known as a reliable source of information on all aspects of HIV and more, and an excellent collaborator in English and French across Canada.

– Ken Monteith

2003

InSite, North America’s first supervised injection site, opens for drug users in Vancouver’s Downtown Eastside

2004

UNAIDS launches the Global Coalition on Women and AIDS to raise the visibility of the impact of HIV/AIDS on women and girls worldwide

2005

Health Canada approves a rapid HIV antibody test for sale to health professionals in Canada, enabling point-of-care testing that can provide accurate test results in two minutes

CATIE launches the first phase of its Capacity Building Project, designed to help ASOs integrate HIV treatment information into their client services

The 150th issue of CATIE’s TreatmentUpdate is published.
I was diagnosed with HIV in 1987. I was 23 and things were different then. I won’t go into details but you can imagine what it was like to be told that you no longer had a future. I spent the next 19 years coping, not coping, living, loving, losing and always learning.

Up until 2006, I didn’t even know what an ASO was (AIDS Service Organization). I was doing fine on my own. But things changed for me in 2006, again, and I needed support and I needed knowledge.

I have always been fascinated in bridging the gap between science and the humanities. I also think that as a patient, the best tools that I have to manage my chronic illness are a healthy state of mind and knowledge about my virus and about treatment. That’s what CATIE does so well as an organization — to help empower people living with HIV to manage their health and, in general, to foster a spirit of cooperation amongst the various organizations that serve PHAs and the various communities that have been effected by it.

From the time when I was on treatment for hepatitis C, feeling quite overwhelmed in the middle of AIDS 2006 in Toronto, CATIE has remained a catalyst for me. I have been a volunteer, served on its Board of Directors and been contracted on a project. For me, CATIE is about working with dedicated, smart and kind people. It’s about forging friendships, about learning and sharing information.

And above all, being involved with CATIE has been about tapping into my sense of purpose.

I’m at the point in my life where I am moving forward in new and exciting directions and I will be less involved in the HIV community and more just living my life as a person with dreams and desires.

I have no doubt that CATIE will be there with me every step of the way of this new path. Whether it’s looking for information or spending time with the friends I made there.

My journey is, well, who would expect it to be anything but unusual? Yet somehow it has never felt insurmountable and having an organization like CATIE around for 20 years has certainly made the steps along the path enlightening and enriching.
Results from a pilot study of DNCB in HIV infection

1993

DNCB is a chemical used to develop color film. It has also been used in air conditioning and refrigeration equipment. A small amount of 10% DNCB solution was put on a 25-millimetre patch of skin “usually on the forearm.” Over the next three days swelling and redness at this site should have occurred. If this did not happen subjects “repeated this dose at weekly intervals until sensitization [redness, swelling, itching] occurred.”

QHS-Chinese herb for PCP?

1995

When questioned at the conference about long-term results from her original group of 13 patients, Ms Paul said that four subjects no longer use the herb. One subject developed dementia and is dying; another developed the life-threatening brain infection ‘crypto’ (Cryptococcal meningitis); a third developed severe rectal warts, seizures and Kaposi’s sarcoma. She has not been able to locate the fourth subject. One of her subjects took 20 times the normal dose and developed nerve damage.

A cocktail of 5 anti-HIV drugs

1996

Researchers used six subjects who had become infected within the past six months. Subjects received standard doses of AZT, ddC, ddI and interferon-alpha with or without 3TC. In some subjects, the use of combination anti-HIV therapy caused a dramatic decrease in the amount of HIV detected in their blood.

Indinavir and 2 nukes — the big study

1997

Doctors recruited over 1,000 PHAs for this study to compare the effects of triple therapy -- indinavir with AZT (or d4T) and 3TC -- against double therapy with a combination of two nukes -- AZT (or d4T) and 3TC. PHAs receiving triple therapy had their risk of developing AIDS or dying fall by 50% compared to PHAs receiving double therapy. This study confirms the benefit doctors have seen in some of their patients who use protease inhibitors.

HIV still in the picture, but treatments could last for years

1997

Although these findings tend to disprove hopeful theories of HIV eradication put forth last year at the Vancouver international AIDS conference, they arrive in the company of encouraging news as well. The researchers have found that by driving HIV levels down as low as possible and virtually arresting viral replication, the threat of drug resistance is greatly minimized. In fact, each of these studies reports that the trace virus found in resting CD4+ cells had not developed resistance to the therapy in use. This implies that many patients may continue to live healthily for years, provided they comply faithfully with their treatment regimen.
When I started working at CATIE in 1993, there were no effective treatments and people living with HIV and AIDS were trying everything to stay alive—complementary therapies, radical diets, experimental drug trials, you name it. CATIE, a tiny NGO at the time, was trying to provide clear information about all of these approaches and others, and to support people living with HIV to make informed decisions about their health care.

I was proud to be involved in CATIE’s early peer education activities, its signature publication Managing Your Health - A Guide for People Living with HIV/AIDS, its phone and later web-based information services, and its advocacy work with communities, governments and industry to intensify research and accelerate drug access.

