

THE

POSITIVE SIDE

WINTER 2016 VOLUME 18 ISSUE 1
HEALTH INFORMATION & VIEWS



Happy Birthday
ART!

Looking for HIV services near you?

Healthcare, counselling and support are closer than you think.



Find HIV and hepatitis C services near you.

EDITOR'S LETTER

Happy birthday, ART! The year 2016 marks two decades since effective HIV meds first came on the scene. After a mystery virus mercilessly killed people by the thousands, new medication combos that could suppress the virus allowed people to literally rise from their deathbeds. Cured of previously incurable AIDS-related illnesses, people living with HIV could suddenly resume their lives. Today those potent pills are more potent, simpler to take and the side effects are a whole lot easier to swallow.

And the major turning points in the treatment story keep coming. We've now learned about the power of treatment *as prevention* (maintaining an undetectable viral load can dramatically lower the risk of transmitting HIV) and of the huge health benefits of starting treatment ASAP.

To mark this milestone, we devote much of this issue to exploring the lifesaving impacts of antiretroviral therapy (ART). How has ART changed what it means to be HIV positive? Treatment activist Darien Taylor kicks things off with a historical and personal perspective in "Treatment Turns 20." Dr. Philip Berger offers a gripping account of how dramatically care has changed during his 35 years working the front lines. Counsellor John Larsson tells us that HIV is about so much more than just a virus. Four HIV-positive people recount their relationships with their meds. CATIE's Sean Hosein looks at the past, present and future of how we approach treatment. And Dr. Lisa Barrett reports on the myriad views of what it means to be poz.

HIV treatment is a medical success story. But, as veteran activist Tim McCaskell attests to in "The Push for Access," progress has been hard fought and too many people around the world still lack basic access. So the struggle continues.

The lack of HIV care pushes many to leave their home countries to secure treatment and build a better future. In "Border Crossings," Esther and Marvelous describe their journeys from Zimbabwe to Canada to do just that.

We hope you enjoy this special edition. Send your feedback and wishes to me at dkoenig@catie.ca

—Debbie Koenig

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From the Front Lines
Programs for PHAs coming of age

4

Profile
Esther and Marvelous's stories
of surviving and thriving

6



TREATMENT TURNS 20

9

Treatment milestones

11

A doctor's perspective

12

Access for all

15

A counsellor's perspective

16

PHA perspectives

18

Poz identities

20

Evolving approaches to treatment

21

Anti-Inflammatory Diet

Easy ideas and recipes for quelling
chronic inflammation

23

Ask the Experts

Menopause and HIV

26

Art Posi+ive

Dancer and choreographer Benoît Lachambre

28

Visual AIDS

Reflections

30

Living Long with HIV

4 specialized services for older people living with HIV.

Thanks to effective treatment, far more people with HIV are living into their 60s, 70s and beyond. So all that talk you hear of an “aging population” also applies to HIV. In fact, UNAIDS estimates that roughly one-third of HIV-positive adults in high-income countries are 50 years and older. A growing number of agencies across the country are stepping up to offer services that meet the needs of people who are aging with HIV. Here are just a few:

Workshop Series: Planning for the Long Term

AIDS Committee of Toronto (ACT)



Since 2011 ACT has been hosting this supportive and educational workshop series for people growing older with HIV. It gives participants an opportunity to learn about HIV and aging and to connect with others in a safe environment. The series of 10 weekly sessions is offered every spring and fall. Each week, guest speakers provide information on a range of topics related to physical health, emotional wellness, HIV and aging. Afterwards, a group discussion, facilitated by two trained volunteers, allows participants to address their feelings and experiences, support one another and share information and referrals.

Some of the topics the group has discussed include healthy eating; new developments in HIV treatment; managing conditions related to HIV and aging; building healthy relationships; sexual health; ways to reduce stress, anxiety and depression; enhancing memory; and improving self-esteem. The response has been overwhelmingly positive. Post-workshop, many people develop plans to enhance the quality of their lives based on what they learned, while others simply state that participating kept them from feeling isolated.

To find out more or to register, call 416.340.8484, ext. 283.

Supportive Housing

AIDS Committee of Newfoundland and Labrador (ACNL), St. John's



Established in 2006, ACNL's Supportive Housing is open to people with HIV and/or hepatitis C who need help securing affordable housing on a long-term basis. All six self-contained, wheelchair-accessible apartments are connected to the Tommy Sexton Centre, the community hub where ACNL delivers its programs. Although anyone living with HIV and/or hep C who is over 16 can apply, all of the residents who currently call these cozy apartments home are over the age of 50. In addition to affordable housing, residents are offered a host of support services—counseling, peer support, life-skills programs, advocacy, medical referrals and home care.

ACNL executive director Gerard Yetman notes that the demand for supportive housing has declined in recent years, due mainly to the number of people whose health has improved thanks to effective HIV treatment, to the point that they can resume their work lives. However, Yetman anticipates that demand will grow again in the near future as the number of older people living with HIV in Newfoundland increases.

To learn more, call ACNL's housing coordinator at 709.579.8656 or visit acnl.net/supportive-housing.

Peer Support Group

MIELS-Québec, Quebec City

Among its many support groups, the community HIV organization MIELS-Québec offers one for long-term survivors. This group for men diagnosed prior to the advent of antiretroviral therapy in 1996 meets once a month to share a meal, visit local attractions and do activities together.

They call themselves *Les aventuriers*—the adventurers. In the summer months, the group has gone hiking, kayaking and picnicking; in the winter, bowling, to the movies or a museum. Among the more popular outings was a river cruise on the St. Lawrence.

By participating in organized events, the men build friendships in a setting where they don't need to worry about being judged and where they can connect about something other than their diagnosis. Participants have commented that they "had a blast being an adventurer and meeting others" and that the group helped break years of isolation.

With more than 20 members and an average of eight to 10 people on each excursion, the group has become a vibrant crew that spends much of its time together laughing.

If this sounds like it might be for you, call 418.649.1720 or visit www.miels.org.



Positive Seniors University

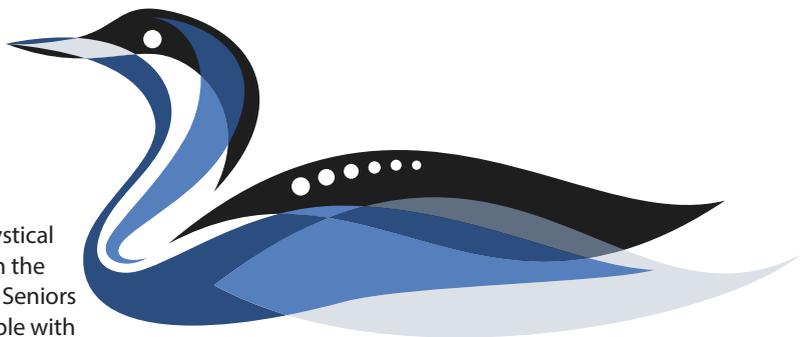
Maple Ridge, British Columbia

Located just outside Vancouver, Loon Lake Camp is a mystical place nestled among the trees, where the air is filled with the sounds of lapping water. In this tranquil setting, Positive Seniors University presents a four-day workshop geared for people with HIV from across BC who are 55 and older. By fostering connections and a sense of empowerment, this program offers a distinctive model of community development.

Each participant is invited to take part in the day-to-day facilitation by presenting a workshop to the rest of the group. (A train-the-trainer session beforehand helps participants develop their facilitation skills and overcome nervousness.) This puts HIV-positive seniors at the heart of the program—building self-esteem and leadership skills while mentoring and learning from each other. The themes of the workshops are as varied as the interests and skills of the facilitators—from healthy sexuality to critical thinking to using creative arts to reframe aging.

The retreat provides a space where people can talk about their health challenges, share their cultural heritage and recognize their strengths and resiliency. Participant feedback suggests that the university has succeeded in achieving its goals.

To learn more call, Positive Living BC at 604.893.2258 or email support@positivelivingbc.org.



RESOURCES

Survey of programs and services – *Directory of Promising Programs and Services for Older People Living with HIV in Canada*, published by the Canadian Working Group on HIV and Rehabilitation, is available at www.catie.ca.

Compassionate Care in a Changing Landscape – This video series is used to educate staff at long-term care facilities about the care needs of people with HIV. Watch the videos at www.hivlongtermcare.com.

The Impact of Polypharmacy on Older Adults Living with HIV – This report from CTAC outlines the risks of taking five or more medications and ways to reduce those risks. Check it out at www.ctac.ca.

Border Crossings

The stories of 2 Zimbabwean women who did what it took to survive.

BY SANÉ DUBE

PHOTOGRAPHS BY MICHELLE GIBSON





Esther

Esther and Marvelous are both animated storytellers. It's hard to be anything but mesmerized in their presence. I spent an afternoon with each of them in conversations peppered with boisterous laughter. In the quiet moments they wove words together, effortlessly bringing their memories to life. They talked about their lives as HIV-positive African immigrant women living in Canada and the sometimes difficult paths they've walked to get to where they are today. To understand how far they've come, we have to look back.

This chapter of their stories begins in 2006, when Toronto hosted the International AIDS Conference, the largest gathering of its kind in the world. More than 20,000 people gathered to share the latest on HIV. Effective antiretroviral therapy (ART) had already been on the scene for 10 years, but for millions living with HIV in the Global South it was out of reach. While HIV had become

a treatable condition in high-income countries like Canada, in many parts of the world where HIV hit the hardest, thousands were still dying because they couldn't access treatment. When the conference ended, 151 delegates—many of them women, from Uganda, South Africa, Zimbabwe, Rwanda, Eritrea and El Salvador—remained in Toronto, applying for asylum in Canada.

Esther and Marvelous were two of those women. For many in the group, the decision to stay was driven by lack of medical treatment in their home countries and the severe discrimination they faced as people living with HIV. The situation divided the public, as issues relating to immigrants and refugees often do. However, one thing was certain: Geographic location mattered when it came to HIV care. It still does. I caught up with Esther and Marvelous to hear their stories and find out how their lives have changed since moving to Canada.

Esther

Nine years after being granted asylum in Canada, Esther has settled, flourished and lived to experience things she once thought were out of her reach. The decision to stay in Canada and start treatment was life changing. "I turned 50 this year," she says. "I didn't think I would make it this far!"

