

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

WINTER 2013
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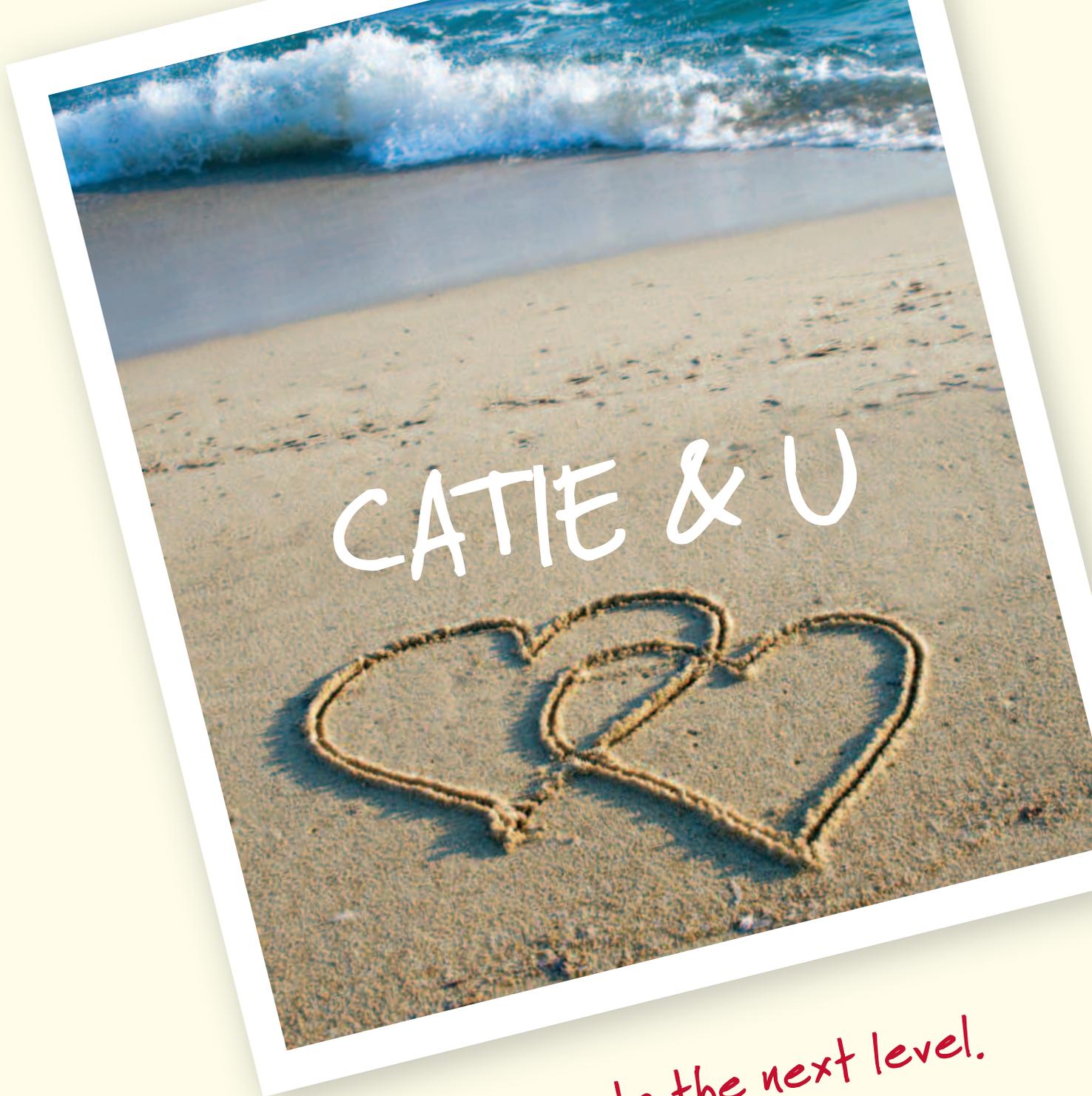
Claudia Medina blows
the cover off secrets,
stigma and denial

THE REAL DEAL

**READY
FOR OUR
CLOSE-UP**
AIDS onscreen

JUST KIDS
*Growing up
with HIV*

**NIGHTY-
NIGHT**
Sleep tight



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EDITOR'S LETTER

This past October, the Supreme Court of Canada delivered its verdict on two cases involving non-disclosure of HIV status during sex. While the judgement dismayed many HIV activists, it did define one situation in which people with HIV do not have to disclose their status before sex—namely, when they have a low viral load (less than 1,500) and a condom is used. Go to www.aidslaw.ca for more info.

These rulings reinforce the false view that prevention rests solely with the HIV-positive individual instead of being a responsibility shared by both people. They may also lead to people with HIV feeling pressure to start treatment, not only for their own health but also to reduce their legal risk.

At the same time, new guidelines are suggesting that people start HIV treatment at higher CD4 counts. This is partly based on evidence that doing so can protect the body from damage caused by HIV, but it's also based on evidence that starting earlier reduces the risk of transmitting HIV.

For people with HIV, all of these changes mark a shift from making treatment decisions based solely on their own health (and readiness to start, of course) to making decisions that include the potential impact on other people. However, it is only the HIV-positive person who must deal with the side effects and risks, many of which are still unknown.

The Positive Side encourages every person with HIV to make the treatment decision that is right for them. And we think the needs of the person living with the virus should always come first. You should not feel pressured to start treatment solely for the benefit of others.

Of course, we are here to provide information and support, whether it's about HIV treatment or another aspect of living well with HIV. In this issue we look at managing lipid levels, getting a good night's sleep and growing up with HIV.

We also have stories of tattoos, beach weddings and meeting *Fashion Television* goddess Jeanne Beker. Would we expect anything less from the great people living with HIV in this country? Absolutely not.

—David McLay

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FROM THE FRONT LINES

What's happening across Canada

Adherence Support

CATIE educator **Melissa Egan** profiles programs across the country that aim to make HIV meds a little easier to swallow.

Sticking to your HIV medication schedule—a.k.a. adherence—is crucial to fight the virus and prevent drug resistance. But “take as directed” isn’t always as straightforward as it sounds. Side effects, drug interactions, depression, an irregular routine and “treatment fatigue” can all throw up roadblocks. A few innovative programs offer people living with HIV support and strategies to overcome barriers and stay on course.

AIDS Community Care Montreal



Starting HIV treatment can be a difficult decision to make; staying on it for years and doing so without support can be even harder. In Montreal, people with HIV who are interested in exploring their treatment options or discussing adherence challenges one-on-one need look no further than AIDS Community Care Montreal (ACCM)'s treatment information facilitator, Sylvain Beaudry. Members can call or visit him to discuss any issues they may be experiencing.

Starting in fall 2013, ACCM will offer the innovative My Life with HIV workshop series, which will focus on antiretrovirals—how to incorporate them into your life, manage side effects and stay adherent. The agency also ensures that clients have the most up-to-date information by inviting pharmacologists and other healthcare professionals to highlight new meds and discuss those currently available.

If you're after a way to stay adherent or have questions about your treatment, ACCM's staff is ready to support you.

treatment@accmontreal.org

HIV Care Program

Windsor Regional Hospital
Windsor, Ontario



One of the most comprehensive adherence support programs in Ontario is the HIV Care Program at Windsor Regional Hospital. This outpatient clinic is run by a group of devoted service providers that includes two pharmacists, physicians, nurses, a psychologist and a dietitian.

Every person who comes to the clinic becomes part of a community of care that emphasizes an attentive and holistic approach to improving adherence. This includes one-on-one counselling, the use of dosette boxes and scheduled medication pickups. A link with the pharmacy gives this clinic its edge—records of when each person is due for a refill help staff track how often prescriptions are being renewed. This can prompt discussion about how patients can be further supported to take their meds.

In recent years, the need for adherence support has expanded, as many long-term survivors are also taking meds for other conditions, such as high cholesterol, depression and osteoporosis. With HIV meds comprising just some of the many pills they must take in a day, this program has become integral to the continued support of people living with HIV.

www.wrh.on.ca



Northern Alberta HIV Program

Edmonton

With a strong focus on treatment programs tailored to each individual, the Northern Alberta HIV Program is a shining example of how excellent adherence supports can make a difference in people's lives. Working to build strong connections with the people it serves has been the model of success for this clinic, which provides care to people living with or affected by HIV across northern Alberta and the Northwest Territories.

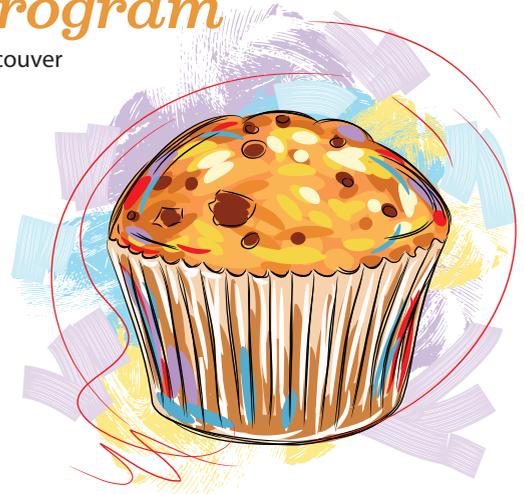
The staff includes a psychologist, social workers, pharmacists and other healthcare providers who place their relationships with patients at the forefront of care. Appointments can last more than an hour and the pharmacist is careful to customize HIV treatment to each individual's life. This involves getting to know a person's work schedule and living situation as well as any confidentiality issues they may be dealing with related to their meds. Understanding the context of a person's treatment in this way makes it easier to pinpoint any barriers to adherence and to find strategies that help people stick with their treatment.

After seeing more and more pregnant women access its services, the program has increased its focus on this group. Clinical pharmacist Michelle Foisy and her team have started a comprehensive treatment support plan that is both collaborative and customized to the needs of pregnant women and new moms. Since its inception, the clinic has seen excellent results, with a transmission rate of less than one percent in the perinatal program (one out of 111 infants was born HIV positive).

www.albertahealthservices.ca

Maximally Assisted Therapy Program

Vancouver



At the crack of dawn, 365 days a year, the doors of the Downtown Community Health Clinic open to offer breakfast to people in the Downtown Eastside. This tiny but busy space in a community where many lack stable housing provides a chance to get out of the rain, enjoy a cup of coffee and access health supports. Some people come for an appointment at the clinic, while others drop in for their daily dose of HIV medication. The clinic has had great success helping its members stay on their meds and the addition of the Maximally Assisted Therapy (MAT) Program has contributed hugely to that success.

The MAT team of nurses, community workers, social worker and pharmacist offers a wide range of adherence supports. Members are encouraged to use services that range from counselling and regular checkups for blood work to appointments with the nutritionist or infectious disease doctor. Additionally, outreach teams travel throughout the city to distribute medication to members regardless of where they are, ensuring that adherence isn't affected by lack of bus fare, having no fixed address, depression or drug use. MAT outreach workers have brought treatment to some of the most hard-to-reach people in Vancouver.

Evaluation of the program has shown that nine out of every 10 MAT clients now have a suppressed viral load and adherence rates appear to be high. The program is also beginning to see evidence of lowered transmission rates.

For a comprehensive guide to preparing for HIV treatment, choosing the right combination and adhering to your medication schedule, see CATIE's *Practical Guide to HIV Drug Treatment* at www.catie.ca. You can also order print copies through the CATIE Ordering Centre at www.catie.ca or by calling 1.800.263.1638. The guide is free for people in Canada.

Got Ink?

4 people with HIV talk about their tats and all that

INTERVIEWS BY RONNILYN PUSTIL



ROBERT MACLEOD, 36

Halifax

HIV+: 8 years

Job: Medical lab technologist



How many tattoos do you have?

Hundreds.

Why so many?