CATIE was one of a very small number of pioneers around the world developing these services. When Highly Active Antiretroviral Therapy (HAART) was shown in 1996 to be effective at reducing viral load and limiting disease progression, HIV was transformed from a death sentence to a chronic and (relatively) manageable infection—in the rich world. But while we justifiably celebrated in Canada and other rich countries after a decade of massive loss, millions of people in poor countries continued to get sick and die, in ever-increasing numbers, simply because they had no access to the life-saving medicines available to us.

While there continued (and continues) to be challenges to face in Canada, I wanted to take what I had learned here and try to adapt it to work at the global level to reduce the disparity in access between rich and poor countries. In the past decade, the same tools of information exchange and focused advocacy that were pioneered by CATIE have been used throughout the world with powerful results. Over five million people in poor countries now have access to HAART. Communities are more informed and engaged in the response to HIV than ever before. While so much still needs to be done, much has been achieved.
ing HAART. Other interventions such as eating fish that is rich in omega-3 fatty acids — cod, haddock, herring, tuna, salmon and sardines — as well as the use of supplements such as L-carnitine and antioxidants need to be tested in HAART-users with high lipid levels in their blood.

Is hepatitis C virus going to become a major STD?

2002 Rates of unsafe sex and, not surprisingly, sexually transmitted diseases (STDs) are increasing in Western Europe and North America. British researchers have done a preliminary study that suggests hepatitis C virus (HCV) infection may be increasingly transmitted sexually in HIV-positive people.

Delaying therapy - the pendulum swings back

2002 Once the benefit of HAART became apparent, doctors were initially aggressive in prescribing it, even for their patients who had relatively high CD4+ T-cell counts. With the passage of time, however, it has become clear that HAART has limitations. As a result, doctors and their patients are increasingly delaying therapy and treatment guidelines have been revised. Yet the important question “When is the best time to start therapy?” has not been answered and is something with which doctors and people with HIV/AIDS (PHAs) struggle.

Clinical trial generates tantalizing hope for a future HIV vaccine, but much research lies ahead

2009 The study team was troubled by the finding that 25% of participants used a large number of therapies—between 21 and 39 different drugs. Depending on the PHA, between eight and 19 of these were prescribed medications, yet physicians were apparently aware of only some of the drugs used by their patients.

The HAART era: AIDS deaths fall but new complications emerge

2006 Given the changes in the causes of death since HAART, more research is needed on helping PHAs survive the many complications that are increasingly a threat to their health.

New evidence changes guidelines about when to start treatment

2009 In the past year, HIV treatment guidelines from high-income countries and regions such as the United States, United Kingdom and Western Europe have changed. Generally, these guidelines now recommend that HIV positive people begin HAART when their CD4+ count has fallen below 350. This is a major shift from the beginning of this century, when treatment was usually delayed until CD4+ counts fell below the 200-cell mark.

Ontario study finds key information may be missing from PHA medical charts

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Pre-exposure prophylaxis (PrEP) is a term given to any therapy that can be taken prior to exposure to HIV in the hope that it will protect the user from HIV infection. …In the CAPRISA Trial 004, researchers tested a vaginal gel containing 1% tenofovir vs. another gel containing placebo. Over two and a half years the tenofovir-containing gel reduced the risk of infection by 39%. This is a major advance in the field of HIV prevention, given the dismal track record of microbicide testing. Readers should note that these findings do not mean that a tenofovir-containing microbicide is ready for sale or distribution. There are issues related to Trial 004 that need to be resolved. The trial results should be viewed as a good first step.
The weight of our loss is great. We remember the very dark times and the many who did not survive them. Yet even then, the faint promise of a better day pulled us along. However uncertainly. And so it does today.

The great news, of course, is that times have changed. Since CATIE’s beginnings, treatment advances have transformed people’s prospects. We do not live in the same world of 20 years ago and we are emboldened by that. And we will continue, with our many community partners, to digest and share the information that will enable this country’s people living with HIV and hepatitis C to face – and surmount – the new challenges.
CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

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Eric D'oyon
Emile Duguay
Nancy Duncan
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2003 – present / Directrice générale,
2003 – aujourd'hui)
Melissa Egan
Bill Ekins
Brian Finch
Ron Foley
Greg Garrison
Elizabeth Graber
Natasha Glicken
John Guenther
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Brian Huskins
Dana Inkster
Ed Jackson
Christine Johnston
Heather Ann Kaldewey
John Kennedy
Paul Kenney (Director, Operations,
1995 – 1998 / Directeur, Opérations,
Zak Knowles
Debbie Koenig
CATIE Staff Members through the Years / Personnel de CATIE au fil des années

<table>
<thead>
<tr>
<th>Year</th>
<th>Names</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997 - 1998</td>
<td>Paul Brophy, Alex Campbell, Bob Gardner (Chair / Co-président), Charles Gillis, P. Ham, Pieter Huisman, Mina Mohamed, William Naumovich (Chair / Co-président), Gerry Oxford, Brian Robinson, Greg Robinson</td>
</tr>
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Records were gleaned as carefully as possible and CATIE regrets any errors or omissions that may have been made.

Nous avons effectué une recherche approfondie de nos dossier et regrettons toute erreur ou omission éventuelle.