Before coming to Canada for the 2006 conference, Esther worked at The Centre, a community organization founded by and for people living with HIV in her home country of Zimbabwe. There, she was a counsellor and educated service providers. By the time she came to Toronto as a member of the Zimbabwean conference delegation, she had already been living with HIV for nearly two decades.

At the peak of Zimbabwe's HIV epidemic, one in four Zimbabweans was living with HIV, a daunting figure for a resource-poor country where

health funding was not a high priority. Although the first case of HIV in Zimbabwe was reported in 1985, the illness was barely talked about when Esther was diagnosed in 1988, shortly after losing her six-month-old child. Her doctor told her unceremoniously, “Your baby died of AIDS and you have it, too.”

“There was so much silence around HIV in the ‘80s,” she says. “The doctors didn’t have a lot of information about HIV for me, much less on treatment. I was diagnosed and sent home. I didn’t expect to live as long as I have.” Intense stigma left Esther feeling hopeless and alone. That began to change in 1993 when she started connecting with others living with HIV. Meeting people who were beating the odds and excelling despite a diagnosis that, at the time was viewed as a death sentence, gave Esther the strength to slowly start rebuilding her life.

A decade after her diagnosis, treatment became available in Zimbabwe but people had to pay out of pocket for it and most Zimbabweans couldn’t afford to. “If you had money, you could afford to pay or go to South Africa where medication was easier to find,” Esther says. “The rest of us relied on medications donated from the West. Some were expired, some were leftovers—whatever they were, we’d take them and use them.”

Esther took what treatment she could until 2006, when she was granted asylum in Canada. The decision to stay in Canada and, as a result, access stable care has changed her life. Today Esther works part-time at the Hassle Free Clinic in Toronto where she supports women with HIV. Esther is also a student—she is working on a degree in sociology and French. “When I tell people that I’m in university, they can’t believe that I went back to school after 30 years. I’ve almost completed my degree and I’m really proud of myself.”

Marvelous

Marvelous and Esther have walked similar paths. Marvelous also remembers using donated medications in Zimbabwe. It was 1995 and she too had a

six-month-old baby who had just died. “I was numb when I was diagnosed. I couldn’t feel anything, I had just lost a baby and I completely shut down when I found out I was HIV positive.”

A crucial turning point came in 1998 when her doctor recommended that Marvelous attend a support group at The Centre, the same organization Esther worked for. Marvelous joined the group and met other women who eventually became a second family for her. “We didn’t have access to treatment, except for the donated medications that were coming from outside the country. The only thing we had was each other and taking care of our bodies the best way we could.”

When Zimbabwe’s economy crashed in the early 2000s, leading to widespread and severe poverty, food shortages and the collapse of the country’s healthcare system, the situation for Zimbabweans with HIV became dire. Program funding dropped dramatically and by 2004, only 5 percent of HIV-positive Zimbabweans had care. HIV-related deaths toppled the country’s average life expectancy to 43 years.

By this time Marvelous was working as a deputy director at The Centre. “I was working in the sector, but it was still difficult for me to access treatment. I finally joined the DART clinical trial to get medication.” [DART was a large clinical trial designed to investigate whether HIV treatment without routine lab tests would work.] The trial, and with it her guaranteed access to medication, ended shortly before she came to Canada in 2006.

Looking back on their first few months in Toronto, both Esther and Marvelous use the word *lucky*. In Canada, people who claim asylum are held in temporary shelters while a decision is made on their case. Esther and Marvelous lived in a shelter for two months, but they were able to access lawyers, healthcare providers and support organizations. Both were granted leave to stay in Canada while their claims were processed, and once they were approved, both women settled in Toronto.

Today Marvelous coordinates skill development and health promotion

programs for women of colour at Women’s Health in Women’s Hands, a community health centre in downtown Toronto. One of the walls in her office is covered by a captivating piece of art—a body map she created in 2007. Body mapping is a form of art therapy in which people with HIV are encouraged to explore their journey with HIV and the effect it’s had on them. At the centre of the piece is a life-size body outline and surrounding it are illustrations and words to mark important events in the artist’s life. Marvelous’ map tells her story in pictures, from diagnosis in 1995 to immigration to Canada in 2006. She still advocates for accessible treatment, drawing on her own experience to educate others. She’s currently the North American co-chair of the International Community of Women Living with HIV, a role she says keeps her connected to the global movement to increase access to treatment for women living with HIV. “I’m open about my status and my story. Sometimes that makes people uncomfortable, but it’s not going to shut me up!”

Today, 15 million people living with HIV worldwide are on treatment, a number that’s growing daily as access expands. In countries like Zimbabwe, many people can now access ART through government-funded health programs and non-governmental organizations, but the most vulnerable still aren’t accessing care. Many of them are in resource-poor, low- and middle-income countries where there is less funding for HIV treatment. For many, treatment costs are prohibitive.

The conference delegates who felt compelled to remain in Canada after the conference in 2006 remind us that for people living with HIV, where you live still matters. In 2016 the world celebrates 20 years of ART, a milestone that will certainly ring hollow for those in regions and countries where treatment is still out of reach. +

Sane Dube is a senior editor at CATIE.

TREATMENT TURNS 20

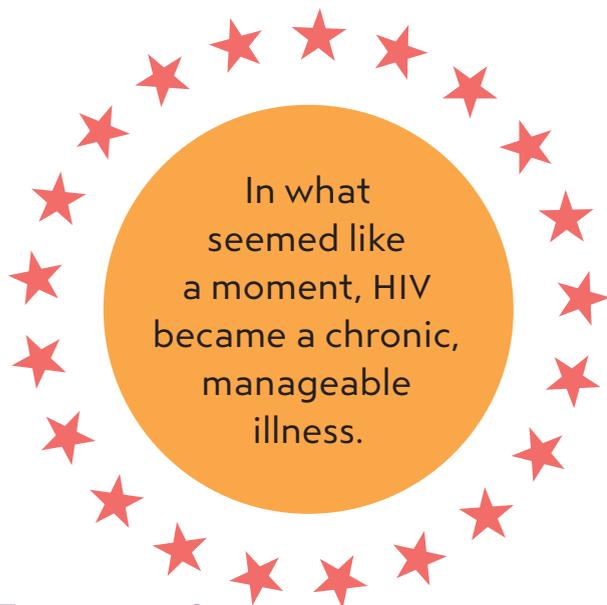
The transformative impact of antiretroviral therapy—on the epidemic, HIV care and what it means to live with the virus.

BY DARIEN TAYLOR

Twenty years ago the lives of people with HIV suddenly changed. Since the early 1980s, we had been living in the shadow of death, watching as friends, lovers and entire communities got sick and died. Our doctors tried to treat the opportunistic infections that occurred as our immune systems weakened; we marched in the streets to demand political action, more funding and better treatment; AIDS service organizations sprang up to offer support; and hospices and care teams were assembled for the dying. But there was little we could do to stop the progression of this terrible disease we knew so little about.

By 1996 more than 4.6 million people worldwide had died from AIDS, more than 10,000 of them in Canada. And some 35,000 cases of HIV had been reported to the Public Health Agency of Canada.

Then, in what seemed like a moment, HIV became a chronic, manageable illness that—given access to good care and treatment—people could live with for many years.



THE END OF AIDS?

It took place before our eyes like theatre. In July 1996, at the XVI International AIDS Conference in Vancouver, one researcher after another spoke of a new concept: highly active antiretroviral therapy, or HAART—a combination of three or more drugs that targeted HIV at different stages of replication, to halt the virus in its tracks. Treatment activists like myself who took pride in knowing all about the development of new drugs were caught off-guard, unprepared, as the game-changing importance of the new combination therapies dawned on us, while we craned our necks to watch the presentation screens in the conference auditoriums. These combinations—or “cocktails,” as they were called—coupled with the new technology of viral load testing, were enabling people with HIV to achieve an undetectable viral load, meaning that the level of HIV in their bodies was so minimal that it could not be detected with the available technologies.

I remember meeting a colleague at the airport after the close of that whirlwind conference and giddily telling her that we were witnessing “the end of AIDS.”

HIT EARLY, HIT HARD!

“Hit early, hit hard!” became the battle cry in the fight against AIDS. Jubilant researchers boldly predicted that the remarkable ability of HAART to slow down the replication of HIV might result in a cure. All HIV in the body might be killed over time by these new combinations—the “eradication theory.” (Unfortunately, they were wrong.)

That same momentous year, a clinical trial established that AZT-based therapy delivered during pregnancy and

labour and later to the newborn could reduce mother-to-child transmission by two-thirds. Subsequently, the use of combination therapy in pregnancy further lowered this risk. Combined with the routine offer of HIV testing to pregnant women, most jurisdictions in Canada now see very few infants born with HIV.

SOBER SECOND THOUGHTS

But these life-saving treatments came with some considerable challenges. In our rush to embrace these miraculous drugs, we tended to at first ignore their side effects, the complex dosing schedules and food restrictions, the handfuls of pills—sometimes in the neighbourhood of 30, spaced out over the course of every day...and night. Without strict adherence, drug resistance could occur, limiting one’s treatment options for the future.

Then people with HIV began to notice strange patterns of fat redistribution on their bodies: hard fat accumulating on their belly (“crix belly”) or between their shoulders (“buffalo hump”) and loss of fat on their face and limbs. These profound side effects—a syndrome that would become known as lipodystrophy—further “marked” people with HIV.

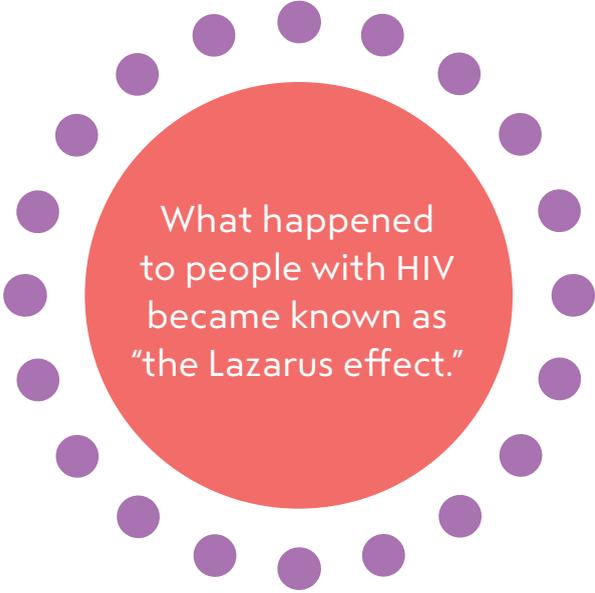
In the initial euphoria of combination therapy, many people with relatively high CD4 counts, myself included, started taking these drugs. When my CD4s were above 500 I began taking a combination that included the protease inhibitor ritonavir (Norvir). I tolerated the diarrhea but as the fat on my upper arms began to disappear, I decided to go off therapy, preferring to wait until my immune system showed signs of weakening. Moving away from the mantra of “hit hard, hit early,” the consensus on when to begin therapy became more conservative, recommending that people start therapy when their CD4s were around 300, unless their viral load was exceptionally high or they developed opportunistic infections.