This is a question I get asked a lot. Tattoos are my passion, my hobby, my obsession. I got each one for a different reason.

What are some of the reasons?

Each tattoo has a unique source of inspiration. When something happens in my life that I feel is significant or meaningful, I add a new tattoo to represent that event. That way, I'll always remember that moment in time.

What do your tattoos represent to you?

My skin is a living canvas of my experiences. My life's story is etched in the lines and shading. I was born

naked and screaming, waiting for my life to write itself on my skin. The connection goes way beyond a needle and some ink: It's about art, expression and sharing.

How do people generally react?

Reactions are mixed. The first impression I give to the world is not an accurate picture of who I am—people think I just got out of prison or I'm a thug. I actually have a successful professional life! But most reactions are positive. People often stare and I get a lot of strange looks. They always want to know why I have so many tattoos. I don't feel I need to justify this in any way. **Simply put, tattoos are my passion and I take pride in them.**

Do you have plans for any more?

Absolutely! As my life's story continues to write itself, there will be more important times and events to represent. I can tell you what I was feeling at the time I got each piece and what it means to me. Years from now, when my life story ends, it will all be there in permanent ink.

MIKE O'SHAUGHNESSY, 40

Vancouver

HIV+: 8 years

Job: IT support tech and writer

How many tattoos do you have?

Many, all over my upper body.

Why did you get them all?

Originally, as markings to remind myself of specific events. Now they are ways to redefine how I'm seen

and how I see myself. In effect, I draw the person and the life I want on my own skin.

What's the story behind them?

Each tattoo was inspired by something important to me—either something beautiful or a life-altering experience.

The first was a small rune that means "See-er of truth." It's over my heart—a reminder to remain true to myself.

The tattoo on my back, designed using tribal styling, hints at wings—representing flight, freedom and, as they extend onto the upper backs of my arms, protection. The designs were extended onto my upper chest and into sleeves for both arms.

The last tattoo to date is a set of letters—LJ, the initials of a man I loved very much, Little John. It was commissioned as he was dying in the hospital in 2005 from AIDS. In the last



real conversation I had with him, I took his hand, as he was almost blind by this point, and traced the letters with his fingers, explaining that he would be, for all time, a part of my skin, of me. He died two days later.

How do people react to them?

Often with a prejudiced sense of who I am.

Frankly, it's useful as a gay man. Sometimes, when I'm walking around late at night, people see a shaved-head, bearded, jeans-and-boots kind of guy with tattoos. It's easy to just leave it at that and be left alone. In other circles, people find them attractive and striking. Those who approach me about them are often surprised and amazed by the clarity and depth of the colour and the overall sense of coherent design. Among gay men, it's often an excuse to touch my arms (*laughs*).

Do you have plans for any more?

At some point I'd like to get my legs done with something evoking earth. Tattoos truly are addictive.



CATHERINE, 34

Montreal

HIV+: 12 years

Job: Self-employed

How many tattoos do you have?

One.

What's the story behind it?

I became close friends with a woman from the Bahamas. We're now like sisters—we say we're sisters by choice. We're both transsexual. When I was visiting her in the Bahamas, four or five years ago, we got the same tattoo: a butterfly. **For me, it's a symbol of being trans.** It's on my left breast.

When I wear something low-cut, you can see it.

Plans for any more?

I'm thinking of getting another one on my arm. I'm an activist when it comes to trans rights, and I'm proud of it. There's a trans logo, which consists of an arrow on top and a cross on the bottom—a combination of the man and woman symbols. I found one on the Internet that's really nice; it's done in a Celtic style. That's the one I'd like to get. I need to be proud of being trans and live it.

I might get it this winter. Since I hate pain, I need a good reason to get another one!

KYLE VOSE, 40

Toronto

HIV+: 10 years

Job: AIDS and anti-poverty activist

What's the story behind your tattoos?

I always wanted a tattoo when I was younger but I grew up religious and was told it was wrong. When I came out, my religion was taken away from me, so I got my first tattoo about 11 years ago.

How many do you have?

Ten. My first one was a flying fire-breathing dragon with blood coming out of his claws. I got another one on my other arm in Hebrew script—*chai*, the Hebrew word for life. On my back I have two tattoos that are for my kids: One is a heart with both of their names in it and the other is a little map of Ecuador, where their mother is from. I also have a tribal tattoo on my back. From my pelvis to my belly button, I have a tribal-floral image with a couple of thistles coming out of it. The flowers symbolize life, but the thistles mean, if you treat me the wrong way, I'll hurt you.

Do you regret getting any of them?

One of my tattoos got me infected with HIV and hepatitis B. I had it done at someone's house who was learning to be a tattoo artist. I don't blame them. You have to know the risk when you're going into something. You can't expect someone else to protect you when it's your job to protect yourself. I ended up in the hospital exactly three

weeks after that tattoo, so I figured it was that.

Do you want to get rid of that tattoo?

That tattoo is a garden—sometimes you plant something and you might not get exactly what you were expecting. I'm very spiritual, so I feel like this might have been given to me for a reason. A lot of people make mistakes, so why am I going to beat myself up for it? I'm going to use it to my advantage, as a stepping stone and not as a crutch.



How do people generally react to your tattoos?

The Hebrew ones get the most reaction. I almost got fired from a job because I offended an Orthodox person with my Hebrew tattoos. And I get a lot of people asking what they mean. That's usually an opening for me to do outreach about what I do.

Do you have advice for people who want a tattoo?

If you're getting a tattoo for a relationship, have a backup plan in case it doesn't work out. You might need to get creative if the relationship doesn't survive.

Plans for any more?

I'd like to get at least one or two more. At age 22, I had Hodgkin's disease. I struggled through it but I survived. After that, I got HIV and hepatitis B. Then I had a heart attack and they didn't think I was going to make it. And now I have diabetes. It's amazing that I'm still here. So I want to get a hand tattooed on my ankle to symbolize somebody or something pulling me back down to earth, to keep me here. There's still more work for me to do—it's not time for me to go yet. +

Far from the Manse and the White Picket Fence



Claudia Medina's teen and adult years threw her more than a few curve balls, taking her life in a direction she could not have foreseen. Today Claudia educates and supports fellow Latinos and HIV-positive women in prison.

BY PETER CARLYLE-GORDGE

PHOTOGRAPH BY MICHELLE GIBSON

Claudia Medina grew up in a rough neighbourhood of Toronto. The only child of a single mother, who emigrated from Bogotá, Colombia, when Claudia was just five, she led a protected life. Her mother sent her to Catholic schools in the safer parts of town because she didn't want Claudia spending time in their neighbourhood. Change came when Claudia was 15 and landed her first job, at a theatre. "I began to make friends and socialize beyond my sheltered world," she says.

Claudia became best friends with a young man whom she fell in love with. Shortly after they met, she began attending his Presbyterian church. At age 16, influenced by his religious practices, Claudia became a born-again Christian. Her life plan included marriage, four children, a nice house and a white picket fence.

But Claudia was also a teenager who was discovering her sexuality. "Sex before marriage for me was always wracked with guilt," she says. "I was young and full of sexual desires, including bisexual ones, but the church had taught me that to act on these without being married was sinful, so I rarely enjoyed sex. The solution was to hide my bisexual desires and to get married."

Not long after becoming engaged, Claudia began to realize that something wasn't quite right between her and her fiancé. They were both young and vibrant, yet a sexual spark seemed to be missing and she wondered why they had sex so infrequently. "I started having an affair to avoid the problems my fiancé and I faced in our relationship," she says, which only compounded her sense of Catholic guilt.

Then, one month before their wedding date, in the middle of a heated argument, Claudia's fiancé admitted that he had been sleeping with men but wasn't happy about it and thought it sinful. Claudia knew that if she blew the cover off of this, her mother and family would never let her see him again and she would lose her love and best friend. So she decided to believe her fiancé when he said that he had closed any gay chapters in his life. They married as planned.

As they settled into their new life, Claudia and her husband knew something was still amiss. They decided that having a child might fill the void. In 1993, at age 23, she gave birth to her son. While pregnant, she had been physically sick and suffered from depression. In Latino culture, Claudia says, women are supposed to be strong and carry on regardless. "I felt that I couldn't reach out to my family because of my depression but also because I wanted to shelter them from my marital problems. And pretending that we had a great family and great life was all a part of fitting in at church."

"We continued to be active in the church," she says, "but I slowly began to realize that organized religion had fed me many lies." Claudia and her husband disclosed their marital secrets to their minister, whose advice was to pray and come to him for counselling. A pivotal moment occurred when she was talking to the minister's wife: The subject of a lesbian march for Gay Pride Day came up. The minister's wife was vicious in her views on

lesbians, which Claudia did not like. "This so-called Christian woman said that she wouldn't let a lesbian even eat from her dog's bowl."

She joined a support group for women married to bisexual men and was appalled by what some of them put up with to keep their marriage going. One of the women described how her husband of 12 years always went into another room to undress. "When I heard that story," Claudia reflects, "I realized that nothing we could do was going to change the fact that my husband was attracted to men." She began to feel that being bisexual was not something that needed to be fixed but something to be embraced.

During her first year as a mother, Claudia was haunted by doubts, depression and illness. Isolated and depressed, Claudia began cutting herself. Gradually, the marriage deteriorated. In April 1994, a combination of ongoing weight loss and concern about being exposed to HIV led Claudia to take an HIV test. The result was positive. "The diagnosis knocked the wind out of me," she recalls. Claudia urged her husband to get tested; he too was positive. They continued to support each other as friends, but the marriage was over. In 1996 she moved out with her son.

Initially, Claudia blamed her ex-husband for her diagnosis, but "my real anger was with myself for being so naive," she says. "I knew that we could get HIV, but I refused to take off the blinders and recognize that HIV could affect me. Looking back now, I can connect all the factors that contributed to my diagnosis: lack of HIV/AIDS information, my religion, low self-esteem,

childhood trauma from seeing violence in my family, and gender power imbalances in the relationships I chose.”

A severe two-year bout of depression followed her diagnosis. The only thing that kept Claudia going was the need to take care of her young son. She wanted to look after him as well as do a better job of looking after herself.

Keen to give back to the community that had supported her when she was first diagnosed and trying to move beyond her depression, Claudia began volunteering at various AIDS service organizations (ASOs)—with the Speakers Bureau at the Toronto People With AIDS Foundation (PWA), Teresa Group and Positive Youth Outreach.

Her first paid job in the field was at Voices of Positive Women. Claudia later became an employee at PWA and in 2006, she and a friend, community activist Samuel Lopez, established *Latinos Positivos*, an advocacy organization run for and by HIV-positive Spanish speakers in Toronto. Many of the Latino people living with HIV in Toronto, and elsewhere in Canada, are new immigrants. They often feel isolated, which Claudia says is in part due to the ignorance and prejudice about HIV in the Latino community and a lack of culturally appropriate services. But today things are improving and newcomers come in to *Latinos Positivos* every week to seek peer support and a sense of community.

Claudia has seen the homophobia that exists in Latin culture from her own family members. “I think the fact that my husband contracted HIV from having sex with men made it harder for my family to forgive him than if he had contracted it through heterosexual sex,” she says. “This homophobia makes it much harder for me to come out to my family as queer.”

To overcome homophobia and HIV-related stigma and discrimination in Latino communities, a lot of education is still needed, Claudia says. In 2008, *Latinos Positivos* produced *Nuestras Caras, Nuestras Historias (Our Faces, Our Stories)*, a Spanish educational

“The more I’ve...
broken down
barriers, the more
fulfilled and happy
I’ve felt in life.”

video that features Latino immigrants to Canada who are living with HIV (see “Art Posi+ive: Latino Positivo,” in the Spring/Summer 2010 issue). The six men and women interviewed—Claudia included—tell their stories about living with HIV.

