

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

WINTER 2010
VOLUME 11 ISSUE 2

Krista Shore and other Aboriginal PHAs in the Prairies carry hope and resilience along their journey with HIV

HEALING PATH

BILLY NEWTON-DAVIS

Living with HIV in the spotlight

RASH DECISIONS

Solutions to problem skin

MIND GAMES

Outwitting HIV's effect on the brain



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CATIE's many free treatment publications include *TreatmentUpdate* and a series of informative Practical Guides. The guides deal with topics ranging from treatment side effects to complementary therapies to nutrition. CATIE also offers a new 2009 edition of *Managing your health*, a must-read manual for people living with HIV, and a new *Living with HIV: starting points* brochure that was developed with the Toronto People With AIDS Foundation. All CATIE publications are available through our website, which also offers a wide array of HIV and hepatitis C resources produced by organizations across Canada.



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Atlantic Canada	11 am – 10 pm	11 am – 7 pm
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EDITOR'S LETTER

Sharing stories is one way to put a spotlight on the challenges faced by people living with HIV (PHAs) in Canada. Sharing stories is also a powerful approach to finding ways to face those challenges. In this issue, we are proud to share the stories of PHAs who face their challenges and put the living in "living with HIV."

In this issue's cover story, "Path to Healing: Full Circle on the Prairies," we hear from a group that is increasingly affected by HIV—Aboriginal people. They have been struck hard by the epidemic but they have taken healing into their own hands, as we hear in the stories of three Aboriginal PHAs from Manitoba and Saskatchewan. And, as cover girl Krista Shore of Regina so radiantly shows, this face of HIV can be full of life, love and hope.

Long-term survivor Maggie Atkinson reports on a growing health concern among PHAs—declining neuro-cognitive function. In "A Mind of Her Own," she explains how HIV affects the brain and provides advice and insight gleaned firsthand.

Juno-award-winning musician Billy Newton-Davis, arguably one of Canada's most famous PHAs, has had to face life with HIV in a way few people have—literally in the spotlight. In an exclusive profile by Gerald Hannon, Newton-Davis talks about his life in showbiz and his life with the virus.

Finally, art posi+ive showcases some films created by a group of HIV-positive Montreal youth. Making these movies was so empowering that the young filmmakers started their own HIV film festival.

Thanks for picking up this issue of *The Positive Side*. In addition to enjoying our stories, we hope you find something that improves your life in some small way—from practical advice on how to handle a rash to an interesting website you didn't know about. As always, send your stars or cherry bombs to me at dmclay@catie.ca.

—David McLay

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calling 1.800.263.1638.

For the Heart, the Hand and the Hungry

CATIE educator **MELISSA EGAN** goes coast to coast to highlight the many different forms support can take.

Handicraft



For Simon Thwaites, an artist and minister living with HIV, attending a CATIE workshop on body mapping—a form of art therapy that sees participants draw life-size outlines of their bodies on paper and then fill them with symbols of their life with HIV—was inspirational in more ways than one. The Nova Scotian, who was familiar with art therapy

after having developed an artistic workshop for fellow members of the AIDS Coalition of Nova Scotia (ACNS) a year earlier, saw in body mapping the idea for a new and powerful project.

Thwaites' Hand to Hand project was born in 2008, just as ACNS was working to get its members more involved and connected to the

broader community. The timing couldn't have been better. During the agency's annual HIV/AIDS Ceilidh (a skills-building and networking gathering), Thwaites led a group of 25 participants through an inspiring six-hour day. Tables were piled high with paints and glitter while participants traced their own hands and the hands of others to create a visual expression of their journey with HIV.

The final products, beautiful posters that document each person's experiences, are divided into themed sections that look at thoughts, feelings and strategies while exploring past, present and future hopes. Each piece is a powerful testament to the courage of an individual, the impact this disease has on people and the unexpected places we find strength. When placed together, the individual pieces connect to create a larger expression of HIV community.

ACNS is happy to share the Hand to Hand project with other agencies across the country. If you would like to experience the Hand to Hand project, your local group can contact ACNS at 902.425.4882 or acns@acns.ns.ca.

Peer Voices

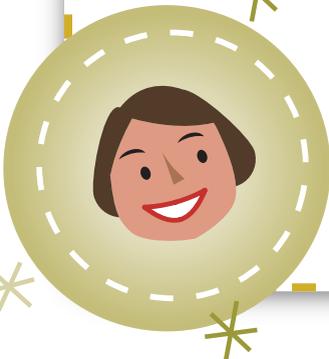
When Mariame learned she was HIV positive, her life came to a standstill. For a while she struggled to cope with her diagnosis but soon felt herself sinking into depression. Fortunately, Mariame found the AIDS Committee of Ottawa, which put her in touch with the provincial Peer Mentor Program run by Voices of Positive Women. With the goal of connecting women to services and support in their area, the program matches an HIV-positive woman in need with another woman with HIV who lives in the same area. The program was a lifeline for Mariame, who, with help from her peer mentor, has worked to accept her diagnosis, disclose to her children and even start mentoring other women.

Covering the province from Thunder Bay to Windsor to Ottawa and offering support in English, French and several African languages, the program is built on a vibrant community of about 40 trained HIV-positive women who volunteer their

time and skills to help other women living with the virus. Every effort is made to match women with similar experiences and to create a supportive relationship. Some mentors accompany women to hospital visits, some help women find local HIV-friendly agencies and support groups—and even attend meetings with new clients—while others provide a sympathetic ear. The goal is always to help women with HIV live positively and independently.

While the program is most often used by women who are newly diagnosed with HIV, it recently expanded to include women co-infected with hepatitis C and is also looking at ways to serve the needs of women who have been living with HIV for several years.

If you're interested in being paired with a mentor or want to help by becoming a peer mentor, contact Voices of Positive Women at 416.324.8703 or 1.800.263.0961 or info@vopw.org.



Good Eats!

Vancouver's Downtown Eastside is notorious for being one of the poorest postal codes in Canada, with many of its residents often struggling to find enough food to live. The struggle was recently made a bit easier by the publication of *Food Lines*, a booklet that lists places to obtain food in the Downtown Eastside.

Community organizations, food banks and faith-based charities are rated and placed on a map of the area.



The booklet was one of the results of the larger Good Eats! project, a workshop series on food security for people with HIV/AIDS (PHAs) living in the Downtown Eastside. The project was a collaboration of several community and university organizations, including the Community Based Research team at the British Columbia Persons with AIDS Society (BCPWA). Podcasts of the workshops are available on the BCPWA website. Topics range from "Stores in the Downtown Eastside" to "Food as Dignity."

To find out more about the Good Eats! project, contact BCPWA at 604.893.2200 or 1.800.994.2437 or info@bcpwa.org.

Meals by MIELS

At MIELS-Québec (Mouvement d'information et d'entraide dans la lutte contre le sida de Québec), lunch is wrapping up and the kitchen is bustling with volunteers from the health promotion team wanting to wash the dishes. Besides people who actually *want* to wash dishes, what makes this scene remarkable is that it happens every weekday at this AIDS service organization (ASO) in Quebec City.

The daily meal program is one example of how MIELS has put volunteerism and food at the core of its health promotion services. As many other ASOs do, MIELS also runs a monthly food bank, which is used by more than 100 people and provides non-perishable foods at about one-fifth of the regular price. There is also a weekly food bank in partnership with Moisson Québec offering free perishable foods.

But the agency goes further than that. In the collective cooking program, members meet once a month to prepare meals and then divvy up the dishes to take home. The agency even runs a community garden during the summer. Members and volunteers are involved in all aspects of the garden, from planning the year's planting to tending the budding shoots. And everyone enjoys the social and mental benefits of getting a bit of dirt under their fingernails.

For more about MIELS' health promotion programs, contact them at 418.649.1720 or miels@miels.org. +

HeartSong

For nearly 20 years, the HeartSong retreat in Manitoba has been providing PHAs and their caregivers a quiet place to reflect and rejuvenate. HeartSong was the inspirational idea of Sister Mary Coswin, member of the Sisters of St. Benedict in Winnipeg. Her intention was to give PHAs a chance to slip out of their usual routines and connect with others who may be experiencing the same struggles.

The annual retreat, held in the spring, is free to 15 to 20 PHAs and is spiritual, not religious, in essence. It is a place where people come to be cared for and to care for others, to share successes and to take time for reflection and quiet contemplation.

Set on the tranquil grounds of the St. Benedict's Retreat and Conference Centre alongside the Red River north of Winnipeg, the HeartSong retreat feels like a secret hide-away. Built in 1960, the grounds are the perfect place to slow down and think. Participants may choose any number of activities from creative writing workshops and marshmallow roasting to mindful meanderings through the peaceful grounds and spiritual contemplation classes. The retreat also holds a remembrance service for those who have passed away, with participants sometimes planting flowers or releasing balloons; Aboriginal smudging ceremonies have also been held.

For more information about HeartSong, contact the St. Benedict's Retreat and Conference Centre at 203.339.1705 or stbenscentre@mts.net.



Enquiring minds want to know: What's inside *your* medicine cabinet?

INTERVIEWS BY RONNILYN PUSTIL



TRACEY NOLAN, 39
Western Newfoundland
Diagnosed with HIV in 1997
CD4 count: 465
Viral load: 250

What's in my medicine cabinet? That's a scary question. I wanted to find out, so I faced my fear and went upstairs to investigate.

My medicine cabinet isn't cute by any stretch of the imagination—just a regular, ordinary, standard cabinet with mirror, no frills. After the deepest of breaths I reached out to open the cabinet and peer inside.

I climbed 12 steps for this?!

On the first shelf is a bottle of camphorated oil that I bought when my husband had an ear situation. There are also a few tubes of creams for his skin irritations (and he's neg!!).

Shelf number two: Three lovely half-used bottles of facial cleanser. (I have a 16-year-old son who's trying ever so hard to keep his face clear, and I must say he's doing a great job.) Toothbrush with a cap, which is also my son's. (I have no memory these days and every toothbrush is mine in my mind, no matter what the colour. After throwing out several of his toothbrushes that I'd used, he got a cap for his current one and now I know it isn't mine.)



On the third shelf I find a ponytail holder for those days I don't want to wash my hair or when I want my hair up when I clean the bathroom. Next to that is Crest Whitening Expressions toothpaste. I like it; other toothpastes make my mouth sore. Tweezers—I can tweeze every day! Too much testosterone, perhaps?

Wonder where my meds are? In my wicker medicine basket in the kitchen. I remember to take my meds because they are right there.

It drives me insane! Also, there's my real toothbrush and a bottle of Myoflex for the aches and pains of everyday life.

