WE’RE 10!
The Positive Side celebrates a decade of positive living
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EDITOR’S LETTER

The Positive Side turns 10 this year! For those of us here at CATIE—and perhaps you can relate—it’s a time that brings up mixed emotions. We’re proud of what we’ve accomplished, but we’re angry that HIV is still rampant in many communities and affects so many lives. We’re happy that we can share the stories of HIV-positive people doing extraordinary—and ordinary—things, but we are saddened that many friends and loved ones are still dying from the disease.

To mark this anniversary, we got in touch with all the people who have appeared on the cover of this magazine and compiled a “where are they now?” retrospective. We were delighted to learn that the majority are surviving and thriving and were eager to fill us in on what they’ve been up to. Their mini interviews reveal that HIV is only one part of life—as it should be.

Perhaps as a testament to the great strides we all have made in fighting the virus, 24 of the cover folk are still here to celebrate with us. The loss of Nicole, Kimberly, Rhonda and Françoise saddens us all, and we honour their memories by dedicating this issue of The Positive Side to them.

While we reflect on the past, we also have an eye firmly fixed on the present. In this issue, we look at HIV in small-town and rural Canada. We also report on the growing realization that people with HIV need to take care of their bones—and, of course, we offer advice on how to do that. Art positive showcases the beautiful beadwork of Ron Horsefall. As well, our experts provide information and advice on vaginal health.

Looking to the future, we can only guess what it will bring. However, we do know that as long as HIV continues to infect our communities, there will be a need for this magazine. Whatever comes, we will be there to share personal stories, practical advice and the latest HIV treatment information, all with the goal of helping you live longer and better.

—David McLay
FROM THE FRONT LINES

What’s happening across Canada

Family Matters

CATIE’s Melissa Egan reports on programs for HIV-positive families.

There are more than 1,500 children and youth living with HIV in Canada. Yet, in many parts of the country, finding supports for them is still very challenging. Though a lack of funds limits what many AIDS service organizations (ASOs) can provide, three programs offer excellent services for HIV-positive families in our three most populated provinces—Camp Positive Family in Quebec, The Teresa Group in Ontario and Camp Mooeba in British Columbia.

Although your local ASO may not have specific programming for families, it may be happy to provide support, information and referrals. Check out www.aso411.ca or call CATIE at 1.800.263.1638 to find an organization close to you.

Camp Positive Family

Nested among the lush slopes of the Laurentian Mountains in Quebec, Camp Positive has been a summertime sanctuary for hundreds of HIV-positive adults from around the province for nearly 20 years. This year, a new camp specifically for HIV-positive women and their families—aptly called Camp Positive Family—will be held in the last two weeks of July, the most popular summer vacation period in Quebec.

André Huot, director of Camp Positive, has seen the population of people looking for HIV support diversifying and so he decided to create Camp Positive Family. The summer 2011 launch of Camp Positive Family is already shaping up to be a success. To ensure that the camp addresses the needs of those who attend, Huot has collaborated with staff and members from three local agencies: Stella, an agency that works with women in the sex trade; the Native Women’s Shelter of Montreal; and GAP-VIES, an organization with close ties to the Haitian and African communities of Quebec. These organizations offer HIV-positive women and their families support, information and community. Camp Positive Family is expected to be a well-planned and welcoming extension of their efforts.

Activities at the first annual Camp Positive Family will include workshops on HIV meds and adherence, yoga for the whole family and discussions about disclosure. Campfires and family-oriented theme evenings as well as culturally appropriate menus encourage community building and time for women to connect with each other. Children and youth will have opportunities to enjoy the outdoors, make new friends and benefit from the facilities at Camp Kinkora, where the camps are run.

For more information, get in touch with André Huot at andreh@ccs-montreal.org

THE POSITIVE SIDE Summer 2011
The Teresa Group

When asking around for resources for families with HIV in Ontario, the first words you’ll likely hear are “The Teresa Group”—and for good reason. The Teresa Group is one of the few Canadian organizations that focus specifically on the needs of families affected by HIV. Started in 1990 with just five families, the Toronto-based ASO currently serves nearly 400 families and more than 700 children. Its dedicated staff has become the go-to resource for practical assistance and emotional support for families living with HIV.

The organization works alongside a team of other community agencies and the Toronto Hospital for Sick Children to ensure that its programming meets the needs of its clients. For example, many families that use The Teresa Group’s programs are not just living with HIV but also struggling with poverty. So the agency has created a practical assistance program that offers an impressive range of supports: It provides welcome-home baby supplies, free formula, diapers, a children’s clothing bank, assistance with public transit fares, packed lunches for school and tutoring for students in grades 2 to 12.

In addition to offering practical help, The Teresa Group holds support groups that address the emotional needs of children and youth affected by the HIV of a family member. These groups provide young people with a safe space to discuss the unique challenges they face. Facilitated and supported discussions have broached such topics as stigma and disclosure. And activities with themes such as bereavement, personal growth, self-care and relationships have been well received by participants. Children explore their ideas, feelings and experiences using storytelling, role-play, art, music, games and other creative forms of expression. The success of this organization is rooted in its sensitive and holistic approach to working with children and families.

Find The Teresa Group online at www.teresagroup.ca

Camp Moomba

For many children, whether they themselves live with HIV or they are affected by its presence in their family, life with the virus can be isolating. Finding peers who understand what they are going through can be difficult. In British Columbia, children impacted by HIV have a place to go where they can let go: Camp Moomba. Since 1997, the overnight camp has provided a safe space for children and youth age 6 to 17, where they can find support and friendship and connect with other children who share similar experiences.

Moomba is an Australian Aboriginal word that means “join together to have fun”—and the camp certainly aims to ensure that everyone involved is enjoying themselves. Activities include kayaking, swimming, fishing, music, rock climbing, arts and crafts, archery and hiking. Older campers partake in two-night camping adventures.

Operated in partnership with the Vancouver YMCA and the Western Canadian Pediatric AIDS Society, Camp Moomba is located about one hour outside of Vancouver, on the shores of the Indian Arm River, surrounded by beautiful forests and mountains. Because many of the families whose children attend Camp Moomba cannot afford to pay for camp, all of the transportation and camp costs are covered.

Once a specialized summer camp for fewer than 20 children, Camp Moomba is now open year-round and hosted more than 100 kids in 2008. Friendships made in the summer can stay strong during winter ski camps, Christmas activities and leadership development programs. Young adults who attended camp as children often return to become counsellors.

For more information, visit www.campmoomba.com +
Hope and Dignity

HIV has not extinguished these cherished values in Peggy Frank of Victoria. On the contrary, even after more than 20 years, she continues to nourish them in herself and in her HIV-positive sisters and brothers in Africa.

photograph by Sharon Channer

The year was 1987 and I was a 33-year-old graduate student at Simon Fraser University in Vancouver. With the international development charity World University Services of Canada (WUSC) I had travelled to Zimbabwe—once referred to as the “Jewel of Africa” because of its social policies and economic prosperity at the time. There, the earth smelled warm, the sky shone blue and every turn in the road held surprises.

In a country that was seven years independent, I witnessed the complexities of development: the human need for housing, education and jobs and the challenges facing rural farming populations colonized into poverty. The excitement and optimism of the country’s people seduced me into remaining behind when the other students headed back to Canada. I hoped to study land-use planning in the romantic Zambezi Valley in the north of the country.

For the next five months, I wandered northern Zimbabwe, sailed in parasite- and crocodile-infested waters with a Zimbabwean sweetie, danced to African drums, proudly delivered a young Tonga mother’s baby in the belly of a boat in the Kariba District, and gagged on goat intestine at a meeting about rural community realities. I was treated to African hospitality and embraced by University of Zimbabwe professors, who assured me that my research was needed.

Upon returning to Canada, I asked to be “tested for everything.” My doctor’s phone call to the university common room informing me of my new “status” was a shock. As I put down the receiver, my hopes for a future as a development worker seemed dashed. I took the bus home to lie in bed and die.

But I did not die. Instead, I reached out for help and was pulled back on my feet by HIV support groups in Vancouver. I listened to my new peers’ brave pioneering stories, and together we mourned our annual losses of friends and loved ones. On World AIDS Day in 1988, we marched silently through the streets of Vancouver, enduring hateful shouts and spitting from those we passed.

A few years later, I represented myself at the Tax Court of Canada to demand that the cost of the vitamins and supplements that kept me alive be allowed as medical expenses. I included in my case the costs of Therapeutic Touch, a healing technique for facilitating strength from within that helped me deal with both the symptoms of my HIV and the emotional losses I felt. The court ruled in my favour and now people living with HIV in Canada can claim these medical costs on their personal income tax return.

After my victory in court, I continued my return to active community life. I played soccer, ran and built my dream home on Salt Spring Island, off the coast of British Columbia. I volunteered for African causes and worked on sustainable development, land claims and community planning.

One day in 1989, on the ferry to Vancouver, I met an amazing man named Dave, who invited me to share dinner and his home-baked pie. I still remember our first kiss. I stopped to announce that I was HIV positive. He responded: “I have two choices. I can leave now and never get to know you, or I can love you for as long as we have together. Let me kiss you.”