What happened to people with HIV became known as “the Lazarus effect.” Like the biblical character Lazarus, who was miraculously raised from the dead, people living with HIV were essentially being raised from their deathbeds by these new therapies. Many of us experienced “survivor’s guilt,” the philosophical puzzle of “why me?” after having seen so many die only to find that we had been spared and granted a new lease on life.

There were economic and social repercussions, too. Many of us had been forced to give up our plans for the future, education and careers, had lost loved ones by the dozens and had ourselves been sick for years. It took real courage to re-engage with the world at large again, to go back to work and to risk falling in love again. For me, as someone who had been lucky enough to stay employed throughout these years of uncertainty, my big commitment was a mortgage on a small house in Toronto’s rather down-at-the-heels Parkdale area. I hoped to be around to pay it off—and in three years I will have.

In the meantime, researchers were working to develop new drugs with fewer side effects. Successive generations of combinations slowly became easier to take.

With clinical trials such as the SMART trial, which started in 2001, the HIV community began to realize that there was going to be no reprieve from strict adherence to the medication regimens. No structured treatment interruptions, no “drug holidays,” only relentless day-in, day-out adherence. And so it remains to this day.



What happened to people with HIV became known as “the Lazarus effect.”

THE MEANING OF “UNDETECTABLE”

In 2008, a group of physicians in Switzerland released the controversial Swiss Statement. It held that HIV-positive people posed “no risk” to their sex partners if they had an undetectable viral load for at least six months, were on ART and had no sexually transmitted infections. Though the Swiss Statement had many detractors who questioned the scientific evidence informing it as well as its application to the sex lives of gay men, it heralded the current period of treatment (now commonly called ART) when research has confirmed that ART can indeed greatly reduce the chance of transmitting HIV when one’s viral load is suppressed. In addition to huge health benefits for HIV-positive individuals, we learned that HIV treatment could also be used to prevent HIV.

These findings have led to the development of pre-exposure prophylaxis (PrEP), perhaps the most promising HIV prevention strategy since the condom. With PrEP, taking the antiretroviral drug Truvada daily enables people who are HIV negative to have safer sex with partners who are HIV positive. In HIV-negative people who take it, Truvada acts to prevent HIV from gaining entry to their immune

system. Though guidelines for the use of Truvada for PrEP continue to stress the importance of using condoms, some HIV-negative men and women experience difficulties in using condoms consistently, and Truvada provides them with additional protection.

THE PENDULUM SWINGS...AGAIN

As antiretroviral drugs have become easier to take with the advent of one-pill-once-a-day regimens with few side effects (such as Atripla in 2006) and we have gained a better understanding of the effects of chronic inflammation on the body caused by the ongoing presence of HIV, we began to re-examine the question of when to start treatment. Recently, results from the START trial showed the significant health benefits of beginning soon after diagnosis, even if your CD4 count is still high, signaling the revision of treatment guidelines.

THE NEXT 10 YEARS

Unfortunately, ART does not cure HIV. Nor does it eliminate much of the immune dysfunction and inflammation that over time can lead to heart and bone disease, neuro-cognitive problems and other health concerns. The search for answers to these problems will likely lead researchers beyond the realm of ART.

Challenges still remain in identifying people who are HIV positive, ensuring that they stay in care, receive treatment and are able to maintain an undetectable viral load. Though our conference rallying cries may insist that no one be left behind when it comes to treatment access, the fact is that throughout Canada many individuals and communities are left behind when it comes to HIV testing and accessing good treatment—Aboriginal people, refugees, people with mental health issues, people who use drugs, people in small towns and rural areas who must travel great distances for care. Equitable access is an important—and surely an achievable—hurdle to overcome in the next 10 years. *

Darien Taylor is CATIE’s former Director of Program Delivery. She cofounded Voices of Positive Women and is a recipient of the Queen Elizabeth II Diamond Jubilee Medal. Darien has been living with HIV for over 20 years.



TREATMENT MILESTONES

1981

► The first reports of what will become known as AIDS among gay men and people who use injection drugs.



A Doctor's Perspective: Care Then & Now

BY DR. PHILIP BERGER

In the late '70s and early '80s, a group of about a dozen downtown Toronto doctors had in their medical practices large numbers of gay men and some injection drug users. Similar situations existed in Montreal, where the Clinique médicale l'Actuel became a focal point for HIV care, and in Vancouver, where the BC Centre for Excellence in HIV/AIDS was established in 1992. These doctors had patients who experienced a fair number of sexually transmitted infections. They also had patients who presented with weird infections similar to infectious mononucleosis (mono). They came to our offices with fever, rash, sore throat, swollen glands and minor laboratory abnormalities.

These peculiar infections resolved, and the doctors just attributed these temporary illnesses to another infection picked up in the bathhouses or through needle sharing on the streets. No one put these individual cases together and wondered whether some common condition could explain their individual patients' illnesses. Yet an epidemic—the AIDS epidemic—was exploding before our very eyes.

Toward the end of 1980 and early 1981 we began to hear rumours of a strange disease that was affecting gay

men. These rumours came mostly from patients who were visiting friends and partners in the United States. We heard of a life-threatening pneumonia and a new skin cancer called Kaposi's sarcoma, which were hitting gay men in large urban centres—particularly New York, San Francisco and Miami.

On June 5, 1981, the U.S. Centers for Disease Control (CDC) in Atlanta, Georgia, published the first report of five gay men who had been struck with *Pneumocystis pneumonia* (PCP). This was the first official medical publication describing a new disease that eventually became known as AIDS. I can't boast to normally read CDC reports; however, my partner in medical practice at the time, Dr. Michael Rachlis, subscribed to them. So, fortuitously, I was able to read the first report describing PCP soon after it was published.

Those first few years of the early '80s were very scary. It quickly became apparent, in particular to primary care physicians and general practitioners, that there were no experts in the field of HIV and AIDS. There were no consultants or specialists who had any more experience than we did and there was little or no medical literature on the

1984

► French scientists, led by Françoise Barré-Sinoussi, identify the virus responsible for causing AIDS: HIV.

1987

► The U.S. Food and Drug Administration (FDA) approves the first antiretroviral drug, AZT.

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

subject. As an example of how little information was available, doctors actually used to clip articles from various medical journals and keep them in files—an unimaginable task today when tens of thousands of articles are published annually on HIV.

The identity of the virus responsible for causing AIDS was not conclusively determined until the spring of 1984, and the first HIV antibody test did not become available until 1985. So for the first four and a half years after AIDS was described in the CDC reports, we doctors had to rely entirely on our clinical assessment to deduce if someone might be infected with this strange virus that caused AIDS. Early on it became apparent that people at risk presenting with swollen lymph nodes were likely infected with the virus. Detecting enlarged lymph nodes in men at risk for HIV meant that doctors were examining doomed men.

For the first 15 years after AIDS was first reported, serious illness, an avalanche of deaths and very little hope characterized the epidemic. Although small strides were made in the late '80s and early '90s, illness and death rates were not substantially reduced until 1996 with the advent of combination therapy, otherwise known as HAART (highly active antiretroviral therapy).

In the '80s and early '90s many physicians felt shell-shocked as we watched our patients wither away and die after a ferocious onslaught of life-threatening infections and tumours—often as many as five such fatal conditions occurring simultaneously in one patient. Physicians could do very little except rely on the most noble traditions of medical practitioners, which were to be unconditionally available and to be kind. In many medical practices, four to six patients a month were dying. The death certificate accompanied examining equipment in the doctor's medical bag on house calls to the dying. Doctors bore witness to entire social groups that were wiped out by AIDS. No reminiscing, no remembering significant events, no collective memory and no evolution of group relationships over a normal lifespan.

THE LANDSLIDE ENDS

HIV care has advanced substantially over the past 35 years. Barriers to patient autonomy have been broken down and human rights for people with HIV have been largely secured. Over the past 19 years, people—both those dying of AIDS and those not yet sick, at least in so-called developed countries—have benefited from research sponsored by the pharmaceutical industry, and many patients

have experienced spectacular and unimaginable improvements in their health. Patients in developing countries have not been treated as kindly by the pharmaceutical industry and still lag far behind in achieving access to the full range of antiretroviral medications available in Canada.

In the spring of 1996 I saw a patient who was acutely ill and who was admitted to hospital with a gastrointestinal disorder. He was fairly wasted and had just developed new Kaposi's sarcoma lesions in the palate of his mouth. While in hospital, he started antiretroviral therapy. When I saw him about four weeks after he started treatment, the Kaposi's sarcoma lesions on his palate had completely disappeared. This was the first time, in all my years of being an AIDS physician, that I had ever witnessed the regression and disappearance of Kaposi's sarcoma. In fact, if anyone had told me that Kaposi's sarcoma could be treated to the point of making lesions go away forever, I would



have thought that they had gone mad. He was not the only one. Whereas previously men with Kaposi's sarcoma were marked men, in 1996 they watched with exhilaration as the purplish grape-like nodular lesions of Kaposi's, which had ravaged their bodies, faded away, disappearing from their skin and virtually laid to rest in the medical history books.

At the end of June 1996, I visited a patient who was dying at home with AIDS wasting syndrome and AIDS dementia. That was just prior to my departure to the Vancouver International AIDS Conference. I went to visit him to bid my final

1990

- ▶ Canada's Health Minister announces funding for a national AIDS strategy.
- ▶ Canada's Emergency Drug Release Program allows access to unapproved treatments for AIDS-related conditions.

1993

- ▶ It's discovered that some people's HIV has resistance to AZT even though they have never taken the drug. This means that drug-resistant HIV can be passed from person to person.

farewell. Around the same time he also began taking the new medications. By the time I got back from Vancouver, three weeks later, he was no longer bed-bound or house-bound; in fact, he had resumed his life of partying in the bars and on the streets of Toronto. That patient remains alive and very well today with an immune system that is functioning at the same level as someone without HIV.