Wonder where my meds are? In my wicker medicine basket in the kitchen. It houses my multivitamins, ibuprofen, selenium (which is supposed to be great for cholesterol) and saquinavir (Invirase)—I also take ritonavir (Norvir) but it needs to be refrigerated.

My basket serves the purpose and I remember to take my meds because they are right there—unless I choose to forget, at which time I enjoy the most blissful medicine-free 60 seconds of all time. What freedom!

GORDON McDERMID, 56
Winnipeg
Diagnosed with HIV in 1986
CD4 count: 707
Viral load: undetectable

My medicine cabinet is full of soaps, body washes and hand cleaners—I have lots of those in there, I don't know why. I guess I'm stockpiling them because I don't like to run out of stuff.

The stuff that generally should go in a medicine cabinet is in a plastic box on top of a shelf in the bathroom. If anyone should lose a limb, I have enough bandages and gauze pads in there to stop the bleeding. At one point I bought more bandages because I looked in the medicine cabinet and there weren't any in there so I thought I had run out. Then I realized I already had Band-Aids in this plastic box.

If anyone should lose a limb, I have enough bandages and gauze pads in there to stop the bleeding.

There's also cough drops, hydrogen peroxide, tweezers and tape in there. And a thermometer, which I can't read because I have CMV (cytomegalovirus) and I'm blind. I'm not a hundred percent blind; I've still got about two percent of my vision. I'm hopeful for stem cell research to come around and rescue me before I go into darkness.

I don't keep my medications in the bathroom because of the moisture. I keep them in a steel box in a cupboard in the living room because I'm supposed to store them in a cool, dry place. All my HIV meds are in there, as well as my neuropathy med and ganciclovir (for the CMV). My vitamins are in the kitchen in a cupboard—lots of garlic tablets (it's an antiviral), vitamins C and E, calcium, a multivitamin, zinc, selenium, vitamin B₁₂, magnesium, flaxseed and cod liver oil.

I developed AIDS in 1995. I had MAI [a kind of *Mycobacterium avium* complex], PCP and toxo[plasmosis]. I lived through that and everyone was stunned. I almost died four times but I'm still here. I think humour is an important aspect of surviving AIDS and keeping your spirits up. Plus, I've never given up hope. I'm listening to a book now that's called *You Can if You Think You Can*, and it has this quote that I've adopted: "Keep up the fight if hope is out of sight." Even if you don't see it, hope is still out there.

IAN, 49

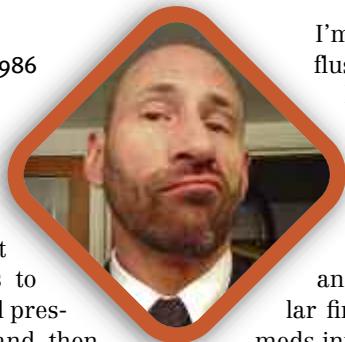
Vancouver

Diagnosed with HIV in 1986

CD4 count: 350

Viral load: 150

You have to see my medicine cabinet to believe it! Inside are the meds that I currently take—drugs to manage pain, high blood pressure and depression—and then there are the expired drugs—from Advil to Tylenol 3's to Percocets, migraine meds, naturopathic remedies, lots of things that end with "an" or "pam," muscle relaxants, asthma sprays and other ancient prescription and over-the-counter pills. I've had numerous roommates, a few of whom



have died, and I inherited their pills as well. I don't even know what some of those pills are for. It's basically a pharmacy in there.

There are no HIV medications in my cabinet. I was diagnosed in 1986. In 1993, I did a brief stint of AZT and ddI, but I was having such bad side effects that I decided to opt out of HIV treatment. The idea was that if my health declined I would reassess this. It hasn't, and so I haven't gone back on HIV treatment.

I would say that three-quarters of the meds in my cabinet have expired. In preparation for moving in with me, my boyfriend recently cleaned out the bathroom and found the oldest medication I had—dated 1995. He was quite concerned, as he used to work for a drugstore and says that meds become toxic when they're past their expiry date. So the next time I go to the drugstore I'm going to ask if I can give them my expired medications for disposal. My boyfriend thinks this is a great idea.

I don't even know what some of the pills are for. It's basically a pharmacy in there.

I'm not comfortable with flushing pills down the toilet because they're toxic to the fish and the environment. And I know that some people on the street go through dumpsters and medication is a popular find, so I don't throw my meds into the trash. That's a big reason why the medicine cabinet just starts to overflow.

So I've become a medication hoarder. I think of it this way: If you're told you're going to die next year, then everything you've got becomes precious. Besides, I've lived way beyond my expiry date, and I'm still good.

ALEX McCLELLAND, 31

Toronto

Diagnosed with HIV in 1998

CD4 count: 390

Viral load: undetectable



I'm living between my two parents' houses at the moment because I recently moved from Montreal to Toronto to start a Master's program at York University and I don't have my own place here. I am actually literally living out of a suitcase right now, so when I go from one house to the other, I bring my meds.

My medicine cabinet is actually a LeSportsac zip-up black bag.

My medicine cabinet is actually a LeSportsac zip-up black bag. In there right now are my HIV meds—atazanavir (Reyataz), Kivexa (abacavir + 3TC) and ritonavir (Norvir). Ritonovir apparently has to be refrigerated, but my doctor told me it's no big deal because it only goes bad after four months (and I have to renew my prescription every month), so I'm trusting him on this one.

There are a couple of other things in my "medicine cabinet": Advil, Robaxacet for my back and probiotic pills. Back when I was on Sustiva (efavirenz) I think I destroyed my intestines, so I pump myself up with probiotics to help make my stomach healthy.

In a separate LeSportsac bag—I have a matching travel set—is my toothbrush, toothpaste, floss, fluoride rinse (I'm all about oral hygiene right now), deodorant, cologne (Issey Miyake) and a razor and shaving cream, although I can't really grow a beard.

When I was a child, I moved back and forth between my parents' houses because they were divorced, so I'm used to being a nomad. But I'd love to have a giant medicine cabinet with a big shiny mirror. Maybe one day... +



Builder of a Better, Fairer World

Friend and colleague John Plater reflects on the life and legacy of **James Kreppner**, one of Canada's first AIDS activists.

With the passing of James Kreppner on May 14, 2009, Canada lost a powerful voice for AIDS activism. Though James' life was cut short at age 47 as a result of complications from HIV and hepatitis C infection, his work as one of Canada's first AIDS (and hepatitis C) activists will live on. His legacy is one of advocating for access to treatment, ensuring a safe and secure blood supply system, and protecting and promoting human rights.

At a small family memorial, James' older brother John related a story that sums up much of James' life. He recalled that when James was six years old he went to his older brothers and announced that he knew what he wanted to be when he grew up. "What do you want to be?" they prodded. "A fireman, an astronaut? Tell us. What?"

"A lawyer," exclaimed James.

"Why on earth a lawyer?"

"Because I want to help people," he earnestly replied.

"Why not a doctor? They help people."

"Because I've spent enough time in hospital."

James had been born with severe factor VIII hemophilia. He was the second of two boys with the condition in a family of six children. Born in 1962 in the Toronto area, James spent much of his childhood in and out of hospital receiving care. Sometime during a visit for a blood transfusion in the early to mid-1980s, James was infected with HIV and hepatitis C. It wasn't until 1987 that James, then a successful student specializing in Soviet Union studies in the political science program at York University, learned of his HIV status.

Healthy and unwilling to be deterred from his childhood ambition, James transferred at the earliest opportunity to Osgoode Hall Law School. Upon graduation in 1989, he articulated with the federal Department of Justice, embarking on what he was expecting to be a long and distinguished career as a litigator. But James' health caught up with him as he was finishing his studies; he was experiencing

extreme fatigue and had to call on his deepest reserves to write the Bar admission exams.

As he donned his formal barrister's robes and received the call to the Bar, James began a life of close health calls and permanent disability. At a low point he had a meagre 88 pounds on his 6-foot-tall frame. He developed an autoimmune disorder that was a dangerous mix with hemophilia because it could lead to extreme blood loss—and it did on more than one occasion. One crazy night in a downtown Toronto hospital emergency ward, he lost a third of his blood volume through gastrointestinal bleeding. Another time, his wife, Antonia "Smudge" Swann, returned to their apartment to find it covered in red. Most people would immediately dial 911 to report a violent assault. Instead, Antonia called the hospital to find James admitted with a lung ailment.

HHealth challenges didn't stop James from advocating for a better world. In the early 1990s, he became involved in the AIDS activist movement in Toronto. He was on the board of the Toronto People with AIDS Foundation (TPWAF) and was a founding member of the Canadian Treatment Action Council (CTAC) and the HIV/AIDS Legal Clinic of Ontario (HALCO).

During that time, James was invited to participate in the Canadian Hemophilia Society's campaign for compensation for people infected with HIV through the blood supply system. He played a key role in advocating for—and ultimately securing in September 1993—compensation from the Ontario government for people infected with HIV through blood transfusions (the Multi-Provincial/Territorial Assistance Plan). He subsequently became a lead plaintiff in the class action lawsuit that in 1999 led to the 1986–1990 Hepatitis C Settlement Agreement, which offered compensation to people infected with hepatitis C through blood transfusions

but only during a five-year period in the late 1980s. After, James continued to advocate publicly and politically for broader hepatitis C compensation at the provincial and national levels.

Not satisfied with simply securing recompense for past mistakes, James also insisted on assurances that the Canadian blood supply be protected against future catastrophes. Acting as an advisor to local, provincial and national levels of the Hemophilia Society, he was a key figure in the push for and involvement in the Commission of Inquiry on the Blood System in Canada (the “Krever Inquiry”), testifying before the inquiry on two occasions. Recommendations from the inquiry ultimately led to the creation of Canadian Blood Services (CBS) and Héma-Québec in 1998. The CBS would become a large part of James’ life, and he, part of its. James’ depth of knowledge and insight led to his appointment to the agency’s board of directors in 2002, where he served right up until his passing.

James was a champion of patient rights and access to HIV treatment issues. He was a community advisor to the Canadian HIV Trials Network, where he poured over countless research proposals and ethics reviews, demonstrating an uncanny ability to challenge the best and brightest scientific minds. At the same time he had a wonderful ability to distil the true value (and sometimes lack thereof) from the most dense scientific literature and transform it into understandable advice for the reader of a newsletter or a companion in a hospital waiting room. People living with HIV and/or hepatitis C share stories of seeing their doctor about treatment options and then contacting James for an explanation that often amounted to a second opinion.