Dave had an airplane adapted for short takeoffs, with skis for landing on snow and ice. He was also the proud new owner of a small farm beside a grass airstrip. He loved adventure, and adventure in an airplane is magic! We landed on remote beaches and walked on ancient glaciers. We even flew from Salt Spring Island to Miami one winter, dodging hurricane-force winds along the way.
Life was perfect until the shadow of HIV began to darken my life. First it stole my energy, then my ability to do the recreational activities I enjoyed. Next it took my job and, ultimately, my feeling of worth. I was unable to find the energy to even write, paint or draw. It seemed I had little time left. In the recreational activities I enjoyed.

I was illegal for people who were HIV positive to enter the United States. Regardless, we headed through Los Angeles to Belize—a sick woman in a wheelchair and a healthy man.

Our destination was a shack on a remote coral reef. The island, less than a mile long, had recently been whipped by hurricane winds and was almost deserted. The utter simplicity of life, the coconut milk, the incredible snorkelling and a sense of awe rekindled my soul. After two weeks, I was swimming a mile to see octopus, lobsters and frog fish. Phoenix-like, I rose from the ashes.

At home on SaltSpring Island, I continued to recover. We had two more happy years, and then in May 1997, Dave died in an accident at work. Why had I lived while he, the healthy one, died? I struggled to understand life and death. I read, wrote poetry, learned to sculpt and attended workshops on grief and loss. Therapeutic Touch remained central to my life, keeping me grounded. (I have since become a Therapeutic Touch practitioner and still practice and offer workshops.)

I decided to use HIV to connect positively with African communities.

Reports on rising rates of HIV infection across sub-Saharan Africa reminded me that I had something in common with my African sisters and brothers. I decided to use HIV to connect positively with African communities. I started by informing myself and others about the growing pandemic in Africa. I also lobbied Canadian officials for universal access to medication in Africa.

My efforts grew and in 2006, with the help of friends and an energetic new partner, I cofounded the non-governmental organization positively AFRICA. Our goal was and still is to link people in Canada to grassroots African community groups working for change. We focus on those groups without any other source of support and try to assist them until they find stable, sustainable help.

Funds delivered through positively AFRICA provide food, healthcare and other essentials—and along with them, dignity to HIV-positive people. The support also brings hope to struggling local grassroots organizations. Dignity and hope are critical to keeping the flame of life burning.

Over the years, I have returned to Africa a few times, visiting Rwanda, Kenya, South Africa, Lesotho and Zimbabwe. During my trips I have seen that my African peers and I are alike in many ways. We have known abuse, struggled to overcome depression and have seen a future where doctors have not. I have met Africans with incredible courage and undying hope. Despite the shortage of water, food and shelter, heroic local leaders continue to work together to create strong partnerships. My openness about being HIV positive for more than 20 years remains a powerful message for those who equate AIDS with stigma and death.

As a woman living with HIV in Canada, I have the freedom to be open about my HIV status. I have power in my relationships and receive a disability income that covers my basic life expenses. The realities of Africa keep me humble. I try to imagine being a young Maasai girl, cut ceremonially as I entered the world of womanhood. Could I follow an older man—a husband chosen for me while I was still in my mother’s womb—to a strange village, to become his third wife? Would I be able to plow fields by hand and carry enough water to keep my family alive? Could I do this while battling HIV?

To Africans—and to my Canadian peers—I respectfully offer my skills, including Therapeutic Touch workshops and sessions, and I spread awareness of HIV. In exchange, women have shared their experiences: rape and torture in Rwanda, fear and beatings in Lesotho and Kenya, abandonment in South Africa and the systematic destruction of infrastructure in Zimbabwe. In my eyes, all of these experiences are linked to domination (either colonial or patriarchal) and, ultimately, they underlie the HIV pandemic.

We learn from one another and grow from each other’s strength. Through sharing our stories, hope passes back and forth between us. When I leave a workshop and I know that people are feeling enlightened and empowered with the tools to live longer, I smile.

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To mark our 10-year anniversary, *The Positive Side* caught up with the HIV-positive people who have graced our cover.

**Interviews by RonniLyn Pustil**

We’re feeling nostalgic. Since our first issue in fall/winter 2001, when Aboriginal activist Kecia Larkin posed for the cover just days before giving birth, *The Positive Side* magazine has covered life with HIV by sharing the stories of those who are living it. Leafing through the past 17 issues, we at CATIE were amazed at all the passionate, courageous, enchanting voices we’ve had the honour of publishing.

You may not know this, but those 17 issues represent only the current incarnation of the publication. Originally a newsletter, *The Positive Side* was published a full 10 years earlier in 1991 by the Treatment Information Exchange, a fledgling Toronto community group dedicated to sharing between people with HIV what little we knew about HIV at the time. From the start, *The Positive Side* published holistic health information that expressed the real-life experiences of people living with HIV and, in a tradition that continues today, it often featured a story and photo of an HIV-positive person.

Given that tradition, what better way to celebrate our 10-year (or arguably our 20-year) anniversary than with a rendezvous with our cover folk? We checked in with 24 of our cover subjects to learn about life since we first featured them. Their interviews will surprise and inspire you. So here’s to them and to you, our readers. But most of all, here’s to the day when there’s nothing left to cover but the cure.
Owen is a very kind, gentle, deep-thinking young man. He is a typical nine-year-old who loves video games, Lego and helping others. My daughter, Rakiya, is finishing her last year of high school and is looking forward to post-secondary education next year as an honour roll graduate.

How has being a mother informed your role as an activist and advocate, and vice versa?

I’m a single mom with two children who parents, advocates and works part-time as a peer research assistant. As a mother, I have had to think about my future and my children’s future. I have had to think about what I have taken for granted in the past and how I can change the future for the better.

What’s changed for you since you appeared on the cover?

I am healthier, stronger and more outspoken. I’m also more selfish about the time I volunteer or commit to the AIDS movement because I’ve been living with HIV for more than two decades and I have to balance what I give my energy, health and expertise to.

In 10 years...

I hope to document the stigma and negligence faced by the most vulnerable HIV-positive people in the medical system in Canada.

**KECIA LARKIN, 40**
Victoria, BC
Diagnosed with HIV in 1989
CD4: 300   VL: undetectable

“A woman moving to another stage of life with HIV, from 18-40 and on...”

You and your very pregnant belly graced the first cover of The Positive Side in 2001. Six days after your interview, you gave birth to your son. How is he?

How has being a mother informed your role as an activist and advocate, and vice versa?

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In 10 years...

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**JIM WAKEFORD, 66**
Sechelt, BC
Diagnosed with HIV in 1989
CD4: 500   VL: undetectable

“While racing the virus, beating back illness and defying death, I helped create Casey House Hospice, brought the AIDS Quilt to Toronto and launched two constitutional court challenges. Now I am reinventing myself.”

How would you describe your health?

Apart from elevated triglycerides and degenerative discs in my spine, my physical health is good.

How goes the fight for legal medicinal-grade marijuana?

The federal government has failed to provide a meaningful alternative to the right to use marijuana for medicinal purposes. Medicinal-grade marijuana should be available to PHAs regardless of ability to pay and it should be safe and free from contaminants, something the clubs cannot guarantee. When I can find marijuana grown organically for medicinal purposes and I can afford it, I use *indica* strains for pain and as an alternative to sleeping pills; *sativa* strains help with anxiety and appetite.

In 10 years...

Dare I hope to be cured of HIV infection? Dare I hope for research on medicinal marijuana?

I recently completed antibiotic therapy for a stubborn infection connected to Bio-Alcamid correction. (Bio-Alcamid is a gel injected under the skin to fill deforming, wasting hollows from HIV-related lipodystrophy.) I felt that my surgeon had injected too much product and that it was uneven. I couldn’t get used to the feeling of this alien material under my skin, so I decided to have it removed.

I consulted another surgeon, who agreed with me about my complaint. He is removing some product by squeezing it out. It’s a slow, painful process. After my third session, I erred on the prophylaxis antibiotic dosage and acquired an infection. It was difficult to treat because with no blood flow through the Bio-Alcamid, the antibiotic doesn’t easily reach the bacteria. The infection troubled me for three months, requiring numerous visits to the emergency room and weeks of intravenous antibiotic treatment. In the midst of it, I suffered a kidney stone.

The next Bio-Alcamid drainage session should be the last. The small amount remaining in my cheeks should suffice to address the wasting that drove me to get the product in the first place.
In one word, define this moment in AIDS:

Kecia: **Negligent**  
Jim: **Lull**  
Jake: **Heartrending**  
Louise: **Disappointing**  
Jane: **Still fighting**

---

**LOUISE BINDER**, 61  
Toronto

“I was diagnosed in 1994 but infected for at least six or seven years before that.”

CD4: 860  
VL: undetectable

“An HIV-positive woman dedicated to working for the cause of human rights.”

Are you experiencing any specific issues around HIV or your treatment?

Sure. I’ve had chronic colitis ever since I was infected and the drugs irritate it. I have to inject myself twice a day for the Fuzeon, and that’s not exactly a picnic with the bruises and bumps. But it’s a good medication so I’m willing to put up with that. I’ve got peripheral neuropathy in my feet, but that’s kind of the breaks. I have osteopenia, so I take a lot of prescription calcium and get regular bone density tests...just the usual bucket of bitching and complaining.

Since 2003, when you were on the cover of our women’s issue, what would you say has changed for women with HIV?

There is more of an understanding of the difference between men and women and, therefore, the need to look at treatment and prevention for women through that lens.

What has changed for you personally?

There have been great changes in my sense of self-esteem, the things I value in my life and how I measure my worth.