The advent of anti-HIV drugs in 1996 fundamentally transformed the landscape of the HIV and AIDS epidemic in developed countries. The firsthand initial experience of AIDS physicians was also reflected in the epidemiological reports issued by the Canadian government. For example, in 1993, 1,838 new cases of AIDS were reported to federal government health officials. By 2014, that number had dropped to 188 cases. In the year 1995, the deaths of 1,764 Canadians were attributed to HIV infection. By 2011, that number had dropped to 303 deaths.

POSTSCRIPT

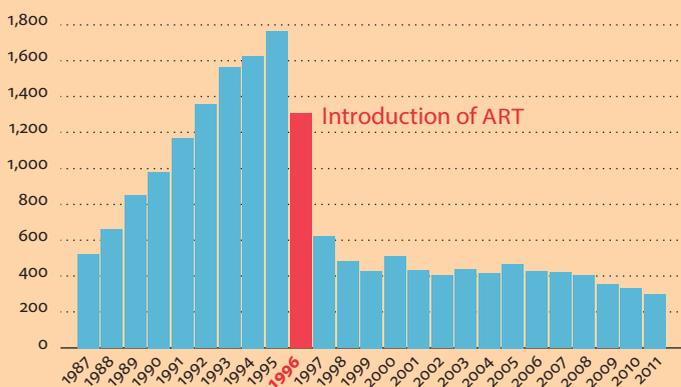
It is peculiar which memories are burnt into people's minds. For me, the images of unyielding suffering and

stubborn goodwill of many dying men and women with AIDS, both in Toronto and Africa, is a constant companion whenever contemplating the AIDS epidemic. But one memory stands out: an obscure moment in a conversation at an early AIDS conference shortly after AZT monotherapy came on the scene. I was introduced to two American AIDS doctors. One was an infectious disease pediatrician, short in height with an oval-shaped face and sleek black hair in a quasi-pompadour style. He was dying of AIDS. But he was confident at a time of utter despair that combination therapy would in the future arrest the epidemic of death and control HIV—he declared so with biblical certainty. He was right but he never lived to see his prediction become reality and transform the lives of countless people. And I never got his name. ✨

Dr. Philip Berger has been working on the frontlines of the AIDS epidemic for 35 years. He is medical director of the Inner City Health Program at St. Michael's Hospital in Toronto and the former chief of the Department of Family and Community Medicine.

Fewer Deaths ★

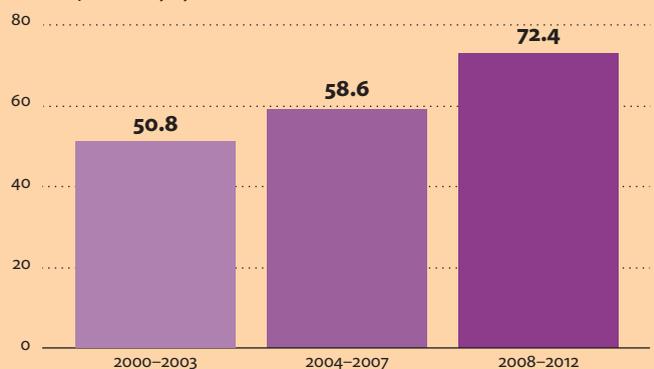
HIV-related deaths



At the start of the epidemic, AIDS was for most a death sentence. Most people died within months or a few years. Since the introduction of effective antiretroviral therapy (ART) in 1996, HIV-related deaths have steadily declined in Canada. The number has dropped by 83%, from a peak of 1,764 deaths in 1995 down to 303 deaths in 2011.

Longer Lives ★

Life expectancy (years)



The average life expectancy for HIV-positive Canadians is approaching that of HIV-negative Canadians in similar circumstances. A young person diagnosed with HIV today, who is connected to care and starts treatment shortly after becoming infected, can expect to live into their 70s or longer.

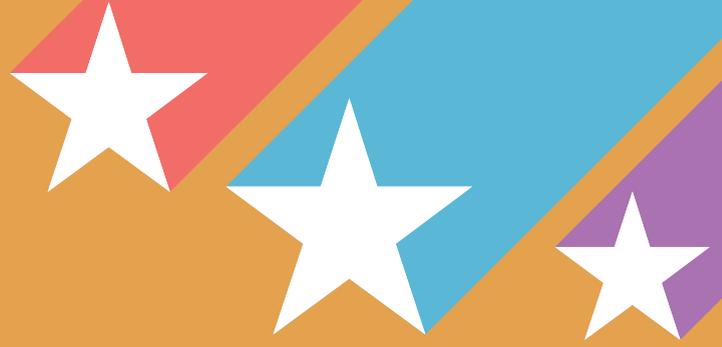
Note: Life expectancies differ based on when a person begins treatment, whether they are Aboriginal, male or female, and whether they use, or have used, injection drugs.

1994

► Researchers discover that AZT reduces the risk of HIV transmission from mother to child during pregnancy by two-thirds.

1995

► The FDA approves the first protease inhibitors, a new class of antiretroviral drugs.



The Push for Access

BY TIM MCCASKELL

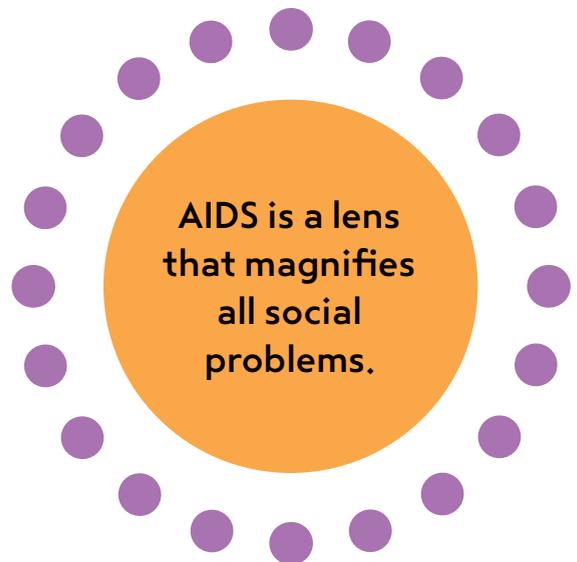
When AIDS first started decimating communities of gay men in the early '80s, those in power were largely indifferent. Why spend resources to save the lives of a group so widely reviled? It was not until well-known people started getting sick and it was recognized that anybody could get HIV that panic ensued and a public health response was mounted—protecting the uninfected from the infected. The head of Ottawa's Federal Centre for AIDS even opined that the solution to the epidemic was to isolate the “reservoir of infection”—in other words, those of us who were poz would soon die off and AIDS would be no more.

The fight for access to treatment was largely left up to the infected and a few allies. When the HIV drug AZT was first shown to slow progression of the virus in 1986, Kevin Brown, of the British Columbia Persons with AIDS Society (now Positive Living BC), delivered a petition to then federal Minister of Health Jake Epp, calling on the government to facilitate access. Brown left empty-handed. When doctors applied for permission to access unapproved AIDS drugs through Health Canada's Emergency Drug Release Program—a program explicitly created to allow such access to unapproved drugs—they were turned down flat.

It wasn't until the emergence of AIDS ACTION NOW! (AAN!) in Toronto, the burning in effigy of Health Minister Jake Epp at Toronto City Hall, a public consumption of unapproved drugs at a press conference on Parliament Hill, and repeated activist interventions aimed at shaming the

Mulroney Conservatives throughout the 1988 election, that the Emergency Drug Release Program was finally opened to requests in 1989.

But government wasn't the only problem. In 1989, the pharmaceutical company Bristol-Myers Squibb, for example, refused to release its experimental treatment, ddI, until a summer-long picket of its Canadian offices by a mother desperate to access the drug for her dying son,



1996

▶ Triple combination therapy—also known as highly active antiretroviral therapy (HAART) and later ART—becomes the standard treatment for HIV.

1997

▶ The number of HIV-related deaths drops substantially for the first time in Canada.

the occupation of its offices by AAN! activists and a wave of bad media publicity.

Such actions strengthened the notion of a poz identity, and government and pharma soon recognized that they had to listen to the voices of people living with HIV and respond to our needs. One way to amplify our voices was through treatment information: AAN! launched the Treatment Information Exchange (TIE) to encourage people living with HIV and their doctors to demand cutting-edge treatments. TIE soon morphed into the Community AIDS Treatment Information Exchange (CATIE), which later became the national organization it is today.

But AIDS is a lens that magnifies all social problems. When new treatments for the opportunistic infections that many with HIV were dealing with finally began coming on line in the early 1990s, many couldn't afford them. Financial access became an issue. It took a four-year campaign by AAN! before the Ontario provincial government established the Trillium Drug Plan to cover the costs of drugs.

While provincial programs, such as Trillium, provide access to eligible residents, the undocumented, refugees, the homeless and those living in remote areas across the country still face serious barriers. Many fear to even test for HIV because of stigma, discrimination and criminalization. Aboriginal people, who are disproportionately affected by the epidemic in this country, are only half as likely to have access to life-saving antiretroviral therapy as non-Aboriginal people.

Internationally, treatment access often depends on the wealth of one's country. AIDS activists in South Africa managed to win a treatment rollout there, and fought off a lawsuit by big pharma trying to block access to cheap generic drugs. But elsewhere in the developing world, despite international programs, many people living with HIV still die without access to basic medical care.

In a world where profit is often deemed more important than human lives, access to treatment is still a political struggle. *

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.



A Counsellor's Perspective:

It's About More than Just a Virus

BY JOHN LARSSON

In 1996, everyone was very excited, elated, about the new treatment "cocktails." But those of us who had been working in the field for a while recognized pretty quickly that this new hope presented a double-edged sword: Yes, it was great, but it was really going to f*** with people's heads.

Before antiretroviral therapy (ART) came on the scene, my work as a counsellor often consisted of helping people with AIDS to navigate their new frightening reality. We spent a lot of our time helping people to be as comfortable as possible as they died. Back then, when you met someone with AIDS, you knew that that person would very probably die. Looking back, I think we did a really good job of connecting and engaging with these clients. We saw ourselves in them.

We would set up and facilitate support groups for people living with HIV and bereavement groups. There was a lot of death in our work: the death of a person's partner or the client's own imminent death. We worked to make sure that hospital food actually got to people with AIDS who were hospitalized—it was often left outside the door. We organized care teams and we challenged healthcare providers who could be homophobic and ill-informed. And because so many people were too ill to come to the office, we did a lot of home and hospital visits.