More recently, Claudia also shared her story in the 2012 documentary *Positive Women: Exposing Injustice*, about how the criminalization of HIV non-disclosure impacts HIV-positive women in Canada. “The issue of criminalization is very important to me,” she says. “I believe that everyone has to take responsibility for the risks they take when having sex, instead of playing the blame game.”

In 2009, Claudia took on the full-time role of women’s prison program coordinator at the Prisoners’ HIV/AIDS Support Action Network (PASAN). PASAN is an ASO that provides education and support to prisoners and ex-prisoners in Ontario on HIV, hepatitis C and harm reduction. Claudia delivers educational workshops and provides support to women living with HIV in prison. “I love the work I do. The system has let these women down,” she says. In her job, she helps fill a gap in services for women who have been in trouble with the law, who are marginalized because of [societal] attitudes. “I let them know that they are not alone and that someone out there cares about their health and livelihood.”

Claudia has balanced her work in the HIV community with the challenges and joys of being a mom. When her son was three, Claudia tried telling him about HIV, “but he was too young,” she recalls. “When I mentioned that mommy had HIV, his response was ‘Well, I want HIV too, like mommy.’” After her son turned seven, she began to explain more. He wondered, for instance, when she was paralyzed with depression why she wanted to lie on the couch. Those conversations were sometimes difficult, but Claudia thinks it’s important for parents to be open with their children: “We think children are fragile but they are intelligent and often know if something is wrong,” she says. “So you need to talk to them.” It’s also essential, she believes, to reassure them that you’ll be around for a long time yet.

While Claudia still struggles with depression, she feels stronger and more optimistic than ever before. When first diagnosed, she thought she’d be dead by age 40. That didn’t happen; in fact, she only recently started taking HIV meds after being positive for over 18 years. And now, in her early 40s, she likely has another 30 to 40 years ahead of her.

“What I need to stay away from in order to stay alive is stress. I’m always trying to find balance in my life, so I can fully enjoy it. Part of that balance comes with helping others; I, in turn, help myself. I feel more connected with the universe,” she muses. “The more I’ve fought and broken down barriers, the more fulfilled and happy I’ve felt in life.” +

Find out more about *Latinos Positivos* at www.latinospositivos.blogspot.ca or PASAN at www.pasan.org

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



Vancouver AIDS Memorial

Location: Sunset Beach West, Vancouver

Artist: Bruce Wilson

Nestled into the side of the hill at the base of Broughton Street in the city's West End, the Vancouver AIDS Memorial pays homage to residents of British Columbia who have died of AIDS-related illnesses.

Championed by HIV physician Dr. Joss de Wet, the memorial was a decade-long journey that touched the lives of many individuals throughout the province. In 1994, after seeing many of his patients and friends die from AIDS, Dr. de Wet began a campaign to have the memorial built. Once Sunset Beach was selected as a location, a competition was held to determine the design. From more than 70 submissions, the steel ribbon with a view of English Bay was chosen. Construction was completed in 2004.

The undulating steel structure has a warm, rusty patina, from which the names of those who have died are cut. Every day, names on the memorial are adorned with flowers and notes are slipped between the letters—tokens of love, remembrance and evidence of how much people are missed. Artist Bruce Wilson dedicated this landmark “to the memory of those lost to HIV/AIDS, to the caregivers who eased their passing, and to those who live with the presence of their absence.”

Positive Living BC hosts an annual candlelight vigil here, where the sound of the nearby ocean serves as a soundtrack.

A tour of AIDS
memorials from
coast to coast

Gone

but Not Forgotten

BY MELISSA EGAN,
BARB PANTER
AND DEBBIE KOENIG

Parc de l'espoir (Park of Hope)

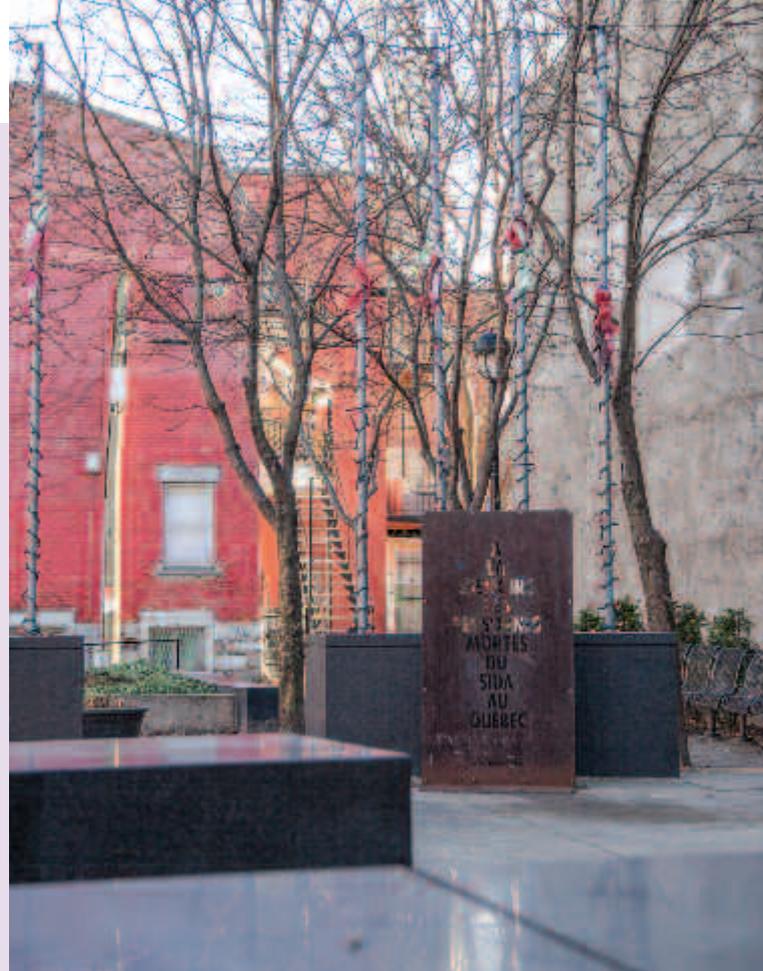
Location: St. Catherine and Panet Streets, Montreal

Artist: Marc Pageau

On December 1, 1990, an ACT UP (AIDS Coalition to Unleash Power) Montreal demonstration ended with 1,400 black ribbons being tied to tree branches in an empty lot in Montreal's Gay Village, to commemorate the lives of those who died from AIDS in Quebec. Days later, the City proceeded to remove the ribbons. That January, people tied ribbons in all the colours of the rainbow on those same trees, with the names of people who had died of AIDS written on them. Teddy bears and other objects of personal significance were placed at the foot of the trees over the course of several months. This marked the start of a campaign to claim the site as an AIDS memorial park.

Years later the battle was finally won when the municipality agreed to designate it a commemorative park: In the summer of 1996, the park was officially inaugurated *le Parc de l'espoir* (Park of Hope).

Large blocks of polished black granite (symbolizing death) are juxtaposed against the garden (which represents life). On sunny days, people congregate on the blocks to watch the crowds on St. Catherine Street flow by.



The AIDS Memorial

Location: Cawthra Park, Toronto

Designer: Patrick Fahn

Landscaping: Alex Wilson



The AIDS Memorial in Toronto was the brainchild of a group of gay men led by AIDS activist Michael Lynch. In 1988, Lynch founded a volunteer committee to make his vision a reality. At first, a temporary memorial was erected each year for Lesbian and Gay Pride Day. Two years later a design competition was held for a permanent memorial, which opened in 1993 outside the 519 Community Centre.

The memorial provides a space for everyone touched by AIDS to grieve, remember and celebrate those who have died from AIDS-related illnesses. Fourteen concrete triangular pillars, arranged in a semi-circle, hold stainless steel plates on which the names of those who have passed are engraved. Patrick Fahn designed the memorial so that there would be room for new names to be added.

Every June a vigil is held in the park and the names of those who died that year are added. Sadly, the names of both Michael Lynch, who died before the monument was completed, and Alex Wilson, who designed the landscaping around the structure, are now engraved among them.

Poems by Michael Lynch and Shoshanna Addley welcome visitors to the memorial. Addley's poem pays tribute "To Those Unnamed":

Our strength, though withered and sapped,
regenerates here.
Each name on each standing stone remarks
thousandfold
upon those unmarked from sea to sea...

Newfoundland and Labrador AIDS Memorial

Location: ACNL, St. John's, Newfoundland

Artist: Don Short

Artist Don Short designed and created this multimedia panel with the help of staff and volunteers at the AIDS Committee of Newfoundland and Labrador (ACNL), where it is housed. Unveiled in the summer of 2010, it pays homage to the lives of people with HIV who were either ACNL clients or volunteers at some point since the AIDS service organization opened its doors in 1988. In Short's words, the memorial "pays tribute to the courage of individuals who faced AIDS head-on, despite the barriers, stigma and isolation they often confronted when fighting the disease."

The sculptural montage consists of a wooden base with a faux finish and a painting of a beachside AIDS memorial. Around the painting, plaques hold the names of people who have lost their lives to AIDS-related illnesses. A row of



pictures and descriptions along the bottom highlight memorials that have taken place in Newfoundland since the epidemic began. Running across the top, these words sum up the spirit of the work:

We light a candle for those we have lost.
They have shown courage in the fight against
HIV and AIDS.
Their light cannot be extinguished.

The Canadian AIDS Memorial Quilt



Location: National project; stewardship transferred from the NAMES Project in Halifax to the Canadian AIDS Society in Ottawa

The AIDS Memorial Quilt was conceived of in San Francisco in 1985. The first time it was displayed—in October 1987 in Washington, DC's national park, the National Mall—its 1,920 panels covered an area larger than a football field. This inspired an outpouring of interest and support and led 35 countries to create their own quilts. Today, the combined quilts form the largest community art project in the world.

The Canadian AIDS Memorial Quilt was born in 1989. It now consists of more than 600 3 × 6-foot panels, each one stitched in memory of someone who has died of an AIDS-related illness. Groups of eight panels are sewn together to form 12 × 12-foot sections. When displayed in its entirety, the Canadian quilt takes up more than 18,000 square feet, honouring the lives of those who died while also drawing attention to the scale of the epidemic. The colourful designs and loving personal messages pay tribute to people young and old, from every walk of life and all parts of the country. The quilt evokes powerful emotional responses from those who see it.

The Canadian panels can all be viewed online at www.quilt.ca. The site also describes how you can create and contribute a panel of your own. +

We would like to acknowledge the countless ways that people in cities, towns and rural areas across the country have memorialized their loved ones who have died as a result of HIV/AIDS. If you

have a photo or story of a memorial that you would like us to post online, email us at contribute@positiveside.ca

In recent years, people have also created online memorials to pay tribute

to their lovers, friends and family members. www.aidsmemorial.info is a catalogue of permanent memorials, digital memorials and ceremonies from around the world.



Since 1984, an estimated 523 babies have been born HIV positive in Canada. What's it like navigating school, a social life and health care for a child born with the virus?

BY SHARI MARGOLESE

GROWING

ILLUSTRATION BY
JOSH HOLINATY

UP

WITH HIV

Shortly after the birth of my only child in 1993, I was diagnosed with HIV. Six weeks later, my son received his diagnosis: HIV positive. Those were the dark days of HIV and the prognosis of babies born with the virus was grave—many did not survive beyond their second birthdays. As a mother, I can tell you that those early days were very scary. Our family is one of the fortunate ones to have survived until potent antiretroviral medications became available.

HIV can pass from an HIV-positive woman to her child during pregnancy, during delivery, or after giving birth if she breastfeeds her newborn. Thanks to effective treatments and advances in care, the risk of transmission from mother to child (vertical transmission) has dropped dramatically in Canada, from as high as 33 percent in the early '90s to less than two percent today. This reduced risk, coupled with the fact that HIV has become a chronic manageable condition for people who can get care, has led many more people living with HIV to have children.