In 10 years...

I will be running my own businesses, writing books and making movies.

---

**JANE WALLIS**, 52  
Gananoque, Ontario

Diagnosed with HIV in 1990  
CD4: 650  
VL: undetectable

“My 20-year-old virus and I are living peacefully and quietly with a loving husband and supportive family and friends.”

Since 2003, what would you say has changed for women living with HIV in Canada?

The huge loss in 2010 of an organization geared specifically to HIV-positive women in Ontario: Voices of Positive Women. This means a loss of connection to other HIV-positive women, loss of peer support, loss of programs and loss of a voice for HIV-positive women at conferences and other venues. I feel that the opportunity for newly diagnosed women in Ontario to grow and learn from each other and get involved is now lost or at least diminished.

What has changed for you personally?

I met Rex in December 2002 at a karaoke night at our local Legion and we were married the next summer on a boat. We are friends, we laugh frequently, and any squabbles are about silly things. Almost eight years later, we remain a mixed-status couple.

In 10 years...

I take life day to day, but it would be great to be retired, having won a lottery, and sipping piña coladas somewhere in the sunshine for the winter and travelling throughout Canada in the summer.

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**In Memoriam**

*The Positive Side* would like to honour the memories of three women who appeared on the cover of the Spring 2003 issue.

**NICOLE HICKS**  
**KIMBERLY JOHNSON**  
**RHONDA STEVENS**  
**FRANÇOISE GROTHÉ**, whose interview appears on page 14, passed away during the preparation of this article. This issue of the magazine is dedicated to these four women.

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**Playlist: Soundtracks of their Lives**

<table>
<thead>
<tr>
<th>Kecia Larkin</th>
<th>Jim Wakeford</th>
<th>Jake Peters</th>
<th>Louise Binder</th>
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<td>“Wandering Star” by Portishead</td>
<td>“Blowin’ in the Wind” by Bob Dylan</td>
<td>“Nights on Broadway” by the Bee Gees</td>
<td>“Bird on the Wire” by Leonard Cohen</td>
</tr>
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</table>
BRIGITTE CHARBONNEAU, 64
Ottawa
Living with HIV since 1994
CD4: around 800  VL: not sure
“I mentor others in their time of need.”

How would you describe your health?
Since becoming positive, I’ve developed bronchial asthma, type 2 diabetes and high cholesterol. I’m having a hard time with my diabetes and bouts of depression. After 16 years with this virus, at times I am still in denial…until it’s time to take those awful drugs that can leave you with some bad side effects.

Since 2003, what has changed for women living with HIV?
Most of the women I know have become strong advocates for others and more so for themselves. I have learned to speak up about my health and other issues I believe in.

What has changed for you personally?
I became a grandmother to four more—two from my daughter and two from my son. I now have eight grandchildren! The hardest part of my life is the deaths of so many good friends. The grieving never seems to stop.

In 10 years...
I’ll have more wrinkles and lots more grey hair, but I’ll be happy to have my partner at my side and both of my children with their families.

CINDY REARDON, 42
Toronto
Living with HIV for 16 years
CD4: “in the 800s”
VL: “in the tens of thousands”
“I am a beautiful woman, from the tip of my toes to the bottom of my nose and every place in between.”

How would you describe your health?
My overall health living with HIV is excellent. I have never taken antiretroviral therapy. In fact, I haven’t had any issues of concern with my HIV.

Since 2003, what has changed for women living with HIV?
The research community is recognizing women as a separate group from men. Women are being taken seriously concerning HIV-related issues and not seen only as people who can get pregnant.

What has changed for you personally?
I recently had a spinal cord injury that has left me without the ability to walk. I need to learn all over again how to go to the washroom by myself, how to walk and how to coordinate my hands properly. The injury left my spinal cord stunned and angry. The nerves must find new pathways in order for me to achieve my goals. If they don’t, I will be in a wheelchair for the remainder of my days.

In 10 years...
I see myself happy and content, as I am now. I consider myself a long-term slow progressor, so I see my HIV counts staying relatively the same.

Laurette Lévy
Anything sung by Baroque counter-tenor P. Jaroussky
Brigitte Charbonneau
“I Believe” by R. Kelly
Cindy Reardon
“Comfortably Numb” by Pink Floyd

THE POSITIVE SIDE  Summer 2011
Tracey Conway, 43
Sault Ste Marie, Ontario
Living with HIV since 1998
CD4: approx 980
VL: undetectable

“An advocate for improved healthcare for women and children at risk and improved access to general healthcare in rural communities.”

Are you experiencing any specific issues around HIV or your treatment?
The biggest issues are the continued stigma and discrimination from uneducated and intolerant individuals. A lot of this comes from people who work in social services. Many of these so-called professionals still hold archaic beliefs about HIV and operate on prejudicial assumptions when dealing with individuals living with HIV.

Since 2003, what has changed for women living with HIV?
One of the biggest changes is an opportunity for women with HIV to lead a full and productive life. This includes having a relationship, having children and planning a future.

What else has changed for you personally?
I had my daughter, Leah Cassandra. When I was diagnosed, I thought I was going to die imminently. I never thought I would have sex again, let alone give birth to a healthy child. She is a great inspiration in my life. Also, one significant improvement for me has been moving to a once-daily treatment regimen. I no longer have to take a boatload of pills and I am less likely to miss a dose.

In 10 years...
I see myself still involved with community-based research, working on women-specific issues, and possibly expanding from the HIV field to women at risk as well as isolated communities.

SHARI MARGOLESE, 48
Mississauga, Ontario
Living with HIV for 18 years
CD4: 800 VL: undetectable

“A passionate and loving community advocate, mom, daughter, sister and friend with a zest for life, chocolate, work, travel and the occasional margarita!”

Are you experiencing any specific issues around HIV or your treatment?
My biggest issue is arthritis, which is partially HIV-related. I take over-the-counter medication and medicinal marijuana to relieve the pain.

Since 2003, what has changed for women living with HIV?
In the 1990s, HIV-positive women were discouraged from having children. Now, due to advances in antiretroviral therapy and support from healthcare providers, they are able to have safe and healthy pregnancies. However, people are still dying and we still have no cure.

What has changed for you personally?
I am now living as a single mom of a young adult. Now that my son is older (18), I have a bit more time on my hands and I’ve begun to focus more on pursuing some of my own interests. It is important to me that my time be spent on projects that directly affect the lives of people living with HIV.

In 10 years...
I will be retired in a warm climate, writing books and entertaining my grandchildren.
FRANÇOISE GROTHÉ, 66
Montreal
Living with HIV for 28 years
CD4: 980  VL: undetectable
“An adventurous, happy-go-lucky person.”

How would you describe your health?
My health was terrific up until last November. I got the flu vaccine and a few days later I started feeling really sick; but every time I get that vaccine I don’t feel good, so I didn’t make anything of it. By December I was in excruciating pain in my legs and arms, and my doctor sent me to the ER. I spent two weeks in the hospital, but they had no answers. I’m still deteriorating. I have one arm that’s not working and I’m basically walking like a paraplegic. Yesterday I couldn’t cut a potato and I cried for two hours. Before this happened, I was in perfect health, bicycling an hour a day, so it’s very hard for me not to associate this with the vaccine. But I’m hoping it’s viral and it will get better.

You were on the cover of the magazine for a feature story about long-term survivors. And now it’s six years later. How does that feel?
Well, I’m still here. In 2013, it’s going to be 30 years. So I guess I really am a long-term survivor.

Since you appeared on the cover in 2004, what has changed in your life?
I walked the Camino de Santiago de Compostela. It was the biggest accomplishment of my life. I crossed all of Spain—580 km—it took me two months to do it. I walked about 15 to 20 km a day, for two months, with my 10-kilo backpack.

In 10 years...
Good God, I’ll probably be dead. I’m going to be 76, are you kidding? If I’m the way I was before November, no problem. But if I’m the way I am now, there’s no way in hell I want to be around.

Editor’s note: Françoise Grothé was eventually diagnosed with Lou Gehrig’s disease. “Once she was diagnosed and knew that it was degenerative, my mother didn’t want to live any longer,” her daughter Nathalie told The Positive Side. “She had such a full life that there was no way she was going to be a burden on us or on society. All of her friends and family were there to see her every day until the very end. Everybody loved her.” Françoise passed away March 31, 2011.

In one word, define this moment in AIDS:
Ron: Hopeful
Françoise: Latent
James: Encouraging
Devan: Optimistic
Maggie: Hope
DEVAN NAMBIAR, 50
Toronto
Living with HIV for 22 years
CD4: 500   VL: undetectable

“A free spirit living a human experience.”

How would you describe your overall health?
Good, with all the joys of getting wiser.

Are you experiencing any specific issues around HIV or your treatment?
The biggest challenge is monitoring my cholesterol levels and maintaining my bone health. It is tiresome to always be conscientious of what I eat. My regimen of exercises (resistance training, cardio and yoga), meditation, spiritual practice and healthy diet is crucial to my well-being.

What has changed for you personally since you appeared on the cover in 2004?
I work in the LGBT sector, am completing my studies in addictions at McMaster University and write a blog for www.positivelite.com. I climbed the Himalayas to two of the oldest Hindu temples at 11,200 feet (and wrote about it in my blog). I am deepening my spiritual practices and taking language classes in Hindi and Sanskrit.

