

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SUMMER 2012
VOLUME 14 ISSUE 2

ART FOR OUR SAKE

Stephen Andrews and
other HIV+ artists in
Canada paint a picture
of the epidemic

TREAT HIV TO PREVENT HIV

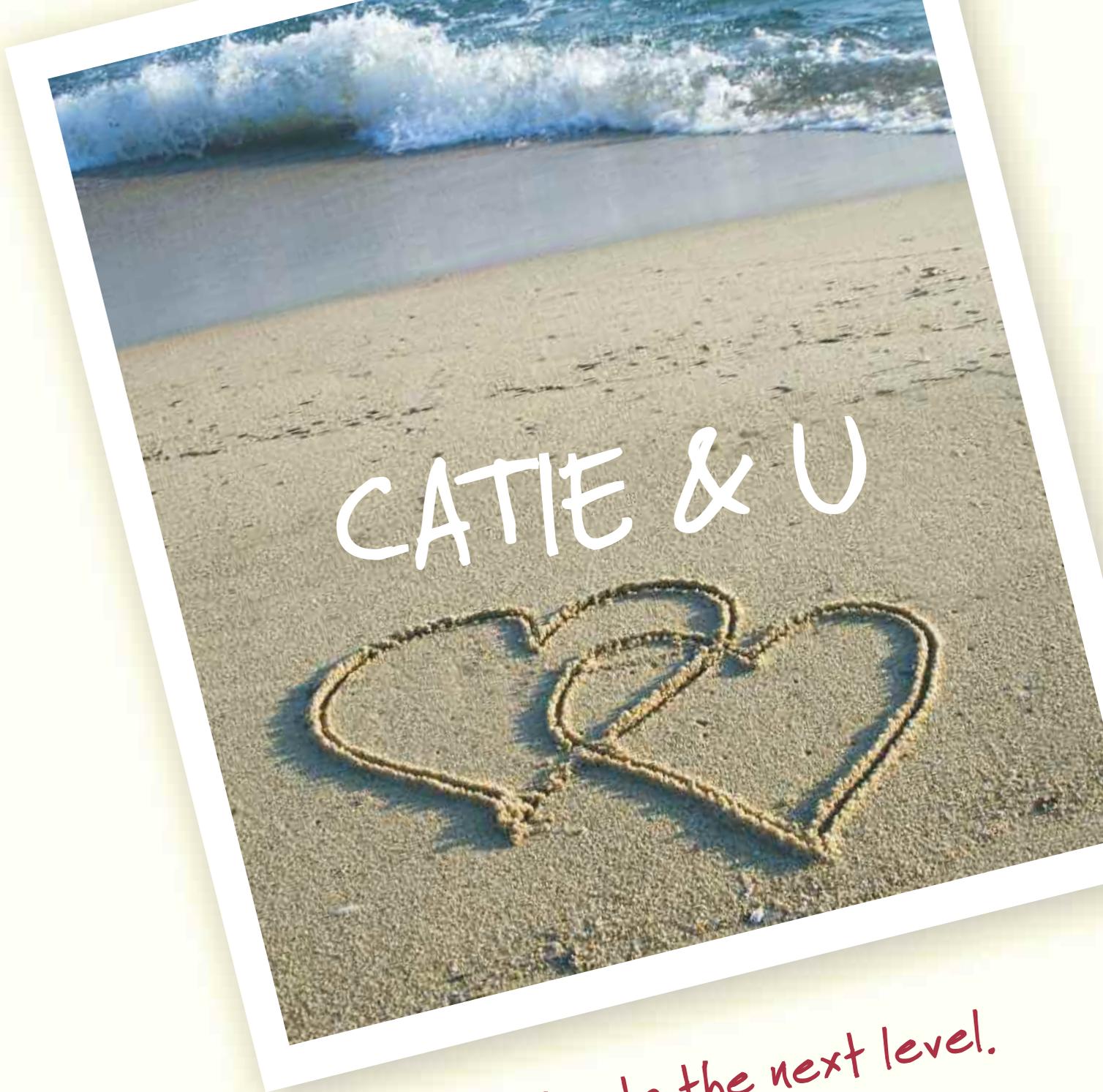
*Public health and
personal rights*

PINS AND NEEDLES

*Tips for peripheral
neuropathy*

CREATURE COMFORTS

*PHAs and
their pets*



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EDITOR'S LETTER

Many threads weave art and AIDS together, creating a tapestry over the past 30 years of the epidemic. The early epidemic hit Canada's art community particularly hard, leaving threadbare spots filled with fear, despair and sadness. Later, as medical treatments improved, richness returned to the tapestry as HIV-positive artists channelled their energies into creating works that reflect the current realities of living with the virus. I am particularly excited to present a story that explores this tapestry and shares the lives and art of four HIV-positive Canadian artists. Reading "The Big Picture" opened my eyes to a world of beauty and power. I hope it does the same for you.

The other two feature articles in this issue complement the artistic with the medical and the social. We look at some of the factors to consider before starting HIV treatment in "On Your Mark, Get Set, StART." In "Treatment Benefits for All?" we explore some broader social implications of our growing understanding that being on HIV treatment can lower the risk of HIV transmission.

Finally, our regular columns bring the much-loved mix of humour, info and inspiration. Programs for Aboriginal people living with HIV are highlighted in From the Front Lines. Chatty CATIE probes people about their pets—and they don't hold back. Ask the Experts offers help with peripheral neuropathy. We also get inspired by lawyer and activist Jeff Keller and artist Andrew McPhail.

We hope you enjoy the variety assembled in this issue. It's a great reminder that life with HIV is its own rich tapestry.

—David McLay

Correction: In "A Hard Day's Work" in the Winter 2012 issue, we stated that the only job in Canada that HIV-positive people are not permitted to do is that of emergency medical technician. In fact, this exclusion varies across the country. For example, it applies in Ontario, but Alberta has no guidelines around HIV status and this occupation.

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For the First Peoples

Trevor Stratton and **Melissa Egan** source out organizations that foster the health and wellness of HIV-positive Aboriginal people.



All Nations Hope

Regina, Saskatchewan

All Nations Hope is bursting with people as its lunch program gets underway. This small agency brings together Aboriginal people living with HIV and/or hepatitis C over meals, workshops and support services. Founded in 1995, the Aboriginal AIDS service organization (ASO)—the only one in Saskatchewan—has been steadily increasing its reach around the province.

All Nations Hope has a strong connection to the people who use its programs. When you walk in the door and are greeted by the welcoming personality of community outreach worker Wesley Keewatin, you can't help but feel a sense of family. Keewatin makes those first steps inside easy for even the shyest newcomer.

In addition to community outreach and HIV and hep C education, the organization offers a women's group and a men's group, which both use talking circles, ceremony and arts and crafts as pathways to healing. The Place is a safe space for people to socialize, grab a bite or cup of coffee, get some clean clothes or just hang out. The community also gathers for Friday afternoon matinees, quarterly Aboriginal life-skill sessions and youth leadership training.

www.allnationshope.ca

306.924.8424 or 1.877.210.7622

2-Spirited People of the 1st Nations

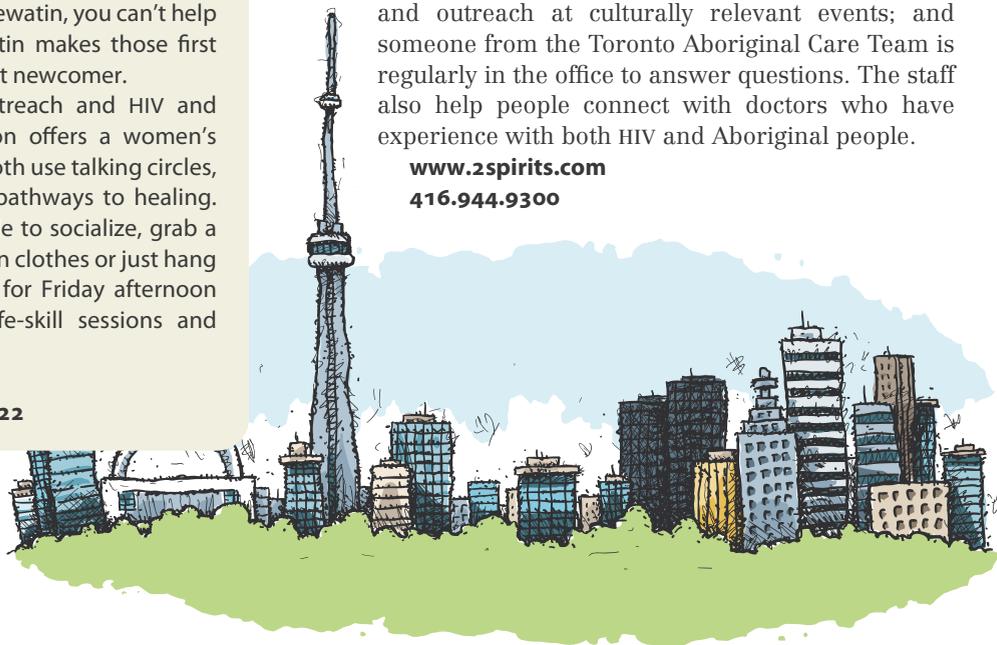
Toronto

The hectic buzz of downtown Toronto's busy Yonge Street is not the first place you'd expect to find an organization that makes so many people feel welcome, but that's exactly where you'll find executive director Art Zoccole and the dedicated staff of 2-Spirited People of the 1st Nations. This energetic group has been providing services to gay, lesbian, bisexual and transgender Aboriginal people in Toronto for nearly 20 years. The staff is a small and committed group (some have been involved since day one) who make sure that members are always connected to the support they need. More than 80 volunteers drive members to appointments and other services and help the organization collect much-needed donations from around the city.

2-Spirits is there for those who are newly diagnosed with HIV. The client care coordinator helps people access local services; awareness and knowledge are fostered through educational workshops and outreach at culturally relevant events; and someone from the Toronto Aboriginal Care Team is regularly in the office to answer questions. The staff also help people connect with doctors who have experience with both HIV and Aboriginal people.

www.2spirits.com

416.944.9300





Labrador Friendship Centre

**Happy Valley-Goose Bay
Newfoundland and Labrador**

Tucked into the small town of Happy Valley-Goose Bay, on the ruggedly beautiful east coast of Canada, the Labrador Friendship Centre has been offering services to Metis, Inuit and Innu people in the area since 1974. The Friendship Centre's vibrant HIV/AIDS Labrador Project opened in 2000 in response to the Labrador HIV/AIDS Surveillance Study, which found a gap in knowledge about HIV among Aboriginal communities in the area, and out of a strong desire to educate as many people as possible about HIV and AIDS.