The issues faced by children growing up with HIV are varied and complex. First and foremost, they are kids and young adults subject to all of the joys and challenges that other young people experience growing up—from the terrible two's to cramming for high school exams, from finding a first job to going on a first date. But over and above the usual bevy of growing pains, they have additional concerns, such as health issues and deciding if and how they will disclose their HIV status at school and to their

family and friends. Of course, these are issues that adults living with HIV face, too, but the context is different. As my own son so wisely informed me, "Mom, I know you know what it is like to be a teenager and I know you know what it is like to have HIV...but you have no idea what it is like to be a teenager with HIV." Today, thanks to the advancements in HIV treatment that have prolonged my son's life and the lives of many (but sadly not all) of his peers, I am humbled and grateful to be able to help their voices be heard, as they share stories of strength, fear, love and hope.

"YES, I AM BRAVE." These are the words of 10-year-old Sage as she describes her decision to talk about growing up with HIV. Sage chose not to use her real name because her friends don't know that she has HIV. "My mommy says it's our secret because other kids can be mean," she says. As a pre-teen, Sage has known for only a short time that she is HIV positive. "I don't really know anything about HIV yet. I do know I have special blood though." She says that her doctors are teaching her to understand things. She bashfully admits, "I'm shy, so I don't ask many questions." Fortunately, Sage's mom, who is also HIV positive, accompanies her to every hospital visit and asks the doctors questions in front of her daughter. Sage likes her doctors, who she says "are nice and care about me."

Because Sage's mom tested negative for HIV when she was 12 weeks pregnant, she did not receive treatment in

time to prevent the virus from being transmitted to her daughter. Then Sage was hospitalized with pneumonia just days before her first birthday. “She was greyish purple and her life was leaving her body,” recalls Sage’s mom. An HIV test was requested and three weeks later, the family was shocked to learn that Sage and her mom were HIV positive, and that her mom had seroconverted while pregnant. It is cases like Sage’s that lead some advocates to call for ongoing testing during pregnancy.

SAGE, WHO HAS REMAINED STABLE

on her first regimen of Kaletra (lopinavir/ritonavir) and Combivir (AZT/3TC), says, “I have taken meds my whole life...I don’t like taking them because they make me feel like I’m going to barf.” She copes by drinking lots of water. She admits that sometimes she forgets to take her meds, but her mom reminds her. Now in grade 5, Sage is already a strong advocate for her own health care: “I want them [the meds] changed to something that won’t upset my stomach. I’m going to tell the doctor.”

Like Sage, 19-year-old Josh began taking antiretroviral therapy before his second birthday. Whereas Sage was born in the era of combination antiretroviral therapy (ART) and has not developed drug resistance, Josh was born early in the epidemic, when AZT monotherapy and other less potent therapies were the only options. “There were a lot of pills, they were hard to swallow and they tasted bad,” he recalls of some of the more difficult-to-take early treatment regimens. As a result, his HIV is resistant to two classes of drugs, nukes (NRTIS) and non-nukes (NNRTIS). Now a young man, he has faced serious challenges with medication.

Josh has also encountered disclosure dilemmas when it comes to his meds. When he was 10, he wanted to have sleepovers with his friends. Although he was able to do this, he had to make sure he either took his pills before leaving home or packed them in a bottle and discreetly took them with water from the tap while he brushed his teeth. “Other people never asked questions because no one ever saw me take my meds,” he says. “I kept it really low-key.”

In the recent past, “pill fatigue,” a desire to avoid revealing his meds at work and partying contributed to a less-than-perfect adherence record. “It made me feel more normal and in control of my life to not take them,” Josh says. “It’s hard to drink alcohol and take HIV meds.” His inconsistency with taking meds created serious health problems, including a low CD4 count, an increasing viral load and a low platelet count. “I didn’t know it

“MOM, YOU HAVE NO IDEA WHAT IT IS LIKE TO BE A TEENAGER WITH HIV.”

was killing me to not take them,” he says in retrospect. More recently, Josh switched to taking his pills once daily. Because this is relatively easy, his adherence has improved, his CD4 count has increased and his viral load is now suppressed. At 19, Josh’s options for HIV therapy are limited, emphasizing the need to discover new ways to treat HIV.

A budding advocate for youth living with HIV, Josh joined a panel of experts at the International AIDS Conference held in Washington, DC, in July 2012, to discuss his life growing up with the virus. Studies presented during this session indicate that there

may be some adverse effects of ART on growing children. Dr. Jason Brophy, a pediatric infectious diseases specialist at Ottawa’s Children’s Hospital of Eastern Ontario, agrees and is currently conducting studies to look for kidney and bone health problems and treatments for high lipids among his young patients. Some studies have shown that among children living with HIV, there is a higher incidence of delayed motor and language skills and attention deficit disorder (ADD). Other studies have shown that many adolescents with HIV experience depression and other mental health issues.

During his session in Washington, Josh described how the learning disability dysgraphia (a deficiency in the ability to write) and ADD have been issues in his life. He rhetorically asked fellow panelists: “What causes these problems: HIV or the meds?” His query was astute; it’s exactly what researchers hope to answer regarding the mental health and physical and cognitive development of growing children.

Despite these health issues and the fact that children can be quite ill when initially diagnosed, Dr. Brophy says that once they are in care and on treatment when it’s deemed necessary, “the vast majority of children with HIV in Canada are the picture of health.”

AS SCIENCE CONTINUES TO LOOK FOR ANSWERS to some of these issues, life goes on for children growing up with HIV.

Both Sage and Josh have known about their HIV status from an early age and both are still learning about how HIV affects them at different stages of their lives, how to handle secrets and how to manage their health and emotions along the way. “I have known all my life that I have HIV,” Josh says. “But I didn’t really know what it meant until I was about 13. That’s when I learned that HIV was an STI (sexually transmitted infection), and that I had an STI, and I hadn’t even had sex yet.” Josh describes the proverbial sex talk as “not the average

If you are the parent of an HIV-positive child and you’re looking for more info, check out Chapter 16 from *Managing Your Health on “Children and HIV.”* It looks at how HIV affects children differently, steps to take to keep HIV-positive children healthy and how to talk to kids about HIV at different ages. View the chapter online (at www.catie.ca) or order a free copy of the guide through CATIE’s Ordering Centre (www.catie.ca or 1.800.263.1638).

RESOURCES FOR POSITIVE YOUTH

MEDICAL SERVICES AND ASOS

BC Women's Hospital, Oak Tree Clinic (Vancouver)

HIV clinic for women and children
www.oaktreeclinic.bc.ca

Children's Hospital of Eastern Ontario, HIV Program (Ottawa)

www.cheo.on.ca/en/referringhivprogram

Hospital for Sick Children, HIV Clinic (Toronto)

HIV clinic for children and teens
www.sickkids.ca/go-positive

PYO—Positive Youth Outreach (Toronto)

Peer program that offers social and peer support, a monthly learning series and service referrals
www.positiveyouth.com

Ste. Justine's Children's Hospital, HIV Clinic (Montreal)

www.chu-sainte-justine.org/HIV

The Teresa Group (Toronto)

Focuses on the needs of families affected by HIV
www.teresagroup.ca

YouthCo (Vancouver)

HIV and hep C info for youth in British Columbia
www.youthco.org

OVERNIGHT CAMPS

Camp Positive Family (The Laurentians, Quebec)

andreh@ccs-montrea.org

Camp Moomba (Gibsons, BC)

www.campmoomba.com

STORIES AND INFO

Bye-bye, Secrets

Hopes, Wishes and Dreams

Books of art and writing by children living with HIV in their family.

Know it! and Do it!

Guides published by the Canadian Aboriginal AIDS Network for Aboriginal youth.

The Positive Side

"From the Front Lines: Youth blaze the trail" (Spring/Summer 2010) – about youth groups taking the lead in HIV treatment, prevention, education and activism

"The Truth About Youth" (Summer 2007) – about what's needed to better serve HIV-positive youth

sex talk" and says he was "freaked out" to learn that he would one day be discussing his HIV status with sex partners.

Fortunately, Josh has mostly had positive experiences with disclosing and feels good knowing that his longtime friends support him. Before he shared his status with his friends, Josh would respond to questions about his health with partial truths but rarely the whole story. Then, when he was 14, he felt the need to tell somebody. On their daily walk home from school, Josh simply came straight out and told his friend. "She acted surprised, gave me a consoling look and asked if I was OK." After assuring her that he wasn't about to die, Josh explained that he was born with HIV and offered to answer any questions she might have. That was six years ago and, while they don't see each other often, Josh and his confidante keep in touch and will always have a special bond.

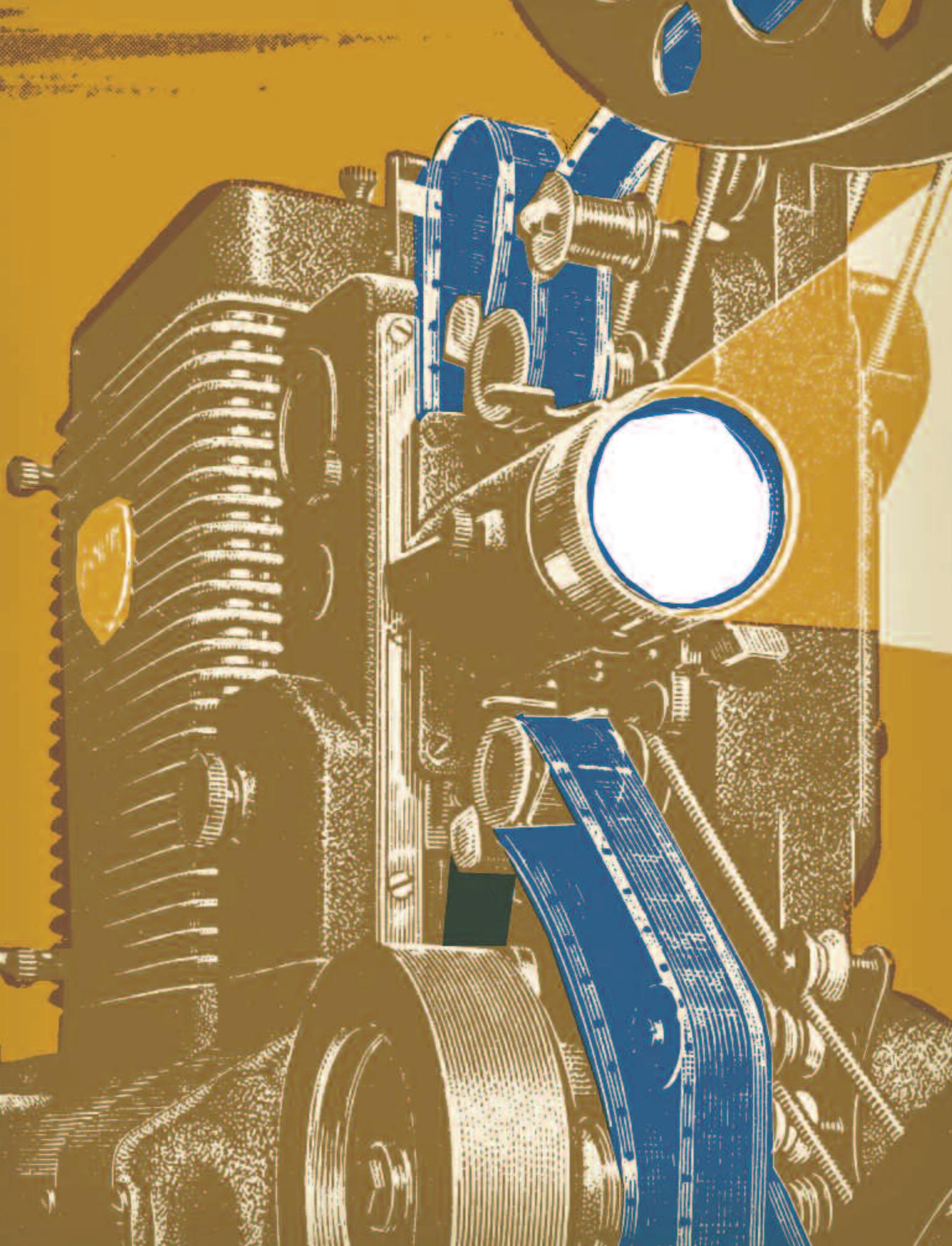
In recent years Josh has shared his status with most of his close friends, all of whom are supportive. When he thinks about disclosure, he follows the wisdom of a slightly older peer who advised him: "If somebody doesn't like you because you have HIV, fuck them!" When he's feeling frustrated or angry because of unresolved issues, he says, "I just kind of handle it through chilling with my friends—I find that peaceful."