In 10 years...
Hmm...at 60—living by the seaside with my man and my cat, more time for my spiritual practices and spending more time with my family.

MAGGIE McGINN, 54
Edmonton
Diagnosed with HIV in 1992
CD4: 1,300   VL: undetectable

You were on the cover of the magazine for a feature story about long-term survivors. And now it’s six years later. How does that feel?
First thought: F___’n great! But seriously, I’m in great health and I’m doing what I was planning on doing when I was diagnosed and should have done years ago.

What have you been up to since you appeared on the cover in 2004?
I am an undergraduate Bachelor of Science Nursing student in my third year at the University of Alberta with a consistent 3.2/4.0 average. Clearly, the oldest in my class! My older daughter won gold medals in swimming in the National Special Olympics in London this past summer. My younger daughter is in her second year of a law degree and is engaged to be married in August. So I am very busy studying and planning a wedding!

In 10 years...
After working as a nurse in Canada for a few years, I plan to travel and work as a nurse in New Zealand and Australia.
Brian Huskins, 48
Toronto
Living with HIV for 20 years
CD4: “I always hover around 400.”
VL: undetectable

“I am a person who works for change. Without change, we are stagnant.”

How would you describe your health?
Good. My greatest challenge is managing my asthma.

You appeared on the cover with your partner, Neal Abdool, for our feature on serodiscordant couples. Now, six years later, you’re married! Has it gotten harder or easier to maintain serodiscordancy over the long term?
HIV is a subtext of our relationship and is something that has been there since we met. It really isn’t a question of harder or easier. It is a fact of life, and we give it very little thought in our day-to-day interactions. Other issues—such as communications, finances and household chores—are our challenge, as they would be for any couple.

In 10 years...
Hopefully I will have published at least one book and be doing the talking circuit!

Joe Average, 53
Vancouver
Living with HIV for 28 years
CD4: 650
VL: undetectable

“An HIV-positive artist committed to creating awareness through painting and photography.”

Are you experiencing any specific issues around HIV or your treatment?
The biggest issues at present are the psychological effects of lipoatrophy. I have dropped 40 pounds in body fat and muscle. I recently created a short film with a good friend on the subject of my lipoatrophy and how it has and is affecting me.

How would you define this moment in AIDS?
On one hand, this moment in AIDS is a good one (as in, I am still around to talk about it). On the other hand, I am very upset with the media. They’ve painted HIV/AIDS as something you can live a long and healthy life with. Consequently, people, especially young people, are being lax with their concerns about safe sex. This frightens me. What the media doesn’t report on is what living with HIV/AIDS involves. For me, in the past 10 years it’s been a full-time job managing the physical and psychological side effects from the drugs.

In 10 years...
I have learned with HIV to live in the present and try not to worry or speculate about the future.

David Hoe, 67
Ottawa
Living with HIV since 1985
CD4: 760  VL: undetectable

“A man committed to transformational change and love.”

How would you describe your health?
Very good but with joint pain and treatment-induced peripheral neuropathy that are still pains in the proverbial. Also, I’m not sure if it’s HIV related, but I’m very concerned about memory and cognitive issues.

You appeared on the cover of the magazine for a feature about sexual health. How is your sex life these days?
My sex life is evolving into deeper intimacy now that I am in a monogamous relationship with an HIV-negative partner. We got married in South Africa in 2008. Merging our two erotic fields of different generations and cultures on a regular basis is like all other aspects of intimacy—it is a constant exploration of play, spirit and stewardship in keeping it alive; sometimes it’s messy and not always to do with fluids. One of the joys of aging is an enhanced sexual erotic fantasy life.

In 10 years...
I see myself as impishly sublime with a somewhat creaky body, still building a meaningful life.
Sandy Lambert, 51
Vancouver
Living with HIV for 14 years
CD4: 1,008  VL: undetectable
“A First Nation positive male who advocates on behalf of all Aboriginals living with HIV/AIDS for a better quality of life.”

How would you describe your health?
Fabulous.

Are you experiencing any specific issues around HIV or your treatment?
I still have challenges with lipodystrophy. I have enlarged breasts (gynecomastia) and I will be seeing a surgeon for reduction surgery, which is currently not paid for by BC Medical.

What have you been up to since appearing on the cover of the magazine?
Most of my time is spent living life to its fullest and volunteering on a variety of committees, including those of the Renewing Our Response provincial Aboriginal advisory group and the provincial STOP HIV/AIDS (Seek and Treat for Optimal Prevention of HIV/AIDS) program.

In 10 years...
I’ll continue to help make policy and procedure changes that will help our communities.

In one word, define this moment in AIDS:
Brian Huskins: Diluted
David: Expanding
Sandy: Rejuvenated
Brian R.: Optimistic

Brian R., 65+
Toronto
Living with HIV for 22½ years
CD4: 600+  VL: undetectable
“A retired nonprofit arts administrator who is still active in the local ASO community.”

Are you experiencing any specific issues around HIV or your treatment?
I’m dealing more with the other things, like being 65+. You become part of the invisible aging population. In the gay community, you’re old at 40. And L’Oréal doesn’t work on men so much!

In the cover story you appeared in, you talked about the financial stresses of growing older with HIV. Have things gotten better or worse for you?
I am still living below the poverty level. Twenty years ago, people like myself who are longtime survivors had to quit our jobs, go on disability and get our Canadian Pension Plan early. We missed out on accumulating a pension where we were working, so 20 years later you’re an old fart living on government pensions and occasional part-time work. If you are living in a larger community or city, there are more services to guide and help in times of need. But, of course, the struggle continues all over Canada to improve direct services as we survive and live longer.

Have you gone through any big changes since appearing on the cover in 2007?
Just before I was on the cover, I had open-heart bypass surgery. Now I am almost a new person. It has been like getting 10 years back. I have increased energy and drive, and a new outlook and purpose. I have become very active at my local Y and am now teaching Stretch and Strength classes. At this point, my HIV status is only one aspect of my life.

In 10 years...
I see myself celebrating 32 years of HIV-positive living, still active.
DARIEN TAYLOR, 53
Toronto
Living with HIV for 22 years
CD4: 450  VL: undetectable
“One of the very first women with HIV in Canada to get involved in treatment activism and to open up the HIV movement to include women living with HIV.”

Have you gone through any big changes since appearing on the cover in 2008?

My girlie magazine cover for The Positive Side was, as a friend of mine put it, a “last hurrah” before age, gravity and menopause caught up with me.

How has age caught up with you? Do you think HIV is playing a role?

Once you turn 50, all sorts of health monitoring tests are recommended: bone density, mammograms, coloscopies and such. These tests bring you face to face with your aging body. For example, my bone density is not great. Aging or HIV? Who knows? I don’t worry too much about the answer to that question, but I do supplement with calcium.

In 10 years...

I will be speaking grammatical Spanish and pursuing textile arts in Oaxaca, Mexico, where I have purchased a little house.

DANIEL-CLAUDE GENDRON, 42
Montreal
Living with HIV for 13 years
CD4: 630  VL: undetectable
“An HIV-positive man fighting against the virus with a pencil.”

What have you been up to since you appeared on the cover with Super-Poz, the comic-book super hero you created?

Many wonderful things have happened—the most remarkable is the publication of the first issue of Super-Poz. I participated in Café des Arts at Montreal’s Gay Pride 2010, where, for the first time, the graphic novel was available. Since then, it has been available in Priape stores across Canada.

But not everything has worked out as well. I lost my job last fall after eight years of employment. The board of directors and the management of an HIV community organization decided, due to a shortage of funds, that the social re-integration I’ve been advocating for 10 years didn’t stack up to other services offered to people living with HIV. It is this social re-integration, however, that saved my life. I therefore made the choice to contribute, at least for the moment, in my own way—through drawing.

What one super power do you wish to have?

To cure.

In 10 years...

I would like to have my own place to exhibit art.

**In one word, define this moment in AIDS:**

Darien: Momentary
Daniel-Claude: Apathy
Krista: Progressing
KRISTA SHORE, 28
Regina, Saskatchewan
Living with HIV since 2007
CD4: 935  VL: undetectable
“A mother, first and foremost, an educator, an activist and an advocate in the HIV/AIDS movement in Canada.”

How would you describe your health?
I feel very blessed with my health and ability to have healthy children. I maintain a drug- and alcohol-free lifestyle with proper nutrition, sleep and exercise. I love smudging, Reiki, attending traditional talking circles and seeing my Elder regularly. I make an effort to maintain balance within the physical, emotional, mental and spiritual quadrants as well as regular monitoring and proper healthcare, treatment and support from the Western ways.

You mentioned in your cover story that you wanted to start a baby formula program in Regina for HIV-positive moms who can’t afford it. What’s happening with this?
I met a lot of challenges and barriers due to pregnancy and being HIV positive. I had a lot of trouble in regards to baby formula and getting it covered under my disability insurance. I’ve been working to start up my own Aboriginal AIDS organization that focuses on and provides services, including a formula program, to help at-risk women during pregnancy and after birth. I want to provide our women with access to care, treatment and support that is sensitive to pregnancy, so that they and their children have the best possible fighting chance when faced with an HIV diagnosis and pregnancy.

In 10 years...
I see myself sustaining my health to the fullest. I see myself happily married and guiding my children to live a happy and full life. I see myself continuing my involvement in my community and being a knowledgeable educator and a support for people living positively.