For those who knew him well, James was never just a treatment egghead. He was a true renaissance man. A dinner conversation following a day of meetings would range from the latest in treatment options to the politics of the Middle East, from quantum physics to the deeper meaning of an episode of *Buffy the Vampire Slayer*. For any topic, James was prepared to champion a position no matter what the prevailing general consensus might be. Yet, regardless of how vehemently one might oppose his views, no one had anything but the deepest respect and admiration for his devotion to the truth, his personal integrity and his passion for justice.

James’ deep sense of fairness meant that he never wanted to distinguish between so-called “innocent victims” of tainted blood and other people living with HIV. Once when James was in the hospital with an AIDS-related illness, a nurse commented, “Why didn’t you tell us you were a hemophiliac? We would have treated you much better.” James told this story again and again to different groups in

James was well aware that his physical presence helped to serve as a reminder of the price of tainted blood.

order to educate people about what he saw as blatant discrimination against the gay community.

While his HIV and HCV infections advanced, James battled on. In recent years, he directed his waning energy into calling for a liver transplant program for HIV/HCV co-infected individuals in Ontario, fighting the creep of HIV criminalization and defending strong screening criteria and safety measures for blood donations in Canada. Early in 2009, James decided that he would have to retire from the CBS board due to

advanced cirrhosis from hepatitis C and increasingly frail health. This decision was very difficult for James because he was so passionate about his fight to keep the Canadian blood system safe from future pathogens. He was also well aware that his physical presence helped to serve as an ongoing reminder to his colleagues across the table of the price of tainted blood.

It is remarkable that James came to Ottawa as recently as late April 2009 for a CBS meeting, just weeks before he passed away. Remarkable because medical tests had revealed fluid build-up (ascites) from end-stage liver disease, and fluid from his gut was starting to migrate down to his feet, making it difficult to walk. Nonetheless, James co-chaired a good part of the full-day meeting and listened thoughtfully to each and every speaker and group, making notes and keeping the meeting running. It turned out to be his last CBS meeting.

James was proudly one of the rare “outliers” in terms of his HIV infection. He lived with the virus for more than 20 years, becoming the last remaining long-term survivor of his longtime family doctor. James used to say he somehow managed to survive with next to no CD4+ cells for more than 15 years. At low points, when his count dropped to 2, he and Antonia sometimes jokingly referred to his CD4+ cells as Huey and Dewey—Donald Duck’s nephews.

Antonia stood side by side with James through all the years and all the battles, and she continues to advocate for the goals he fought for. Of particular pleasure for James was to see her successfully defend her PhD thesis in economics the month before he passed away. The CBS board members would later tell Antonia that James always proudly told them the details of her activities while rarely discussing his own serious health problems.

As I reflect on the life of my friend James Kreppner, I hear a call to arms for all AIDS and health-care activists. His rich legacy of words and actions calls us to keep on challenging ourselves, and our neighbours, to build a better, fairer world. +

John Plater is a lawyer and hobby farmer in Heathcote, Ontario. He has deep roots in the Ontario HIV and hepatitis C communities.

Web of Positivity

People around the world use the Internet to tell their stories of living with HIV and to share resources with each other through blogs, audio projects, online learning spaces and networking sites. While you probably already know www.catie.ca and other major HIV sites, we would like to suggest a few more spots to visit.

By Heather Ann Kaldeway



My Journey with AIDS

myjourneywithaids.wordpress.com

Kenn Chaplin, a denizen of Toronto, writes that his blog “start[ed] as a year-end letter to a dying friend in 1993, then morph[ed] into a blog. HIV/AIDS is just a part, granted an important part, of my life journey.”



Positive Lite

www.positivelite.com

A new cyber-adventure by Brian Finch of acidreflux.com fame and co-conspirator Brandon Williams. This site brings together “some of the best PHA bloggers that Canada (and New York City) have to offer.”

NAMlife – NAM, UK

www.namlife.org

NAMlife is a website featuring stories from people living with HIV about everything from sex to side effects, transmission to travel, and meds to mental health.



HIV, Women and Motherhood: an audio project – Strategies for Hope, UK

www.stratshope.org/d-audio.htm

In interviews taped at the International AIDS Conference in Mexico in August 2008, 12 positive women share how HIV has affected the joys and pains of pregnancy, motherhood and the desire for children. One of the interviews is with Canada’s own Shari Margolese.



Positive Prevention – British Columbia Persons With AIDS Society

www.bcpwa.org/empower_yourself/positive_prevention

This section of BCPWA’s site features a primer on positive prevention, two campaigns for positive gay men and the Vancouver Harm Reduction Manifesto, as well as articles about people living with HIV, safer sex, disclosure, mental health and viral load.



Adding Life to Years: A Guide to HIV and Depression – Ontario AIDS Network

www.ontarioaidsnetwork.on.ca/hivdepression

Written primarily for front-line community support workers, this guide can also be used by people living with HIV who want to learn more about coping with depression and how to access mental health services.

The Positive Project

www.thepositiveproject.org

A US website containing hundreds of video interviews of people living with HIV. And they’re searchable.



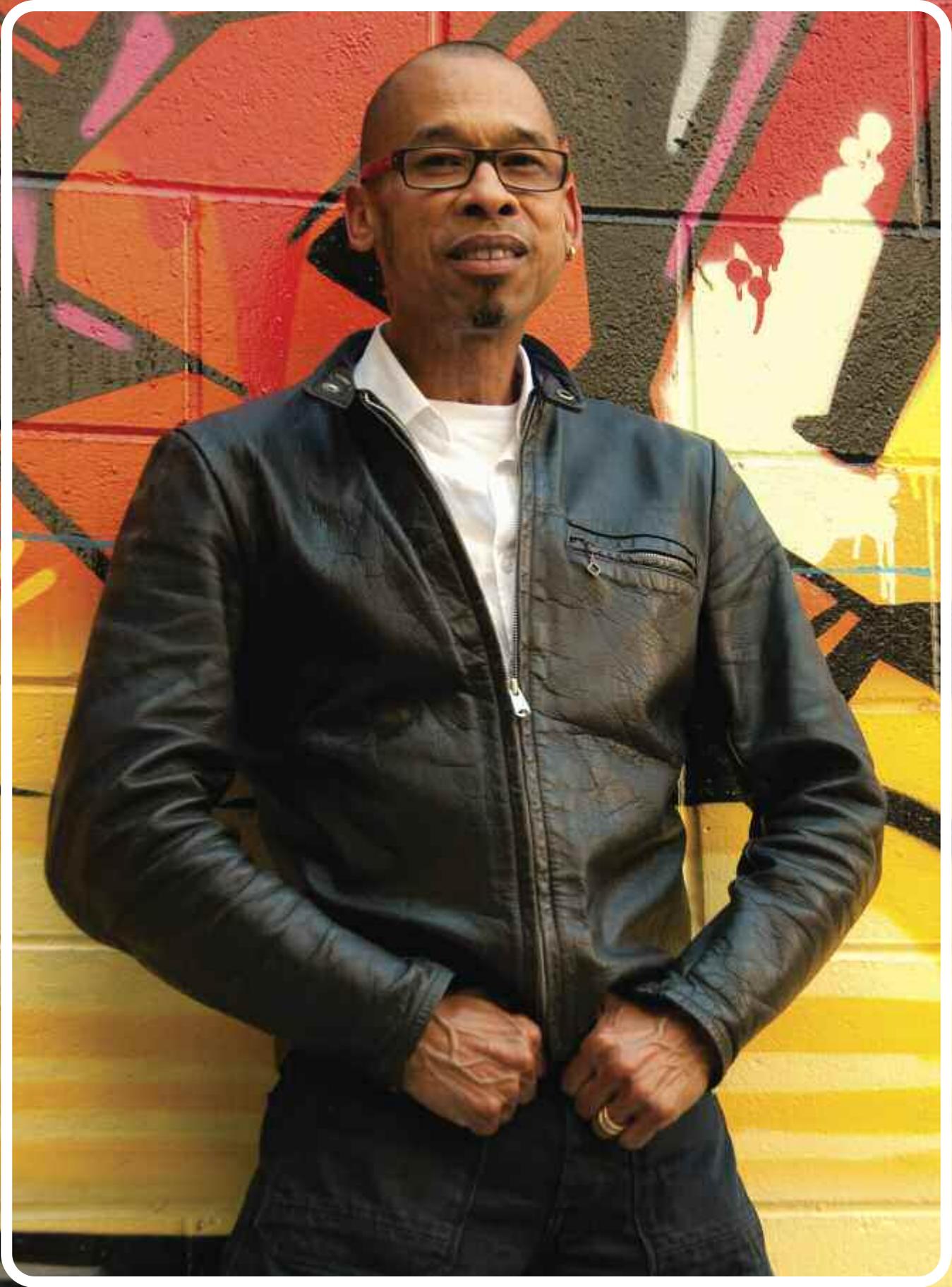
Global Network of People Living with HIV/AIDS

www.gnpplus.net

The website of the only worldwide network representing all people living with HIV and AIDS provides an overview of the organization and how it’s working to combat the virus worldwide. If you’re looking to make a difference on a big scale, this is the place to start.



Did we miss your favourites? If there’s an HIV site you think we should consider for future recommendation in *The Positive Side*, please email the link to us at web@catie.ca.



The **b**est decision I ever made

Being an artist in the public eye is difficult. Coming out as an HIV-positive artist in the public eye is even more so, as **Billy Newton-Davis can attest. But his decision to disclose was one of the best he ever made.**

INTERVIEW BY GERALD HANNON

PHOTOGRAPHS BY JOHN PHILIPS

Billy Newton-Davis may be a 58-year-old man—an incipient geezer—but he has a boy’s smooth skin, a boy’s unpredictable energies and jumpy conversational style and a boy’s simple heart. When first you meet him, you half expect him to suggest a game of tag because...well, just because there’s so much exuberance in him looking for an outlet and there you are and there he is and there’s his dog and, gee, wouldn’t it be fun?! So maybe you think: Here’s one

more ditzy entertainer. And maybe you might be tempted not to take him seriously. But maybe you’d better think again. There’s a grown man’s courage in him, and a grown man’s sense of what’s right and what’s wrong, hard won, and he’s the tougher for it.

I watch him perform at the Church Street Fetish Fair in Toronto on August 16. Slim, slight and tightly built, skin the colour of cappuccino foam, he’s not exactly a fetish poster boy (the shaved head and the swirling tattoo on his right shoulder and bicep help, but sartorially he’s standard issue gaybourhood: white tank top, black boots, blue jeans unbuttoned at the top). A four-time Juno award winner who’s

performed over a long career with the likes of Gloria Gaynor, Sammy Davis Jr., The Nylons and Celine Dion, he seems at home on a small stage before a small audience, dancing, belting out his most recent Juno winner, “All You Ever Want,” regularly imploring his listeners not to ignore the many community groups asking for donations. “Give from your heart,” he tells us (an injunction he takes seriously—he supports humanitarian causes ranging from awareness of HIV/AIDS to housing for the mentally challenged).