By conducting outreach and workshops at events around the region as well as visiting schools and communities, the HIV/AIDS Project continues to thrive. It has built strong relationships with NunatuKavut (the Labrador Metis Nation) and other local networks to plan prevention programming. The HIV/AIDS Project is dedicated to increasing participants' comfort in discussing sexuality and drug use while connecting them to the wide range of services offered at the Friendship Centre.

www.lfchvgb.ca
sdiamond@lfchvgb.ca
709.896.5144



Vancouver Native Health Society

From the street it's easy to miss this unassuming grey building, but the Vancouver Native Health Society (VNHS) has become a centre of support for Aboriginal people in the city. Established in the Downtown Eastside in 1991, this stable and well-respected organization provides frontline care to over 1,500 people living with HIV, many of whom are struggling with issues of addiction, homelessness, mental health and poverty. The Society uses the medicine wheel in its holistic approach to the complex lives of its clients.

The Positive Outlook Program for people with HIV offers activities that address participants' physical, spiritual, mental and emotional needs and guides the creation of trusting relationships between clients and healthcare services around the city.

Every Wednesday, more than 50 women connect over a healthy meal and some lively conversation. A play area for children, free haircuts, manicures and clothing are also part of this supportive program. The Dudes' Group, a unique space for men to trade stories and wisdom while sharing a meal, is another one of the agency's success stories. Offered every second Thursday, it consistently draws nearly 60 male clients. Primary healthcare is offered to all the women and men who attend the groups.

VNHS staff approach their work with a deep respect for First Nations cultures. Its welcoming drop-in as well as its food bank, counselling, a program to help people with HIV stick to their pill-taking schedules and on-site physicians, nurses and social workers allow clients to get what they need in a place they trust.

www.vnhs.net
604.254.9949

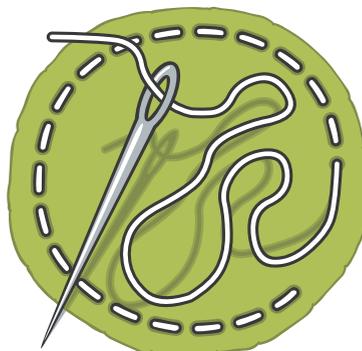
Native Women's Shelter of Montreal

The Native Women's Shelter of Montreal has been offering shelter and support to Aboriginal women and their children since 1987. As part of its constantly evolving services, it created the Holistic Health Project—a program to support women affected by homelessness, the sex trade, HIV, substance use and family violence—that is open to all Aboriginal women, regardless of status. Its activities include a quilting project designed to raise awareness and break stigma around HIV and sessions with Aboriginal Elders who provide traditional teachings on health. "The Project really focuses on finding balance between the four aspects of health—spiritual, emotional, physical and mental," says project leader Carrie Martin.

Two years ago, the shelter set up an onsite medical clinic, which includes testing for HIV, hepatitis C and other sexually transmitted infections (STIs). When a woman tests positive, Martin works with her to seek medical care at a local clinic. The Project also presents workshops on HIV, hep C and STIs and hosts talking circles for women who use substances.

www.nwsm.info
514.933.4688 or 1.866.403.4688

Aboriginal people living with HIV can also check in with the Native Friendship Centre of Montreal.
www.nfcm.org or 514.499.1854





Best in Show

5 people with HIV tell the truth about cats and dogs

INTERVIEWS BY **RONNILYN PUSTIL**

MARK LIPTON, 43

Toronto

HIV+: 17 years

DOG: Bingo Falafel Lipton, 14

BREED: Rat terrier

NICKNAMES: Bingus, Bakalaka, Mr. Handsome.

What made you decide to get a pet?

I didn't. My ex-boyfriend came home one day in 1998 and said: "I got you a present. This will save your life." And he presented me with this crazy puppy he had rescued. I'd been having difficulty dealing with my HIV diagnosis. Many of our friends were dying and I was feeling very lonely and depressed.



And did Bingo save your life?

Yes, in many ways. He also got between me and the boyfriend, and when I had to choose between them, I took the dog and ran. For the first few years Bingo didn't let me have strangers in the house. He would bark at them or attack them, which forced me to choose who I brought home more carefully. In this way, he kept me in check.

How does Bingo affect your quality of life?

He keeps me active because I have to go to the park with him several

times a day. He keeps me centred because I have to step away from whatever I'm doing and give him my focused attention a few times a day. He reminds me to eat, because when I feed him, I remember to eat myself.

Does he still attack strangers?

He's mellowed as he's gotten older. Also, I've since gotten married and my husband is much better at domesticating and training him. I had accepted that I had a wild dog, but my husband has tamed him...and me as well!

Does Bingo do any tricks?

Absolutely! Bingo can sing. And he can balance a cookie on the tip of his nose and hold it there until you say "go!" Then he flips it and catches it in his mouth.

What has Bingo taught you?

He's taught me to breathe, to trust and to stretch. He's taught me great patience. He's taught me how to love.

RICHARD BAKER, 42

St John's, Newfoundland

HIV+: 24 years

DOG: Charlie, 9 months

BREED: Border collie and lab mix

NICKNAME: Charlie Brown

Why did you decide to get a pet?

My partner and I lost Sonny, our 10-year-old black lab, last May. Shortly after, we realized we couldn't live without a dog. So we started looking for a small dog (Sonny was 120 pounds). I found out that there was someone looking for a good home for a 10-week-old pup that was left on their doorstep. When we went to see him, we fell in love, but he was going to be big. We thought for a minute and then found out that he was born the day

that Sonny passed away. Talk about karma! We had to get him.

How does having a pet affect your quality of life?

Charlie makes me feel needed.

He motivates me to go outside for walks, which is hard for me with my medical conditions. And without him, my mental health would be a lot worse.



Does Charlie do any tricks?

He can pick up bricks with his teeth and carry them around the yard.

What has your dog taught you?

That love, laughter and patience go a long way.

CHARLENE ANDERSON, 50

Victoria, BC

HIV+: 21 years

2 CATS: Min, 12, and Mr. V., 5. When we first got Mr. V., they said he was a girl so we called him Miss Vivien, but then he developed testicles so we changed his name.

DOG: Pekoe, 4

BREED: Pug

NICKNAMES: Pekoe is the only one with nicknames—Pig and Squeako.

How do your pets affect your quality of life?

They make me participate in life. Having responsibilities makes me accountable, especially having a dog. I have to walk her a few times a day, which keeps me motivated. I've developed some good relationships because of her; there's a group of us that goes on dog walks five days a week. And she keeps me calm. When things are going on, there's nothing better than having my little Pig curl up in my lap. It's unconditional love from all three of them.

Do they all get along?

Yes, but the dog knows that she's at the bottom of the food chain. When the cats go by, she just looks the other way.

Do any of your pets have remarkable talents?

Pekoe does everything: She rolls over on command, dances and gives you a high five and high 10. She also enjoys dressing up. In Victoria we have the Big Gay Dog Walk, as part of Pride week activities. Pekoe has won the prize for best tricks and the prize for best-dressed pet—she wore her pleather vest and rainbow tutu. She was in the newspaper; they called her “the essence of Pride.”



What have your pets taught you?

Pekoe has taught me to not judge people. We go to an off-leash dog park where you get the big burly dogs with their big burly owners who look scary until you get them to talk about their dogs and they turn to mush. Also, I volunteer and I'm on the board at AIDS Vancouver Island. I bring Pekoe there sometimes and she loves everybody unconditionally.

BRENDA CAMPBELL, 54

Regina, Saskatchewan

HIV+: 2 years

14 CATS: Pinky, Sambo, Babykins, Cocoa, Noodles, Miss Tippi, Rascal, Peekaboo, Minnie, Jellybean, BJ, the Bear, PJ and Pinto, the kitten.

Whoa! How do you keep track of them all?

I try to keep them inside because I live on a busy street. When they do go out, they always come home, except for Rascal. That one I've got to watch.

Do you have any favourites?

Babykins—and he knows it. He's spoiled rotten. He sleeps with me all the time, just curls up in my arms. He's adorable. Of course, they're all adorable. Sambo's the gay cat. I always have to chase him to get him off Babykins. He's also toothless.

Why 14 cats?

I'm the cat lady! My eyes are green and my sign is Leo. Some people actually know me as the cat lady; they don't know my real name. I have so many because no one wanted the kittens from the last batch, so I ended up keeping them.

Are there ever any catfights?

Sometimes. When the full moon is out, they act up.

How do your cats affect your quality of life?

If it weren't for them, I wouldn't be around now. I've been off cocaine for over three years because I realized that I wasn't taking good care of my cats. They are more important to me than drugs. I'm a breast cancer survivor, I have MS, hepatitis C and HIV. **My cats give me the will to live.** It's hard work taking care of myself and all the cats, but it's worth it.

Do any of your cats do special tricks?

Sambo used to steal my bra every time I went into the bath. Also, he doesn't usually cuddle up with me, but whenever I get my cheque, he curls up to me. It's like he knows it's tuna day.

What have your cats taught you?

I grew up on the streets, and my cats have taught me that I could love and be loved unconditionally.

DENISE BECKER, 53

Vernon, BC

HIV+: 22 years

DOG: Ziggy, 3

BREED: Doberman pinscher

NICKNAMES: The Zigster, The Zigmeister, Zig, Puppy Dog, Poppit. His show name is Liberty's Walks with a Friend.

Why did you decide to get a dog?

Why not? They are the greatest companions. Dobermans are smart, short-haired, loyal, indoor dogs—and they're great defenders. They are also astoundingly good at picking up men.

Does having a dog affect your quality of life?

Absolutely! When I am sad, he comes over and licks my tears. In the morning, he gets me out of bed with incessant whining. During the night, he gets up and comes to my side of the bed just to check on me and then returns to his bed. He sleeps on my feet, which is not only warm but also comforting. He makes me feel safe from intruders when I am on my own.

Does Ziggy have any remarkable talents?

When I say “dead dog,” he falls to the ground; then when I say “doggy heaven,” he circles the table; and finally when I say “pearly gates!” he reaches up and licks my nose. He's a show dog so he can stand like a statue for about a minute without moving. He licks me when I say “kisses” and he licks my boyfriend when I say “Kirk kisses.”

What has your dog taught you?

Ziggy has taught me to always forgive. Dogs seem to have huge hearts and forgive humans for some crazy things. Also, he's taught me that he will never judge me for anything and he would defend me to the end. He's sad when I am away and glad when I come home. He makes me feel wanted and needed—in fact, loved.



Is it true that Ziggy has his own Twitter page? What does he tweet about?

Yes. I am amazed at all the other dogs and cats that have befriended him. Ziggy tweets a lot about his owner and writes things like “Breakfast: kibbles again!” His Twitter handle is @akaLordVader. +



Love is patient

All Due Respect

Lawyer and AIDS activist **Jeff Keller** takes on stigma and discrimination in his mission to ensure that people are treated with the respect they deserve.

BY **ASTRID VAN DEN BROEK**

PHOTOGRAPH BY CURTIS TRENT

Jeffrey T. Keller doesn't consider himself an activist. "I don't think of myself as one," says the Edmonton-based family law lawyer, "because I have a full-time job too." Full-time job or not, it's hard not to see an activist's desire to disturb the status quo in this man who has written an essay titled "On Becoming a Fag" and has "HIV+" tattooed on his forearm.