FRANCISCO IBÁÑEZ-CARRASCO, “the other side of 40”
Toronto
Living with HIV for 25 years
CD4 and VL: “You don’t ask a lady her age and an HIV poz guy his counts.”
“A somewhat-edgy longtime AIDS survivor involved in working in community-based research, educating emerging HIV researchers and writing about sex.”

Are you experiencing any specific issues around HIV or your treatment?
A number of them—I deal with them optimistically, one at a time.

One of the topics you research is stigma. What is your experience with this?
As a gay man on the other side of 40 living with HIV and with some body changes due to age and lipoatrophy, most of the stigma I sense radiates from inside the gay communities, from our fearful obsession with youth and beauty.

How would you define this moment in AIDS?
A moment of apparent respite in Canada, with a great deal of delusion about the social, cultural, mental and physical effects of HIV.

In 10 years...
The HIV/AIDS field will be highly professionalized, with lots of busybodies, but epidemiologically similar, entrenched in disparity, stigma and delusion. I see myself fabulous and old, a bit curmudgeonly but surrounded by young students learning together. ✪

Overflowing with Life
These pages cannot contain all that these awesome people have done. Check out www.positiveside.ca for the full interviews.
The results of David Vereschagin’s first-ever bone scan, performed in 2009, threw him for a loop. At age 52, he was told that he had the spine of a 70-year-old. He was cautioned against activities that might strain the bones of his spine because they could fracture.

This unsettling news was all the more surprising because Vereschagin had experienced very few health problems since testing HIV positive in 1995. In fact, for 10 years after his diagnosis he remained healthy without anti-HIV medications, beginning treatment only in 2005, when his CD4 count fell below 300—he had waited until his count fell below 200, he would have been at risk of life-threatening complications. Since starting treatment, his CD4 count had risen and until that bone scan his only other setback had been a bout of kidney stones, a problem that was mostly under control.

Unfortunately, the caution against “spine-straining” activities included the gym workouts he had come to love. The warning “really put a fear of weight training into me,” Vereschagin recalls, “like one day I was going to lift too much and suddenly hear my spine snap.” His workouts were a significant part of his healthy living routine and Vereschagin couldn’t give them up: “I just did it with a lot more anxiety.”

In the meantime, his HIV specialist muddled the waters with a surprising opinion: She “wouldn’t have bothered” with the scan, because “nobody knows what to do” with the information scans provide. Vereschagin recalls feeling caught in the middle of these conflicting points of view and “hopelessly muddled” by this extra twist.

What exactly is going on with people with HIV/AIDS (PHAs) and their bones? Is it possible to find some answers without anxiety and confusion? Let’s give it a shot.

**Hold on to your bones**

Bones are strong, but they aren’t solid—their texture is dense in some spots but spongy in others. *Bone mineral density (BMD)* is the measurement that doctors use to evaluate the density, and by extension the sturdiness, of a bone. Bone density can vary between bones (for example, Vereschagin was told he had low spine BMD but that his hips were fine) and it changes over time. That’s because bones are living parts of your body, constantly being worn away and rebuilt. From our mid- to late-20s (when bones are at their strongest) into old age, bones erode slightly faster than they are replaced, gradually weakening the skeletal structure.

In other words, losing bone density is a normal part of aging and is not a problem when the degree of loss is small. Healthy bones are so sturdy that we can afford to lose quite a
bit of bone density without any serious risk of breaking them. Loss of a moderate amount of BMD is called osteopenia. If the loss continues, bones become porous, fragile and prone to breaking—a more serious condition known as osteoporosis. Neither condition typically causes any noticeable symptoms, so they can easily go undetected until a bone breaks.

Dr. Jason Szabo, assistant professor of family medicine at McGill University, suggests that the best way to think of bone density is “as a bank account. You build it up when you’re young, with good nutrition and exercise. Then beyond a certain age, you’re making small withdrawals each day. If you haven’t built up a good ‘balance’ earlier, you’re more at risk of becoming overdrawn—that is, getting osteoporosis.”

Traditionally, in people without HIV, bone problems are most common in postmenopausal women because hormonal changes lead to a significant decline in BMD. But men with HIV are developing bone problems at an unusually early age, and postmenopausal women with HIV are more likely to develop osteoporosis and osteopenia than their HIV-negative counterparts. Figures vary, but studies suggest that osteoporosis may affect about one in 10 PHAs. And many studies have found that osteopenia (less severe bone loss) affects 30 percent or more of PHAs.

**A bone of contention**

The next question is: Does osteoporosis translate into an increased risk of breaking bones for PHAs? That’s certainly the case in postmenopausal women with osteoporosis, with or without HIV, so it might seem a foregone conclusion for PHAs as well. But some experts (like Vereschagin’s specialist) argue that the studies we have so far are not conclusive and that we need to do more research before we can say for sure.

Dr. Szabo is less optimistic. “We know, because of several large observational studies, that HIV greatly increases the risk of osteoporosis. Prospective studies—the kind that tell us about the outcomes [of a disease or treatment]—are much more limited. But some data do suggest that osteoporosis in people with HIV is a risk factor for fractures. I suspect that as years go on, we’ll see greater numbers of osteoporotic fractures in our HIV-positive patients.”

One study found that HIV, independent of other risk factors, increased the risk of broken bones in men by about 40 percent. While this does not appear to be the case in younger HIV-positive women, more research on older women with HIV is needed to say whether they are at higher risk of breaking a bone due to their HIV status.

**What’s behind the bone loss?**

What causes one person to develop bone disease and another to maintain strong healthy bones into old age?

**Traditional risk factors** for osteoporosis include:

- a family history of the disease
- being 65 or older
- low body mass (i.e. having a very small or thin frame)
- smoking
- heavy alcohol consumption
- long-term use of certain medications, such as glucocorticoids (for example, prednisone) for more than three months
- conditions that inhibit the body’s absorption of nutrients, such as Crohn’s and celiac disease
- a sedentary lifestyle
- hyperthyroidism
- low calcium intake
- early menopause in women (before age 45)
- low testosterone in men

People with HIV have **additional risk factors** for osteoporosis, including HIV infection itself: the degree of BMD loss has been shown to increase with the duration of infection. But evidence also suggests that some anti-HIV drugs, such as protease inhibitors, may be a risk factor for osteoporosis. Some studies have also suggested that the anti-HIV drug tenofovir (Viread, also in Truvada and Atripla) might have an impact on bone density, but this is not so simple. Studies found that in the year after starting the nuke, people showed rapid loss of bone density, but after this initial decline, the rate of bone loss stabilized. The take-home message: If you are taking protease inhibitors or tenofovir, you probably shouldn’t switch away from them purely because of concerns about bone loss. If you are on tenofovir and see a significant loss of BMD, you should talk to your doctor about getting tested for phosphate wasting, as tenofovir use can lead to low levels of phosphate, a mineral needed to keep your bones healthy.

**Getting scanned**

Knowing the risk factors for osteoporosis can help you avoid some of them and may flag a potential problem before it occurs. However, it’s entirely possible to have several risk factors and never develop osteoporosis. Many experts believe that the best way to know for sure if there is bone loss is to get a bone scan. A bone scan is a painless, non-invasive procedure that can identify whether you have experienced significant bone loss, whether there is early loss (that may or may not worsen), or whether there is nothing to worry about. A bone scan also provides a baseline against which to compare future results.

Current guidelines recommend measuring BMD in all women and men age 65 and older; in adults 50 and over who have certain risk factors for fracture (such as long-term use of certain medications, smoking and high alcohol intake, or a fragility fracture); and in men and women under the age of 50.
if they have a disease or condition associated with bone loss (such as a chronic inflammatory condition or uncontrolled hyperthyroidism). There are currently no guidelines for the use of bone scans in PHAs, but many experts believe that HIV should be added as a risk factor for osteoporosis and that PHAs go and over should go for bone scans every few years.

Keep in mind that the BMD results of a scan are only one of several risk factors for fracture and that many people diagnosed with osteoporosis never break a bone. Although not all experts agree on what should be done with the results from a bone scan, there are some things you can do to live well with osteoporosis.

TREATMENT OPTIONS

Prevention is the best medicine when it comes to your bone health. And many of the things you can do to prevent osteoporosis also prevent bone loss in people who already have osteopenia or osteoporosis. Basically, you’re never too young or too old to start strengthening your bones.

Vitamin D₃ and calcium are essential for healthy bones. Almost every part of your body needs calcium to function properly. When you don’t get enough, the body takes it from your bones. So, if you aren’t getting enough calcium from your diet, you may want to consider supplements. For your body to absorb calcium and other minerals, it needs vitamin D₃. The sunshine vitamin is now widely touted due to widespread deficiency among Canadians and its many health benefits. (To find out about the daily recommended amounts, see CATIE’s Practical Guide to Nutrition for People Living with HIV, available online and through the CATIE Ordering Centre.)

Exercise makes bones denser and improves posture and balance, especially weight-bearing exercises (such as walking and Tai chi) and those that enhance core stability and strengthen muscles—all good for preventing falls and fractures. People with severe bone loss should be careful not to overstrain their bones and should check in with a doctor or sports therapist to determine the “right amount” of strain for them.

Do your bones a big favour: Avoid smoking and limit caffeine and alcohol intake.

Take precautions to prevent falls. For example, use salt or sand when the ground is icy, clear stairs, avoid walking on smooth surfaces with stockinged feet, secure loose rugs and cables.