As for Sage: "I know a lot of people, but I don't have a lot of friends. I am too shy." She does, however, like to talk about her friends at Camp Moomba (which Josh also attended) and a very special counsellor in whom she confided about her HIV status. Moomba is a summer camp in British Columbia where kids from across Canada impacted by HIV can connect and support each other. Friendships formed there can last beyond camp years, as they have for Josh. The experience is invaluable. Sage says that "the only other kids I know with HIV are at Camp Moomba."

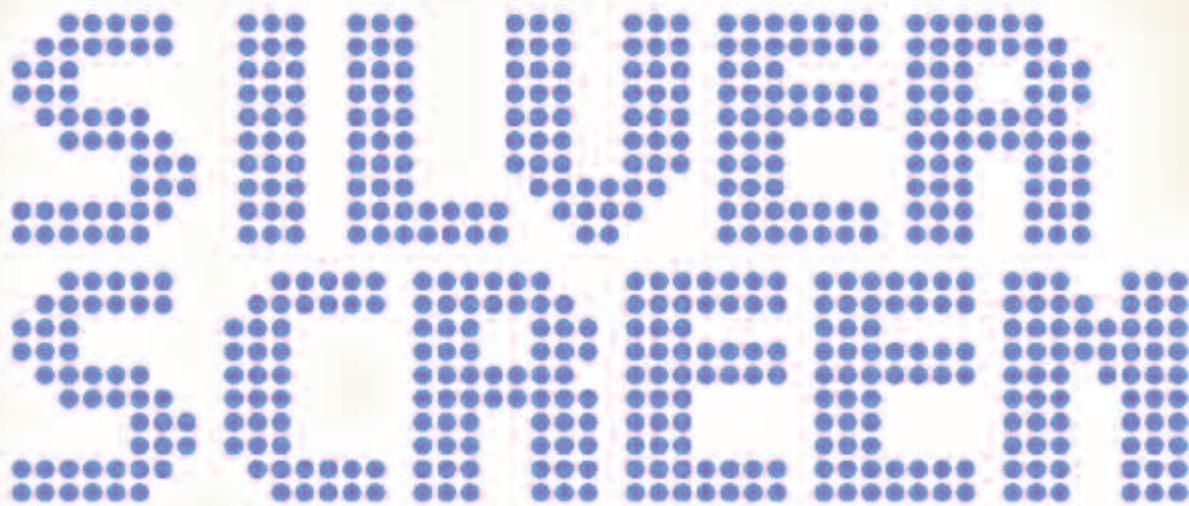
BOTH JOSH AND SAGE HAVE HOPES and dreams for the future. Sage, who likes "everything about school," hopes to someday become a veterinarian. "I like riding my bike and shopping," she says, giggling, "and shoes and clothes." She looks to her mom, a strong advocate for positive Aboriginal women in Manitoba and across Canada, as a role model and wishes she could travel with her to learn and teach about HIV and meet other HIV-positive children. "I would like to be like mommy," she says proudly. Her mom, like me, hopes to affect attitudes so that her daughter can live a more "normal" life. "There is a lot of ignorance around us," says Sage's mom. "Because of the stigma in our community, we have to remain secretive."

Sage, who loves her community, hopes to someday become a jingle dress dancer (participate in the jingle dress dance at a powwow); ironically, the colourful, decorated dress is considered a healing dress. As for Josh: "My mom always told me to follow my bliss." For him, that means one day opening his own auto shop—and anything to do with the outdoors. Both Josh and Sage hope to someday have families of their own. They also share two dreams: that the day will come when they won't have to take meds anymore and, of course, that a cure is found. +

Since shortly after her HIV diagnosis in 1993, Shari Margolese has advocated for people living with HIV to ensure that they have an opportunity to be meaningfully involved in the research, programming and policies that impact their lives. Shari is a leading advocate for reproductive justice for people with HIV and a regular contributor to *The Positive Side*.



AIDS ON THE



Wondering what DVD to rent? Or thinking about hosting a movie night? **Darien Taylor** highlights a few AIDS-related movies worth watching.

"If you know your history, then you would know where you coming from."

—Bob Marley, *Buffalo Soldier*

Though we come from diverse backgrounds and life experiences, people living with HIV all share a common history: the history of the AIDS epidemic. But some 30 years into this epidemic, many of us scarcely know the stories that serve to bind us together as a community. Like the stories of most stigmatized identities, our shared history is difficult, painful and challenging, but it also speaks to the strength and resilience of people with HIV.

Movies offer us one way to connect to those stories and a window into the historical trajectory of AIDS. So, as the weather grows colder, why not gather together your friends with HIV and the people who love and support you around the modern campfire—the TV screen? Grab a warm blanket and a big bowl of popcorn and spend an evening learning the stories that unify us and make us proud to be who we are. A monthly movie night exploring the history of HIV could make for a cozy, inspiring, even therapeutic way to while away the cold winter.

The beginning is as good a place as any to start your viewing. Two entertaining and informative films that deal with the origins and early history of AIDS are the docudrama ***And the Band Played On***, based on the 1987 best-selling book of the same name, by American journalist Randy Shilts, and ***Zero Patience***, an AIDS musical by maverick Canadian filmmaker John Greyson. *And the Band Played On* presents a scathing critique of government and medical responses to the emergence of AIDS. It sets out the facts, while *Zero Patience* assumes that you know these facts and weaves a campy Canuck yarn that turns these "facts" on their head.

And the Band Played On was first shown at the Montreal World Film Festival in 1993, then broadcast on HBO and later released in movie theatres. It takes us back to the early 1980s, as gay men in major American cities are beginning to die of an unknown illness. Doctors, politicians and gay leaders grapple, with varying degrees of competence, with the disease that would eventually become known as AIDS. Of particular interest is the film's account of the ugly competition between French and American research labs to claim the dubious distinction of discovering the virus that causes AIDS—a competition that unfolds as the death toll mounts. The film also documents the

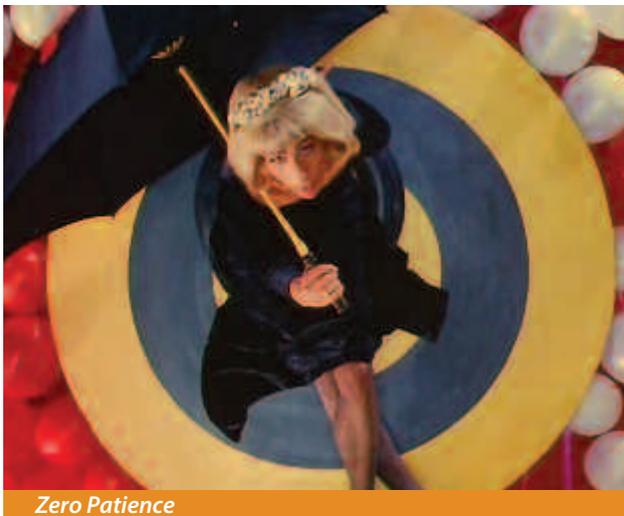


And the Band Played On

attempts by public health officials to close gay bathhouses in San Francisco, in order to contain the spread of HIV, and the subsequent resistance from gay community leaders who see this as an attempt to control their lives. *And the Band Played On* introduces us to French Canadian flight attendant Gaetan Dugas, whose sexual exploits became a sort of gay urban legend in the late 1980s. As a result of Shilts' investigative journalism into the origins of AIDS, Dugas became known as "Patient Zero," the man who allegedly introduced AIDS to North America. (It is now known that this wasn't the case.)

In addition to its sharp rebuke of politicians and AIDS researchers, this early Emmy Award-winning film brought Hollywood star power (including Matthew Modine, Lily Tomlin, Alan Alda and Richard Gere) to bear on what was still a relatively taboo subject. Recall that then-U.S. President Ronald Reagan did not publicly say the word AIDS until 1987, the year Shilts' book was published—a full six years after people first became aware of the disease in the U.S. and after 21,000 Americans had already died of AIDS.

Canadian filmmaker John Greyson's surreal musical *Zero Patience* premiered at the Toronto International Film Festival in 1993—the same year that *And the Band Played On* premiered in Montreal—



Zero Patience

and went on to receive much recognition in Canadian cinema and queer theory circles. Its plot is delightfully convoluted, involving time travel, a buoyant soundtrack by Glenn Schellenberg and a cameo role as Miss HIV for Michael Callen, an early American AIDS activist who championed the rights of people with HIV. The film's title alludes to "Patient Zero" Gaetan Dugas, whose reputation, tarnished in *And the Band Played On*, is rehabilitated by Greyson, who portrays his engagement in early AIDS research as helping to establish AIDS as a sexually transmitted disease preventable through safer sex. The title also alludes to the urgency of AIDS activism. When *Zero Patience* came out, Greyson and others involved in the film said: "We wanted to explode the opportunistic myth of Patient Zero...[and] celebrate the courage and sass of an international AIDS activist movement that has tirelessly fought for the rights of people living with AIDS."



Philadelphia

Jonathan Demme's *Philadelphia* is a must-see film: It was the first mainstream Hollywood movie about AIDS to reach a broad audience. *Philadelphia* chronicles the final days of gay lawyer Andrew Beckett (played by Tom Hanks, who won an Academy Award for his performance), who is unjustly fired from his law firm when his health begins to fail as a result of AIDS, and the dawning sympathy and politicization of his attorney Joe Miller (played by Denzel Washington), whom he hires to defend him against this unlawful dismissal. Though Beckett wins his case and receives loving support from his partner, family and friends, there is no happy ending to *Philadelphia*, conceived of and brought to the screen in the early 1990s, when AIDS still conveyed a death sentence. Attending this film when it was first released, I recall that sobs could be heard throughout the darkened theatre as this film drew to a close—I was certainly trying hard to compose myself as the lights went up.

In addition to its North American premiere at the Toronto International Film Festival in 2005, Nova Scotia resident Thom Fitzgerald's film *Three Needles* was shown at the 2006 International AIDS Society



Three Needles

Though this film sometimes sacrifices the facts about HIV for the sake of a more coherent plot, it is important in its efforts to engage with HIV issues beyond North America.

Viewing these four films—available at your local video store or on Netflix or Amazon—may inspire you to check out other movies about HIV. Last year, two major movies about AIDS, **United in Anger**, a history of the AIDS activist group ACT UP (AIDS Coalition to Unleash Power), and **Vito**, about activist/writer Vito Russo, screened in theatres. And in Montreal, there's the HIV/AIDS film festival VIHsion. Online you can check out some of the more than 100 fascinating interviews with members of ACT UP New York that make up the **ACT UP Oral History Project** (www.actuporalhistory.org).

Know your history: It will make you proud. +

Conference in Toronto. Starring Stockard Channing, Olympia Dukakis, Sandra Oh, Lucy Liu and Chloë Sevigny, this ambitious film tells three stories of HIV transmission worldwide. In rural China, the black-market trade in blood results in the spread of HIV throughout a small village. In South Africa, the myth that sex with a virgin can cure AIDS has dire consequences in an orphanage. And in Montreal, a second-rate porn star searches for a way to pass his mandatory HIV test despite the fact that he is HIV positive.