I meet this quadruple threat—singer, dancer, composer, lyricist—a few days later at his home, a midtown apartment on St. Clair Avenue that he shares with his partner of 15 years. (Their relationship is off limits to interviewers, but the dozen perfect roses centred on the coffee table are Billy’s 15th anniversary gift to the man he says “makes every day like an anniversary.”) They clearly love art—there’s not a wall that doesn’t host at least one painting, many of them by friends, and one of which brings Billy, briefly, to tears. It was painted for him by a 17-year-old girl with Down syndrome who had watched him perform at a benefit. It’s a childlike drawing of a dancing girl, and the text encircling it reads: “I would love to be a meringue [*sic*] dancer on stage.” It hangs in his work room, so it’s always visible to him from his computer desk. Another portrait that touches him deeply is a photograph of his great-great-grandmother, an exceptionally beautiful woman, rather formally dressed and, therefore, he thinks, possibly a house slave. He shares his office with Caruso the canary, and the whole apartment with Lola, a Kerry Blue terrier, a dog his partner rescued, who now sits attentively at our feet as we talk.



William Davis, Jr. was born in Cleveland, Ohio, the son of a factory worker from South Carolina and an entrepreneurial mom from Alabama. (He would add “Newton” when he joined the Screen Actors Guild in Los Angeles—the organization already had a Billy Davis, Jr. on its roster. Newton was a name he’d heard once, and loved.) The family ran a record store when he was growing up, and music informed his life for as far back as he can remember. “I was always singing and dancing,” he says, “and by the time I was five years old I was singing solo at the Metropolitan Baptist Church in Cleveland. I love the Baptist world I grew up in, and I will always be a Baptist. I always knew I was gay, too, and I remember reading *Ebony* and *Jet* magazines, and coming across this article on the Pearl Box Review, a show featuring black drag queens, and I was fascinated.” It would not have been easy to come out, given his church affiliation and the times, but he told his parents he was gay when he was 18. They were not enthusiastic. “Many African-Americans have a real issue with homosexuality,” he says, though adds, amusingly, that his mother had a gay friend who enjoyed coming over and trying on her hats (his parents are quite elderly now and have, over the years, come to accept him).

But in 1973 he didn’t find much acceptance. “It was a rough summer with my dad,” he remembers. Billy had graduated with a fine arts degree from Ohio University, fallen in love for the first time and told his father he’d had enough of Cleveland, that he was leaving for New York. It had always been his dream, he says, to end up in New York City as a singer or dancer or both—whatever Broadway could give him. That summer, he started to live that dream, and it was as giddy and crazy and luscious as he could have hoped. Gloria Gaynor was topping the disco charts that year and he auditioned for her show, wearing, he says, “silver



granny shoes and purple tights,” and though they told him to come back in proper attire, he got the gig. The show toured through the States, Mexico and Europe—big time for a boy from Cleveland—and he also served as Gaynor’s valet, developing a personal relationship with her. Back in New York after the tour ended, he auditioned for more roles, and he kept landing them. He appeared in the Broadway musical revue *Bubbling Brown Sugar* (which opened on Broadway in 1976), then in *Eubie!*, a revue featuring the music of ragtime and jazz composer Eubie Blake. He followed that in 1978 with a long run in the Broadway revival of *Stop the World, I Want to Get Off*, starring Sammy Davis, Jr.

It was not all bliss. The business was still remarkably homophobic. (“You could be gay backstage,” he says, “but not on stage.”) Billy turned, through a mentor he’d met at college, to Scientology. It would be part of his life for 13 years. He has mixed feelings about it today. “It got me off drugs,” he says (he had started experimenting in college), “and showed me saner ways of being in the business and gave me some clarity on life issues.” But he felt that they wanted to “audit out” gayness and promiscuity.

He came to Toronto in 1980 with a touring company of *Eubie!* The papers here singled out his performance for

special praise, and a friend told him he could be a hit in this town. His first reaction: “Toronto? Oh, please. I want to live in New York City.” He stayed, though, partly because the Church of Scientology valued his presence as a celebrity in the city. While he initially may not have been enthusiastic about Toronto, Billy grew to love the place (he’s still a landed immigrant but thinks it’s about time he took out citizenship). He found success early, in a show called *Toronto, Toronto*, and followed it with appearances in *Ain’t Misbehavin’* and *Shimmytime*. By the mid-’80s he would launch a recording career and win two Junos in 1986 for best

Has coming out with his positive status had an impact on his career? Not so’s you notice.

R&B/Soul recording and most promising male vocalist. He was not a happy homosexual, though. He was a closet case who didn’t feel part of the gay community, partly because he was still involved with Scientology until 1985 or so, when he finally left.

In November of 1986, Billy was suffering from what he thought was a persistent flu and saw his doctor. He was told he was HIV positive. “I felt myself gasping for air,” he says. “I didn’t faint but I came so close. I never dreamed I would get it—I’d been living on health foods and I felt invincible. When I left his office at Bathurst and Dundas, I cried on the street and then called my best friend, went to see her and she hugged me and held me.” He was in a bad relationship at the time, with a married bi guy who would eventually die of AIDS. They were having safe sex, as Billy understood it. When they had a fight, though, he’d go to the baths and he wasn’t always careful. He believes it took just one guy and one moment during one of those visits to contract the virus and change his life forever.

After his diagnosis, Billy felt he had to hide being positive—from fear of jeopardizing the career he’d worked so hard to create. He would live in that limbo for years and credits his time in *The Nylons*, which he didn’t join until 1991, for “giving me the freedom to be myself. The boys knew my status. One day Micah Barnes said to me—and we were very competitive and both big-headed—he said, ‘Billy, enough is enough. You are an amazing performer and you have a loving heart. Let it go.’ And I let it go.”

Billy let it go on television. In 2000, he’d agreed to an interview with Sylvia Sweeney on a Vision TV show called *Centre Stage Chronicles*, on the condition that they not discuss his HIV status. In the middle of the interview, she suddenly asked him about it. He broke down and cried, but afterwards when she showed him the footage he says he felt “it was the most beautiful moment. I decided then, enough with the hiding. And when the program broadcast, I got the most beautiful notes and letters and cards and I realized if I shared my story, others would benefit, that they’d be more aware, more cautious, that if they’re positive, they’d learn that being positive can maybe be a positive experience.”

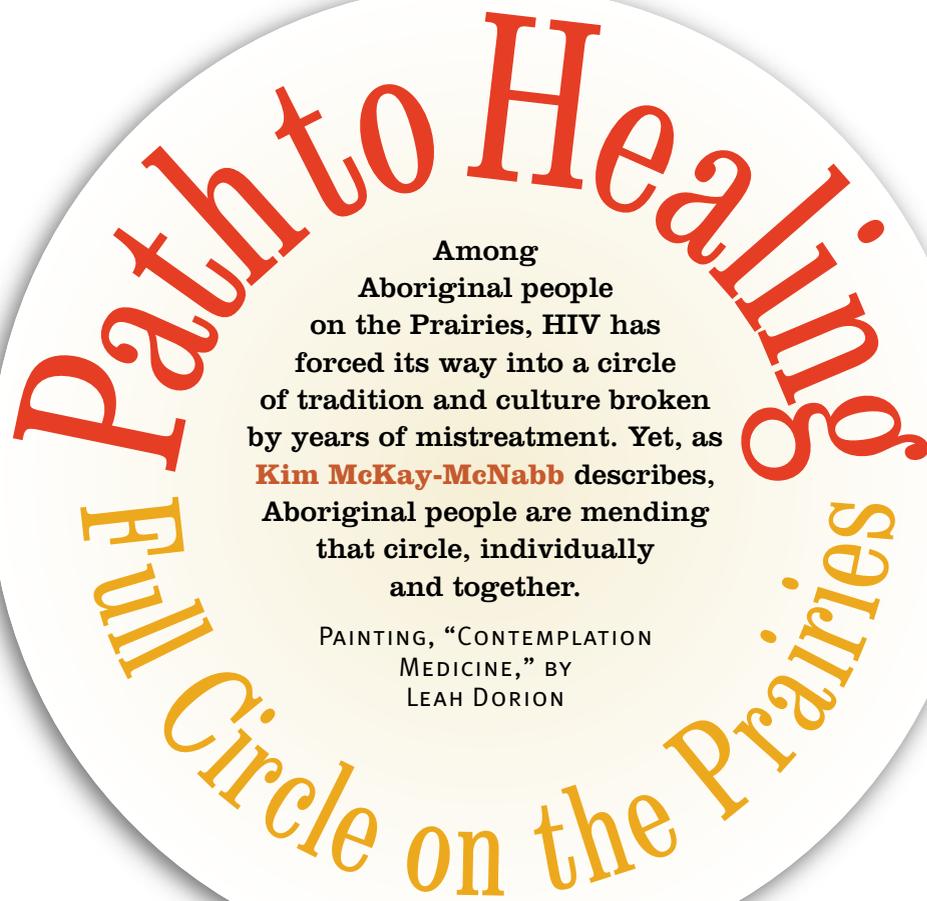
As coming out with his positive status had an impact on his career? Not so’s you notice. *All You Ever Want* won him a Juno for Best Dance Album last year, and these days he’s working on a new dance album. Billy says he doesn’t care about the people who might think ill of him and that he considers himself a lucky guy. He decided not to take AZT when it first became available, relying instead on herbals and Chinese medicine. He’s on antiretroviral therapy now—his partner and his doctor long ago weaned him off herbals (he was losing weight and his CD4+ cell count was plummeting). Three or four years ago he took a drug holiday—“it was fabulous”—but his CD4+ cells dropped and he’s back on his meds.

It’s mid-afternoon now. Lola, asleep at our feet, lost interest in us long ago but Caruso is still up to the occasional attention-getting warble. Billy, sitting beside me on the sofa, is animated and effusive still. He doesn’t seem to tire. I have one more question for him. I want to know the words that have meant the most to him of all the words he’s written and sung over so many years. “No one’s ever asked me that,” he says, and he grows still, and he’s thinking. “It’s from a song I wrote called *Decision*. It goes, ‘You’re the best decision I ever made.’ I wrote it for my partner, but it covers this decision, too, the decision to tell.”

That’s a man talking, not a boy. A grown man who isn’t ashamed to speak from the heart. +

Gerald Hannon dates back to the Jurassic period of gay activism. Although he is the winner of multiple National Magazine Awards, he’s proudest of the 15 years he spent at *The Body Politic*, the magazine that helped shape the community we know today.