Instead, Keller says, "I'm just helping on the side." To be fair, his work from the sidelines is considerable: He writes, he teaches and he has made valuable contributions to the AIDS movement. The passionate and eloquent presentations he has given at public forums, conferences and AIDS vigils have run the gamut from sex education and HIV prevention to mental health to HIV and criminal law. Until recently, he was vice-chair of the Canadian AIDS Society (CAS) board and, before that, the chair of HIV Edmonton.

Keller is the kind of lawyer—and man—who fights against injustice at every turn. He advocates for the

mistreated and defends the vulnerable. If his work doesn't tell you that, then the "Respect everyone" tattoo on his inner right forearm will.

You could say that respect is the thread that runs throughout his life's work—his studies, his advocacy work and his career as a lawyer. Growing up in Smalltown, Saskatchewan, Keller experienced firsthand how it feels to be disrespected and bullied. Now, he advocates for the rights and dignity of his clients and all people with HIV. In his personal interactions, he makes sure to actively listen and make a person feel like "a respected human being rather than a nameless person."

In 1994, Keller wrote "On Becoming a Fag," an essay that was published in the *Saskatchewan Law Review*. In it, he weaves together a moving account of his personal development as a gay man and his relationship to the "fag" label with a history of how religion, medicine and the law have persecuted gays and lesbians over the centuries.

The article caused an uproar in the province's legal community, prompting numerous letters to the editor and letters from lawyers who threatened to cancel their subscriptions.

Later that same year, Keller learned he had HIV. He was in the middle of studying for Christmas exams when he received the news at the University of Saskatchewan medical clinic. His doctor told him that he might have five years left before he got AIDS and would probably die within two years after that. Keller quickly sunk into a depression, barely making it through classes in the daytime and zoning out in front of the TV at night. But he trudged on, pushing himself to go to classes every day, determined to finish law school along with the rest of his class. "I took on the attitude that this stupid little virus was not going to control my life."

Right away, Keller was prescribed AZT, the only drug available at the time. A few years later, when effective anti-retroviral therapy (ART) became available, he switched to a combination of

the newer meds. Because he loathed the side effects and it was virtually impossible for him to deal with the gastrointestinal side effects while performing his demanding job for the Chief Justice of Alberta (where he worked after graduate school), he stopped the meds. With his doctor tracking his CD4 counts every four months, he managed to stay off ART until his counts started dropping eight years later.

Despite the side effects of those early drugs, when ART was introduced, Keller says he saw that “there was light, that things were going to get better and that we weren’t going to die.”

Right from the outset, the then 26-year-old was quite public about his HIV status. “It wasn’t a secret,” he says. “I was already known as the loudmouth gay guy in law school—I’d been talking about being gay and gay rights—and I figured AIDS was just one more thing to talk about.” Keller was the first openly gay male law student at the University of Saskatchewan. (“There had been a lesbian the year before,” he says. “Thank god for her!”)

Back then, fear and ignorance about HIV and AIDS ran more rampant but, for the most part, those around him were supportive. One professor taught a class in constitutional law and promoted quarantining gay men, but Keller simply avoided him. Similarly, there were different cliques of students, which allowed him to avoid one clique and opt for another.

Keller’s educating of others has taken many forms. At times, it involves talking directly to people. Like the time a fellow student pulled Keller aside, worried because he had just shaken Keller’s wet hand. Keller had to tell the student that he had simply spilled some water, that a person can’t become infected with HIV that way and that he could relax. Oftentimes, his awareness-raising has taken the form of public speaking. Other times it

comes via the tattoos he sports on his body, such as the “HIV+” tattoo.

Inspired by an article in the U.S.-based *POZ* magazine about a guy who had “HIV+” tattooed on his arm, Keller decided to follow suit. The tattoo was, in part, a political statement—a reaction to conservative writer and political

“These tattoos are like my scars of emotional battles survived and lessons learned, since most emotional battles don’t leave visible scars.”

commentator William F. Buckley Jr.’s infamous 1986 op-ed piece in *The New York Times* in which he suggested that those who are HIV positive be tattooed as such. It was also a personal statement that he had control over his own body: “It was about claiming my body when it can sometimes feel like this virus and all the do’s and don’ts (‘take these meds at this time,’ ‘don’t share razor blades’...) are controlling your life.”

His other tattoos (including a red ribbon with the date of his diagnosis on his right shoulder, and the words *Love is patient* over his heart) serve as

a mental touchstone for him. “In a novel I read, the main character said that scars and wounds should be considered beautiful because they’re reminders of a battle survived,” Keller says. “These tattoos are like my scars of emotional battles survived and lessons learned, since most emotional battles don’t leave visible scars.”

What has always driven, and continues to drive, Keller is his wish for others to avoid what he went through and his determination that all people be treated with the dignity and respect they deserve. He believes that if we were all treated like we mattered, then we would do away with stigma and discrimination. As a result, we would start treating our own bodies and ourselves with more respect and we would be able to take steps to prevent infection. For Keller, this is key to preventing HIV/AIDS.

In his law practice, too, he advocates for the mistreated. He loves representing children whose parents are fighting for their custody. He sees himself as playing a role in their lives, treating them with dignity and helping to build their self-esteem.

Since stepping down from the CAS board after four years (he felt the need to slow down), Keller continues to work as staff counsel with Legal Aid Alberta, but sees this as a time to re-evaluate his life. Keller also ended a painful year-long relationship last year, and a nine-and-a-half-year relationship before that; as he puts it, it’s time to pull over to the side of the road to re-examine the map of where he’s going. And with his health in the condition it’s in—he’s been undetectable for more than two years now—the future looks bright.

If Keller’s tattoos are a map of his journey with HIV, what’s the next route to be laid down? “It’s so un-original,” he laughs, “but it has meaning in my life: *Carpe diem*, on my left bicep. It’s a reminder of things to do: Seize the day, keep going.” +



From Injection to Infection

In the early 2000s, facial wasting—the loss of the fatty layer just under the skin on the face, particularly in the cheeks—was a real concern for people with HIV on anti-HIV therapy. With its signature sunken cheeks and resulting gaunt appearance, facial wasting can cause a lot of psychological and emotional distress. It can affect one's self-esteem and it carries a huge social stigma because it pinpoints people as HIV positive. Needless to say, many people with HIV who were affected by it looked for ways to improve it.

Facial wasting has been linked to the anti-HIV drugs d4T (stavudine, Zerit) and, to a lesser extent, AZT (zidovudine, also in Combivir and Trizivir). Fortunately, these drugs, especially d4T, are no longer commonly used in Canada now that other meds are available. As a result, facial wasting is much less of a problem today. Changing drugs was a way to stop the wasting but it usually didn't reverse it.

Facial fillers—synthetic polymers injected under the skin to replace the lost fat—was another option. One commonly used product was poly-L-lactic acid (Sculptra). However, Sculptra is absorbed into the body after a few years and new implants are then needed. Another product used was polyalkylimide gel (Bio-Alcamid). Initially, it seemed that Bio-Alcamid

A Canadian doctor advises people with HIV who have facial fillers to take extra care when having dental work done.

was advantageous because, unlike Sculptra, it was a permanent implant and would not degrade. However, reports began to emerge from Western Europe of inflammation and infections in both HIV-positive and -negative people with Bio-Alcamid implants. As a result, several plastic surgery societies now discourage the use of Bio-Alcamid and other permanent implants.

FINDING INFECTIONS

In 2005 Sculptra was not available in Canada—it would become available in late 2009—and Bio-Alcamid was still experimental. Dr. Mona Loutfy, an infectious disease specialist at the Maple Leaf Medical Clinic in Toronto, and her colleagues set up a study with 36 participants to assess the permanent filler. The study was designed to last only two years; however, Dr. Loutfy began to notice infections and other complications in study participants and in other people with facial fillers. The research team decided to extend the study to four years and now has plans to continue for a total of 10 years.

In late 2011, the research team reported on the four-year study. It confirmed that the use of Bio-Alcamid can be associated with complications over

the long term. Infection was one of the most common complications seen in the study. After an average of three years following injection, about one in four people had a confirmed or suspected infection in the face. In some cases, these infections were troublesome and required long-term treatment with antibiotics and surgery.

THE LINK TO DENTAL WORK

Interestingly, the researchers found that people with confirmed infections had had prior dental work. It is possible that this work, which included routine dental cleaning, may have damaged or contaminated the Bio-Alcamid implants with bacteria, leading to infections. As a result, Dr. Loutfy recommends: "HIV-positive people who have facial implants should always tell their dentists, hygienists and surgeons—any oral healthcare professional—about their implants prior to receiving any dental care."

She also has recommendations for oral healthcare professionals: Avoid injections into the upper gums leading into the cheek area, because they might puncture the implant and lead to infection. As well, she suggests that dentists offer their patients with facial fillers a broad-spectrum antibiotic one hour before dental work, including routine cleaning, to reduce the risk of infection. +



Treatment Benefits for All

CATIE's **James Wilton** explores the use of HIV treatment to reduce the risk of HIV transmission. Do the personal and public health benefits coincide or clash?

ILLUSTRATIONS BY KELLY SCHYKULSKI

The journal *Science* named it the breakthrough of 2011 and *Time* magazine ranked it among its Top 10 medical breakthroughs of the year, so you may have heard of the term “treatment as prevention” by now. If not, we can fill you in. It has at its core the idea that HIV treatment can reduce the risk of HIV transmission, and it is set to mark a historic shift in how we think about the HIV epidemic.

When effective antiretroviral treatment became available in 1996, forward-thinking researchers began speculating that the drastic drops in viral load that occur when people with HIV take treatment might reduce the risk of passing the virus to others. But there was no evidence to back up the idea. In the past few years, as more and more studies confirm this theory, the distinction between treatment and prevention has become increasingly blurred. Last year the strongest evidence supporting the use of treatment as prevention was announced: A study known as HPTN 052 demonstrated that starting antiretroviral treatment earlier could dramatically reduce the risk of HIV transmission among serodiscordant heterosexual couples (in which one partner is HIV positive and the other is HIV negative)—by 96 percent. Some researchers now say that treatment IS prevention, and we are hearing bold claims that the end of the epidemic is within sight.

In real-life terms, treatment as prevention involves getting more people with HIV diagnosed and on treatment. While ending the epidemic is a laudable goal, what does this mean for individual people with HIV—the people who face every day the reality of living with the virus and being on HIV treatment? There are concerns that these public health efforts may come at the cost of the rights of HIV-positive people. At the same time, treatment as prevention could improve access to the services needed for people with HIV to live healthy lives.

TWO PERSPECTIVES

We can think of treatment as prevention in two ways: as a prevention strategy for individuals and as a public health strategy. Both have implications for people living with HIV and each raises its own set of issues.