Our aim was to improve people's quality of life. Many had very strained relationships with their families even prior to AIDS, and they often had a strong need to reconnect with them. We would facilitate family meetings, so that some reconciliation might take place.

1998

► Post-exposure prophylaxis (PEP)—the use of HIV drugs by an HIV-negative person to prevent infection within 72 hours of being exposed to HIV—is pioneered.

1999

► A single dose of nevirapine is found to effectively reduce transmission from mother to child during pregnancy, leading to a dramatic drop in the number of babies born with HIV.

ore Virus



We were present. We listened to people's fears and anxieties about "the bogeymen that come out at night." We witnessed. We showed respect. They felt heard and taken seriously, so they were not alone with their grief.

The future was uncertain. Or for some whose health was bad, the future was quite certain. So, we helped people identify and act on their short-term goals. We'd help them transition out of work or move from the apartment they could no longer afford into a cheaper place.

I think we helped people find some direction and joy at a time when things looked so bleak. People's lives were shortened in a way they couldn't have predicted, so they needed help to see their lives in a way that made sense and was manageable. The irony is that that's the only way to live, as none of us ever knows how much time we have.

Those early days were chaotic and the people I met were an incredible, eclectic, dedicated, fierce bunch. There was a lot of suffering, but also a lot of laughs and a lot of dark humour. I know people who say, "Don't *ever* tell me I was brave!" but bravery is what I saw. In spite of their condition, people managed to smile and find purpose. People are amazingly resilient and have a huge capacity to find joy.

When 1996 arrived, we in the HIV community had been hanging on by our fingernails, hoping to find something soon. People with AIDS were doing whatever they could to hold themselves together with the few drugs and alternative therapies that were out there.

And then there was a sudden shift.

We started to hear stories of miraculous recoveries: people getting up from their deathbeds to return to work. At the AIDS Committee of Toronto (ACT) we saw an immediate drop in our client base. This wasn't just about people getting on drugs, it was that people suddenly had hope so they took a holiday from AIDS.

Through the evolution of treatments, our clients' health improved. People didn't get sick as often and they bounced back from illnesses. In counselling, we started dealing more with how clients could manage the side effects from their medications. Some clients had had AIDS for a long time and it had really taken its toll. They were not as quick to catch up health-wise, having been through the hell of a lot of partially effective or bad meds. Many had been told to prepare for an early death, so they did. Now they faced the daunting task of living. But through all of this, a common thread was people's resilience.

Depression, anxiety and trauma—that's just the name of the game, especially for clients who have been around HIV for a long time or who come into the marginalization of HIV from a previous experience of marginalization. A lot of the acting out we see—things like hyper-sexuality, extreme substance use and self-harm—have their roots in trauma, anxiety and depression.

Today the main issues I see in counselling are depression, anxiety, trauma and stigma. HIV isn't so much about death anymore, but in some people's minds HIV is distasteful, dirty, and you're judged as unworthy if you have it. For those with access to meds, their bodies are most likely going to be OK, and they will likely live into old age. But that's not what life is all about.

As a counsellor, I'm not only dealing with my clients' blood work and meds. We talk about their lives, their relationships, their mental health, their trauma. People are not, and never were, just the virus in their bodies.

In the early days we usually didn't have time to work through those issues. We were scrambling to deal with the immediate realities of death and dying. But today we have the luxury of time, to explore people's life experiences. And there's a lot that people have to deal with. There always has been. *

John Larsson (formerly John Gaylord) is a social worker who has been counselling at ACT for more than 20 years. He works with people living with HIV, their partners, friends, families and others with HIV-related concerns.

2006

▶ Atripla, the first 3-drugs-in-1 pill is approved.
▶ Dr. Julio Montaner introduces the concept of treatment as prevention at the International AIDS Conference: widespread testing and ART for those

who test positive, to improve a person's quality of life and prevent transmission. This "test and treat" strategy, pioneered in BC, is now used in many jurisdictions worldwide.

You + ART

Tell us about your relationship with antiretroviral therapy:
Is it your BFF, your mother-in-law, your longest relationship...?

INTERVIEWS BY RONNILYN PUSTIL, SOPHIE WERTHEIMER AND DARIEN TAYLOR



JONATHAN POSTNIKOFF, 31
Treatment outreach coordinator at Positive Living BC Vancouver
Diagnosed with HIV: 2010
CD4 count: 980
Viral load: undetectable
Taking ART for: 5 years

I had read blogs about atrocious side effects and met people from the early days of treatment who told horror stories of a time not-so-long passed and what I thought I had to look forward to. For me, this is what HIV treatment represented. Not to mention that, once made, this decision would follow me for the rest of my life, keeping me to a schedule I'd never be able to forget, a constant reminder of the microscopic organism using my own body's cells against it.

For these reasons and others, it took me a year and a half to become comfortable enough to begin HIV meds, to feel confident enough to take my pills at the same time each and every day.

At first it seemed like an arduous task. I took my meds in secret, hoping they would work but skeptical they might not, constantly shrouded in worry that I might have forgotten to take my dose. As time went by, it became a part of my routine, as second nature as brushing my teeth or going to the bathroom. I realized that all of the fears I had had were no longer relevant, at least not for me.

When my viral load became undetectable a month after starting treatment, it gave me the sense of empowerment

I had lost when I was first diagnosed. My fear and anguish dissipated and I felt more like the person I used to be.

Five years later, without having missed a dose, I don't view taking my meds as a reminder of something negative but rather as something that gives me control over my health—for maybe the first time ever.

ART is like a supportive partner whose help I can't live without.

GLADYS K., 40
Peer researcher
Toronto
Diagnosed with HIV: 2006
CD4 count: 966
Viral load: undetectable
Taking ART for: 4 years

When I started taking HIV medications, I had a love-hate relationship with them. I had to start treatment in 2009 because I got pregnant.

As much as I had read and learned about the meds and their side effects, I was freaked out. I didn't feel ready to start but I didn't have a choice, as there weren't many choices for pregnant HIV-positive women. I had to suck it up for 40 weeks.

I didn't have morning sickness or any issues with the pregnancy itself, but I had the worst side effect from my meds. My diarrhea was so bad that I wished I had morning sickness instead. My stomach turned just looking at the pills. I honestly thought my intestines were going to come out. But I did it for my baby. I wanted my baby to be OK, and it worked—at the expense of my gut.

I couldn't wait for my baby to pop. The day that baby was out, I was done with the meds. My doctor knew I was stopping my meds and we were going to revisit the issue

when I felt I wanted to start taking them again. My CD4 counts stayed pretty high until late 2011, and then my doctor and I discussed what meds were available.

Because of my previous experience on HIV meds I really wanted to make sure that I was mentally prepared this time. My doctor was very supportive and instrumental in that process and so was my pharmacist. In 2012 I became pregnant for the second time. My specialist and I immediately sat down and discussed which regimen would likely work best for me.

I started my new meds in August 2012. Thank goodness HIV meds have improved. I experience no side effects whatsoever. My meds and I are now getting along just fine. My adherence is not 100% but I can say that **this is the longest relationship I've had**. I take four pills once a day, and I decide when I take them, whether with or without food. I'd like to eventually try one pill a day, but I'm in no rush to switch.



RICHARD AUGER, 57
Volunteer at an HIV
community organization
Gatineau, Quebec
Diagnosed
with HIV: 1994
CD4 count: 1,400
Viral load: undetectable
Taking ART for:
21 years

I started taking HIV meds shortly after I was diagnosed and I've had a long friendship with what I think of as my "vitamins." I view them as vitamins because when you think of them as pills, you have sickness in mind. I try to put sickness aside and tell myself that I'm taking vitamins for my health.

When I started ART, the medications were worse than the disease itself. Some pills made me really sick, so I changed regimens frequently. And there were too many pills to swallow. I also had liquid meds, which were disgusting! Some meds gave me frightening leg cramps and with others my head never felt clear. When I stopped those, it was like returning to this planet. Back then, I had no desire to take my meds. Some days I felt like I was asleep at the switch, in a dream. I slept almost 24 hours a day. It was awful.

After living with those side effects for too long, I asked my doctor if any new treatments were available. Once I switched to the new meds, things got so much better. The drugs were easy to take, the side effects were much better. Apart from a bit of a cholesterol problem, I don't have any issues now.

Over the years I've been on so many different meds, which messed me up a bit, but I persevered and stayed

on treatment. It's been 12 years now that I've been in this fairly stable relationship. I love life!

I know many people who say, "I'm fed up with taking pills," and they stop taking them. But it doesn't bother me anymore. It's not that complicated: We eat every day, so we can take a pill every day.

For someone who is just starting treatment now, I would advise them to not worry about it. If you take it as you're supposed to, you will have an undetectable viral load and you can live a pretty normal life.

I think of ART as a friend because it keeps me alive and in good health. It allows me to keep going, to do things that I enjoy. I can do volunteer work and help people. Without my meds, I wouldn't be here and I wouldn't be able to help others. When you have a friend, you want to see them every day if you can because they help make your life good.



ANN FAVEL, 49
Edmonton
Diagnosed
with HIV: 2008
CD4 count: 500
Viral load:
undetectable
Taking ART for:
3 years

My antiretroviral medication, Complera, is kind of like an old flame who has come back into my life.

Let me explain. I used to be a heavy opiate user and now that I'm off those drugs, I don't like putting meds of any sort into my body. I can't avoid the feeling that they are going to cause problems at some point.

I told my doctor I didn't want to take a lot of pills, so when he told me about a single pill combination, I agreed to start that.

So this old flame came back into town. He said he had changed. I worried that he could hurt me, because he has in the past. I have to admit, I also felt some love for him. I know his faults, but I know the good in him, too.

It's complicated. Sometimes he does make me feel bad. I have stomach problems—acid reflux, heartburn and sometimes when I eat, I get the heaves. A while ago, I had to go to a gastroenterologist and get a scope to see what was going on.

Complera and I have been together for about three years now. I have learned to trust him. He was my first. I've been true to him. Every morning, as soon as I get up and eat my breakfast, there he is.