Path to Healing

Among
Aboriginal people
on the Prairies, HIV has
forced its way into a circle
of tradition and culture broken
by years of mistreatment. Yet, as
Kim McKay-McNabb describes,
Aboriginal people are mending
that circle, individually
and together.

PAINTING, "CONTEMPLATION
MEDICINE," BY
LEAH DORION

Full Circle on the Prairies



As a First Nations woman whose family has been touched by HIV, I have seen firsthand how our communities in Canada are being affected by HIV/AIDS. In my various roles as a woman, a sister, a mother and a researcher, I see every day how the impact of HIV has become a huge health challenge for Aboriginal people in Manitoba and Saskatchewan.

Aboriginal people are overrepresented in the HIV epidemic. In Canada in 2007, 21 percent of all new cases of HIV that contained information on ethnicity were in Aboriginal people. Aboriginal people make up only 4 percent of the Canadian population. The impact is even more profound in Saskatchewan and Manitoba. During the same year, 38 percent of all new cases in Manitoba were among Aboriginal people. The number was higher in Saskatchewan, where Aboriginal people accounted for nearly half, 49 percent, of all new cases. This is staggering, given that

Aboriginal people made up only 15 percent of the population in these provinces.

Women, youth and people who inject drugs are carrying the burden of the epidemic in our communities. In Saskatchewan, injection drug use was at the root of nearly two out of every three HIV infections (63 percent) among Aboriginal people in 2007. Women accounted for 60 percent of Aboriginal infections that same year, and young women are particularly vulnerable: Of Aboriginal HIV diagnoses in the 15 to 19 age group, 85 percent were in women, and in the 20 to 29 age group, 59 percent were in women.

Specific social, economic and behavioural factors contribute to the disproportionate rates of HIV infection in Aboriginal people in Canada. Poverty, substance use (especially injection drug use), sexually transmitted infections and lack of access to health care services increase

our vulnerability to HIV/AIDS. One of the main social factors contributing to our vulnerability is related to our communities' experience of residential schools and the "Sixties Scoop," two traumatic events grounded in The Indian Act, 1876, which gave the Canadian government almost complete control over Aboriginal people and their lives. The damaging story of residential schools is well known. The Sixties Scoop refers to the period from 1960 to the mid-'80s when First Nations children were removed from their homes, taken from their parents, siblings, *kokums* (the Cree word for grandmothers) and *mooshums* (grandfathers) and adopted into homes outside of their community and often into non-Aboriginal families.

My family endured both the residential schools and the Sixties Scoop. My mother attended a residential school and this had an impact on our experience as a family. Before children were forced to attend residential schools, First Nations communities discussed sexuality—it was an important part of life. But during this period of forced institutionalization, the parenting skills that would have been passed on from mother to daughter and father to son were lost.

We are just beginning to heal from this piece of the history of our peoples. And part of that healing is to address the HIV epidemic among us. Margaret Akan, chief executive officer of All Nations Hope AIDS Network (ANHAN) in

Regina, points out that rebuilding connections to our culture is part of mending the circle: "ANHAN is using the teachings of our Elders and our culture to build stronger individuals, families and communities. This is the only way we are going to move forward with the multitude of health and social issues impacting the Aboriginal population." ANHAN is the Aboriginal AIDS service organization (ASO) in the two provinces, though all the ASOs in the region have many Aboriginal clients and offer services specifically for Aboriginal people with HIV/AIDS (APHAs).

Saskatoon HIV Aboriginal Reduction of Harm Program (SHARP) is another example of Aboriginal people leading the response to HIV. Started in 2008, the program, a collaboration including Saskatoon Tribal Council, AIDS Saskatoon and local health agencies, brings a holistic view of health to APHAs and those at risk in Saskatoon's inner-city neighbourhoods. The goal is to reduce the number of new cases of HIV and other sexually transmitted infections by helping both HIV-positive and HIV-negative Aboriginal people in the community.

Healing is also occurring one person at a time. I had the honour of sitting down with three APHAs from Manitoba and Saskatchewan. These strong, resilient people who walk with their heads held high on their own journey shared their stories with me... and here I share them with you.



Krista Shore

"I started to stand up for myself and say, 'This is me. This is my story.'"

KRISTA SHORE IS A 27-YEAR-OLD FIRST NATIONS WOMAN, originally from Peepeekeesis First Nation in Saskatchewan. She currently lives in Regina with her partner and two children. Krista was diagnosed with HIV in 2006.

Krista was involved in the child welfare system from a young age. "I experienced a lot of violence at a young age: drug and alcohol abuse, sexual abuse, physical abuse. By the age of 12, the year my mother was murdered, I had my first experience with alcohol and drugs."

A life of addiction affected Krista's ability to parent, and in 2006 and 2007, her children were taken into care. She felt desperately alone without them and so began to work on getting them back. Krista had been sober for nearly three months when she learned that her children were going to be placed in care permanently.



Lana Bear

“I had lost my kids for good. I really believed that. The following year I tried to commit suicide, I overdosed, I was stabbed and I ended up homeless. I had a real deep self-hatred. I used drugs. I liked the needle. Then I met a man involved in a gang. During that period, I lost my dignity, my pride, my looks and my self-respect. I’m lucky that I am still alive. I got a diagnosis of HIV within half a year of the last time I was with that man. In February of 2006, 10 years to the day that I learned my mother was murdered, I found out I was HIV positive. How I got my diagnosis was harsh. I resent the way I was told by the doctor, so blankly and bluntly: ‘I got something to tell you. You are HIV positive.’ Luckily, my sister was there with me and I knew the nurse. I didn’t go back to using.”

In order to get her life back on track, Krista developed ties with a few community agencies in Regina. She found a place to stay and got back in touch with her children. “I prayed to God the Creator to help get me through this. I just kept thinking of my kids. I slowly started doing the work to maintain my recovery.” And she succeeded—her children came home in 2008 and 2009.

“I reached out for help. The more I tried to move forward, the more help I received. I got in contact with All Nations Hope AIDS Network (ANHAN) and they really supported me. I didn’t realize all the support that they could offer a person living with HIV. I feel grateful for it. Through All Nations Hope, I applied to attend a women’s retreat. I didn’t even include my HIV status on the application. I was afraid to tell people. But at the retreat I felt inside of me that it was all right to tell them.”

Through the ANHAN retreat, Krista was put in contact with another APHA, Ron, who was attending the retreat as a speaker. “Meeting Ron really soothed me inside. It diminished the shame, the pain. I wasn’t alone. He lit a fire inside me and I felt that I needed to find a space within the circle. I started to stand up for myself and say, ‘This is me. This is my story.’” She adds, “All Nations Hope and the Canadian Aboriginal AIDS Network have been a great part of my journey. It feels like family being surrounded by other APHAs.”

Krista and her partner are expecting their third child. Though she has built a strong community to assist her, she is now facing another challenge in her journey: trying to access support during her pregnancy. “I have a good doctor, but we need more resources for pregnant women and mothers with HIV.” In Regina, there is no assistance to access costly baby formula for HIV-positive mothers, who cannot breastfeed due to the risk of passing HIV to the baby. “I would like to start a baby formula program here, not only for myself, but for our communities.”

Post script: Since the time of the interview, Krista and her partner have welcomed a healthy baby girl into their family.

LANA IS A 42-YEAR-OLD FIRST NATIONS WOMAN FROM Muskoday First Nations in Saskatchewan. After spending 28 years on the street and being incarcerated for long stretches of time, she was diagnosed with HIV in 2006.

“I never knew about HIV until about five years ago when everybody on the streets started talking about how bad it was. But I didn’t really care because I was on drugs and I didn’t take the time to listen. I thought I probably already had it. Then I got really sick and was hospitalized. After I was told that I have HIV, I didn’t feel sad or anything. Now, although I

“I feel it’s very important for people on reserve to have more services, more activities for children and more support.”

have emphysema and asthma and have been on home oxygen for a year, I am taking my HIV pills every day and I’ve been keeping all of my regular appointments. It’s been about one year since I used anything. I am happy for myself.”

“I have a lot of support in my immediate family—my six children and my partner. Then there are the people at my AA meetings. I have the nurses who work at the STD centre. And the health representative from Muskoday First Nation, Rhonda, has helped me through thick and thin.”

“The Prince Albert Sexual Health Clinic and the health committee here on reserve have HIV workshops, but there isn’t enough counselling. We need more activities and support groups. I think that people with HIV should be heard more. We should have HIV support groups to talk about our issues confidentially and openly, like at an AA meeting. Then people might come out of their shells more and talk about it. I feel it’s very important for people on reserve to have more services, more activities for children and more support for people like myself.

“For me, it’s helpful having everyday things to do, a little of everything... praying, house cleaning, going for walks and visiting my children. I never really looked after my kids; my mother did. I couldn’t take care of them. I had a lot of anger. Now I try to spend as much time as I can with them. I spent a lot of time on the streets and I want to make up for that. My prayers are now answered. I am on my healing journey. Thank you, Jesus.”

Kinzie

“My story with HIV really starts in Canada. Now I feel healthy. I am not ashamed of who I am.”

KINZIE IS A 47-YEAR-OLD FIRST NATIONS GAY MAN FROM Cross Lake First Nation in Manitoba. He was born in The Pas and currently lives in Winnipeg with his partner and his cats.

Kinzie is a child of the Sixties Scoop, the practice of removing First Nations children from their homes and communities and giving them over to non-Aboriginal families. His adopted family raised him in Texas (Kinzie still has contact with them today). Once he learned about his biological family being from Canada, he moved here and started to come to terms with his identity as a First Nations man. Kinzie has been living in Canada for five years and has reconnected with his family, an experience he says has been both rewarding and challenging.

When Kinzie learned he was HIV positive, he was living on the streets, prostituting, drinking and using drugs.

“When I first found out, I felt dirty and gross and I wanted to rub off my skin. There was so much stigma in the '80s. I felt that people were looking at me like I was a disgusting faggot. So I delved more into drugs to cope.”

But coming to Canada started his journey of healing, which involved identifying himself as a gay First Nations man who has HIV. “My experience of living with HIV in Canada has been better than in the States. My story with HIV really starts in Canada. Now I feel healthy. I am not ashamed of who I am.”

“I have my Aboriginal God behind me, my Caucasian God behind me and my Christian God behind me. I call my mom every morning for prayer before I go to school. I get a lot of my strength from God, my family, my partner and my kitties. And I have a lot of support through my aunty and uncle, who assisted me to meet the rest of my biological family at a family reunion.”