A prevention strategy for individuals – An HIV-positive *individual* may want to use treatment to reduce his or her risk of passing HIV to others. Research shows that people living with HIV who are on treatment and have an undetectable viral load are, on average, less likely to pass HIV to others. However, there are several caveats and gaps in the research, which make it difficult to know exactly how well this strategy would work for each individual. (For more on

viral loads and the biology of HIV transmission, check out “Sex, Drugs and Viral Load” in the Winter 2008 issue of *The Positive Side*.)

A public health strategy – Since we know that treatment can reduce the risk of an *individual* transmitting HIV to his or her partner, it follows that increasing the number of people on treatment in a *community* prevents a large number of transmissions. The overall goal of treatment as prevention from a public health perspective is to increase the number of HIV-positive people with an undetectable viral load in a population and thereby decrease the number of new infections.

SEEK, TEST, TREAT

A major challenge to the success of such a public health strategy is the large number of people who are HIV positive but don't know it. In Canada, about one quarter of people living with HIV are unaware of their status. If people don't know they are HIV positive, then they can't consider starting treatment and are unlikely to have an undetectable viral load.

To tackle this issue, health officials have developed a “seek, test and treat” strategy, whose goal is to *seek* out undiagnosed individuals, *test* them for HIV, and *treat* those who test positive and are ready to start antiretroviral therapy.

Increasing the number of people who get tested is good for both the health of people with HIV and for HIV prevention. For people living with HIV, it can mean getting diagnosed sooner and getting the treatment and support they need. (Many people in Canada aren't learning about their status until they are in the late stages of HIV infection and this often means worse health outcomes.) For HIV prevention, more testing can mean diagnosing more people at an earlier stage of infection. People can then take steps to prevent passing the virus.

Reactions on the ground have been mixed: Treatment as prevention has been hailed as a “game-changer” but some worry about the potential for coercion and that services may focus exclusively on testing and treatment.

Ken Monteith, the executive director of COCQ-SIDA in Montreal who was diagnosed with advanced HIV in 1997, has concerns that a treatment as prevention strategy could potentially pressure or mislead people into getting tested and starting treatment for the sake of broader public health goals. “When I hear ‘seek, test and treat,’ it sounds aggressive to me. We need to make sure that a person consents to being tested and to starting treatment,” he says. “People

must have the right to say no. We need to make sure that measures are in place for people to have their decisions respected and to make those decisions based on complete information about the advantages and disadvantages of being tested and starting treatment.”

The Canadian HIV/AIDS Legal Network's executive director, Richard Elliot, is worried about the shift to routine testing and about “opt-out” testing (where a healthcare provider tests unless the client or patient refuses). “The healthcare provider should always ask if you would like to be tested and testing should only be done if the person accepts that offer, rather than just presuming that someone consents to an HIV test unless they specifically say they don't want one. This is an ethical obligation and a human right.”

Elliott also stresses that informed consent requires that people be aware of the possible negative consequences of testing positive for HIV. For example, he notes that people

with HIV can be criminally prosecuted for not disclosing their HIV status to sexual partners and that there is a possibility for health information, including a person's HIV status, to be shared. He says that these “are things people need to understand in order to make an informed decision.”

Even when testing is “opt-in,” the issue of informed consent isn't always straightforward. For example, the four major acute-care hospitals in Vancouver now offer an HIV test to each and every person who is admitted. As Marcie Summers, executive director of the Positive Women's Network in BC, points out, “If you've been admitted with a case of acute appendicitis, are writhing around in pain, and someone offers you an HIV test, how informed will your consent be?”

STARTING TREATMENT EARLIER

To further the aims of the public health approach to treatment as prevention—increasing the number of people on treatment—another strategy is to have people with HIV start treatment earlier than current treatment standards.

Many guidelines in developed countries currently recommend starting treatment when a person's CD4 count drops below 500. However, in light of the recent evidence that starting treatment earlier may improve the health of people living with HIV and lower the risk of transmission, the U.S. Department of Health and Human Services, which produces the granddaddy of HIV treatment guidelines, recently changed its guidelines to recommend starting treatment in *all* HIV-positive people who are ready to start.

“We need to make sure that a person consents to being tested and to starting treatment.”

In the UK, guidelines released earlier this year do not recommend earlier treatment but advise clinicians to discuss with everyone who tests positive the potential for treatment to reduce HIV transmission. Quebec's HIV treatment guidelines acknowledge that treatment could be considered for lowering the risk of HIV transmission, and updates to the guidelines, currently underway, are expected to address in greater depth the concept of treatment as prevention.

This movement toward recommending treatment earlier has been met with some criticism. "The worry is that treatment is being suggested earlier than is generally indicated for the benefit of the patient," says Monteith. "Putting someone on treatment for the benefit of the public, and not primarily for the benefit of the person living with HIV, is ethically questionable."

Murray Jose, executive director of the Toronto People With AIDS Foundation and living with HIV for 21 years, is also concerned. "These changes represent a fundamental shift toward a public health approach to treatment instead of focusing on the well-being of the person living with HIV," he says. "The evidence isn't conclusive that the health of a person with HIV is going to be improved by starting treatment earlier. In fact, it's possible that the opposite is true because these drugs can be toxic and we don't know a lot about their long-term side effects, particularly for the newer medications."

Despite these concerns, Jose recognizes that giving people the option to start treatment earlier to reduce their risk of transmitting HIV to their sex partner(s) is important. "People living with HIV should absolutely be given all the options. But I worry that newly diagnosed individuals may feel unduly pressured to start treatment in order to reduce their risk of passing HIV to others."

HOLISTIC CARE

AIDS service organizations from coast to coast to coast have long known the value of providing holistic care to people with HIV. Testing and treatment are crucial pieces of the puzzle but not the whole story. Many people with HIV look for different kinds of support when they are first diagnosed and also when they decide to start treatment. A holistic approach can help people stay connected to their care team, stick to their pill-taking schedules, provide emotional support and ensure that more people achieve an undetectable viral load.

Jose believes that engagement in care needs to improve in Canada. "There is just no excuse for the poor access to prevention and treatment services that exists in Canada, particularly among Aboriginal populations, prisoners and newcomers to Canada," he says. "If we can use this new evidence on treatment as prevention to push for improved access to services, then that's great, but the focus and motivation needs to be the health and well-being of the person living with HIV, not just prevention."

Dr. Julio Montaner, director of the BC Centre for Excellence in HIV/AIDS and a lead proponent of treatment as prevention, has been a driving force behind a pilot project in BC called STOP HIV/AIDS. The project, focused on Vancouver and Prince George, aims to cut HIV transmissions by expanding HIV testing, treatment and support services.

Marcie Summers has had the opportunity to learn about STOP HIV/AIDS and to see treatment as prevention in action. "One of the main goals of the project is not just to increase HIV testing but also to engage people living with HIV in care. Quite a few of the initiatives that are part of the STOP HIV/AIDS project are improving engagement in care quite effectively, particularly for people who have fallen through the cracks of

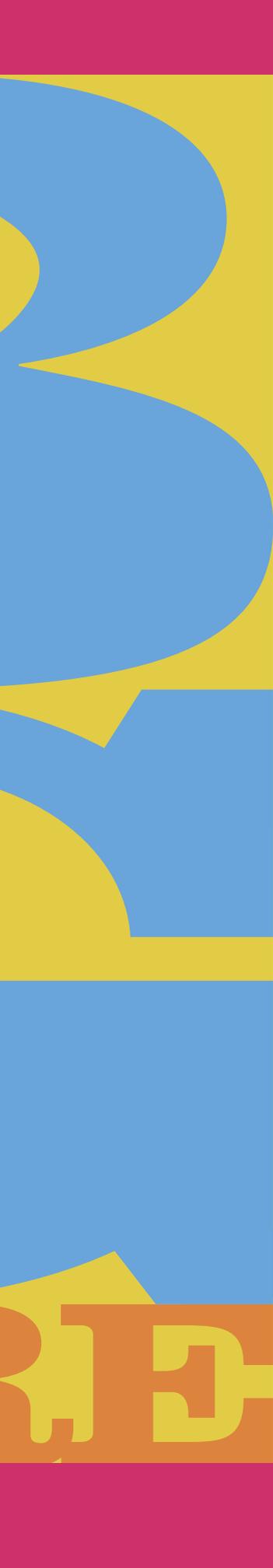
our healthcare system. This includes people who have tested positive and haven't accessed healthcare or people who were on meds and went off them for some reason. There was initially a lot of skepticism about STOP, and there still is, but there are some really good initiatives going on."

STOP HIV/AIDS is a concrete example of the momentum that is building toward a shift in HIV policies and programs. Promising research on treatment as prevention has led to strong arguments for better integrating treatment and prevention services, but the rights of people living with HIV need to be at the centre of this new approach.

The Legal Network's Richard Elliott thinks this is possible: "Public health goals and human rights are largely complementary. Achieving the highest attainable state of health for the individual and for all individuals are human rights goals. In the big picture, if you go about pursuing public health goals without protecting and respecting the human rights of individuals, then people's trust in the health system will erode and achieving HIV prevention goals is going to be more difficult. Scaling up treatment should be done both because it's good for individuals who need treatment and because we know that treatment is a way to protect public health more generally." +







Peter Carlyle-Gordge takes a look at HIV art and HIV-positive artists in Canada. Here are four of our favourites.

A

rtistic expression can be many things. It can be educational or a call to action. It can be soothing or shocking. It can reflect our times and passions. At its heart, however, it is an expression of the individual artist and his or her engagement with life.

Artists have been involved in the HIV epidemic since its earliest days, when there was little to medicate and much to terrify. In the U.S., ACT-UP's artistic offshoot Gran Fury helped push the epidemic in the face of the establishment, reminding us all that SILENCE=DEATH. Slowly, politicians and people began to get the message: Stop pretending that AIDS isn't happening and start taking action against it. A too-complacent and bigoted world needed to be shocked into spending money, developing drugs and finding a cure.

Canadian HIV-positive artists and their HIV-negative allies were also addressing the epidemic. General Idea—composed of Felix Partz, Jorge Zontal and AA Bronson—is one of the country's best-known collectives of AIDS-activist artists. Active from 1967 to 1994, by which time both Partz and Zontal had died of AIDS, they were pioneers of early conceptual and media-based art.

General Idea addressed the AIDS crisis with work that included some 75 temporary public art projects from 1987 to 1994. Their major installation, "One Year of AZT/One Day of AZT," was featured at the Museum of Modern Art in New York City and now resides in the collection of the National Gallery of Canada in Ottawa. The irreverent collective is perhaps best known for its 1989 AIDS graphic, inspired by Robert Indiana's iconic LOVE image.

While art was drawing attention to the unfolding epidemic, HIV-positive artists were living with a disease that, at the time, was usually fatal. For many, art was a way of processing this grim future and honouring those who had died of AIDS. Bob Sirman, director of the Canada Council for the Arts in Ottawa, was involved in Canada's art community during those early years of the epidemic. Art can be therapeutic, he explains: "We all have great challenges to find meaning in life. I think art helps us to find a sense of order and meaning when huge challenges like HIV come up."