Darien Taylor is CATIE's former Director of Program Delivery. She co-founded Voices of Positive Women and is the recipient of a Queen Elizabeth II Diamond Jubilee Medal, awarded to Canadians who have demonstrated an exceptional commitment to HIV/AIDS work. Darien has been living with HIV for over 20 years.

The sister article "Le sida dans le cinéma" in *Vision Positive* explores HIV in French cinema.

AIDS GOES TO THE MOVIES

Here is a short list of the features and documentaries made in North America since the start of the epidemic:

AIDS: No Sad Songs (1985) – First major Canadian doc made about what was at the time a taboo topic. Explores the social and emotional effects of AIDS on people living with HIV and their loved ones.

Parting Glances (1986) – Indie film about a gay couple in New York City. One of the first American feature films to portray AIDS.

Doctors, Liars, and Women: AIDS Activists Say No to Cosmo (1988) – Award-winning short that documents AIDS activists taking over the editorial offices of *Cosmopolitan* magazine after it ran an article claiming that a straight woman could safely have unprotected sex with an HIV-positive man.

The Ryan White Story (1989) – Made-for-TV movie based on the true story of Indiana teenager Ryan White. In 1984, White became infected with HIV from contaminated blood treatment for his hemophilia and fought for his right to attend school after being expelled because of his infection.

Common Threads: Stories from the Quilt (1989) – Academy Award-winning doc about the lives and deaths of people commemorated in the AIDS Memorial Quilt.

And the Band Played On (1993) – Docudrama on the early history of AIDS, based on the bestselling book by Randy Shilts.

Zero Patience (1993) – John Greyson's AIDS musical about how the media, government and scientists responded to AIDS in the '80s.

Philadelphia (1993) – First mainstream Hollywood movie about AIDS. A successful young gay lawyer living with HIV takes his employer to court for wrongful dismissal.

Angels in America (2003) – A six-hour HBO miniseries adaptation of the Pulitzer Prize-winning play about the intertwined lives of people affected by the growing AIDS epidemic. Set in New York City during the Reagan administration.

Three Needles (2005) – Three stories about the AIDS epidemics in South Africa, China and Canada, from Halifax-based writer and director Thom Fitzgerald.

We Were Here (2011) – Doc in which four gay men and one straight female nurse share stories about how they were impacted by the epidemic in San Francisco.

Positive Women: Exposing Injustice (2012) – Four HIV-positive women (including Claudia Medina, see profile on page 8) talk about the impact of Canadian laws that criminalize HIV non-disclosure.

United in Anger: A History of ACT UP (2012) – Doc about the direct actions of ACT UP (AIDS Coalition to Unleash Power) to combat corporate greed, social indifference and government neglect.

The Normal Heart (pre-production) – The book and play written by activist Larry Kramer about his efforts to raise awareness about AIDS in the '80s, to be turned into a feature film.

If you have a favourite flick you'd like to add to this timeline, email us at contribute@positiveside.ca and we'll add it to the list online.





A good night's sleep is an elusive dream for many people living with HIV. Former insomniac **David Evans** tells us how to hit the hay and sleep soundly.

Sleep Tight

Before starting HIV medication, flight attendant Terry Wong never had a problem with jet lag or sleeping. “I could sleep just about anywhere anytime,” he recalls. “If I was tired and there was a bed, I would pass out and be snoring in minutes.” Diagnosed with HIV 15 years ago, Terry’s health took a nosedive seven years later—his weight dropped from 175 to 109 pounds and his CD4 count plummeted to zero. He was hospitalized for a week and started HIV treatment immediately. The meds saved his life but when combined with flying, they made getting some shut-eye a thing of the past.

Once on treatment, Terry started to gain weight and his health steadily improved, allowing him to return to work shortly afterwards. That’s when the insomnia hit: “When you’re switching time zones regularly, juggling your sleep and medication schedule without missing a dose becomes very complicated.” At first, he took his meds with lunch when in Vancouver. That meant that from his regular destination, Hong Kong, he had to take them at 3 am. He would call the hotel front desk to order a wakeup call and room service for that time, so he could take his pills with food. This threw his whole sleep schedule into a state of disarray. “My sleep was terrible,” he says. “I couldn’t sleep at all. It was the darkest period of my life.” In addition to the headaches and diarrhea he experienced as side effects from the medication, Terry constantly felt groggy, irritable, weak and depressed. After several years of this, he suffered a nervous breakdown.

Like Terry, many people living with HIV experience sleep problems. These can occur at any stage of HIV infection.

Upwards of 75 percent of people report sleep issues on a regular basis. Some have difficulty falling asleep, some have trouble staying asleep (due to poor-quality sleep or frequent nightmares) and others wake up too early. Then there are people, like Jasmine, who have the misfortune of experiencing many or all of the above.

For years, when Jasmine went to bed at night she found herself wide awake, staring at the clock for hours on end. “If I fall asleep now,” she would calculate, “I’ll get only five hours of sleep...now only four hours...”—a vicious circle of insomnia and anxiety. Once she finally nodded off, she had problems staying asleep and achieving a deep sleep. As a result, she awoke each morning feeling sluggish. “It was very frustrating because it took a long time to get my engine up and running, ready to start the day.” When she started working night shifts, the problem only got worse. “When I’m sleep-deprived, I’m not as quick with my thinking or speech. I’m off my game and have to push myself to get stuff done.”

KEY TO QUALITY OF LIFE

Sleep is vital to our health and well-being: It can help regulate our hormones, reduce stress, manage our weight and improve immune function. As many of us know all too well, a lack of sleep can impair our memory, affect our ability to focus, deprive us of energy and leave us more susceptible to infection. Over time, this can lead to depression and anxiety, which can make it even harder to sleep.

Poor sleep can also make it more challenging to adhere to a pill-taking schedule—something that is crucial for

successful HIV treatment. Dr. Julio Montaner, director of the BC Centre for Excellence in HIV/AIDS, stresses the importance of identifying sleep disturbances caused by HIV treatment early: “It is my job to be proactive and monitor for potential side effects. The more I can support people’s HIV treatment and help them be free of side effects, the more they are likely to be able to adhere to their medication regimen. Patients should be encouraged to bring up issues early as opposed to suffering in silence.”

GETTING TO THE ROOT OF THE PROBLEM

Identifying the nature of a sleep problem and figuring out what’s behind it is step number one, best done in conversation with a knowledgeable doctor or nurse. For people with HIV, the root cause tends to be one or some combination of the following:

- HIV itself – HIV-infected cells in the brain, which produce neurotoxins and chemical signals that may impair the sleep of some people.
- medications – such as efavirenz (Sustiva, also found in Atripla) used to treat HIV, interferon used to treat hepatitis C and other drugs prescribed for HIV-related illnesses.
- mental health issues – such as depression and anxiety.
- alcohol and drug use – heavy drinking or using drugs, especially stimulants such as cocaine, speed and ecstasy.

Other causes of sleep problems can include changing hormone levels (for example, high or low levels of thyroid hormone, changes in estrogen levels during menopause and declining levels of free testosterone), calcium and/or vitamin B₁₂ deficiencies, and infections (including a cold or flu).

After years of tossing and turning, Jasmine was determined to pinpoint the cause of her problems. The efavirenz she was taking as part of her HIV treatment was a possible culprit but not an obvious one because she had been taking the medication for years without side effects. The vivid dreams, nightmares and insomnia that some experience when taking this drug normally occur when people start the medication and tend to diminish or go away with time. But when Jasmine switched HIV drugs, it was confirmed: “My sleep was much better within days. It was definitely one of the things that had been causing me problems.” Working nights was another—but more about that later.

HOW SLEEP WORKS

When we sleep, we alternate between periods of non-rapid eye movement (NREM) and rapid eye movement (REM). One cycle takes about 90 minutes to complete and typically consists of five stages. Stage 1 is a drowsy sleep that usually lasts five to 10 minutes. During stage 2, our muscle activity diminishes and body temperature drops as we lose consciousness. Stages 3 and 4 are characterized by a deep, restorative sleep when the growth hormone responsible for cellular regeneration and muscle development is released. Stage 5 is REM sleep: Our eyes move back and forth rapidly and dreaming occurs as a result of increased brain activity.

People’s sleep needs vary, but most of us need seven to nine hours per night. This is known as “sleep architecture”—

the total time asleep and the duration of NREM and REM periods. A good night’s sleep depends on the right balance between these different stages. Various factors, such as light, stimulants and poor sleep hygiene, can disrupt this balance. The goal for insomniacs is to restore this balance.

STRATEGIEZZZ...

Finding the solution that’s right for you might not happen overnight, but persistence and trying different strategies with the support of a knowledgeable doctor can go a long way. Here are some suggestions:

Stay away from the light! Light at night is one reason why many people don’t get enough sleep. Our circadian rhythms respond to the light and dark around us. Derived



from the Latin words *circa* and *diem*, meaning “around a day,” the term describes our sleep/wake pattern, hormone release, body temperature and other bodily functions over a 24-hour period. In the past, people would wake up with the sun and go to bed with the moon, but the lightbulb changed all that. Bathed in artificial light long after the sun has set, many of us find our patterns out of sync with our body’s biological clock. And our sleep suffers from it. (Research suggests that it may also contribute to cancer, diabetes, heart disease and obesity.)

In the absence of light, our bodies release the hormone melatonin, which helps us get to sleep. When we are exposed to light, the release of melatonin is suppressed and makes sleep more difficult. Any kind of light has this effect, but the “blue light” emitted from electronic devices makes it particularly easy to disregard the body’s readiness for sleep. That is why it is important to sleep in total darkness. The best way to achieve this is with a specialized window covering that blocks outside light (a “blackout blind”), but a sleep mask is effective as well. It is also important to eliminate all sources of light in the bedroom, including all

blinking lights or display screens, by turning them off, taping over them or removing them altogether.

Cut back on caffeine. Caffeine is the world's most consumed psychoactive (mind-altering) drug and can be found in coffee, tea, soda, energy drinks and chocolate. Coffee is the most popular choice, with 65% of Canadians drinking an average of 2.8 cups per day. With its ability to boost energy, increase alertness and improve mood, it is a simple solution for a quick pick-me-up. Unfortunately, it can also disrupt sleep patterns. A central nervous system stimulant, caffeine increases the heart rate, core temperature and blood pressure, which, in turn, can increase the time needed to get to sleep, decrease sleep duration and limit your time spent in deep sleep.

Caffeine has a half-life of five hours—that's how long it takes to metabolize half the amount circulating in your system. So if you drank a 12-oz coffee containing 260 mg of caffeine at 8 am, there would be 33 mg of caffeine left in your system by 11 pm, which is more than enough to disrupt sleep.

Want to sleep better? Here are some caffeine tips:

1. Limit your consumption after 10 am.
2. Reduce your overall intake—withdrawal symptoms like headaches can occur within 48 hours after you stop and can last two to nine days. If this happens, you're on the right track!
3. Decaf does not mean caffeine-free—that same coffee still has 20 mg of caffeine.

Check your meds and supplements. Review with your doctor all the medications and supplements you're taking to determine if any of them could be to blame. Dr. Montaner points out that it's essential to find the medication regimen best suited for each individual—one that is highly effective and can be taken long-term without disrupting daily activities. "Antiretroviral therapy is a lifelong proposition," he says. "This is a marriage that has to work."

Some cough and cold medicines, Gravol, antihistamines and other over-the-counter remedies are used to help people sleep; however, these can exacerbate underlying sleep problems and, when used over time, can lead to anxiety and depression.

Get your vitamins and minerals. If you have a calcium or vitamin B₁₂ deficiency, taking a B-complex vitamin along with calcium and magnesium supplements can help your muscles relax.