At first things were easy, but lately he's causing me some pain. Sometimes I feel like I'm tied down to him. There are plenty of days when I feel like he's stayed too long and I'd love to give him the boot. But I understand that in many ways we're good for one another. *



Poz Identities

BY DR. LISA BARRETT

I have worked with a wide range of people with HIV since about 2000, first as a PhD student working in an HIV clinic and then later as an MD—from long-term survivors who were diagnosed in the '80s and '90s to those who learned they were HIV positive in the past six months, from people in their 20s to an 86 year old.

What it means to live with HIV and to be on treatment varies dramatically depending on how and when you were diagnosed. If you were diagnosed with an opportunistic infection in an emergency ward 25 years ago, HIV and its treatment are likely to represent something very different than if you found out you are HIV positive because you went to an STI clinic for routine screening while you were healthy and well. For those diagnosed in the early days, treatment used to mean something unpleasant—dreaded side effects and countless pills. So, sometimes, when I suggest switching drug regimens, a person diagnosed years ago will at first be very hesitant to switch because new drugs back then were sure to be a bad experience, very different from new drugs today. By contrast, some newly diagnosed people take the news of an HIV diagnosis almost lightly and don't think it's a big deal at all. It can even be hard to convince some people that they need another appointment.

Another example of how this dramatic shift in attitude plays out is that back in the day, everybody would see our clinic psychologist after being diagnosed whereas now only half of our HIV patients take us up on that support. I've certainly noticed a shift even in the last five or six years.

Most people do have concerns though, especially about their sexual relationships. One young woman who was born with HIV came to our clinic shortly after moving to Canada. She had settled into her new life as a university student and

was starting to think about sex, disclosure and if she was ready to have a relationship. We talked more about the facts around transmission and ways to develop relationships and deal with disclosure than about medical issues. She is gradually thinking more about her sexuality and how she wants her sex life to look, something she had written off until a year ago. Other folks who come to our clinic are much less concerned about new partners and the risks of transmission.

But we provide everyone with information on how they can reduce their risk of transmission in the context of their personal choices, and we offer to talk to people's sex partners. If they feel it would be beneficial to them, we have a frank discussion about sexuality and HIV.

What I try to tell people is that an HIV diagnosis is significant—it's not something to trivialize—but if you get on effective antiretroviral therapy and we work on this together, you'll be around well into old age. We'll both be hobbling around my office together when we're 102!

All my patients know my pill-taking mantra: If you take this, it will work, and it will probably work forever. So let's work together to get you (or keep you) taking your antiretrovirals *every single day*. Text reminders, apps, alarms, stickie notes, whatever it takes. I tell people that most of us have bigger commitments than taking a pill once a day and going for regular checkups. With effective treatment and ongoing care, HIV can be very manageable. *

Dr. Lisa Barrett is an infectious diseases doctor whose work focuses on people with HIV and hepatitis C. She is also an assistant professor at Dalhousie University in Halifax and a researcher who leads a team at the university's Senescence Aging Infection & Immunity Laboratory.

2009

► UNAIDS calls for the implementation of programs to work toward the virtual elimination of mother-to-child transmission of HIV by 2015.

2011

► The HPTN 052 trial shows that HIV treatment drastically reduces the risk of transmitting HIV.

The Evolution of HIV Treatment

BY SEAN R. HOSEIN



The arrival of the AIDS epidemic in Canada and other countries was scary on so many levels. We watched in shock as previously healthy young men became ill and were robbed of their vitality and eventually their lives. In the early '80s, scientists had few answers to many of the questions that people and the media posed about AIDS. Perhaps most chillingly, the new disease primarily affected groups that were despised by our broader society, and for years authorities largely turned their backs to the growing epidemic. Neglected by the state, many people with HIV felt a deep sense of a betrayal, abandonment and isolation. This resulted in anger and incited AIDS activists to mobilize and create a plan to deal with the epidemic.

Things began to change but only very slowly. In 1983 French scientist Françoise Barré-Sinoussi discovered HIV and in 1985 the first HIV test became commercially available. But the number of people who died from AIDS kept growing.

The first licensed drug, AZT, had to be given intravenously. At the doses initially used, the drug was toxic. Eventually an oral formulation was made but it had to be taken in high doses every four hours and usually only people in clinical trials could gain access to it. The worst part was that it didn't cause lasting remission from AIDS. AZT was followed by ddI, d4T and 3TC. These chemical cousins of AZT belong to a class of drugs called nucleoside analogues, or nukes. We now know that nukes are very useful when taken with anti-HIV drugs from other classes, but back then all

that was available were nukes. Activists had to pressure regulatory agencies to test combinations of new drugs because if each drug were tested on its own, any remission would be temporary, as HIV could easily overcome a single drug.

Some brave individuals decided that their lives couldn't wait for the slow pace of research so they travelled to Mexico, Japan and Europe to import drugs that had seemed promising in test-tube experiments. They effectively ran their own clinical trials. Enterprising people in the U.S. established cooperatives called buyers' clubs. These clubs sold experimental drugs and supplements as cheaply as they could to HIV-positive people. At home people tested a range of compounds. Although buyers' clubs were prohibited in Canada, activists working with doctors and helpful bureaucrats would later liberalize restrictions to bring in life-saving drugs. Ultimately, none of these bootleg antivirals significantly reversed the course of AIDS, but at the time they were all that were available.

Then, in 1996 at the International AIDS Conference in Vancouver, everything changed for the better. Researchers announced some stunning results: For the first time, people who had been deathly ill with AIDS had seen their health improve thanks to a combination of at least three

Instead of having to take dozens of pills, an entire regimen can now be found inside a single pill.

2012

► The FDA approves the use of the HIV treatment drug Truvada for preventing HIV (pre-exposure prophylaxis, or PrEP).

2014

► The PARTNER study reports that HIV treatment reduces the risk of transmission among gay men.

START

Last spring the results of a large clinical trial called START were announced. The findings clearly show that starting treatment upon diagnosis, even when one's CD4 count is over 500, prevents many cases of serious, life-threatening illnesses and significantly reduces the risk of death. This has added to the evidence that HIV should be treated as soon as possible after diagnosis. The researchers also found that less than 1% of study participants experienced serious side effects.

So, the longstanding question of "when is the best time to start treatment?" is no longer a question. We now have the answer: We know that the best time to start is as soon as possible.

anti-HIV drugs. The drugs were from at least two different classes; the newest one was called protease inhibitors. For the first time in the history of AIDS treatment, we heard reports of people's CD4 counts rising and staying up.

Initially, because I had seen so many failed therapies and so many people die, I was somewhat skeptical about the new medicines. But after returning to Toronto, I saw the change with my own eyes—people who had entered the hospital with life-threatening infections were leaving in much better shape. These new potent medicines were called highly active antiretroviral therapy (HAART).

Though people were deeply grateful for the life-saving effect of HAART, we soon heard about the side effects of the first-generation meds. For some, it was explosive diarrhea, for others it was severe nausea or the loss of their sense of taste or skin problems or painful nerve injury.

And then there was the sheer number of pills people had to take. In the mid-90s many people had to take a fistful of pills two or three times daily, sometimes on a strict schedule, with food and water restrictions. And people with HIV had to learn a new word: *adherence*. Recovering from AIDS and staying well depended on being able to take all those pills every day, day after day, without interruption.

By the late '90s, a new set of side effects appeared: changes in body shape and appearance as fat, particularly in the face and also in the legs and arms, disappeared. It took

some years of clinical trials to show that two nukes—d4T and to a lesser extent AZT—were linked to the side effects we now call HIV lipodystrophy syndrome. Today, leading treatment guidelines no longer recommend that these drugs be used for most people with HIV.

Fast-forward to today, nearly 35 years since AIDS first appeared: Treatment has changed radically. HAART is now simply called ART. Leading U.S. guidelines now recommend that a class of drugs called integrase inhibitors be included in a person's first regimen. Instead of having to take dozens of pills, an entire regimen can be found inside a single pill that is taken just once daily, either with or without food. And the new meds are much easier to tolerate.

I remember in the early '90s counselling people on the phone or in person at the CATIE office about their treatment options. In those troubled times it seemed far-fetched that anyone with HIV would ever live to see a day when they could stay healthy, have families and live into old age. Today when I hear HIV-positive people complain about aging-related issues, although I don't say this, on the inside I'm happy for them because they have survived the worst years of the epidemic when so many others did not.

The power of treatment is so amazing that researchers increasingly expect that many young adults who are infected today and begin ART shortly thereafter will live into their 70s. That is a far cry from the dismal forecasts of the '80s and early '90s.

When it comes to HIV treatment, so much has changed since 1981 and more changes lie ahead. Researchers are testing long-acting formulations of HIV drugs, which, if effective, would need to be taken only once every three or six months. One day it may even be possible to create a treatment that only needs to be taken once a year. Although a cure is not likely within the next decade, researchers are hopeful that someday they may be able to put HIV into remission, so that a person does not have to take medicine every day as they do now. Treatment is still imperfect, but change for the better is on the way. ✨

Sean Hosein has been working for CATIE since its doors opened in 1990, providing people across the country with treatment information. He is CATIE's Science & Medicine Editor and author of *CATIE News* and *TreatmentUpdate*.



2015

► The START study confirms that when a person starts HIV treatment when their CD4 count is high, they dramatically reduce the risk of developing serious illnesses and dying. This confirms

that everyone should be offered treatment as soon as possible and causes treatment guidelines to be revised.



Calming the Flames

How diet can help cool chronic inflammation.

BY PAMELA FERGUSSON

Inflammation is a hot topic right now (no pun intended), especially for people living with HIV and other chronic conditions. Simply put, inflammation is our body's natural response to infection or injury.

There are two types of inflammation: acute and chronic. With acute inflammation (a hangnail, for example), injured or infected cells signal the immune system to respond with a cascade of healing chemicals. The site of the infection or injury may get swollen, warm and sore as the chemical processes of inflammation work to repair the body. Once

healing has occurred, the body sends chemicals to “turn off” the inflammation. The other type is chronic inflammation, in which the immune system is turned on permanently. HIV causes chronic inflammation. Antiretroviral therapy (ART) reduces but does not eliminate this inflammation.

The good news is how well—and easily—inflammation can be reduced through diet. An anti-inflammatory diet should reduce chronic inflammation and the risk of illnesses associated with it, such as diabetes, heart disease and possibly some cancers—problems that are more likely to crop up as we age. With the high fibre content of the diet you can also more easily achieve and maintain a healthy

weight. And the antioxidants will slow aging of your cells, which might help you look and feel younger, too!