The introduction of effective antiretroviral therapy (ART) in 1996 meant that the virus could be brought under control and death could be averted. Art filled with rage, denial and sadness was replaced by life-affirming work. More recently, a new generation of HIV-positive artists is raising again the banner of arts-based activism, marching in the footsteps of their predecessors. The art of four people living with HIV, whose stories we share in the coming pages, illustrates this evolution of HIV and art in Canada over the past 30 years.



“Facsimile” series, 1990–1993 (detail). At the core of this series are images taken from the obituaries of young men and women who had died of AIDS. Before being rendered on wax tablets, the images were faxed and photocopied, slowly erasing the identity of each person, similar to the way that AIDS was erasing large swaths of the community. “Those directly affected by the pandemic used the work as a memorial,” says artist Stephen Andrews. “Some people came to an art gallery for the first time just to see the portrait of their loved ones.”

The Lazarus: STEPHEN ANDREWS

The work of noted Toronto artist Stephen Andrews hangs in many collections and art galleries, including the National Gallery in Ottawa. Now it can also be seen in Toronto at the Trump International Hotel and Tower, which commissioned a 950-square-foot mosaic version of his work “A Small Part of Something Larger.”

In his early days, Andrews often worked in monochrome and made collages, drawings and photographs. Then came AIDS. He was diagnosed in 1992 but thinks he may have been positive since 1985.

The year after his diagnosis, 15 of Andrews’ friends died. In the same week Andrews lost his partner—landscape artist, writer and theorist Alex Wilson—and his studio mate Rob Flack, whose work in the period leading up to his death focused on vibrant depictions of the chakras and other internalized healing energies.

Andrews himself wasn’t in good shape. “My health went off the rails,” he says. “I was losing my sight, had about 40 T cells and weighed about 100 pounds.” But his “glass-half-full” personality kept him philosophical about it all: “I figured I had a good body of work and I was resigned to the idea that the end might be soon. I was ready to go.” And then it occurred to him that he was basically just waiting for an appointment with death.

His art kept him going and kept him in the present. “Denial was my friend and I stayed on today’s page, not the future or past.” Indeed, the pages that Andrews found himself drawn to at this time were the Proud Lives



obituary pages from Toronto’s *Xtra!* newspaper. These commemorative photos would become the starting point for his “Facsimile” series (see image above).

“It was produced from 1990 until 1993, during the time when many people were dying weekly and there was still widespread ignorance and fear about the disease,” Andrews says. “It was also prior to the construction of the AIDS memorial behind the 519 Community Centre, so my intention was to memorialize my friends, colleagues and the community that was stigmatized.” Andrews says his art was

never intended to shock people. “I find that [shock] is a less-than-useful strategy to convince an audience to engage in dialogue.”

When ART became available, Andrews experienced what many at the time referred to as the Lazarus effect—he came back to health from near death. He regained his energy and it seemed as though life’s train wreck might have a happy ending after all. “When my health returned, I began working in colour,” Andrews says. “Suddenly there was promise of a future and I wanted it to be in Technicolour”—similar to the moment in *The Wizard of Oz* when Dorothy is blown out of Kansas into Oz and the film turns from black and white to colour.

Andrews’ work spans 30 years and has been exhibited in Canada, the U.S., Brazil, Scotland, France and Japan. Describing the evolution of his ideas over that time, Andrews says, “Generally, there is a news story behind a given body of work—be that AIDS, war or advances in surveillance technologies. The ideas embodied in these stories are like irritants and the work accretes around them like pearls.”

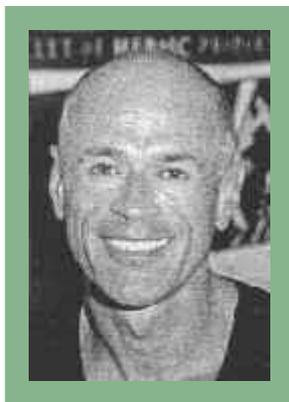
The Community Voice: TIKO KERR

Artist Tiko Kerr's work evokes the spirit of Van Gogh and Dali. Colour and light are primary in the Vancouver artist's vision but they take second place to his strong intuitive sense of movement and spatial orientation. For Kerr, everything is alive. His buildings lean and warp and threaten to topple, while streets heave. The colour is intense and richly pigmented.

Kerr spent his time between studios in Australia and Vancouver until he was diagnosed with HIV in 1985. "It was a huge shock and of course there were no drugs, not even AZT, to treat it," he says. "I came back to Canada and got great care at St. Paul's Hospital." His art served to keep him going, even as his health slowly declined. His goal became to accomplish at least one thing every day. At one point, Kerr admits, that goal was simply to get out of bed.

Today he has a renewed perspective and has learned how to raise his voice when needed. In 2005, Kerr took on the Canadian government, demanding access to experimental antiretroviral drugs that were his only chance of survival. The government initially said no, but after 10 months of a very public campaign, Health Canada reversed its decision in Kerr's favour. Access to those experimental drugs allowed Kerr to return to health and to creating his art.

Kerr says that much of his HIV-focused work since his revival in 2005 involves psychological portrayals of his hospital treatments (see image below) as well as a series of self-portraits that were painted on the vast accumulated



medical paraphernalia—pill bottles, syringes and vials—that is a byproduct of antiretroviral therapy.

During the more than three decades that Kerr has been an artist, his work has become a complement to the task of dealing with HIV. "When the virus was strong," he explains, "my work weakened, became darker, with quieter themes and solitary scenarios. Then, when a new medical regimen kick-started my immune system, my work soared in intensity, complexity, confidence and scale. The two entities have each become half of a new method of working and digesting the realities of my life."

While Kerr's art-making may be influenced by HIV, his art is not limited to it. "Since overcoming the situation with Health Canada and especially since my community has been so demonstrative in supporting my work and me, there has been a shift to my art becoming more and more a vehicle of social justice."

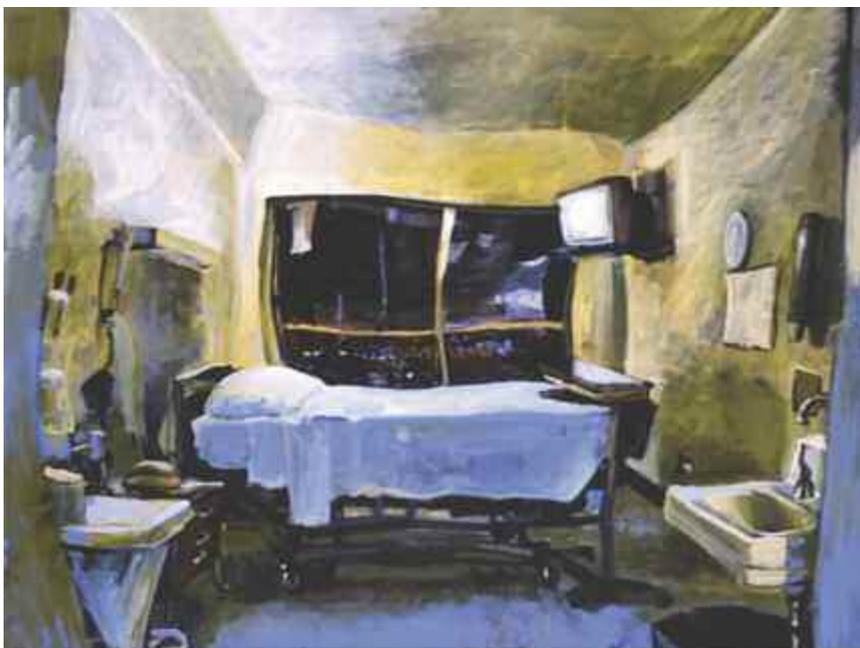
Kerr's series "You Are Here," for example, explored the notion of what Vancouverites call home. The paintings described places on English Bay, shopping carts under expressways, a woman who lives in her BMW, as well as residential buildings in which the renters have faced "renoviction" (a term that has sprung up in Vancouver to describe landlords' attempts to evict tenants on the premise of renovating units before dramatically raising the rents).

"My goal has always been to represent honestly the time in which I live and to give life to images and issues that might resonate with my community, the community that came out to support me when I needed them so badly," he says.

"Meditations on Compassion," 2006.

The painting depicts a vacant room that artist Tiko Kerr became familiar with at St. Paul's Hospital in Vancouver during a period of illness. The only movement in the room, he recalls, was the blue glow of the flickering television.

Kerr began the piece at a time when his anger and frustration were peaking, after 10 months of struggling with Health Canada for access to two experimental drugs. "The working title was 'My Government is Trying to Kill Me,' because if I was to succumb to AIDS, I wanted to leave a record of this injustice," he says. "In January 2006, I received news that the drugs would be available, and with a cooler head, I renamed the painting."



Tiko Kerr and Stephen Andrews survived a time when many other HIV-positive Canadian artists did not. In addition to General Idea's Felix Partz and Jorge Zontal, the art community in Canada also lost to AIDS many other vital members, including Aboriginal ballet dancer Rene Highway, artist Tim Jocelyn, poet and academic Michael Lynch and Newfoundland comedian Tommy Sexton.

The Radical: JEAN-PIERRE PERUSSE

A new generation of HIV-positive artists has been shaped by the current medical and social realities of the virus—longer lifespans for people with HIV, but in a society where the virus is forgotten, ignored or still stigmatized.

Montreal's Jean-Pierre Pérousse, a film and TV actor with training in multimedia, martial arts and dance, has a fondness for artistic propaganda that shocks. Long active in the world of HIV and AIDS, he says he likes to “bang on closed doors”



“Betty Crocker,” 2008.

In this campy piece, Quebec dancer Cynthia Milaire is a classic '50s housewife doing a most ordinary thing—feeding her baby. But the sanitized kitchen and rubber dishwashing gloves belie a fear of infection. “Our intent was to show the stigmatization of even the youngest living with HIV and the paranoia of catching it,” explains artist Jean-Pierre Pérousse.

and bring people out of their ignorance. He does not believe in what he calls “the victim thing.” He says, “I want people to see that you can live with HIV and have a purpose in life.”

Diagnosed in 1996, Pérousse was shocked at the reactions of people in the acting world when he disclosed his status. For one production, he recalls, “I was told that they could not use me, because there was a kissing scene. I was angry and hurt by that rejection. People were so ignorant.”

In 1999, Pérousse founded Radical 5, a company that brings together artists and technicians from all backgrounds, mixing traditional theatre with new media, to create videos, shows and mega-events. He has created and directed many theatrical dance shows for the Bad Boy Club of Montreal (BBCM), which holds large-scale party events, the profits of which are donated to charitable causes, including HIV.

His shows for BBCM have often featured HIV. “At first, I incorporated the AIDS theme in the main show, often as the villain that we were fighting.” In the 1999 edition, Pérousse set out to reflect music and dance from the time of French King Louis XIV to today. “The AIDS era was marked by ‘Why’ by Bronski Beat, preceded by ‘Love to Love You Baby’ by Donna Summer and ‘Sexcrime (Nineteen Eighty-Four)’ by the Eurythmics.”