Kinzie described some of the supports that he was offered through agencies in Winnipeg. The Aboriginal Support Centre helped him get his identification, including his social insurance card. He also saw an ad in the paper about the Nine Circles Community Health Centre. “At Nine Circles, I walked in and asked for the gay men’s health centre, and I got what I needed there. I met my nurse, who I confide in a lot. She’s like my surrogate mom. That’s our little joke.”

“I take care of myself. I am healthy. I’m staying well because of school, my partner and because I love my three cats. They give me strength, hope and courage.” +

Support for APHAs in Manitoba and Saskatchewan

Manitoba

Winnipeg

Kali Shiva Society

204.783.8565
kalishiv@mts.net

Manitoba PHA Caucus

204.940.6057
caucusstaff@yahoo.ca

Nine Circles Community Health Centre

204.940.6000
1.888.305.8647
www.ninecircles.ca

Saskatchewan

Regina

All Nations Hope AIDS Network

306.924.8424
1.877.210.7622
www.allnationshope.ca

AIDS Program South Saskatchewan

306.924.8420
1.877.210.7623
www.aidsprogramsouthsask.com

Saskatoon

AIDS Saskatoon

306.242.5005
1.800.667.6876
www.aidssaskatoon.ca

PLWA Network

306.373.7766
1.800.226.0944
plwa@sasktel.net

Saskatoon HIV Aboriginal Reduction of Harm Program

306.956.0300

Prince Albert

Prince Albert Sexual Health Clinic

306.765.6540

National

Canadian Aboriginal AIDS Network

604.266.7616
1.888.285.2226
www.caan.ca

Kim McKay-McNabb is a First Nations Cree woman from George Gordon First Nation in Saskatchewan. She is a wife, a mother to four sons and one daughter, a PhD clinical psychology student at the University of Regina and an assistant professor at the First Nations University of Canada. She has a passion for working with Aboriginal communities who are affected by HIV/AIDS in Canada.

Leah Dorion is a Métis artist currently living in Prince Albert, Saskatchewan. Her work incorporates many symbols, teachings and stories from her First Nations and Métis community. For more information about Dorion’s artistic vision and practices, check out her website at www.leahdorion.com.

A Mind of Her Own

Long-term survivor **Maggie Atkinson** adds cognitive problems to her list of HIV-related issues. Here she takes a walk down memory lane and shares what she's learned about protecting her brain.

ILLUSTRATION BY PHIL



ILLUSTRATION © PHIL/WWW.I2ART.COM

promises

PROTECT

I first noticed a slight reduction in my ability to think clearly in 1993, when my CD4+ cell count fell below 200. I just didn't feel as sharp.

A year later, when I got PCP, the life-threatening pneumonia that is a hallmark of AIDS, my handwriting deteriorated so much that I had to concentrate to write legibly. About five years ago, I started having trouble remembering names of famous people. Over the next couple of years, these memory lapses progressed to the names of colleagues and then friends, which was awkward, to say the least.

I also began to have difficulty finding words. It started with complex words. My brain would substitute another similar-sounding or simpler word. My sentences began to be filled with "thing" or "stuff" or "you know." As it got worse, I forgot everyday words. As an AIDS activist, I used to speak in public regularly. Gradually, I began to shy away from those activities because it was embarrassing to be fumbling for words. I was acting like a stereotypical geriatric, not a 40-something lawyer.

Fortunately, about two years ago, I found some strategies that helped and I've gotten much, but not all, of my functioning back. Based on my personal experience and some additional research, here is what I learned about protecting the brain.

First, some terminology

The term *cognition* refers to the high-level functions of the brain, such as speaking, seeing, calculating, processing information, remembering, planning and problem-solving. When these processes are reduced, experts use the term *neurocognitive impairment*, or *NCI*.

When reading about NCI, you find very similar-sounding terminology. *Dementia*, for example, is a general term that refers to a severe decline in cognitive function that interferes with daily activities. It is not a disease itself but a group of symptoms that may accompany a disease or condition. *AIDS dementia complex* is a term introduced in 1986 to refer to the severe cognitive deficits and motor and behavioral changes associated with advanced HIV disease.

With advances in HIV research, our understanding of the effects of HIV on the brain has become more nuanced. Now, experts often speak of *HIV-associated neurocognitive disorders* (*HAND*). This umbrella term covers a range of disorders of increasing severity—from asymptomatic (signs of impairment on neuropsychological tests but no loss of function in day-to-day life) to mild (signs of impairment in both tests and daily living) to the most severe form, *HIV-associated dementia* (*HAD*).

How common is NCI among PHAs?

Experts are still not sure how common NCI is. Since the advent of highly active antiretroviral therapy (HAART), rates of the severe form—HAD—have declined dramatically in the developed world, from about 50 percent down to as low as 2 percent. University of Alberta's Dr. Chris Power, one of North America's leading neurologists, has estimated that about 7 percent of the more than 3,000 patients in the HIV clinics in Calgary and Edmonton have HAD.

Milder forms of NCI may be more common, and researchers in the United States are taking an in-depth look at this issue in the CHARTER (CNS HIV Antiretroviral Therapy Effects Research) study. Their results, released this past summer, indicate that the rate of NCI was 52 percent among



It was embarrassing to be fumbling for words. I was acting like a stereotypical geriatric, not a 40-something lawyer.

1,555 middle-aged HIV-positive volunteers—with 21 percent having mild impairment, 29 percent moderate and 2 percent severe.

Similar findings have been made by Dr. Sean B. Rourke, a neuropsychologist, scientist and the director of research in the Mental Health Service at St. Michael's Hospital in Toronto. Having done neuropsychological testing on more than 500 people with HIV/AIDS (PHAs), he found NCI prevalence ranging from about one-quarter to one-third among people with HIV and up to 50 percent in people with AIDS, excluding those with conditions that can also cause NCI (such as depression or a history of traumatic brain injury). Dr. Rourke notes that his data are slightly biased because he sees patients who have been referred for cognitive problems.

There is not yet a general consensus on these data, but it is clear that NCI—especially its milder, subtler forms—may be touching a large proportion of PHAs.

What causes NCI?

HIV enters the brain early on in the course of infection. Although it doesn't infect brain nerve cells (neurons), HIV damages them both directly and indirectly. Proteins from HIV-infected cells cause the release of certain chemical

Acronyms

HAD – HIV-associated dementia
HAND – HIV-associated neurocognitive disorders
NCI – Neurocognitive impairment

messengers (neurotransmitters), which, in turn, cause inflammation, excitation and even cell death. In a less direct fashion, HIV infects other cells in the brain that cause a release of toxins that damage that organ.

HAD is associated with advanced HIV disease, and although rates of HAD are declining, the milder forms of NCI are not necessarily following suit, says Dr. Ian Everall, a professor of psychiatry at the University of California, San Diego. He speculates that while HAD may be caused by the direct toxicity of HIV in the brain, milder forms of NCI are caused by secondary processes brought on by low-level presence of the virus: “HAD is a product of uncontrolled viral replication and immune suppression, so when we control replication with HAART, we get less HAD. But perhaps we are still living with low-grade infection and inflammation, which is subtly affecting the neurons and causing mild neurocognitive disorder.”

Along with HIV and aging (see next section), there are many other factors that can cause or contribute to NCI, depending on their severity, including: depression, concussion, learning disabilities, alcohol or other substance-use disorders, non-HIV-related neurologic conditions (such as epilepsy and multiple sclerosis), systemic diseases (such as high blood pressure, diabetes, asthma and thyroid disease), hepatitis C virus and vitamin B₁ and B₁₂ deficiencies.

Aging and NCI

Aging affects the structure and function of the brain, slowing it down, making it less accurate and reducing its capacity to store and retrieve memories. Again, scientists have a range of terms for the severity of this decline, beginning with *age-related cognitive decline*, which is associated with normal aging. *Mild cognitive impairment*, evidenced by poorer memory and performance on neuropsychological testing, is seen in about 20 percent of those over 70. The

most severe impairment is dementia, one common cause of which is *Alzheimer’s disease*. This irreversible illness severely and progressively affects cognition, behavior and motor functions and day-to-day living. Most often found in people over 65, its incidence doubles about every five years from then. Approximately

50 percent of HIV-negative people over 80 have Alzheimer’s.

“It is a concern that with the aging of the HIV population we may be seeing additional effects of age [on NCI],” says Dr. Power. He hasn’t seen much Alzheimer’s in HIV-positive patients until they’re in their 70s, but some studies have shown signs of Alzheimer’s disease in the brains of PHAs much earlier. In a small substudy of brain samples from HIV-positive people over 55, Dr. Everall and his colleagues from the National NeuroAIDS Tissue Consortium found beta amyloid plaques, a characteristic of Alzheimer’s disease, in 35 out of 36 brains.

For years, doctors and PHAs have suspected that HIV causes accelerated aging of the body. It wouldn’t be surprising if the virus had this effect on the brain, too. In a recent small study, the blood flow in the brains of PHAs appeared similar to that of HIV-negative people who are 15 to 20 years older. Dr. Rourke says that with neuropsychological testing “in those [HIV-positive people] with mild neurocognitive disorder, I am seeing an accelerated aging, like 10, 15 or even 20 years older.”

Do you have HAND?

If you suspect that you have a problem with your cognition, the first step is to see your doctor. He or she may refer you to a specialist for further testing. Diagnosis of HAND involves neuropsychological testing that evaluates different parts of brain functioning. If you have signs of mild neurocognitive disorder, your doctor will take a full history

Penetration of anti-HIV drugs through the blood-brain barrier

	Higher	Intermediate	Lower
Nukes (NRTIs)	abacavir AZT	FTC 3TC d4T	ddI tenofovir ddC
Non-nukes (NNRTIs)	delavirdine nevirapine	efavirenz	
Protease inhibitors (PIs)	boosted amprenavir boosted darunavir boosted indinavir boosted lopinavir	amprenavir atazanavir boosted atazanavir indinavir	nelfinavir ritonavir saquinavir boosted saquinavir boosted tipranavir
Integrase inhibitor	raltegravir		
Fusion inhibitor			T-20

Adapted from Letendre S, et al, 13th CROI, 2006, Abstract 74

and perform tests to determine the conditions that might be causing the impairment.

HAART for HAND

“HAART is the cornerstone of treatment for HAND,” Dr. Power says. Early intervention with HAART can reduce the risk of HAND and decrease symptoms. From a number of recent studies, it appears crucial to begin HAART before the CD4+ count falls below 200—how much earlier is not certain. It may well be that HAND, even if it is not affecting daily functioning, should be an indicator for treatment.