Seek peace of mind. If an underlying emotional issue is keeping you awake, seeing a psychologist, counsellor or other health professional can help with depression, anxiety and other issues. A healthy support system and meditation, yoga or acupuncture can also help you rest easier.

Avoid sleeping pills. Sleeping pills offer a short-term solution for some people, but using them over the long-term can create dependency, negatively impact sleep architecture and make you feel drowsy the next day.

You are getting sleepy... A bedtime routine is essential for quality rest. We know its value for children, so why do so few adults have one? A consistent bedtime routine, which ideally starts 60 minutes before hitting the hay, helps

you prepare for sleep by giving your day closure, quieting your mind and relaxing your body. A few pointers:

1. Turn off all electronics.
2. Dim the lights to start the release of melatonin.
3. Listen to soft music.
4. Set the temperature in your bedroom between 16°C and 20°C and make sure the room is well ventilated.
5. Have a hot bath. The rapid drop in body temperature that occurs when you get out will help you fall asleep.
6. Spend time reading, stretching or meditating.
7. Try some deep breathing in bed: Inhale for five seconds, hold for two seconds, exhale for five seconds. Repeat until asleep.

When Jasmine gets home from her night shift, around 3 am, she says it's not as easy for her to "do the whole wind down/relaxation thing, the way a person who works regular hours would." Instead, she finds that putting on a pair of blue-light-blocking glasses for two to three hours before bed helps; in fact, she swears by it. She starts wearing them toward the end of her shift and doesn't remove them until she's in bed with the lights off. She also makes a point of exercising (cross-training, kick-boxing, roller-blading or biking) during the day, which helps with her sleep. Although working nights isn't easy, her modified regimen of anti-HIV drugs combined with these lifestyle changes has helped.

As for Terry, after years of trial and error, he now has a roster of strategies that have turned his formerly sleepless nights into long, uninterrupted deep sleeps. He tweaked his medication schedule (he now takes his meds at 7 or 8 pm in BC and at 9 or 10 pm in Asia) so that he no longer needs to call for room service in the middle of the night. He consulted with a dietitian who recommended light meals (nothing greasy) before a flight to reduce jet lag. When travelling, he routinely orders hotel turndown service, to make sure his room is completely dark at bedtime (he also tapes the curtains to the wall to make extra sure that no light comes through when day breaks). Regular Chinese acupressure massages and use of the hotel steam rooms or a bath help him relax before bed. Emotionally, he is now faring much better. When asked how he sleeps, he says unequivocally, "Like a baby." +

For 23 years, David Evans woke up feeling the same way he did when he went to bed. Desperate for answers, he did his own research, met with specialists and completed an overnight sleep study. Blood tests turned up nothing. Meds for sleep, anxiety, depression and daytime drowsiness produced more side effects than benefits. His relationships and finances were a mess and he had difficulty holding down a job. He became isolated and considered suicide as he longed for a state of non-existence.

Fast-forward to today: David's sleep is under control and he is leading an energetic life. He no longer needs caffeine, naps are a rarity and he takes no sleep medication. Since transforming his own life, he now dedicates his time to helping others sleep soundly. He has delivered the workshop "Better than Counting Sheep" at Positive Living BC and Vancouver Friends for Life Society. For more info, visit www.sleepstudent.com

ASK THE EXPERTS

Get answers to your treatment questions

Managing Lipid Levels

“My doctor said that my lipid levels are cause for concern. Any do’s and don’ts you can share?” —JB, Brandon, Manitoba

MAREK SMIEJA

Infectious Diseases Specialist
McMaster University
Hamilton, Ontario

Most experts agree that HIV infection can cause abnormal lipid levels and heart disease. We’re also fairly certain that the main reasons more people with HIV suffer from heart disease are smoking, high cholesterol and some HIV medications that can affect cholesterol levels.

If someone is a smoker and has abnormal lipid levels, I first try to help them quit smoking, or at least cut back. Next, a dietitian helps them find ways to lower their bad cholesterol and overall risk for heart disease through diet and regular exercise. Keep in mind that cholesterol is just one risk factor of heart disease. Even if these changes don’t improve a person’s cholesterol levels, there are still effective ways to reduce overall risk of heart disease.

The HIV meds known to increase bad cholesterol and triglycerides include some protease inhibitors and some older nukes, such as d4T and probably AZT and ddI. Every person starting HIV treatment should have a blood test to measure their lipid levels. I give my patients the same test six months later. If the latter reveals high bad cholesterol or triglycerides despite healthy lifestyle choices, we may change their HIV meds or start them on cholesterol-lowering drugs. While seeking to lower cholesterol, I recommend frequent testing. Once a person’s level is considered safe, I recommend that they continue to test regularly though less frequently—generally once a year.

The Lowdown on Lipids

Our bodies contain thousands of different kinds of fat, known as lipids. When you have your “cholesterol checked,” three of these fats are measured:

- **HDL cholesterol** (high-density lipoprotein, also known as “good” cholesterol), which removes bad cholesterol from the blood
- **LDL cholesterol** (low-density lipoprotein, also known as “bad” cholesterol), which can build up in the arteries and lead to heart disease and other health problems
- **triglycerides**, which can also increase your risk for heart disease if levels are too high

Sometimes the body outsmarts our attempts to reduce cholesterol by producing extra bad cholesterol, even when people exercise and are diligent about their diet. When this happens, medications from a class of drugs known as statins can help. Major studies show that these drugs dramatically reduce a person’s risk of heart disease–related death.

Taking both a statin and a protease inhibitor can produce various side effects—some minor and some more serious though rare. In my opinion, too many people stop their statins because of minor side effects. It’s important to remember that suffering a heart attack or stroke is a serious consequence of not taking these drugs. In the same way that millions of people remain alive because of HIV drugs, many people are still around today because of statins.

There’s a lot of interest in natural treatments. Such approaches can be somewhat helpful, but changes in lipid levels generally occur as a result of a combination of lifestyle changes and drug therapy.

JAMES SNOWDON

Pharmacist
Snowdon Guardian Pharmacy
Toronto

Treatment of abnormal lipid levels is integral to improving the heart health of people living with HIV. It should start with a healthy diet, exercise, smoking cessation, managing hypertension and diabetes. These are the cornerstone of any treatment do’s and don’ts.

HIV medication combos frequently include drugs that elevate cholesterol and triglyceride levels. One option for people on HIV treatment is to switch from the presumed offending agent to another antiretroviral medication. The recent introduction of more lipid-friendly drugs within existing classes (such as the protease inhibitor darunavir (Prezista) and the non-nukes etravirine (Intelence) and rilpivirine (Edurant)) broaden the options. In addition, new classes of drugs (integrase inhibitors such as raltegravir (Isentress) and CCR5 inhibitors such as maraviroc (Celsentri)) offer more options for people starting therapy and for those who need to switch drugs.

Lipid-lowering therapies that have been investigated in people with HIV include fish oils (see interview with Cheryl Collier, opposite), statins, fibrates, ezetimide, niacin and combinations of these therapies.

Statins can significantly reduce bad cholesterol and triglycerides. Drug interactions between statins and antiretrovirals are very common. For example, some protease inhibitors can raise the concentration of statins and can lead to statin toxicity. However, atorvastatin (Lipitor) and pravastatin (Pravachol) are less likely to interact. The newer rosuvastatin (Crestor) does not interact with many drugs.

Fibrates are a class of drugs that can reduce triglycerides significantly

in people living with HIV. It is unclear if this triglyceride reduction alone is significant enough to alter cardiovascular risk. Fibrates are generally well tolerated; gastrointestinal upset is the most commonly reported side effect.

Ezetimide (Ezetrol) appears to have minor cholesterol-lowering effects when taken alone. According to one study, when taken with pravastatin, it lowered levels of bad cholesterol more effectively.

Niacin appears to be well tolerated and reduces triglyceride levels significantly and bad cholesterol to a lesser degree. A concern is the increase in insulin resistance that it can cause.

There is little information available on the efficacy or safety of people with HIV using a combination of therapies, so this should only be done with strict caution.

CHERYL COLLIER

Clinical Dietitian
BC Women's Hospital and
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Vancouver

Your nutrition choices can help reduce your bad cholesterol. This involves cutting back on certain foods and adding heart-healthy foods to your diet. Both saturated and trans fats raise bad cholesterol. Most saturated fat comes from processed foods, fatty cuts of meat, high-fat dairy products and tropical oils, such as coconut and palm. Instead of fatty meat, you can eat leaner meat, skinless poultry, fish, legumes and vegetarian protein, such as peas and beans or soy protein. Select lower-fat dairy products and steer away from highly processed foods. You don't need to eliminate high-cholesterol foods, but try to eat less of them.

Incorporate more of the following into your diet:

- Fibre, particularly soluble fibre – it prevents the absorption of bad cholesterol from the food you eat. Good sources include oatmeal and oat bran, barley and psyllium. Increase fibre by including vegetables, fruit and whole grains with meals.
- Nuts – almonds, walnuts and other tree nuts can help reduce

cholesterol. They are a source of healthy fat and are high in calories, so if you're trying to lose weight, limit your portion to a quarter cup a day.

- Omega-3 fatty acids – cold-water fish (such as salmon, sardines and trout) are an excellent source and can help lower triglycerides. If you don't like fish, these oils are available in capsules. Ask your doctor for advice on dosage.

For clients with high cholesterol who are also struggling with unwanted weight loss, I look at what is contributing to the weight loss and help them reach and maintain a healthy body weight. Replacing saturated fats with high-calorie healthy fats from nuts, avocados, and olive and canola oils can help cholesterol levels and boost calorie intake.

It's more common, however, for people to work on losing extra weight and exercising (both are good for the heart). For people who don't currently exercise and are finding it hard to start, I suggest participating in an activity they enjoy once or twice a week. Once a consistent routine is achieved, they can start exercising more.

Lifestyle changes take time. Start with one to two key goals and go from there. Diet and exercise can make a difference, even in situations where HIV medication is contributing to high cholesterol or triglycerides, but it's important to recognize that sustainable change takes time.

TASLEEM KASSAM

Naturopath
Clinic Director, Effective
Health Solutions
Calgary

Vegetables are not very sexy. We'd all rather eat a corn dog than sit down to a plate of vegetables. But the reality is that the more vegetables you eat, the better. Lots of vegetables and moderate amounts of fruit should be the mainstay of our diets. I tell my clients to think of meat as a condiment. Many people find this shocking, but meat should take up no more than a quarter of the real estate on your

plate. Vegetables and whole grains should fill the rest of your plate.

You can also grind up flax seeds and sprinkle them on a salad. Flax seeds help keep the arterial system working well because they're high in fibre and omega 3-fatty acids.

The less you eat processed food that comes out of a factory, the healthier you'll be. It can be difficult to do on a limited budget because processed food is often less expensive (plus the

Most people who make the right changes to their diets see the payoff in their blood work results.

food industry has a vested interest in tempting you with factory food, which generates profit).

I also recommend the following supplements:

- Krill oil – a type of fish oil that contains the antioxidant astaxanthin (a pigment, or carotenoid, responsible for making shrimp and flamingos pink), which can improve lipid levels. Make sure you get a balanced intake of carotenoids (mixed carotenoids); and
- Vitamin B complex – contains pantothenic acid (B₅), useful for correcting lipid metabolism and raising good cholesterol even when medications, diet and exercise have been tried to little avail. Pantothenic acid should not be taken on its own but as part of a B complex. You may want to supplement this with pantothenic acid (a derivative of pantothenic acid) to help manage lipid levels.

Most people with HIV are already taking more medication than the average person. It's a lot for the liver to process. In my opinion, it's best to try to manage your cholesterol naturally, if possible, because taking a cholesterol-lowering medication adds to the liver's workload. Most people who make the right changes to their diets see the payoff in their blood work results. +

Call of the Wild

From “Dangerboy” to designing man, **Morgan McConnell** has developed an impressive body of work inspired by his passion for nature.