In 2008, Pérousse teamed up with Montreal photographer Bob Hendricks to produce *Per7eption*, a poster series of seven photographs that represent how people with HIV perceive society and how society perceives them (see image, left). For example, the poster “Bond 00+” depicts Montreal DJ Mark Anthony posing as James Bond with a martini glass and shaker full of pills and a gun on the table in front of him. The poster’s intent, Pérousse says, was to show the public perception of HIV as a deadly weapon. “It was also to show that the James Bond figure represents how an HIV-positive person feels sometimes about the dilemma of living.”

Pérousse has changed meds many times and has had many side effects. He recently found a combination that works and gives him new energy. Sadly, his partner gave up the struggle last year and drowned himself. “Art expresses who I am and it can help with healing,” he adds. “It gives purpose to life and you can get lost in it.”

The New Old-School Activist: **JESSICA WHITTBREAD**

Now studying at York University in Toronto, Jessica Whitbread was diagnosed with HIV almost a decade ago, at age 21. Like some of her fellow activists and artists at the beginning of the epidemic, Whitbread takes a blunt approach to what it is like to live with HIV and believes strongly in the role of art to both shock and educate.

Whitbread put her belief into action when she collaborated with queer feminist artist Allyson Mitchell to create a poster as part of a 2011 Day With(out) Art campaign led by AIDS ACTION NOW! The attention-grabbing “Fuck Positive Women” (see image, right) was one of a series of posters created by local Toronto artists to highlight current issues around HIV. Merging the worlds of art and activism, the controversial posters were plastered across Toronto during the weeks leading up to December 1 (World AIDS Day) to provoke discussion and dialogue.

While the reality of living with HIV has changed since the early days of the epidemic, the art created by Whitbread and Pérusse carries echoes from that time: It reminds a too-complacent world that HIV still affects many lives. “We are not losing creative artists on the same scale as 15 years ago, but the impact on individual lives has been immense,” says the Canada Council’s Bob Sirman. “HIV has impacted almost everyone, not just artists living with it.”

Sirman says that art can be a medium for people to try to make meaning from what appears to be random and chaotic. “Whether it’s painting, theatre, writing, cinema or dance, art can be a powerful means of framing and expressing life’s narrative and making sense and meaning from it all. If art gives purpose to the artist, then, of course, it is healing as well.” +

Winnipegger Peter Carlyle-Gordge is a former writer for *Maclean’s*, *Time Canada* and *The Financial Post*. He has also worked as a CBC Radio broadcaster and producer and is a former UK correspondent for *The Toronto Star*. In the 1980s he was president of the Village Clinic (now Nine Circles Community Health Centre), a key player in the HIV epidemic in Manitoba.



“Fuck Positive Women,” 2011

“Sometimes you wake people up by provoking them,” says co-creator Jessica Whitbread. “Our aim was to make people realize that a woman may be positive but she is also a mother, a daughter, a lover, a friend, a wife, a human being.”

Needlework may imply a traditionally feminine and passive pursuit, but the message is defiant and empowering. “Why can’t we express an urgent, horny, powerful and open message about positive women and sexuality?” asks Allyson Mitchell, who collaborated with Whitbread on the piece. “Why aren’t women allowed to be subjects of their sexuality rather than objects?”



THE POSITIVE SIDE OF ART

The Positive Side has a long history of celebrating HIV-positive Canadian artists. “Not Your Average Joe” in the Spring/Summer 2005 issue featured an interview with celebrated Vancouver artist Joe Average, who created the “One World, One Hope” image for the XI International AIDS Conference held in his hometown in 1996—the same conference that announced the results

of the first effective anti-HIV treatments. Canada Post later used his iconic image on a stamp.

The Art Positi+ve column that runs in every issue of *The Positive Side* shares the stories of artists living with HIV and has featured Montrealers Shayo and Laurette Lévy, Haligonian Simon Thwaites, Aboriginal artists Ron Horsefall and Wabishki Myeengun, plus many others. Check out www.positiveside.ca to read more about HIV-positive creative types from all corners of this country.



On Your Mark, Get Set,

START

HIV treatment can be a lifesaver, but before you start, you'll want to be mentally and emotionally prepared.

M

ost people with HIV start taking HIV treatment (sometimes called antiretroviral therapy, ART or HAART) sooner or later. Maybe you are preparing to start, or maybe you know someone who is. Part of getting ready is thinking about how treatment may affect your life. Here we suggest some questions to consider. Two HIV-positive women share their stories of walking the HIV treatment road. And a handy ART Start Checklist identifies some of the issues you may face when starting treatment.

Why are you starting HIV treatment?

HIV treatment reduces the amount of HIV in the body, allowing the immune system to partially recover. More importantly, by taking ART and staying on ART, your chances of living for many years are tremendously increased. We are now learning that ART can lower the risk of HIV passing to sex partners in certain situations. For some people with HIV, this is a reason to start treatment. But the most important reason to start treatment is to maintain your health.

What does HIV treatment mean to you?

Treatment can mean different things to different people. You may see the need to start treatment as a sign that your health has deteriorated. Or you may think of treatment as a positive step that you're taking to maintain or improve your health.

Will you be able to take medication on a regular, ongoing basis?

To keep your treatment working, you must stick to your pill-taking schedule (this is called adherence). Skipping doses can lead to drug resistance, which will cause your treatment to stop working and, ultimately, will limit your treatment options. Before you start, you want to be sure that you're ready to take pills every day as directed.

Have you thought about the ways your pill-taking schedule may affect your daily life?

Taking medication on a daily basis will have an effect on your life and your lifestyle. Think about your daily routine and whether you'll have to make any changes to accommodate your pill-taking schedule.

What about work and social situations?

Who knows your HIV status? Could taking meds or having them around your home or workplace reveal your status to anyone? If this could be a problem, think about how you might be able to manage it.

Do you know the possible side effects of the antiretroviral drugs you will be taking? Will you be able to deal with them?

Side effects don't affect everyone the same way—for some people, they may be barely noticeable, but for others, side effects can interfere with daily life. Look at the most likely side effects of the drugs you're considering. Are you more worried by the prospect of some side effects than others? Before starting treatment, try to learn as much as you can about these side effects and how to cope with them. Usually, there is quite a bit you can do. The good news is that medications commonly prescribed today for people starting treatment are generally well tolerated.

How will you pay for treatment?

Antiretroviral drugs are expensive. Some people with HIV have private insurance, often through their job, that can cover some or all of the costs of antiretroviral drugs. Other people rely on provincial or territorial assistance programs to cover their prescription drug costs. Talk to your doctor and your pharmacist about this issue. You can also check out Federal, Provincial and Territorial Drug Access Programs at www.catie.ca.

Feel free to discuss these questions with your doctor. You could even take the ART Start Checklist (on page 25) to an appointment and use it to discuss your treatment options.

For more information about starting and staying on HIV treatment, check out *A Practical Guide to HIV Drug Treatment* at www.catie.ca. You can also order print copies through the CATIE Ordering Centre at www.catie.ca or 1.800.263.1638. The guide is free for people in Canada.

Laura, 41

Montreal

Living with HIV since 2005

At the end of 2010 I found a new HIV doctor, around the same time that I started to think about treatment. My previous doctor had never suggested treatment, and I was content with his position because I felt fine. I wasn't for or opposed to taking treatment, I was just happy that I was in good health.

In contrast to my previous doctor, my current one talked about treatment during our first visit. I supposed that he was preparing me for the eventuality of starting medication. This immediate in-depth talk on medical options had an impact on me: It made me think about the seriousness of having HIV. During our talk, he discussed the importance of sticking to treatment after starting. As he spoke, he referred to a chart of antiretroviral drugs on the wall in his office, explaining the different families of drugs and exploring options for me.

At that time, my CD4 count was between 400 and 450 and my viral load was around 100,000. These counts were standard for me. I have never been overly concerned with counting the numbers. My approach to managing my infection has been to be aware of how my body feels. I attribute this approach, in part, to Tom, the amazing support worker I met soon after my diagnosis. He encouraged me to listen to my body and not become obsessed with the numbers.

Recently, my HIV doctor talked to me about research that suggests that it's better to start treatment earlier rather than later. So I thought more about treatment, and I talked to a few trusted friends who live with HIV, including Tom (he is no longer my support worker, but rather, a dear friend). They suggested that it was a good time for me to start therapy. Having these people weigh in on the situation has been instrumental in my decision-making process.

At the end of 2011, I passed a milestone: I completed my graduate studies. With that stressful journey behind me, I feel that now is a good time to start my life with medicines. I have worked to get myself on my partner's work health insurance program. When Tom recently asked me whether I was ready to start—one of the most important steps in preparing to start—I answered, "Yes."

I am confident that I will be able to stick to my med schedule. I do not want to experience drug resistance, so this is a motivator to keep on track with taking my pills on time. Some of my family members have serious diabetes and they inject insulin several times a day. They manage their lives with a difficult, chronic, medicine-dependent condition. Moreover, other family members do not have access to medicines for life-threatening ailments. So, I tell myself that if they can do it, I can do it too. Above all, I'm grateful to live in a place where I can get the drugs that I need to stay alive.

Silke Haller, 46

Toronto

Living with HIV since 1989

I was diagnosed with HIV one month after my partner died of AIDS from a blood transfusion. When I was diagnosed, they said: "Get your affairs in order. You have about two years left to live." It was horrible.

I felt cheated and angry with my partner, even though it wasn't his fault. I figured that there was no point in going to a doctor because I was going to die anyway. I had always done the right thing and my life had been boring, so I said to myself, "Now I'm going to have a good time. I'm going to party, do everything I want to do, live life and then die." I didn't see another doctor until 1997.

I heard one night on the radio that they had found meds that could save people with HIV. When I finally got my blood tests done, my viral load was 2,000 and my CD4 count, 795. My counts stayed high until 2011. Then, during a very stressful time, they dropped from 459 to 79 in just two months. With that, my doctor said, "You have to start meds today."

It was stressful not knowing how I would pay for my meds because I had no health benefits and no disability insurance. Also, I feel that I didn't get the support I needed, which was really hard. Maybe it was because I worked in the health sector and people didn't think I needed it. So I turned to my family for support and did my own research.

I had one serious complication with starting treatment. My doctor told me that I'd have to stop the steroids I take for my asthma because they interact with the HIV meds. I did, and I

developed serious breathing problems as a result. I repeatedly told my doctor that I couldn't breathe. He just kept telling me to lose weight. Then one day last September, I was having such trouble breathing that I went to the hospital. They immediately put me in the intensive care unit because my blood oxygen level was so low. I almost died.

Otherwise, I haven't had many problems with ART side effects. I was tired for the first month but now I have no problems at all. The main issue is with my breathing.

I take my pills with my supper. If I'm eating out, I bring them with me. It's not like people know they're HIV meds; they could be anything.