Which combination of drugs to take is another question. Some antiretrovirals are better than others at passing through the blood–brain barrier, which keeps many toxins out of the brain and spinal cord. Recent studies, including CHARTER, indicate that having a regimen with more drugs that can penetrate the barrier leads to reduced rates of NCI.

Some researchers have developed a system of ranking the ability of antiretrovirals to penetrate the blood–brain barrier (see chart on p. 23). However, there are no official guidelines as to whether or not to change a HAART regimen if you have an undetectable viral load but are showing signs of NCI. That is an individual decision between you and your doctor.

Forget Me Not: Dealing with the symptoms of NCI

Your doctor can refer you to rehabilitation experts, such as physical and occupational therapists, who can help you to deal with the effects of NCI on your daily functioning. I asked two professionals for their tips.

Sheila Thomas, occupational therapist at the Sherbourne Health Centre in Toronto, works one-on-one with PHAs: “It all depends on your needs and goals. Sometimes it’s a matter of creating a routine—always put keys in the same place, associate taking meds with certain things like getting up in the morning, plan to do recurring things on the same day of the week. It depends on how you take in information best. Some people do better with visual cues like Post-it notes, others with an auditory alarm such as a timer. Minimize distractions by not having the TV and radio on when you’re trying to talk to someone. Pace yourself throughout the week: Try to spread things out so you’re not doing everything at once. Leave yourself extra time. Electronic calendars and a cell phone or personal organizer with phone numbers in it can make life easier.”

Dr. Sean Rourke, a neuropsychologist, scientist and the director of research in the Mental Health Service at St. Michael’s Hospital in Toronto, notes that a diagnosis of mild neurocognitive disorder, though initially stressful, can be therapeutic. “In a way, it can be a relief to find out that you really do have a problem and it isn’t all in your imagination.” He suggests some compensatory strategies: “Lists, date books, use them strategically. You may need to write things down to crystallize them better. If you have short-term memory problems, take more time to prepare things, practice a few more times, write it down. Retrieval is often a problem with HIV. Don’t overdo it, but have the main concepts written down in front of you to rely on, to get back on track. You may need more time, and you may have to build in these pieces to compensate, but you can still do it well.”

Nutrition and more

When I first did neuropsychological testing with Dr. Rourke 10 years ago, I asked what I could do to preserve my memory. He told me: “Whatever helps the heart, helps the brain.”

I found two fairly similar approaches—the Pritikin Program for Diet and Exercise created by Nathan Pritikin (www.pritikin.com) and The Spectrum Lifestyle Program founded by Dr. Dean Ornish (www.pmri.org/lifestyle_program.html)—that have proven results in reducing heart disease, cancer, diabetes and their contributing factors. (You can also read more about these programs in *The Pritikin Edge* by Robert E. Vogel, 2008, and *The Spectrum* by Dr. Dean Ornish, 2007.)

Last August I went to the Pritikin Longevity Center in Florida for two weeks and saw a 30 percent drop in my cholesterol and a 50 percent reduction in my insulin levels. I also felt 15 years younger, physically and mentally. In a nutshell, this is the recommended lifestyle at the Pritikin Center:

- diet: fruits, vegetables, beans, soy, fish, whole grains, no added fat, nonfat dairy, no added salt, little or no coffee and alcohol
- vitamin D₃: 1,000 to 2,000 IU/day, depending on test results
- exercise (aerobic, resistance, flexibility): 6 to 7 days per week
- stress management: meditation, yoga
- no smoking
- sufficient sleep

With respect to diet, Lark Lands, a medical journalist, editor and longtime AIDS treatment educator and advocate (www.larklands.net), suggests taking plenty of natural anti-inflammatories, as inflammation plays a key role in the processes that block and damage arteries. Avoid fats that promote inflammation, such as partially hydrogenated oils (“trans fats”) and polyunsaturated vegetable oils. Some examples of naturally anti-inflammatory foods and seasonings are: ginger, turmeric, bioflavonoid-rich fruits (such as colourful berries, grapes and citrus fruits), omega-3 fatty-acid-rich foods (such as wild, fatty fish, flaxseed and walnuts) and garlic (eating more than a couple cloves of raw garlic may interact with some drugs, so speak with your doctor and pharmacist about possible interactions with your meds).

According to Lands, many of the mental changes experienced in HIV disease may be the result of advanced vitamin B₁₂ deficiency. This deficiency can cause memory loss, confusion, chronic fatigue, decreased reflexes, unsteady gait, weakness, neuropathy and depression. B₁₂ deficiency is common in PHAs and older adults. Unfortunately, the tests commonly used to assess B₁₂ status may not be reliable, often indicating that a person has “normal” levels when, in fact, there is a deficiency. Consequently, vitamin B₁₂ therapy based on symptoms, rather than test results, is recommended.

To maintain general health and protect mental functioning, Lands recommends taking a high-quality multivitamin, an antioxidant formula, fish oil (try to find mercury-free

Work Those Brain Cells!

Learning new things is highly valuable when it comes to your brain health. The best activities are progressively challenging, mentally rewarding, novel or surprising and demanding of focused attention. Here are some ways to exercise your brain:

- learn to play music
- learn a language
- do crossword puzzles (must be challenging) or jigsaw puzzles (more than 500 pieces)
- play ball or juggle
- crochet or knit
- use your “other” hand
- take dance lessons
- play bridge

kinds), vitamin B₁₂, folic acid and N-acetyl-cysteine (NAC).

Exercise

A number of studies in sedentary seniors who took part in fitness programs have shown that exercise improved their cognition. Exercise may promote the growth of brain cells and increase human growth hormone, which can help cognition.

Exercise is important, especially when you're HIV positive, because it may prevent or help a slew of conditions (including diabetes, high blood pressure, chronic kidney disease and depression) that might adversely affect cognition.

Learning ballroom dancing, particularly tango, may be good not only because of the physical exercise and social interaction but also because of the mental benefits. “There are trends that suggest that tango is good for working memory and divided attention,” says Patricia McKinley, associate professor at the McGill School of Physical and Occupational Therapy. “I think that any challenging dance would be good for you.”



“Whatever helps the heart, helps the brain,” says Dr. Sean Rourke.

Fitness for the brain

A couple of years ago, I saw Dr. Norman Doidge, Toronto psychiatrist and researcher, speak about his book, *The Brain that Changes Itself*. He explained how the brain is plastic and therefore can change based on what you do and think. He also mentioned the success of the Brain Fitness Program (BFP) in improving the memory of healthy seniors. I went online and read about the early impressive results of the IMPACT study (Improvements in Memory with Plasticity-based Adaptive Cognitive Training), a randomized, double-blinded prospective study of the Brain Fitness Program by researchers from the Mayo Clinic and the University of California, San Francisco. Among 524 HIV-negative seniors, those using the BFP had a 131 percent increase in brain processing speed. Their memory improved to that of individuals 10 years younger on average. Their neuropsychological test performance was significantly better than the active controls. And 75 percent of participants self-reported positive changes.

I purchased the computer program. Although there was no evidence that it could help people with HIV, I thought, what do I have to lose? I did the 40 one-hour sessions—one hour per day, five days a week, for eight weeks. As a result of the sometimes-grueling exercises, I had a 54 percent increase in brain processing speed, plus I noticed I had much better word recall and short-term memory. I wasn't fumbling for words anymore. I could remember names of people I met. My hearing, handwriting and especially my self-confidence improved.

I recommended the program to a friend, who went to Dr. Rourke for neuropsychological testing before and after doing the BFP. He had a 34 percent increase in brain processing speed. More importantly, he went from testing below normal in all areas to normal, and in one-third of the domains to above average compared to his peers. “Before the BFP I would forget what I was talking about,” he told me. “I was perpetually making lists. I knew there wasn't anything I could do except watch it happen. I felt a mix of sadness, loss and grief. After the BFP, I noticed I wasn't having trouble carrying on a coherent conversation. I wasn't making as many lists. It was easier to get my key in the door, I wasn't fumbling anymore. Now I feel more confident, I feel better.”

“The results are quite amazing,” Dr. Rourke says. “This kind of improvement is unprecedented. We are doing more case studies at our neurobehavioral unit with a view to an eventual trial.”

A work in progress

It's been two years since I completed the BFP and my memory has started slipping a bit, so I've decided to do the program again. Although the results have been shown to last at least five years, some people choose to repeat it to keep themselves sharp. This time I did neuropsychological testing before starting, and it turns out that I am functioning much as I did seven years ago when I was last tested, before my memory started failing. I am looking forward to seeing how I perform after a refresher.

Besides that, I've started to do more things that stretch my brain, such as going to the museum, relearning a language and learning to play a musical instrument. I'm doing jigsaw puzzles and knitting and even brushing my teeth with my left hand. And I'm still trying to follow the Pritikin program as much as possible. Next up? I'm signing up for ballroom dancing, maybe the tango! +

Maggie Atkinson is an AIDS activist, lawyer and long-term survivor with HIV/AIDS. Her motto in life is not “Why me?” but “What can I do about it?”

ASK THE EXPERTS

Get answers to your treatment questions

The Skinny on Skin

My HIV-positive boyfriend is always suffering from some sort of skin affliction, and he's not alone. He and his poz friends often compare (and bemoan) their blotches and rashes. Are there skin conditions that are more common among people with HIV? What can they do about them? – T.P., Toronto



INTERVIEWS BY JENNIFER MCPHEE



CHERYL ROSEN, MD

Dermatologist

Toronto Western Hospital

Before highly active antiretroviral therapy (HAART) came along, skin conditions were extremely common among people with HIV/AIDS (PHAs). Fortunately, those days are behind us.

Today, warts are the most common skin condition among PHAs. They are caused by human papillomavirus (HPV) and can appear anywhere on the body, including the mouth and the genitals. Freezing with liquid nitrogen or applying cantharidin solution or ointments with salicylic acid are three possible treatments. Warts can be quite resistant and may need multiple treatments.

Kaposi's sarcoma (KS) is much less common today than it was before HAART, but it is still seen in PHAs. It can occur on the skin and in the lining of the mouth, nose and throat. KS, which is caused by a herpes virus, appears on the skin as small, flat bluish-red to purple patches that can become raised over time. Because developing KS is related to having a compromised immune system, changing antiretrovirals to make a more effective HAART regimen, which will lead to improved immune function, may help. Surgery, treatment with

liquid nitrogen and several anti-cancer medications are also options. If you notice a new or changing skin lesion, see your doctor. It may be benign, but if it is a form of skin cancer, it's best to treat it early.

Some PHAs also end up with rashes caused by drugs, including anti-HIV medications such as abacavir (see Antiretrovirals and Rash, next page) or antibiotics such as sulfa drugs. Drug rashes can look like hives, blisters or red, scaly patches. The best way to determine the diagnosis of a generalized rash and whether it is related to a drug and how to treat it is to see your doctor.