Get checked for secondary causes. Dr. Szabo recommends getting a thorough evaluation for “secondary causes”—treatable conditions besides HIV that may contribute to the decline in BMD. For example, an overactive parathyroid gland (hyperparathyroidism) or low levels of sex hormones (hypogonadism) can contribute to bone loss. If your testosterone is low, as it is in many HIV-positive men, or if you are a woman with low estrogen due to early menopause or an eating disorder, replacement hormone therapy is available.

Finally, medication may be an option. A class of drugs called bisphosphonates can inhibit the breakdown of bone and, in some cases, increase bone mass. To date, few studies have looked specifically at the effectiveness of these drug treatments in PHAs.

A BALANCING ACT

Shortly after David Vereschagin’s diagnosis of osteoporosis two years ago, his family doctor recommended that he take a combination of calcium, vitamin D₃ and the bisphosphonate risedronate (Actonel). Vereschagin found that within two months of starting this regimen, his urine became very cloudy. Wondering if this could be the calcium passing through him, he brought it up with his kidney specialist, who ordered more blood and urine tests and an ultrasound that revealed possible kidney toxicity. So he stopped taking the calcium supplements. A bout of kidney stones while still taking calcium supplements and again shortly after stopping suggested that the supplements may indeed have caused problems for his kidneys.

For Vereschagin, this episode served as a reminder of how interconnected health issues can often be. “Most of us with HIV don’t have just one health problem,” he says. Dealing with his HIV diagnosis was one hurdle, but “it’s an ongoing process. I’ve had to continually educate myself about HIV, about kidneys, about osteoporosis…everything is interconnected. You have to find what’s right for you.”

For most people, there is no reason to avoid calcium supplements or vitamin D₃, but if you have a history of kidney stones or other kidney problems, it’s worth talking to your doctor to evaluate your situation thoroughly.

It seems that Vereschagin has found what’s right for him and his bones. Results of his kidney function tests are stable and his most recent bone scan suggests that his practice of weight training, yoga, avoiding calcium supplements and taking risedronate is working: It showed a five to six percent increase in spinal bone density. Also, he has had no further problems from kidney stones since that last episode. So he’s set aside his anxiety and continues to exercise, with a renewed confidence that he’s got the backbone to get him through his workouts. Score one for empowered, holistic living.

You’re never too young or too old to start strengthening your bones.
Small-Town Life

HIV in Canada is often seen as an urban issue, but that’s far from the whole picture. Diane Peters talks with people about the challenges and benefits of living with HIV outside the big city.

Illustrations by Tony Heron

It was something you could probably only get away with at a house party in a small town: drinking directly from a wine bottle and alternating swigs with a young woman you just met. That was what 23-year-old George from Louisbourg, Cape Breton, was doing at a recent party—and having a blast.

The new buddies were getting cheerfully drunk when a couple pulled the young woman aside and told her that George was HIV positive and she probably had contracted the disease from sharing that wine bottle. She began screaming and crying.

“You don’t have anything to worry about! You have to drink 12 gallons of my saliva to have to worry about it,” George told her. (He was pulling numbers out of the air, but he was correct that the amount of HIV in saliva is so low that it’s considered impossible to transmit the virus this way.)

Soon, the young woman calmed down and apologized. But the whole incident reinforced for George something he already knew: It’s a huge challenge to live with HIV in small-town Canada. Studies show that rural Canadians have very poor knowledge of the disease. Stigma—and fear of it—has led to silence around the condition in many communities. Meanwhile, people with HIV/AIDS (PHAs) struggle to get timely access to medical care and support service. “There are a lot of challenges for people with HIV and those trying to respond to it in rural areas,” says Tiffany Veinot, a Canadian researcher on HIV awareness in rural communities who is now an assistant professor with the Schools of Information and Public Health at the University of Michigan.

“But it’s not all bad news,” she adds. There are significant benefits to living outside of cities for PHAs, including lower cost of living, family support and service organizations that are constantly improving outreach. We’re not there yet, but HIV may one day be a disease that’s understood across the country.

About 65,000 Canadians live with HIV, but no one collects information on how many of them reside outside of cities. Up until recently, the disease has been looked at by researchers as an urban phenomenon. Now, there’s a growing interest to study HIV in small towns and to document, among other things, education levels about the disease.

“The biggest problem is ignorance,” George says. “Many people only know what they hear from their friends.” George’s experiences are backed up by facts: A study recently published in the Journal of Rural Health showed that among a surveyed group of 1,177 rural Canadians, nearly 25 percent thought the disease was transmitted through casual contact. In contrast, just 19 percent of urban
dwellers believed the same misinformation. Lead author Veinot still marvels that her study revealed that one in four rural residents thought you could get HIV by sharing a glass.

Veinot partly attributes this ignorance to the fact that few people in small towns talk about HIV—her study found that rural dwellers were much less likely to have discussed HIV with anyone. “A lot of people with HIV that I’ve spoken to, as well as their family members and friends, tell me there was a lot of silence about the disease in their community.”

The characteristics of rural populations, Veinot adds, make it more likely that they will have health knowledge that is less current: Poverty rates are higher, people are less likely to be university educated and the population tends to be older. “We have a lot of people in our area who are 55-plus,” says Martino Larue, a PHA living in Price, Quebec, on the Gaspé Peninsula. “They’re still stuck back in the 1980s.

The new generation here knows a lot more about HIV; they read about it on the Internet.”

Religion can also have an impact on HIV knowledge: While some rural Canadians have seen certain churches become very supportive after a member’s diagnosis, other congregations contribute to the knowledge gap by refusing to talk about HIV. John Baker, outreach coordinator for the AIDS Committee of Newfoundland and Labrador (ACNI), sees this when he tries to book speaking engagements at rural schools. “I often get schools that aren’t very welcoming, that just don’t have time for me. These are often schools in tightly knit communities, where what I have to say is deemed inappropriate or not needed in the community. It’s a NIMBY [not-in-my-backyard] mentality.”

Many communities are simply in denial that HIV—along with the activities that pass the virus, such as high-risk sex or injection drug use with shared equipment—exists in their midst. “There’s a real invisibility cloak around certain issues in this community,” says Gary Dalton, of the AIDS Network Kootenay Outreach and Support Society (ANKORS), in the group’s Cranbrook, BC office.

Because

HIV specialists typically work out of major centres, the vast majority of PHAs must travel to get care.

Knowing how word spreads in small communities, many PHAs guard their status with extreme care. In rural Newfoundland, where medications are often delivered by mail, Karen Thompson of ACNI has heard of PHAs sending a friend or family member to the post office to pick up the package, simply so others won’t see them doing it. PHAs in small-town Ontario, meanwhile, will visit walk-in clinics or drug stores in faraway towns just to avoid seeing someone they know. “There’s a real or at least perceived lack of privacy,” says Jenny Gritke, HIV regional resource coordinator for the Regional HIV/AIDS Connection in London, Ontario, which serves not just the city but six adjacent, mostly rural counties.

Caution about disclosure, for small towners, is all about guarding against stigma. “It’s not safe to say in public that you’re HIV positive around here,” says ANKORS’ Dalton, who’s seen newly diagnosed PHAs beaten up and fired from their jobs. After about 20 people became infected in the Newfoundland region of Conception Bay North in the early 1990s, stigma became a huge issue for not just those living with the virus but also many others in the area. For instance, young hockey players from the area struggled to find families that would billet them when they travelled for tournaments—and none of these kids was HIV positive.

Stacey, a PHA now living in Sarnia, Ontario, was diagnosed in 2008 while living in her hometown of Alcona, a small Ontario town outside of Barrie. When news got around, a woman who knew the man who had infected Stacey showed up at her door throwing punches—she said Stacey had driven him out of town, as he had recently moved. One of her daughter’s classmates was pulled out of school (to avoid contact with Stacey’s daughter). Within months, the negativity in town was so overwhelming that Stacey moved.

Along with these social obstacles, small-town PHAS face practical challenges. Getting high-quality medical care, and getting it promptly, remains a serious concern. Because HIV specialists typically work out of major centres, the vast majority of rural PHAs must travel to get care. For Dalton’s clients in BC’s Interior, that means a 13-hour bus ride to Vancouver—“not an easy trip,” he says. Not only is the ride exhausting, but it’s pricey and requires an overnight stay. In the winter, long commutes to the doctor can be made worse—or impossible—by the weather. Some
PHAs don’t own cars, so that means relying on family, friends or AIDS service organizations (ASOs) simply to get to an appointment. Seemingly minor policies on the part of clinics, such as not allowing medical information to be sent via e-mail, can further affect the care and support that a rural PHA receives.

People in rural communities also struggle to find good primary care. About four million Canadians don’t have a family doctor, and the shortage is most extreme in rural areas. And many PHAs find there’s little point being on a waiting list: Overworked general practitioners in smaller towns know little about HIV and many are reticent to add a PHA to their already-full patient rosters. Those PHAs who do have a doctor report a wide range of experiences: Some have doctors who are eager to learn about HIV and keep in close contact with the specialist. Others find that their physicians struggle to figure out where everyday medical care ends and HIV treatments begin—an issue that can strain the relationship with their patients.

Gaining access to other healthcare professionals is also difficult. For three years, Martino searched for a dentist close to home in the Gaspé Peninsula. He got numerous polite brushoffs after revealing his status. Eventually, he found a dentist who agreed to see him. She booked him in the last slot of the day—so she could disinfect her tools with additional care afterward—and still, after the second appointment, she asked him to not return. Martino finally stopped looking locally and went back to a dentist in Montreal—a six-hour drive away—who has experience with HIV.