Overall, I've found it pretty easy to be on treatment and I wish people hadn't made it sound so scary. For me, the side effects weren't as bad as people made them out to be. Hopefully, some people will hear my story and think, "Well, maybe treatment is not so bad." For me, it isn't—and it keeps me alive. +

*"Hopefully,
some people
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my story
and think,
'Well, maybe
treatment
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so bad.'"*

ART Start Checklist



These are some of the issues that might come up when you start taking HIV treatment. Think about how these might affect your feelings about treatment and your willingness to start. Don't let this list scare you—you won't have to face every issue on it. But it may help you decide which possibilities you would or would not be willing to risk.

	This would be a huge problem for me.	This would be a challenge, and I would need some help to manage it.	This would be a bit of a problem for me, but I could handle it.	I would be OK with this.
What if I had to take some medications with food?				
What if I had to take some meds on an empty stomach?				
How do I feel about taking pills every single day?				
What if I had to take pills once a day?				
What if I had to take pills twice a day?				
What if each dose meant taking more than one pill at a time?				
What if I found myself out of the house without my pills and had to go home to take them on time?				
What if other people, such as my family or coworkers, found my pills or saw me taking them?				
Is there a pharmacy where I would feel comfortable going to have my prescriptions filled and to ask questions?				
What if my drugs cause side effects such as ...				
... diarrhea?				
... nausea (feeling sick to my stomach) or vomiting?				
... poor sleep or vivid dreams?				
... skin rash?				
... jaundice (yellowing of the skin or whites of the eyes)?				
... a visibly thinning face or a visible buildup of fat in my belly or elsewhere (lipodystrophy)?				
... high cholesterol levels that could lead to cardiovascular disease in the future?				

ASK THE EXPERTS

Get answers to your treatment questions

Peripheral Neuropathy

“Over the past six months I’ve noticed a burning feeling in my feet. It’s not too bad, but it is constant. I’m worried about it. Should I mention it to my doctor? Do you have any tips on how to handle it?” —J.M., Yellowknife, NWT

CHRISTOPHER POWER

Neurologist, University of Alberta
Edmonton

A myth exists that peripheral neuropathy (PN) is no longer a problem for people living with HIV. However, I work in both major HIV clinics in Alberta (Edmonton and Calgary) and I see several people with PN at every clinic. PN damages the peripheral nerves (the nerves in the body, not including those of the brain and spinal cord) and causes numbness, electrical-like tingling or a painful burning sensation, usually in the feet and sometimes in the hands. It can also cause difficulty with walking and occasionally with bowel and bladder functions.

Other nerve disorders, such as carpal tunnel syndrome or sciatica, can be early indicators of PN. Contrary to what you might hear, PN is still very common among people with HIV, especially as they age and their disease progresses. People with HIV often don’t realize they have it. They frequently see me for another problem and then say something like: “My feet really hurt at night or if I’m on my feet all day. I think my shoes might be too tight.”

The good news is that most people with PN now experience mild to moderate symptoms. In the early ’90s, before antiretroviral therapy (ART), I would see people who would cut the tops off their shoes because anything touching their feet caused horrendous pain. I still occasionally see people suffering from exquisitely painful and debilitating PN but it’s far less common.

Many factors and conditions can cause PN. HIV infection itself can cause neuropathy by damaging nerve cells. You are also at greater risk of developing PN if you are tall, older than 55, have an AIDS-defining illness or your CD4 count falls below 200. People with diabetes can also develop neuropathy, so it’s important to find out if diabetes is causing your PN; if it is, work with your doctor to control your blood sugar. We also know that heavy alcohol use and poor nutrition can lead to nerve damage. Finally, syphilis can cause PN and hepatitis C virus infection can make it worse, so don’t let these conditions go untreated.

PN is also a side effect of various drugs (see interview with Danielle Gourde below). If you have drug-induced neuropathy, you might be able to improve your symptoms and prevent permanent damage by seeing your doctor and changing your medication right away.

DANIELLE GOURDE

Pharmacist, Clinique médicale l’Actuel
Montreal

Neuropathy is a side effect of the older antiretroviral drugs, sometimes called D drugs: d4T (stavudine, Zerit), ddI (didanosine, Videx) and ddC (zalcitabine, Hivid). In Canada, Hivid is no longer on the market and physicians no longer prescribe the other two unless a patient is resistant to newer antiretrovirals. Some other medications prescribed to people with HIV can cause PN as well (for example,

some drugs used to treat PCP and tuberculosis). If you are concerned that you might have symptoms of PN, talk to your doctor.

The first thing we try to do, if possible, is discontinue the drug that may be to blame. At the moment, there is no cure for PN and no medication decreases numbness. For pain relief, options are limited but some drugs seem to work in some people. Some people with mild pain find that amitriptyline (Elavil) helps. This is an old antidepressant that doctors no longer prescribe for that purpose because of side effects at the antidepressant dose. We give it to patients with PN at a lower dose. They take it at night because it makes people sleepy (and many people’s PN symptoms worsen at night). People with more severe symptoms often combine it with pregabalin (Lyrica) or gabapentin (Neurontin)—pain relievers originally developed for epilepsy. The main side effects of these two drugs are drowsiness and dry mouth.

A drug called topiramate is sometimes prescribed for people with HIV and PN alone but usually for people who also have diabetes. It can cause people to lose their appetite and lose weight as a result, which can improve the diabetes of people struggling with their weight.

Opiates are sometimes dispensed for PN pain; however, we try to avoid prescribing them for long-term use as they can be addictive.

PN pain is very different from other kinds of pain, so not all pain relievers are suitable and some interact with antiretrovirals. Finally, prescription drugs are only one part of a possible plan. You and your doctor will need to figure out what works best for you.

TODD TRAN

Occupational Therapist (with expertise in Pedorthics), Women’s College
Hospital; Consultant, Casey House
Toronto

PN affects 30 to 67 percent of people with advanced HIV disease (people who have lived with HIV for many years or have a high viral load or a low CD4 count). I try to work

with my clients' doctors because I believe that a multidisciplinary approach ensures that clients get the best care possible.

For clients who experience more pain when they walk or stand for long periods, we recommend custom-made orthotics and/or orthopedic shoes, which relieve pressure from certain parts of the feet. For clients who have difficulty walking, I also recommend adaptive equipment, such as a cane or a walker with a seat, which allows people to sit down and offload mechanically induced foot pain. I recommend wheelchairs as a last resort for people who are not able to walk about. I want people to be mobile for as long as possible.

When people have a combination of HIV, PN and type 2 diabetes, they can develop a loss of protective sensation (LOPS) in their feet. Clients sometimes ask me, "What's the big deal if I can't feel?" LOPS puts people at risk for self-harm. For example, a person might walk along the floor barefoot and only realize they've stepped on a tack when they notice blood or the tack sticking into their foot. When this happens, the healing time may be longer for a person with HIV (due to immunosuppression) than for an HIV-negative person. And the wound might not heal adequately, which can potentially lead to serious complications. If you have LOPS, you should:

- Examine your feet daily. If you can't bend over or see your feet, put a mirror on the ground and place your feet over it.
- Dry in between your toes after a bath or shower to prevent skin breakdown due to fungi, and wipe away flaky, dead skin in between the toes. If you can't reach your toes, seeing a foot care nurse, chiropodist or podiatrist for regular nail and skin care is vital.
- Don't wear outdoor shoes indoors (to avoid tracking pebbles, glass and debris inside). You may want to wear an indoor shoe to protect your feet from sharp objects, banging them against a bedpost or

Some people with PN use complementary and nutritional treatments to help their nerves recover from PN, a process that can take months or years.

- Alpha-lipoic acid—an antioxidant used to treat PN.
- B-complex vitamins—particularly vitamin B₁₂ injections.
- Vitamin E—to help with oxygen metabolism and blood flow.
- Essential fatty acids—from evening primrose oil and cold-water fish, such as wild salmon, sardines, mackerel and anchovies.
- Acetyl-carnitine—which research has found to be helpful for treating PN. The acetyl form is not available in Canada but L-carnitine is available by prescription.
- Acupuncture—performed by an experienced doctor of traditional Chinese medicine.
- Deep tissue massage for limbs affected by PN—to help stretch and relax muscles.
- Smoking cannabis—cannot help nerves recover, but can lessen pain for some people.

Before taking any of these, be sure to talk to your doctor about your plan for tackling PN.

other injury. Always wear socks with your shoes to protect your feet from seams in the shoe, which can irritate or hurt the skin.

- When buying new shoes, always feel inside the shoes for anything that might irritate your feet.
- Consider orthopedic or accommodative footwear. (Some insurance plans cover the costs of orthopedic shoes.)
- Schedule regular checkups with your doctor or foot specialist.

JOE DACEY

Person living with HIV
Dartmouth, Nova Scotia

I was diagnosed with HIV in 1990 and I first noticed a strange tingling in my feet and hands about three years ago. My PN rapidly became so bad in my feet that I couldn't walk any distance. My doctor is convinced that

the HIV drugs I took in the past caused my disease.

When my PN started, I had a lot of pain in my feet and they felt extremely hot. Now I still have pain but my feet usually feel extremely cold. I take a low-dose, slow-release form of oxycontin four times each day. If the pain becomes excruciating, I take a faster-acting form of the drug. The drugs don't get rid of the pain but they tone it down a little.

Aside from the meds, what helps me most with the pain is my heating pad. I rest my heels on the heating pad on my ottoman, and then I wrap a blanket around my feet and the heating pad to keep the heat in.

I've talked with my doctor about removing the pain receptors in my feet. But without my pain receptors, I could bump into something or break my toe and not even realize it. So, I just keep going the way I'm going. It's about all I can do.

Fortunately, I was able to get enough money together to buy a scooter and a power wheelchair. I use the wheelchair when Access-a-Bus [door-to-door transit for people with disabilities] picks me up for my medical appointments. I can walk around my apartment but I use the power chair to go anywhere else. Typically, I feel best in the morning. On nice mornings, I spend some time outside before the pain gets too bad. I can't wear shoes or even light socks because of the pain. In the summer, I can wear flip-flops outside but I have to be careful to not expose myself to the sun for too long because that can cause other problems due to the HIV medication I take.

Of course, it's very uncomfortable and frustrating. The thing that keeps me going is that I look around and see that some people are much worse off than I am healthwise. I wouldn't wish this on anyone but it would be nice to know someone else who has PN. We might be able to exchange tips. Maybe this article will get people talking and I'll meet someone else who has PN. In the meantime, I try not to let it get to me. +

In the Flesh

When coming out about his HIV status, Hamilton-based artist Andrew McPhail was stuck on Band-Aids—60,000 of them.

INTERVIEW BY **RONNILYN PUSTIL**

"all my little failures," 2008–2012



What moves you to create art?

A lot of the time it seems like tragic things inspire my art—much of my work is about coming to terms with those things that are awful or damaging in life. I think that expressing the overwhelming stuff helps normalize it. You come to a point when you can live with it comfortably and it doesn't overwhelm you anymore.

What inspired you to make "all my little failures"?