It is important to remember that PHAs can develop skin lesions and rashes that are not related to HIV. You should see your doctor about any change on your skin that does not heal.

DEBBIE KELLY, PharmD

Pharmacist

Newfoundland and Labrador HIV Clinic

Whenever a PHA has a rash that might be caused by a drug, we first try to establish whether a drug is the problem or whether something else is to blame, such as a new shampoo, soap or laundry detergent. Once we determine that a drug is the culprit, we assess if the rash is a relatively harmless side effect that the person

can ride out or if it's a sign of a more serious drug allergy. In many cases, people keep taking their medication, but we check regularly to ensure that their rash is improving.

There's not much you can do to prevent rashes caused by medications. If your doctor has advised you to ride out an annoying rash, we recommend:

- applying a non-scented moisturizer after bathing
- using non-scented hypo-allergenic skincare products
- adding packets of colloidal oatmeal to your lukewarm bath
- using antihistamine or corticosteroid cream only after checking with your doctor to ensure that these creams won't obscure a more serious problem

The antiretroviral atazanavir (Reyataz) can cause jaundice (yellowing or darkening of the skin and/or whites of the eyes). In most cases, jaundice is not dangerous, but many people are bothered by it. If you have this condition, it's important to not stop taking your medication. Instead, ask your doctor and pharmacist about other options.

Finally, it's important to note that when you start HAART, any pre-existing skin condition may suddenly get worse. Hang in there. As these drugs begin to restore your immune system, your skin should improve.

AARON HOO, ND
Naturopath
Doctors' Choice Nutrition
Vancouver

When your skin is inflamed, it's often a sign that your "gut" lining is inflamed. This is really a sign that the body's immune system is compromised, because the majority of the immune system resides in the gut wall.

An unhealthy gut lining impedes the digestion of certain foods and results in food sensitivities, which, in turn, can show up on the skin as eczema. The first thing we do for eczema is eliminate certain foods from the diet to pinpoint which foods are causing the problem. We also suggest:

- taking the amino acid supplement L-glutamine
- taking herbs that promote mucous production, such as slippery elm and aloe
- taking digestive enzymes, such as bromelain (pineapple extract) and papain (papaya extract)

A disruption of the bacterial ecology of the gut can cause an overgrowth of *Candida* (yeast) in the body. This can lead to very red, itchy skin. We recommend removing simple sugars and yeast-based foods from your diet and replacing them with healthy fats and proteins. The herb Oregon grape root helps rid the body of excess yeast and probiotic supplements help replenish the body's supply of "good bacteria."

Herbal Interactions

Some herbs can interact with prescription medicines, including anti-HIV drugs, and over-the-counter products. This can change the medication's effectiveness or make worse any side effects of the drugs. Be sure to let your doctor know of all the herbs, supplements and other complementary therapies you are taking.

Herpes infection is quite common among PHAs. We suggest taking zinc orally and applying zinc sulphate topically to help decrease the number of herpes outbreaks and speed up healing of sores. We also suggest taking lysine orally or topically.

Stress takes a heavy toll on the body's immune system, so take time to relax by practicing yoga, prayer, meditation or deep breathing exercises. Your skin will thank you.

FRANÇOIS

Person living with HIV
Montreal



My long, frustrating battle with skin conditions began last December. I've been HIV positive for seven years and I've had psoriasis for much longer. So, when I first noticed lesions on the top of my head, I assumed my psoriasis was back. But these itchy, dry, bloody patches looked quite different from what I was used to.

My HIV physician sent me to a dermatologist who diagnosed me with eczema and gave me a corticosteroid cream. It didn't help. In fact, extremely itchy little blisters started showing up on my hands and then spread to my arms. I went back to my dermatologist, who prescribed a different kind of medication. Again, it didn't help.

In June, while on a fishing trip, my arms suddenly became very red and swollen, and the redness spread to my previously unaffected legs. Naturally, I was quite alarmed. I took the antihistamine Benadryl, which reduced the swelling but not the redness. As soon as I got home, I went to my dermatologist. He took one look at me and said, "My God, what is that?"

He sent me to a dermatologist who specializes in treating PHAs. Thankfully, this doctor had more answers. He told me I had eczema on my head and that the bleeding from the eczema made me susceptible to bacterial infections—specifically bacterial folliculitis and impetigo. He prescribed an antibiotic, and, after taking it four times a day for 10 days, my skin finally began to improve.

Antiretrovirals and Rash

The group of anti-HIV drugs called non-nukes or NNRTIs—which includes efavirenz (Sustiva and in Atripla), etravirine (Intelence) and nevirapine (Viramune)—can cause skin rash, usually during the first few weeks of use. If you develop a rash while taking any of these drugs, contact your doctor.

There have been rare cases of a severe and life-threatening skin reaction among nevirapine (and perhaps one case with etravirine) users. In addition to skin rash (which may be blistering and painful), other symptoms may occur, such as itchy eyes, swelling and muscle or joint pain. If you develop any of these symptoms, call your doctor immediately.

The nuke abacavir (Ziagen and in Kivexa and Trizivir) can cause a severe, life-threatening immune system reaction usually within the first six weeks of use. Fortunately, most HIV clinics now test PHAs to determine if they are likely to develop this reaction to abacavir. As a result of this testing, life-threatening reactions to abacavir are now very rare in Canada.

Skin eruption and rash has also been reported in a very small portion (less than 1 percent) of people taking the protease inhibitor darunavir (Prezista) during clinical trials.

Soon after, I went on another excursion to the great outdoors. As usual, I wore lots of sunscreen and brought along Benadryl. This time, the sun did wonders for my skin.

Anyone suffering through a similar ordeal should see a specialist sooner rather than later. These days, my skin is not completely lesion free. But compared to before, I feel like I've been cured. +

Jennifer McPhee is a Toronto-based freelance writer. Her work has appeared in numerous publications including *Chate-laine*, *The Globe and Mail* and *Childview*.

Lights, Camera, Action!

In the film project *Positive Take*, nine Montreal youth with HIV pick up video cameras and shoot the world as they see it, with the goal of fighting the stigma and discrimination they face.

BY ALBERT MARTIN

L'ombre du doute (*Shadow of Doubt*) shares the story of how Emelyne learned of her status while growing up in an orphanage, Maison Shalom, in Burundi. She tells of her quest to get treatment and how lucky she feels that she has access to meds now that she lives in Canada.





Seropoclub (Club Poz), by Benoit, invites viewers to join a young man on his first visit to an imaginary supper club where HIV meds—and their side effects—are on the menu.

Every generation needs to find its voice and make a difference, and that is as true in the HIV community as it is elsewhere. The first generation of people with HIV/AIDS (PHAs) had their protest marches and die-ins to demand access to lifesaving treatments. Today's young people with HIV, raised in the digital era, are using a new generation's tools to break down the barriers they encounter, such as the ongoing stigma and discrimination associated with the virus.

Positive Take (*Prise positive* in French) is helping brave youth with HIV tackle these issues with creativity. The project was conceived to help HIV-positive youth in Montreal develop the tools and talents needed to share their experiences using video, a medium that is both popular and accessible to many youth. Earlier this year, nine 20-somethings with HIV took part in the project. They were guided by Kim

Simard and Simon Rouillard, two Montreal filmmakers with ties to the city's HIV community.

The project took shape through discussions between CATIE and various Montreal community organizations on how to give young people living with HIV a public voice. These discussions led to a fortuitous meeting with Simard, who also works with Quebec AIDS service organization *Fréquence VIH*. It was clear from early on that her experience and advocacy of participatory media as a communication tool for young PHAs would be a driving force behind the project's success, along with CATIE's support.

Initially, Simard and Rouillard thought the project was simply going to be about teaching these youth the art of filmmaking. But they quickly realized that the teaching would be reciprocal.

Working with these young HIV-positive men and women, Simard and Rouillard came face to face with the everyday reality of living with HIV. For example, the youth sometimes couldn't make it to a session because they were sick or had a medical appointment. "It made us understand a bit what it is like for them to live with HIV," Rouillard says. "We had to adapt to their situation." Simard, who has worked on other projects addressing HIV stigma, recalls, "It's one thing to talk about it, but to share the experience of how the virus affects their lives was a huge lesson for me."

The first, and perhaps most important, issue that Simard and Rouillard faced was disclosure. For many HIV-positive youth, the fear of their status being revealed is a daily reality, and so they often build social and emotional walls to keep their HIV secret and protect themselves. They



In *1 heure et quart* (1:15), Dominic expresses the confusion and despair that weigh upon him as he deals with his recent diagnosis. The chaotic and jarring imagery of urban wilderness was shot within months of his finding out he has HIV.

know that once the news is out it's almost impossible to control, especially in an online world where information quickly goes viral (pardon the pun) with devastating results. "These youth often don't have the support of society," Simard says, "or even of their family."

Simard and Rouillard started the project by exploring techniques of visual symbolism—think shots panning up tree trunks toward the sky to represent hope. Telling a story using symbols did not require the youth to expose themselves or have their faces onscreen—in other words, to disclose their status. While some of the final works use this technique, several of the youth eventually included images of themselves in their films. "The creative process seemed to push them to that point," says Rouillard, who was impressed by the young filmmakers' courage. "They faced their fears while

searching through the house that HIV-positive people build to protect themselves, often despite themselves. They opened a window and said, 'I am HIV positive, I live with it and I can talk about it.'"

Each film is as individual as its creator. "It was fascinating because initially the stories were based on social messages, but with time, the youth developed stories that were very personal," Simard says. "In the end, it was self-affirmation that won out."

The powerful impact of the project might be best seen in what the youth have done since wrapping their films. Inspired by the effect of their films on themselves and others, these young artists turned their attention to creating a film festival focusing on HIV/AIDS. The festival, VIHsion (www.vihision.com), aims to promote their work and other films and videos touching on HIV/AIDS. They hope that the festival encourages

an exchange between HIV-positive and HIV-negative people. For these HIV-positive youth, it might be said that the video camera, not the pen, is mightier than the sword.

The videos produced through Positive Take can be viewed on the CATIE website at www.catie.ca. +

Positive Take is a collaboration of CATIE, Fréquence VIH (www.frequencevih.ca) and Montreal youth group JASE (Jeunes Adultes Séropositifs Ensemble). The project was funded by the Community Innovation Programme run by GlaxoSmith-Kline in partnership with Shire Canada.

Albert Martin is executive director of Fréquence VIH. An HIV-positive writer and activist, Martin believes that art teaches us a great deal about the experience of living with HIV.

All New Edition

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