CONNECT THE DOTS

Here's how the immune system, HIV and diet link up: The gut is our biggest immune system organ, containing immune cells called GALT (gut-associated lymphoid tissue) cells. Healthy GALT cells help to protect the body from disease. HIV attacks GALT cells, even in people taking ART, allowing germs to pass into the body's circulatory system and causing inflammation throughout the body. This increases the chance for diabetes, heart disease, liver or kidney disease, and possibly depression. Switching from a diet that relies heavily on red meat and highly processed and refined foods to one that includes more whole grains, fruits and vegetables, and good protein sources is one of the most effective ways to dial down chronic inflammation.

REFOCUS YOUR DIET

An anti-inflammatory diet includes plenty of vegetables and fruit, beans and lentils, nuts, seeds and whole grains. As a person with HIV, it's important to also ensure that you get sufficient calcium to maintain the strength of your bones, so try to eat calcium-rich foods like cheese, yogurt, sardines (with the bones in) and leafy green vegetables like spinach and kale. Osteoporosis Canada's website is a great resource (osteoporosis.ca).



BOUNTY BOWL

Cook a big pot of your favourite whole grain, such as quinoa, buckwheat or millet. Refrigerated in a sealed container, it can keep for up to five days. Along with canned beans (black, Romano or pinto) or chickpeas, this can form the basis for many meals. Just add sauce, steamed or raw veggies and some tofu, tempeh or oily fish, and you will have a one-bowl inflammation-fighter.



SPINACH SALAD

A spinach salad with strawberries, blueberries or pomegranate seeds is a great idea. Add some nuts and chia seeds for an added anti-inflammatory boost.

Try to consume red meat only a few times a month, replacing it with fish, eggs or seafood. Meat portions should be small, about the size of your palm. Consider eating vegetarian one or two days of the week. Vegetarian chili full of fibre-packed beans is a great high-protein choice.

Increase your protein from plant-based foods such as lentils, tofu or tempeh (made from soybeans). If you haven't tried it, it's time to lose your tempeh virginity! Tempeh also supplies calcium and iron, and soaks up marinades beautifully.

Try to avoid inflammation-promoting foods, such as sugar, white bread, white pasta and white rice, trans or hydrogenated fats and alcohol.

KNOW YOUR FATTY ACIDS

The nutritional powerhouses of an anti-inflammatory diet are omega-3 fatty acids, antioxidants and fibre. Omega-3 fatty acids are also known as essential fatty acids. Our body cannot make them on its own; therefore, we must consume them in our diet.

Two crucial omega-3s—EPA and DHA—are found primarily in oily fish like wild salmon, anchovies and sardines. While fish are the best sources of omega-3s, alpha-linolenic acid (ALA), another omega-3 fatty acid, is found in plant sources such as nuts and seeds, including flax. Although it's best to get your nutrients from food sources, you can also consider an omega-3 or flax oil supplement.

Not all omega fatty acids are desirable—omega-6 fatty acids should be limited, as they tend to promote inflammation. Use oils low in omega-6, such as olive, avocado, flax or canola.

BE PRO ANTIOXIDANTS

Myriad studies, such as the recently completed 10-year ATTICA study examining the link between diabetes and a healthy lifestyle, have shown that eating a Mediterranean-style diet rich in fruits and vegetables lowers the chance of developing inflammation-related diseases.

Brightly coloured fruits and vegetables tend to be excellent sources of antioxidants, helpful tools for reducing inflammation. Try to include more purple and red berries, dark green veggies and sweet potatoes in your meals.

INCREASE YOUR FIBRE INTAKE

Another way to reduce inflammation is by increasing your intake of both soluble and insoluble fibre.

Soluble fibre dissolves in water and forms a gel that slows digestion. This slowing effect may be beneficial to blood sugar levels and insulin sensitivity, helping to control diabetes. It also reduces LDL (or “bad”) cholesterol. Sources of soluble fibre include avocados, beans, nuts and whole grains like oats and millet.

Insoluble fibre is found in whole grains, fruits and vegetables. It prevents constipation by adding bulk to your diet and some studies suggest that it might help reduce your risk of certain cancers.

So take a break from white bread, pasta and rice and try whole grains like quinoa, buckwheat or brown rice.

KEEP IT HASSLE-FREE

If it seems like anti-inflammatory eating takes up too much time and money, keeping your pantry packed with canned beans and whole grains will make it much easier.

Check out our Bounty Bowl recipe (on pg. 24) for a cheap, quick and healthy meal.

Your freezer was made for more than ice cubes. Buy extra bags of frozen fruit and greens like kale and spinach for your smoothies when they are on sale at the supermarket and freeze them for later use.

SAUCES AND TOPPINGS

For a delicious salad dressing or topping for your one-bowl meals, simply mix plain yogurt with chopped herbs. Or use tahini thinned with olive oil and lemon juice.

A sauce made with two tablespoons of almond butter, one tablespoon of low-sodium soy sauce and one teaspoon of ketchup makes a tasty topping for grilled tempeh.



GREEN SMOOTHIE

Boost your intake of greens along with your energy by making a smoothie. Mix ice cubes, half a cup of coconut water, half a banana, half a cup of frozen mango and three handfuls of fresh spinach in your blender, along with some flax meal. If you need additional protein and calcium, add a couple of spoonfuls of yogurt or some fortified soy milk. You can't taste the spinach—promise!



FEED YOUR HEAD, TOO!

Does kale leave you cold? Do whole grains leave you wholly confused? Don't worry; there are lots of great resources to assist your anti-inflammatory quest. Check out www.cookspiration.com. Created by Dietitians of Canada, the site contains many anti-inflammatory recipes. Another good source for recipes that boost the fruit and veggie content of your diet is www.halfyourplate.ca/recipes.

SAVOUR THE BENEFITS

If you are trying to stay your healthiest and reduce your risk of complications like diabetes or heart disease, an inflammation-fighting diet can be a valuable part of a larger doctor-advised program. Regular dental checkups and good dental hygiene, adequate sleep, exercise and stress reduction are also important aspects of an anti-inflammatory lifestyle. It's no surprise that smoking is linked to inflammation—yet another reason to quit.

Fighting inflammation through nutrition puts you in control of your health. Get ready to feel the power! +

Pamela Fergusson is a registered dietitian with a PhD in nutrition. She has worked in Canada, the UK and the U.S. directly with clients and in education and research.



Meno-POZ

“What can I expect as an HIV-positive woman who is entering menopause? Will menopause be different for me because of my HIV status?”

—P.W., Twillingate, NL

INTERVIEWS BY RONNILYN PUSTIL

VALERIE NICHOLSON

Person living with HIV
Vancouver

I am an Indigenous woman living with HIV since 2004. When I was 54 years old, my periods (moon time) became irregular, and when they did come they were very heavy. Then I hit menopause.

When I was going through “the change,” I started to dislike the word *menopause*. What do men have to do with it?! I decided to call it o-pause instead.

I had gone almost a year without my moon time and I was excited, as this is a sign that o-pause is ending. But then I woke up one morning—it was Christmas morning—to moon

time. Another year went by and I woke up to another moon time, this time on my birthday! These irregular periods lasted for three and a half years.

O-pause is a time when our bodies are letting go of our menstrual cycle. It’s a time to pause and acknowledge that our life-giving journey is finished and a new way of life is emerging. A time to pause and say: “This is OK and I will make it.”

My hot flashes were so severe that I would pull my clothes off and stand in front of a fan. A few times I lifted my shirt in front of the grocery store freezer just to feel the cool air. I never got night sweats but my irritability was rampant.

There was no change in my libido and I continued to enjoy sex, though

I did experience vaginal dryness. My doctor recommended a lubricant. When I asked her what else I could do to get through menopause, she replied, “You made it through puberty without help. You will make it through menopause!”

When I started having heart palpitations, I got real scared. My doctor sent me for some tests. The diagnosis: menopause, not a heart attack or heart problems. So if you get heart palpitations during menopause, my advice is to see your doctor right away. Peace of mind is better than the stress of worrying about your health.

Using the medicine wheel helped me to understand that o-pause is part of the circle of life for a woman. I started on my life journey without my

moon time and I am completing it that way. A full circle. Every woman has her own journey and circle of life.

I have osteoarthritis, urinary incontinence, poor memory and liver problems. Was my experience of menopause affected by HIV, my meds or my heritage? I'm not sure, and I'll never know. My grandmother never spoke of this time and my mother never had a chance to go through menopause, as she had a hysterectomy when she was in her thirties.

Today I am a very different woman than I was before o-pause. I am mellower and have a deeper understanding of myself. I have more of a connection with Mother Earth and I love being a grandmother. I see the world through my grandchildren's eyes. I jump in puddles and blow bubbles. I feel wiser and more peaceful.

DR. CYNDI GILBERT

Naturopathic doctor and author
Toronto

Many patients see me for help with reducing menopausal symptoms. A person's HIV status alone has not been shown to impact the timing of menopause or the experiences of hot flashes, sleep problems, depression, irritability and anxiety sometimes associated with menopause.

In my clinical experience, these things can often be managed using natural approaches and therapies. Exercise, a healthy diet, mindfulness or meditation, reducing or quitting smoking and limiting alcohol are the basic foundations for transitioning through menopause. These lifestyle changes can also reduce the risks of osteoporosis and coronary heart disease.

Calcium and magnesium supplements, vitamin D₃ and other nutrients may be needed. Fish oil has been shown to reduce high levels of triglycerides (a fatty substance in the blood), which are sometimes caused by protease inhibitors, sometimes by HIV itself.

To reduce hot flashes, regular acupuncture treatments may be helpful. Soy products, such as tofu and soy milk, which mimic the natural

It's a time to pause
and acknowledge
that our life-giving
journey is finished
and a new way of life
is emerging.

estrogens that decrease after menopause, may help provide some relief from hot flashes. I also try to teach my patients techniques to better manage their stress, insomnia, depression and anxiety.

Some people find that certain herbs help reduce hot flashes, alleviate sleep disturbances and improve sexual desire. Because some supplements can interact with medications you're taking, it's important to always speak to your doctor and pharmacist before taking any of these. For example, St. John's wort reduces the effectiveness of many drugs, including certain HIV meds (particularly protease inhibitors and non-nukes). Therapeutic doses of garlic supplements may reduce drug levels of ritonavir (Norvir) and the older drug saquinavir (Invirase), although more research is needed to confirm these interactions. Before starting any complementary therapy, always consult your healthcare providers about potential interactions.