BY JENNIFER MCPHEE



“The Nest,” selected for the 2008 Scotiabank AIDS Walk for Life campaign

When Victoria-based graphic designer Morgan “Dangerboy” McConnell gets the rare chance to design something exactly the way he wants, it almost always includes a bird, a nest, a tree or some moss. This is a man who loves nature. But he also likes to inject elements of grit and edge into those designs, which gives his work a unique

look and feel. “There’s a fine line between incorporating the outdoors into your art and becoming someone who paints flowers all the time,” he says.

While growing up, nature was a constant in Morgan’s life. His family moved around a lot—by the time he was 15, he had lived in Vancouver, Montreal, Toronto and Richmond. But

wherever they lived, his family spent weekends at a cottage or exploring the local wilds. During long walks in the woods, his parents would point out the inhabitants of the forest and describe what made each creature or plant interesting, unique and/or edible.

It was the 38-year-old’s lifelong fascination with wilderness that inadvertently set him on the path to becoming a graphic designer. After graduating from the University of Victoria’s marine biology program 15 years ago, he landed a contract as research associate at the marine sciences station in Bamfield, a tiny town on Vancouver Island’s west coast. When the gig was up, he wanted to stay in this enchanting little piece of paradise, so he took the only available job—looking after the marine station’s website.

Morgan quickly taught himself the basics of web and graphic design and liked the way technology ramps up the speed of the creative process. “You can go on a tangent and just follow your brain,” he says. “I found that way of working to be really harmonious for me, as opposed to sitting down with a paintbrush and trying to paint something for days or weeks. I don’t have the patience for that.”

A year later, Morgan moved back to Victoria, where a friend (another biologist-turned-graphic artist) helped him land a design job at a local software development company, at the height of the dot-com boom. “We were the crack design team,” he recalls with a self-deprecating laugh. “We listened to loud music and wore ponchos to

work, because we could, because we were artsy designers. We couldn't believe we were getting paid to have such a good time together."

Then, in 2000, Morgan's mother passed away from complications associated with long-term alcoholism and a series of unsuccessful abdominal surgeries. While alive, she had often talked to him about the life-enriching benefits of visiting far-flung places and experiencing different cultures. Decades earlier, his mother had travelled the world while working as a model and radio DJ.

relationships even harder to come by. It had been difficult enough to meet potential partners back in Victoria's small gay community, where he had already felt like a misfit. "I was raised to be the kind of kid who goes out and turns over rocks, looks for crabs at the seashore and picks mushrooms," he says. "That was more my identity than fashion or music or any of the things that a lot of people seem to find important. It wasn't until I experienced larger cities like Sydney that I realized I wasn't weird. There are all kinds of ways of being gay." He was

assortment of clients, including politicians, musicians, a gay porn producer and a Christian book publisher. He also regularly works on AIDS awareness campaigns—work he considers meaningful and important. In 2008, he designed a limited-edition label for Polar Ice Vodka, as part of an annual AIDS awareness campaign that raised \$50,000 for the Canadian AIDS Society.

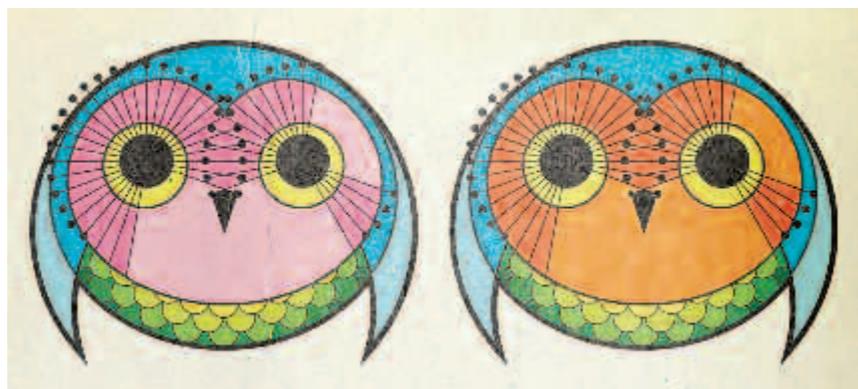
That same year, Morgan won a competition to design the promotional material for the national Scotiabank AIDS Walk for Life campaign. At the time, it was a little nerve-racking, he admits, because it meant coming out to the world as an HIV-positive designer. He wasn't sure how people would react. He worried about being defined by his illness, being seen as HIV-positive first and an artist second.

Instead, there was an outpouring of appreciation for his design of a crow perched in an almost-lifeless tree, holding in its beak a red AIDS ribbon, which flutters in the direction of a patch of new leafy growth. Many people were so moved by the dark yet hopeful image that they contacted Morgan, asking for signed copies. "It was a total shock," he says. "That was definitely a very powerful moment for me."

At the moment, Morgan feels conflicted about his future professional path. Sometimes he thinks about switching careers so he would have more creative energy at the end of the day to work on his own projects. Working as a designer often requires compromising your own vision to satisfy your customers, Morgan explains. On the other hand, he learns new skills and styles by constantly adapting his work for others. "So, when the time does come to create something for my own enjoyment," he says. "I have a much deeper well to draw from." +

To view more of Morgan's work, visit www.dangerboydesign.com.

Jennifer McPhee is a freelance writer who contributes regularly to *The Positive Side*. Her work has also appeared in numerous publications, including *Chatelaine*, *The Globe and Mail* and *Childview*.



Morgan's design for the Victoria-based cupcake company Night Owl

Morgan chose to honour her by using the small inheritance she had left him to recreate her youthful adventures in his own way. After travelling through Asia for six months, he spent a year and a half working as a freelance designer in Sydney, Australia. He also earned spare cash, or sometimes a place to stay, by performing as a fire dancer—a talent that later led to a successful audition with Cirque du Soleil and explains his pseudonym, Dangerboy (it was his stage name). "I first saw fire dancing in a nightclub in Victoria," he says. "It's a mesmerizing blend of martial arts, dance and fire. I quickly immersed myself in practicing it and joined a troupe of young queer performers when I was living in Victoria, before travelling. We all taught each other and grew together."

Not long after arriving in Australia in 2001, Morgan found out that he was HIV positive. At the time, he feared the social stigma of the illness and that it would make meaningful

quickly adopted by the poz community in Sydney, which showed him that HIV doesn't have to be a stigma, nor does it mean an end to love, fun, community and happiness.

A hearty and accepting poz community was one of the reasons why, upon his return to Canada in 2005, he decided to settle in Vancouver instead of returning to Victoria. Shortly after relocating, he met his future husband, Gordon, who shares his love of the outdoors. The couple got engaged under a solar eclipse in Turkey and exchanged wedding vows on a remote beach in Bamfield. The ceremony wrapped up with drumming, fire dancing and a late-night sweat lodge on an isolated beach, complete with whale, otter and eagle sightings.

The couple moved back to Victoria several years ago, partly because Gordon was offered a job there and partly because it felt like the right time to be around family again and lead a simpler life. Morgan now designs for an eclectic



A Night of Glitter and Light

September 9, 2012 marked the 25th anniversary of the AIDS fundraising gala Fashion Cares. **Brian Huskins** was there for the grand finale.

Jeanne Beker! Jeanne Beker! I love you and want a picture with you!" I shouted as I made my way through the crowd like a paparazzo. This photo captures one moment of this year's Fashion Cares that made it an evening to remember.

I went to my first Fashion Cares 15 years ago, when I still lived in Calgary—the first of my yearly pilgrimages to Toronto. In the early days, fashion, entertainment and dancing late into the night left one exhausted, amazed and wanting more the next year. Jeanne Beker, long-time host of *Fashion Television*, was a stalwart HIV/AIDS supporter. In times when people were dying daily from AIDS and the cause was not a popular one, it was celebs like Beker who made living with HIV just a bit more acceptable and gave people with HIV such as myself a feeling of being OK with the world.

I now live in Toronto and was saddened when the event fizzled in 2007 due to a combination of factors, including a change in venue and bad weather. That night we all froze in the cold rainy weather in Toronto's Distillery District. But this past September Fashion Cares came back in all its glory and lived up to its billing as "a night of glitter and light."

The guest list was a who's who of Canadian fashion, entertainment and business. Fashionistas and corporate executives rubbed shoulders with drag queens, people living with HIV, their partners and allies. And headlining was Sir Elton John himself. The entire evening buzzed with energy. What an amazing opportunity to celebrate life, keep people engaged and keep HIV at the forefront of people's minds!

The fact that this 25th Fashion Cares was the last makes this a sad turning point in the history of the AIDS movement. Keeping AIDS in the minds of Canadians is difficult enough and without events like this one, finding creative ways to raise awareness and funds will be a more challenging job for us all. +

Brian Huskins is a strategic planning/communications consultant who has been living with HIV since 1990. Brian was recently awarded a Queen Elizabeth II Diamond Jubilee Medal for excellence in the field of HIV/AIDS in Canada.

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

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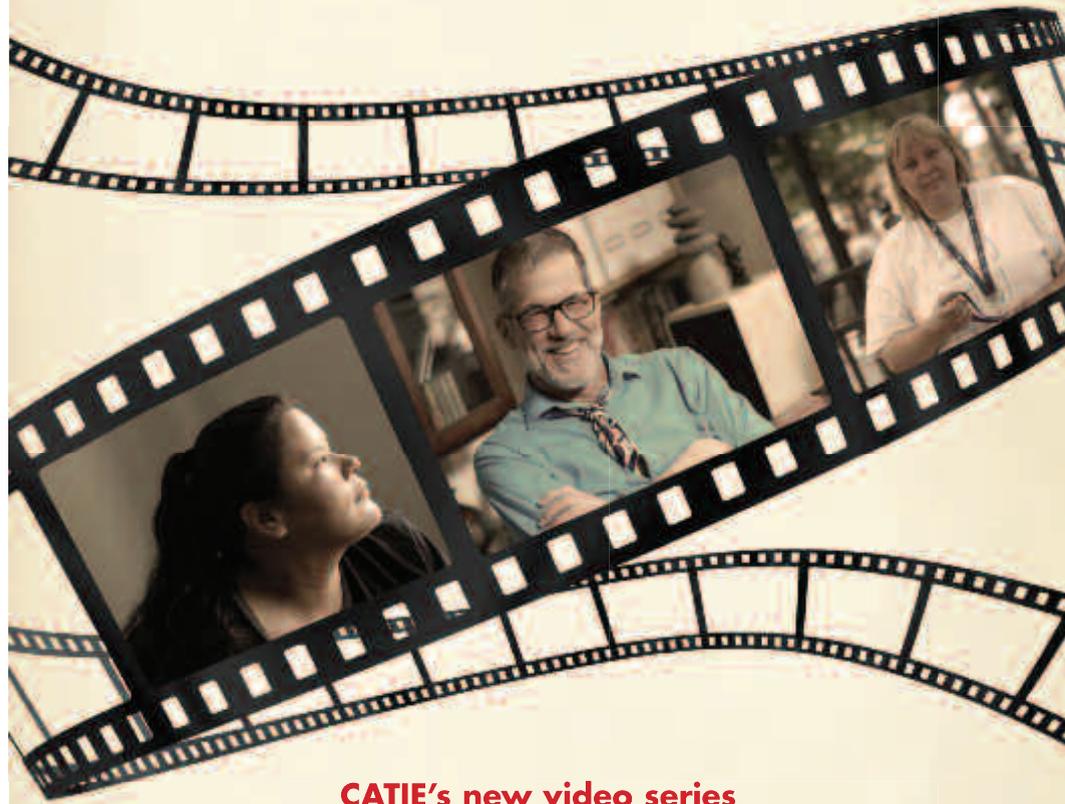
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