But PHAs in rural Canada don’t just need healthcare, they need other kinds of assistance as well: help getting to appointments, emotional support, information about treatment and links to other service organizations. In cities, ASOs provide that kind of practical help. But ASOs that serve rural Canada struggle to stretch their budgets to serve their diverse, spread-out clientele. ACNL, for instance, runs on a small staff and a limited budget, trying to serve the huge expanse of both Newfoundland and Labrador. But most of the organization’s information workshops take place in St. John’s. Its rural clients receive mailings and their face-to-face support is largely limited to times when they come to St. John’s for appointments.

While many of these ASOs cannot offer a wide range of services, they focus on the basics, such as driving clients to their appointments. “Mileage is by far and away my greatest expense,” says Elma Plant, a PHA from Blyth, Ontario, and education coordinator at the Huron County HIV/AIDS Network.

It’s not just financial difficulties that leave these ASOs struggling to stay in operation. In 2005–06, researcher Veinot and study principal investigator Roma Harris of the University of Western Ontario conducted a study on how rural Canadians gain support and pass on information about HIV. During the course of the study, two organizations out of the six with whom they collaborated closed down due to lack of funding (larger ASOs took over service in those areas). “We found there was a lot of reliance on central people who acted as hubs of information,” Veinot says. “If they leave or get sick, the entire information network becomes unstable.”

And there are other barriers to getting good care. Lack of broadband infrastructure means some rural Canadians don’t have good Internet connections, reducing their ability to communicate with their support team and get information. As well, government housing programs are few and far between in small communities, leaving low-income PHAs with fewer housing options. And prevention programs offering needle exchanges or free condoms, for instance, are rare outside of cities.

Still, despite the multilayered challenges of living with this disease in smaller communities, the benefits are compelling enough that many PHAs prefer small-town life—both for personal and practical reasons.

One reason is the affordability of rural life. Martino, for instance, was able to buy a home two years ago, and his mortgage payments are far below the rent he used to pay while living in Montreal—plus, now he has a huge yard.

Family support is another key reason PHAs swear by small-town life. Martino works at his brother’s business and can customize his schedule to work around his health, appointments and volunteer work. And while healthcare is hours away and he often has to rely on the emergency room at a nearby hospital for care, the slower pace of rural life has been much better for his health. In Montreal, Martino worked in a bar, but life in Gaspé is less stressful and it is easier for him to get enough sleep and follow a healthy diet.

The slower pace of his community in Cape Breton fits George’s needs as well. Here, his quieter life affords him
more time to spend with friends. And while stigma may exist around him, his friendships are close ones because “people also have more time to get to know you.”

Elma, who was diagnosed along with her husband back in November 1991, finds community support can be powerful. “By January, everyone knew and the doorbell started ringing with people bearing casseroles and pie.” While she admits it might be easier for her as a straight woman, she’s seen little stigma in her community, directed at her personally or her PHA clients. “Given enough education not based on fear, people in rural areas respond with compassion and generosity.”

Helping to increase the HIV awareness and acceptance in small-town Canada is the hard work of ASOs. Despite their limited budgets and geographical challenges, these organizations have come up with an ever-growing list of ways to help even their most faraway clients.

Lack of funding and infrastructure means these groups have become increasingly adept at linking up with other organizations. “We network,” says Elma Plant, of the Huron County HIV/AIDS Network. “That’s why we have ‘network’ in our name.” The same tight-knit structure of small-town communities that makes keeping a diagnosis secret difficult helps these organizations stay connected. ASO leaders are well known in the community so they get called on to, for instance, speak at events. Plus, newly diagnosed PHAs don’t simply receive a phone number—they get a personalized referral with a name, address and email address.

In Newfoundland, HIV care providers occasionally travel to remote towns to see patients. Not only does this reduce travel for PHAs, but it encourages people who are HIV positive to find peers in their own communities. The ACNL tries to further communication by hosting an annual summer retreat that offers workshops and conversations.

These efforts are making life for those living with HIV in rural communities incrementally better. People in these communities report that they are seeing awareness increase and stigma decrease, and they are also seeing more newly diagnosed PHAs opt to stay put, close to family and friends. This improved environment is helping PHAs. But beyond that, Dalton says, celebrating diversity makes small towns more welcoming and better for all who live there. “Everyone has a piece of that needs to be supported. That’s what community needs: Community needs everybody.”

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**A Unique Voice**

Any story about HIV in rural Canada would be incomplete without special acknowledgement of the impact of the virus on Aboriginal people, the majority of whom live outside of Canada’s largest cities. In “Path to Healing: Full Circle on the Prairies” (Winter 2010 issue), we give special voice to the strong and courageous Aboriginal PHAs living, loving and healing in the Prairies.
Vaginal Health

It’s hard to get information about HIV and women’s health issues. Yes, I’m talking about birth control, yeast infections and menopause. As a woman living with HIV, what do I need to know about my health down there? – E.R., Kamloops, BC

INTERVIEWS BY JENNIFER MCPHEE

MONA LOUTFY, MD
Infectious Diseases Specialist
Women’s College Hospital, Toronto

Certain gynecological conditions that are already quite common among women are even more common, severe and difficult to treat in women with HIV. These include vaginal infections, such as yeast infections and bacterial vaginosis; sexually transmitted infections (STIs), such as chlamydia, gonorrhea, herpes and syphilis; and pelvic inflammatory disease, a potentially serious bacterial infection of the reproductive system.

Recurrent yeast infections can be a warning sign for women who have not yet been diagnosed with HIV. For HIV-positive women, recurring infections can be a sign of a weakening immune system.

The treatments for these common infections are generally the same for women with and without HIV. It’s important to know that having an STI increases your risk of transmitting both the STI and HIV. Bacterial vaginosis may also increase the risk of passing HIV. You can reduce the risk of many STIs by using condoms during sex.

Women with HIV have higher rates of problematic strains of a common STI known as the human papillomavirus (HPV). These problematic strains can cause genital warts, cervical cancer and cervical dysplasia,
an abnormal change in the cervix that can progress to cancer when left undetected.

In the year following your HIV diagnosis, book a pelvic exam, including a Pap test, every six months. Your doctor will do an examination of your inner and outer pelvic area and take a tiny sample of cells from your cervix to check for cervical dysplasia or cancer and various other diseases and infections. If these tests uncover no significant problems, a yearly pelvic and Pap test will suffice.

The condom—despite its relatively high failure rate at preventing pregnancy (12 percent)—is the most common and important form of contraception for women with HIV because it is the only one that blocks the transmission of HIV and most other STIs. To prevent pregnancy, a second method of contraception should be used in addition to condoms. This is particularly important in situations where women don’t have a great deal of control over when or how they have sex.

Some women choose oral hormonal contraception (the birth control pill). However, women on anti-HIV therapy should be aware that there can be drug interactions between some anti-HIV drugs and the hormones in many birth control pills.

Talk to your doctor about your birth control options if you are taking:
- atazanavir (Reyataz; unboosted or boosted with ritonavir [Norvir])
- ritonavir-boosted darunavir (Prezista)
- fosamprenavir (Telzir; unboosted or boosted with ritonavir)
- Kaletra (lopinavir/ritonavir)
- nevirapine (Viramune)
- ritonavir-boosted saquinavir (Invirase)
- ritonavir-boosted tipranavir (Aptivus)

There are other forms of hormonal contraception, including injections and intrauterine devices, that contain other hormones. Talk with your doctor about whether they might be appropriate for you.

**TASLEEM KASSAM, ND**
Clinic Director, Effective Health Solutions, Calgary

Women with HIV are often plagued by stubborn yeast infections that won’t go away. Naturopathic doctors recommend fending off chronic yeast infections by changing your diet. Since yeast feeds on sugar, avoid simple sugars and refined carbohydrates as much as you can; instead choose vegetables and high-protein foods. No diet should be taken to the extreme—a variety of fresh, unprocessed foods is best for optimal health.

Secondly, probiotic supplements are useful to restore your vagina’s flora (healthy bacteria) balance. We are often unaware of our exposure to antibiotics as a regular part of our food supply; this can affect the beneficial bacteria so critical not only to gastrointestinal health but to vaginal health and immune function as well.

During an active yeast infection, I recommend alternating between a probiotic douche and a garlic pessary. To make the douching solution, mix ¼ cup of lukewarm water with ¼ to ½ teaspoon of probiotic powder.

(There is powder available at health food stores or you can simply break open probiotic capsules.) Before showering, flush your vagina with the solution using a vaginal bulb syringe, which can be found in any pharmacy. A large syringe will also work. Make sure you use lukewarm water—hot water will kill the live bacteria and cold water will feel unpleasant.

I advise my patients to use a garlic pessary on alternate nights. Peel a clove of garlic—avoid nicking it and releasing any juice that might cause irritation—and then wrap it in gauze. Form a tail with the gauze to make it easy to remove. Apply coconut or olive oil to lubricate the pessary and then insert it as high as possible into your vagina and leave it there overnight. Allicin, a natural compound in garlic, helps kill yeast. Garlic is an antibacterial agent, so you can also use it to fight off bacterial infections such as bacterial vaginosis.
Naturopathy advocates the importance of addressing the body’s ecological balance as part of treating the infection instead of simply taking the standard prescription medications. It’s kind of like trying to get rid of dandelions without pulling out the roots—you may get rid of one infection but you won’t stop them from recurring.