DR. ISABELLE BOUCOIRAN AND DR. MARC BOUCHER

MDs, obstetrics and gynecology,
Ste-Justine Hospital
Montreal

Menopause is a natural phase for women. [Ed's note: The term *women* is used here to refer to cisgender women, or women whose gender aligns with

with the one they were assigned at birth. Some of the information may not apply to trans women; conversely, some of it may apply to trans men.]

Large gaps exist in our understanding of the effect of HIV on the aging process and menopause. In our clinical experience, HIV-positive women seem to experience as many menopausal symptoms as HIV-negative women. However, a recent small study found that HIV-positive women are more likely to experience more severe hot flashes, which can interfere more with daily life. Women with HIV are more likely to develop osteopenia, a loss of bone density that can lead to osteoporosis. Depression has also been associated with menopause in some HIV-positive women.

Some studies have shown that early menopause is more common among women living with HIV. However, many factors have to be considered when talking about menopause in HIV-positive women, such as ethnicity, CD4 count, smoking, body mass index, drug use and co-infections. It's challenging to distinguish the unique contribution, if any, of HIV among these other factors. We know a lower CD4 count is associated with a higher chance of becoming sick and dying, and managing one's HIV is critical for this reason. It appears that lower CD4 counts are also linked to early onset menopause.

When we see patients, we do an individualized risk/benefit assessment of the use of hormone replacement therapy (HRT)—hormones given to replace estrogen loss. We take into consideration a person's symptoms, comorbidities, age and antiretroviral regimen.

Some studies have associated the use of HRT with an increased risk of breast cancer, blood clots and cardiovascular events. Women with HIV do not have an increased risk of breast cancer, but several studies have found higher rates of cardiovascular disease than in HIV-negative people [see *Treatment-Update 189*, "HIV and menopause," at www.catie.ca]. Alternatives to HRT are available, such as antidepressants for hot flashes and intravaginal estrogen cream for vaginal dryness. +



Significant Others

Award-winning dancer **Benoît Lachambre** transforms the dynamic between performer and spectator.

BY DAVID PELLETIER

Snakeskins



For Benoît Lachambre—dancer, choreographer, founder of the Montreal-based Par B.L.eux dance company and seasoned teacher of contemporary dance—artistic expression is all about sharing and communion. This aspect of his work is so fundamental that since the mid-1990s he’s been breaking down “the fourth wall,” the invisible barrier that separates the spectators from the performers. Borrowing techniques from the world of theatre, Lachambre gives his audience opportunities to watch his shows from different angles, to enter the performance space and to personalize their experience. In his critically acclaimed *Snakeskins*, he even picks up a mic and speaks directly to the audience, acknowledging their presence. The term *iconoclast*, sometimes used to describe Lachambre, isn’t really fitting; his true goal is to unify those on and off the stage, to let the audience fully feel the energy of his shows.

When Lachambre was diagnosed with HIV in the late ’80s, shortly before his 30th birthday, little was known about the disease and there was far more fear than tolerance. He lost friends, collaborators and lovers. Meanwhile, his career as a dancer took off, with his talent sought out both at home in Montreal and in Toronto.

“The diagnosis gave me a sort of ultimatum: Make your choices now because you don’t know how much time you have left,” he says. In those years before effective antiretroviral therapy (ART), it was hard to see the diagnosis as anything but a death sentence. Lachambre immersed himself in his dance to explore a visceral, personal journey. During this period, his intensely physical, even acrobatic, work sought to better understand how his thoughts, emotions, movement and energy flow were affected by his new condition. “This gave me a lot of strength,” he says.

Lachambre’s goal was not to create activist art, though he appreciates the activist art of others: “A lot of people

PHOTOGRAPH: CHRISTINE ROSE DIVITO

around me, people I admire, are or were AIDS activists. Some have died, others are still alive. They have all had an enormous influence on me.”

A decade later, when ART gave people with HIV hope, Lachambre returned to focusing more on using dance to communicate and connect with others. In 1996, he founded his own dance company, which he named Par B.L.eux—a combination of his own initials (B.L.) and the word “eux,” meaning “them”—putting his own work and that of artists he works with on equal footing. In keeping with this spirit of collaboration and humility, Lachambre refers to performances where he dances alone as “fake solos” because he considers the inspiration he draws from others—like fellow dancers Meg Stuart and Fabrice Ramalingom, and composer Hahn Rowe, with whom he performs—so critical to his work.

Lachambre also invites the audience to collaborate and get involved. “Having the audience seated is something that we as dancers respond to. It influences our body, our position.” Lachambre believes that this seated position, which he compares to sitting on a throne, can also inhibit the energy flow of the spectator and make people unable to fully appreciate the performance. So he attempts to build a new relationship with audience members. Depending on the show, spectators might be sitting, standing around or invited to move from one place to another to see the show from a new angle. On occasion, they have even been invited to cross the performance space. “It takes away the presence of the ‘court,’ challenging this hierarchy between the audience and the work,” Lachambre says.

Lachambre’s creative work has led him to explore the link between fiction and reality, and between one’s physical energy and spirituality. He sees social conventions as being obstacles to these connections. The show *Hyperterrrestres*, created

with Fabrice Ramalingom and presented in Montreal at the Festival TransAmériques last May and at the Festival Montpellier Danse last July, explores these themes. Lachambre and Ramalingom were inspired to examine the symbiotic relationship between the physical and spiritual after a trip they took to Hawaii.

“We went to visit a friend who lives in Hawaii, to swim with the dolphins. As soon as we got off the plane, we felt the energy of the island flow through us. I had never felt this so strongly before.” Lachambre says that on the island people are told to be careful about what they wish for because it tends to come true.

While in Hawaii, Lachambre experienced a profound communion with nature. “Dolphins are highly intelligent beings that experience the cycles in their lives together,” he says. “They travel together, sleep together, feed together. Their immense ability to communicate allows them to transmit these cycles, these thoughts, with other species. It’s possible for someone who connects with them to experience these cycles.” The act of responding in a communal way to the surrounding energy was a source of inspiration for Lachambre and Ramalingom in creating *Hyperterrrestres*. “The idea was not to reproduce the experience, but rather to try to respond to each other in the same way.”

This search for intangible connection was also at the heart of *Snake-skins*, a multimedia performance that Lachambre choreographed and dances in. Drawing upon Mesoamerican mythology and using the metaphor of a snake shedding its skin, the piece is about a rite of passage and emancipation. Lachambre uses scaffolding on the stage with a harness attached to explore space and energy while suspended. At points he moves on top of the ropes, suspended above the stage, always trying to maintain balance.

In the early years of the AIDS epidemic, when Lachambre was diagnosed, people with HIV were severely ostracized, but rather than isolate



“Ignorance is also a disease. We need to fight it.”

himself or turn inwards, he chose to reach out to others through his work, a choice that could be considered bold. Have things changed when it comes to stigma? “Yes, but a lot of misconceptions about HIV are still out there. There is still fear. People are not necessarily well informed,” he says. “Even within government funding agencies for the arts, there is panic about the idea of an artist with HIV. People who are HIV positive have the opportunity to learn about their condition, but it’s more difficult for people who are not affected. People often feed their fears instead of overcoming their ignorance, and that is where the monster comes from. Ignorance is also a disease. We need to fight it.”

This is why Lachambre is fighting the prejudice around HIV. He does not name HIV directly but by turning toward others, by speaking to them, to us, through movement, he extends his arm and asks us to join in the dance. ✚

To learn more about Benoit Lachambre and Par B.L.eux, visit www.parbleux.qc.ca/en

Author, columnist, playwright, composer and teacher David Pelletier loves everything that has to do with words. His main playground since 2011 is his bilingual blog *Le sommelier fou* (The Crazy Sommelier).



Reflections

About a year ago, I attended a three-day silent Buddhist retreat in Morin Heights, in the Laurentian Mountains, a half-hour from where I live in Quebec. During these retreats, the participants meditate silently while walking mindfully, enjoying nature and the harmonious landscape. We are allowed to speak only briefly at dinner time. It is a very intense experience.

While on one of these silent walks, I came upon this beautiful water lily growing out of the grey darkness, the bright, warm sun reflecting off the surface of the water. I had to take a picture of it. Water is

a symbol of life. I see myself like the lily or, since this was a Buddhist retreat, a lotus, which flowers from the black mud.

My life today has its roots in the darkness and turmoil of HIV in the 1980s. Following my diagnosis, I experienced shock, grief and depression. I was an activist, involved in the Montreal-based AIDS service organization le Comité des personnes atteintes du VIH du Québec (CPAVIH). I participated in many street demonstrations demanding access to HIV treatments, even though it meant laying down on hard asphalt, exposing myself to the danger of police brutality.

I now realize that was the beginning of my path to peace and tranquility. Reflecting on the past 30 years that I have survived with HIV, I see that I have come to terms with my disease and accepted it. I have achieved my dreams of going to university and becoming an artist and writer. I have a beautiful mosaic of friends.

Photography is about finding the right light. When I write about my life it can be very dark but my photography helps me to find the light amidst the darkness. +

—Gregg Rowe

CONTRIBUTE

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

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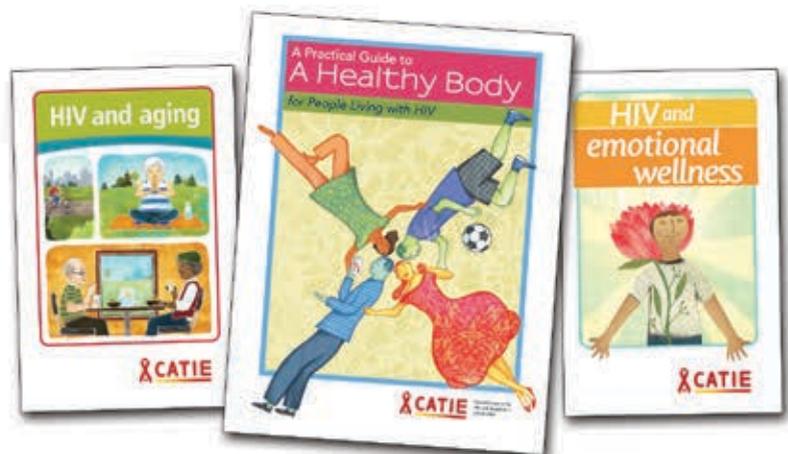
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