I had been working on another piece with Band-Aids—little organic shapes that I would pile in stacks. They looked anthropomorphic, like little body parts. I wanted to make a much bigger piece and I wanted to inhabit the piece in a way, so I thought I'd make something that I could wear. Around the same time, a girl in Mississauga, Ontario was killed by her father because she wouldn't wear her hijab to school. This had a big impact on me, so I decided to make a burka out of Band-Aids.

This lacy, flesh-like garment is made from 60,000 bandages that you systematically stuck together. How long did it take to create?

I've been working on it on and off for about the last four years. I keep thinking it's completed but then it demands to be a bit bigger. I'm starting new works, and I think that once my attention is absorbed with them, "all my little failures" will exist as it is.

I'm thinking of other things to do with Band-Aids. I want to make a tent. People can go inside it without having to wear it. That would take a lot of Band-Aids, so we'll see how that goes.

How have people reacted to "all my little failures" when you've worn it in public spaces as part of your performance art?

When it's in a gallery, the burka is displayed on a mannequin and I usually do some kind of performance at the opening of the exhibit. I've worn it out in the street and distributed Band-Aids

to people or put Band-Aids on people. The performances are very open-ended, as anything can happen when you approach people in the street.

When I performed in Fredericton, people thought I was panhandling and gave me money, which was very nice. Some people thought that it was some kind of political action that had something to do with Iraq and the war. But the most common reaction people have is feeling uncomfortable because I'm covered, so they can't identify my gender. And I'm always like, "Look at my hairy legs. I'm a guy!"

"A veil can at once hide you and reveal you—similar to aspects of living with HIV."

What is the meaning of "all my little failures"?

It holds a lot of accumulated meaning for me, and hopefully that comes across to the viewer. Mainly it's about being covered and hidden but at the same time how your hiding calls attention to yourself and makes you extremely visible. I was thinking about that in terms of being a person with HIV and how if I didn't tell you I had HIV, you probably wouldn't know. A veil can at once hide you and reveal you—similar to aspects of living with HIV and the degrees to which you can do that publicly or not.

Is it the first HIV-inspired piece you've done?

My work has always been informed by my status but this is the first time I've visibly addressed the issue. I wanted to be more open in my work about my HIV status—and to do that I needed to come out more publicly as a person with HIV. When I started making it, I was thinking about hypochondria and the panic and nervousness I go through when I have to deal with a health-related issue, and how I try to

talk myself through it and make myself feel better. It was that hypochondria that initially inspired the piece.

There's a kind of dark humour about the piece.

The work is somewhat humorous because when you see the excess, you think, "This guy's kind of insane." Some people think it's hilarious and some people think it's tragic, but I think that's more about the viewer than the piece. I wanted it to be both, because I think it is both.

What's behind the title?

"all my little failures" suggests blame and self-recrimination. It has a self-pitying tone, but in a mocking sort of a way. And my last name is McPhail, so phonetically it felt close to me.

Why Band-Aids?

I've been fascinated by them as a material for a long time. They're something everyone is familiar with, and yet they're kind of extraordinary—the way they substitute our skin, the way they're a very human-like material. Also, they allude to the body and to damage in a very direct way, in a way most people understand. I think Kleenex alludes to grief in a similarly direct way.

Which brings us to your most recent installation, "CRYBABY."

What's it about?

"CRYBABY" is made up of about 2,000 Kleenexes that are all hand-sewn together into a cloudscape. They're laid out on the floor, so it looks like a fluffy mass. Above them there is a toy plane wrapped in Kleenex. I wet the Kleenex in tears and molded it to the shape of the plane so that the plane looks like it's made out of Kleenex. It hovers over the big pile of Kleenexes.

Were they your own tears?

I'm not that much of a crybaby! I had to use artificial tears from a drug-store...boo-hoo.

What inspired "CRYBABY"?

About two years ago I was on a flight to England and the man in the



"CRYBABY," 2011

seat beside me had a heart attack and died. It was horrific, and I wanted to make a piece memorializing it, something that addresses the overwhelming nature of grief and how it's sometimes so big that you feel powerless in front of it. Kleenex and tears seemed like an appropriate medium to use. The plane and the cloudscape recreate that terrible situation for me. The title has a flippancy to it, so again there's a little bit of humour there. I've been working on it for about a year and a half now.

You draw, paint, sculpt, take photographs—you're a real Renaissance man!

I just have an idea and I have to go to whatever medium is going to help get that idea across.

What's next?

I'm still working on "CRYBABY" and I'm waiting to hear back about some opportunities I've applied for. I applied for a residency in South Africa to work with other people with HIV and make art together. That would be really fascinating. I think there would be lots of commonalities but also lots of differences in how we approach our health. +



Standard of Caring

Dan Small reflects on the Supreme Court's unanimous ruling last fall to keep Insite open.

This photograph of the marquee of a humble inner-city church in Vancouver was taken when the continent's only supervised injection facility, Insite, was under threat of closure by Canada's Conservative federal government. Some years earlier, this same church held a memorial for a much-loved member of the community who passed away from AIDS because supervised injection and adequate harm reduction came too late for him. The pastor asked those present to "thank God for the supervised injection site."

As a last resort to protect the life-saving facility, the non-profit agency that

operates Insite, the PHS Community Services Society, turned to the courts. This high-stakes strategy forced an examination of whether addiction was a criminal matter or a healthcare matter. What ensued was a struggle between the government of Canada, which deployed extensive legal resources, and a charitable organization that relied on pro bono lawyers to defend Insite. If the case were lost, Insite, a place that helps prevent deaths from overdose, HIV and hepatitis C, would be closed. It was winner take all.

On September 30th, 2011, Canada's highest court ruled unanimously in favour

of Insite and decreed addiction a matter for the Chief of Medicine rather than the Chief of Police. The court sent a message: Political power cannot be used arbitrarily when lives are at stake. The federal health minister was ordered to allow Insite to remain open.

This ruling opens the door for supervised injection in other communities, as part of the standard of care to fight overdoses, hepatitis C and HIV. Medical, scientific and legal evidence support the efficacy of supervised injection. The Supreme Court of Canada has shown ours to be a country where everyone—even the most wounded injection drug user living in the shadows of life—is a member of the human family with fundamental rights to the security of their person provided by life-saving healthcare. The ruling has done more than stress a standard of care; it has highlighted a standard of *caring*. +

Dr. Dan Small, a senior manager with the PHS, has been involved in setting up, implementing and advocating for Insite.

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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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Did you know that some HIV-positive men are at a higher risk of getting hepatitis C?

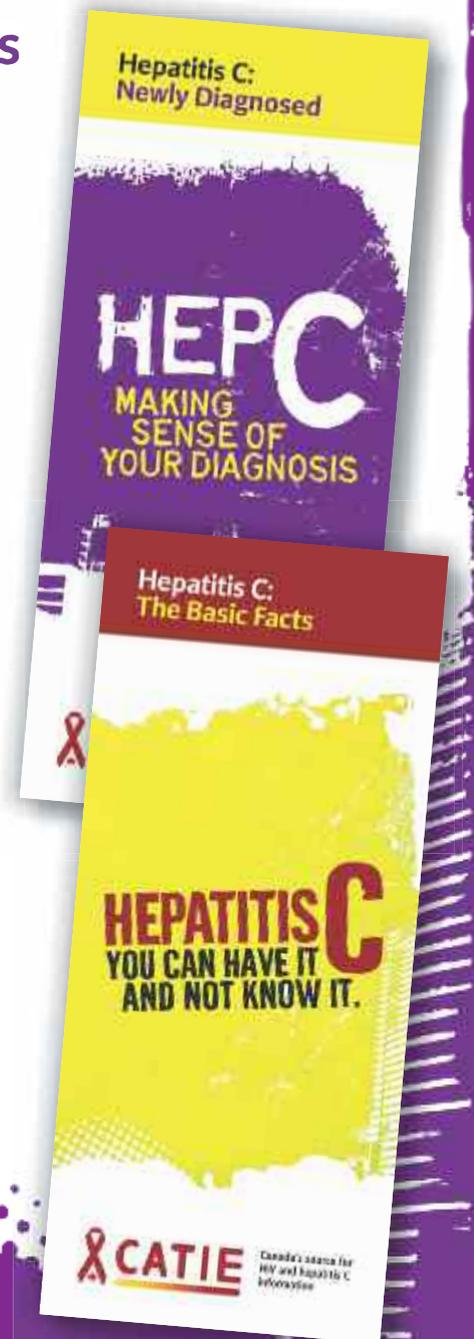
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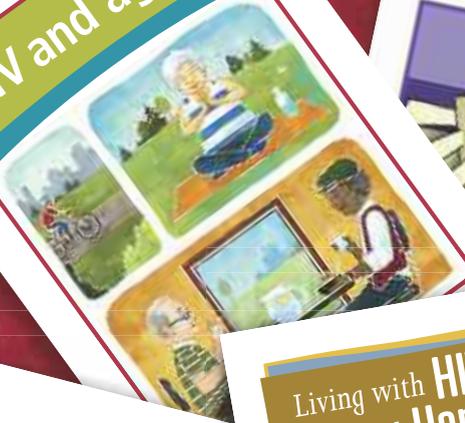


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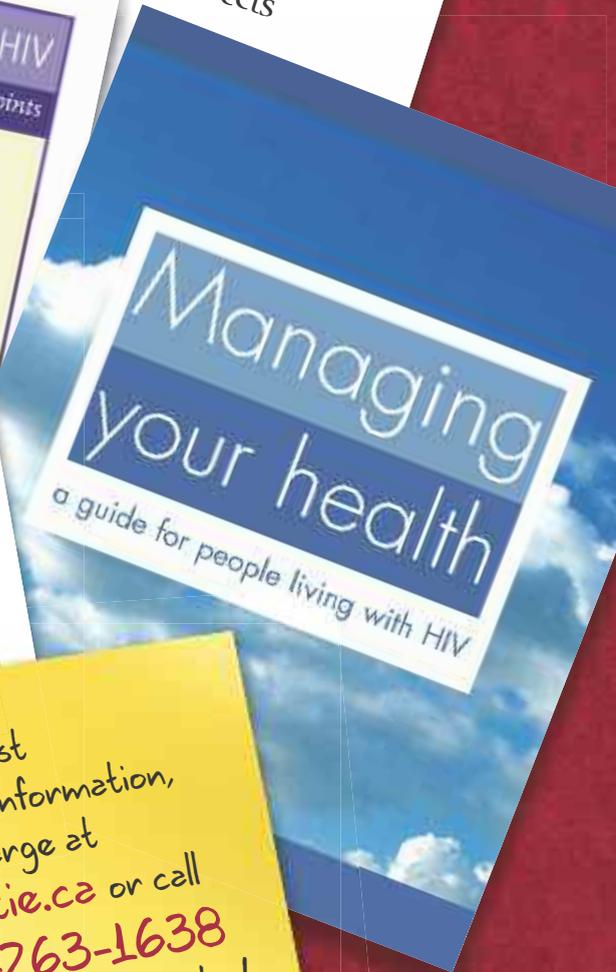
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starting points



Living with HIV
and Hepatitis C
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