DEBBIE KELLY, PharmD
Pharmacist, Newfoundland and Labrador HIV Clinic, St. John’s

In most cases, treatments for yeast infections are the same for all women regardless of whether or not they have HIV. I tend to recommend antifungal creams and ovules (such as Monistat) over the single fluconazole tablet as a first treatment because we don’t want to create instances of fluconazole resistance. If you are taking fluconazole tablets regularly as a preventative measure—which is more common when yeast infections affect the mouth or throat rather than the vagina—your HIV doctor will want to check for interactions between fluconazole and anti-HIV medications.

**Women going through menopause should drink enough fluids to help ward off vaginal dryness.**

There is more and more interest in the effect of probiotic preparations on preventing or treating yeast infections and treating bacterial vaginosis. Although this is a growing area of research, not enough evidence currently exists to show that they do this. It is a difficult area to research because studies are often small and the probiotic treatments being studied can be quite different. More high-quality research is needed to better understand the role of probiotics in treating vaginal infections.

Finally, women going through menopause should drink enough fluids to stay well hydrated and help ward off vaginal dryness. This applies to all women, but it bears repeating because it is so important and yet easily forgotten during a busy day. Talk with a healthcare provider, such as your family doctor, nurse or gynecologist, if you have vaginal dryness.

**Herpes simplex virus outbreaks are often more severe, last longer and may recur more often among people with HIV.**

Bacterial vaginosis is usually treated with the antibiotic metronidazole (Flagyl). It can make you viciously sick if you drink alcohol while taking it, so try to avoid alcohol while taking this drug and for two to three days afterwards. If this is impossible, ask about the antibiotic clindamycin. Be aware that metronidazole, clindamycin and some other antibiotics can disturb the natural balance of bacteria in the vagina and may increase the risk of yeast infections. Clindamycin can also cause diarrhea, especially if you are already having a problem with this due to anti-HIV medications.

Herspes simplex virus outbreaks are often more severe, last longer and may recur more often among people with HIV. I send my patients home with antiviral medications prior to their outbreaks so they can begin their meds the moment they spot a new lesion or feel the tingling that precedes one. This really helps get painful flares under control.

Two herpes medications, acyclovir (Zovirax) and valacyclovir (Valtrex), may increase levels of tenofovir (Truvada and in Atripla), so your doctor should monitor you for adverse effects if you are taking either of these drugs for a long time. They can also affect kidney health.

CHERYL COLLIER, RD
Clinical Dietitian, Oak Tree Clinic
Vancouver

Reams of information exist in the media about using the “Candida diet” to prevent or treat yeast infections. Advocates of this high-vegetable, high-protein diet advise people to avoid simple sugars as well as other foods including some dairy products, fruit, starchy vegetables and starchy foods, such as gluten-containing grain products (anything made from wheat or related cereals such as barley and rye). Evidence does not show that cutting out all these different foods can prevent or treat yeast infections, though limiting added sugars and refined carbohydrates is always a healthy practice. I encourage women with HIV to consider that a balanced diet is important for getting all essential nutrients needed for good health.

Women with uncontrolled diabetes are at increased risk for developing recurrent yeast infections. For this reason and others, it is important to get diabetes under control, which includes working closely with a doctor. HIV-positive women with uncontrolled diabetes are encouraged to eat balanced regular meals, choose higher-fibre foods and limit refined carbohydrates to help manage their blood sugars. This, along with other strategies, such as regular physical activity and taking diabetes medications as prescribed, will hopefully help keep blood sugars under better control and decrease the risk of recurrent yeast infections.
My name is Mashkiki-waabikainini (Medicine Circle of Stones Man); my given name is Ron Horsefall. I am from Pasqua First Nation, Saskatchewan. I am 45 years old and currently reside in Vancouver, BC. The first time I was tested for HIV was December 1996 and I was diagnosed with AIDS. At the time I was living in a room in a single-occupancy hotel in the Downtown Eastside of Vancouver. I had shingles, which was what prompted me to get tested.

After my diagnosis, I was put on HIV meds; AZT was one of them. For about four years, I was on and off meds: The times when I was not drinking were the times I was able to take the meds. My health finally made a turn for the better when I sobered up in 2000. Now my health is good: I’m on therapy, my viral load is undetectable and my CD4 count is 400.

I am a survivor of a residential school. I started attending when I was five years old and I was abused before and while at the school. After leaving, I wanted to distance myself from everything that had happened there and I discovered the best way to do that was to use drugs and alcohol. My addictions led me to ugly places and to a life of high-risk behaviour. I just didn’t care about myself and, more fundamentally, I didn’t love myself.
**BOTTOMING OUT**

In retrospect, I see HIV as a gift—it helped me hit bottom. Trying to manage my addictions and my health at the same time was not working. So I had a decision to make: Get sober and live or keep using and die. After 23 years of drinking and drugging, I reached out. I joined Alcoholics Anonymous, found a drug and alcohol counsellor and eventually saw a psychologist. These were the hardest things I had ever done up to that point.

HIV and the drug and alcohol use were symptoms of more deep-seated problems in my life. Under the surface were some very serious issues—issues that I’ve had to deal with over the years. Addressing them meant turning inward to look at myself and my life and putting away the blame and self-pity I was feeling. I became aware of why I used and why I became HIV positive. It is a very hard road to walk, and I didn’t walk it alone; I had help from a great many people. It was the journey from my head to my heart.

Eventually, doing my own inner work and practicing a healthier lifestyle brought me to a place in my life where I could give back what had been so freely given to me. From 2004 to 2007, I worked with two Aboriginal AIDS service organizations: Healing Our Spirit here in Vancouver and All Nations Hope AIDS Network in Regina, Saskatchewan. I spoke publicly about my life with HIV—something I still do on occasion—and developed workshops for Aboriginal people with HIV. It gave me joy to help people on their own journeys, whether they were HIV positive or not.

The residential school system disconnected me from my culture and spirituality. I knew I was First Nation; however, I didn’t know what that meant. As part of my healing, I embarked on another journey, this time to reclaim my culture and spirituality—my birthright. As I learned about my identity, I became interested in powwow dancing. I decided to make my own regalia (dance outfit) and this required beadwork. Thus began my artistry with beads. I am a self-taught bead worker—I learn from books, videos and the Internet.

**PHOENIX RISING**

I have always been creative; I took art classes throughout high school and at university. For years, low self-esteem and a sense of low self-worth prevented me from pursuing my dream as an artist and I listened to people who said it was hard to make it as an artist. More importantly, I listened to myself when I said, “I’m not good enough.”

However, as I walked my journey I came to see that I was good enough and that I did have potential. Two and a half years ago, I made a commitment to my art and began selling it at arts and crafts fairs. Before that, I had done commissioned work for friends and friends of friends. Then, in September 2009, I learned that the Carnegie Community Centre—a drop-in centre serving the people of the Downtown Eastside—had an arts grant program that was funded by the Vancouver Foundation, Canada’s largest community foundation. I applied and, surprisingly, I was selected. Not only was I very excited, I was also now accountable for my artwork. I had a body of work to produce and had to answer to someone other than myself for it. I had obligations!

The project included a series of beaded circular wooden and metal containers ranging from 1½ to 7 inches in height. I chose the name “Out of the Ashes,” shortened from “Phoenix Rising Out of the Ashes,” to represent how I rose out of darkness and into the light. I dedicated my project to my niece, Lorraine Horsefall, who died of AIDS in 2006. As part of the program, all recipients exhibit their work, and so last summer I had my first art show. Thanks to this experience, I now call myself an artist, without any reservations.

Creating is a spiritual process for me and what comes out is a tapestry of my life.
I hadn’t been very public about being poz before these pictures were captured at the International AIDS Conference in Montreal in 1989. In those days there were real fears that the public health department might start quarantining HIV-positive people. There was a lot of hysteria. Moreover, even though I had done media for the Toronto-based activist group AIDS ACTION NOW! (AAN!) one’s HIV status wasn’t something that most polite Canadian reporters were brave enough to ask about.

AAN!, Montreal’s Réaction Sida and ACT UP New York had agreed to rally outside the conference centre during the opening ceremony. But at the last minute, ACT UP NY suddenly rushed the doors and everybody followed. The next thing I knew, we were on the stage with our signs and banners.

The hall was full of delegates waiting for then Prime Minister Brian Mulroney to open the conference. Instead they got a bunch of angry activists. We had no plan. As I was the spokesperson for AAN!—the largest AIDS activist group in Canada at the time—somebody passed me the microphone. So, I opened the conference “on behalf of people living with AIDS in Canada and around the world.” I denounced the government for its inaction on AIDS, and before we left the stage we read aloud the Montreal Manifesto, a declaration of the universal rights and needs of people with HIV/AIDS.

The moment was a turning point, though I had no idea at the time. Most of us were thinking more about staying alive than about making history. But, from then on, it was clear that people with HIV/AIDS would not be on the outside looking in on discussions about this epidemic. We would be given a place at the table—or we would take it.

Taking Our Place

On June 4, 1989, some 300 activists stormed the opening of the 5th International AIDS Conference in Montreal to demand that their voices be heard. Tim McCaskell reflects on a pivotal moment in Canadian AIDS activism.
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