

# THE POSITIVE SIDE

# LOVIN' WITH HIV

*Valerie Nicholson & Margarite Sanchez:  
It gets better*

**Groundbreaking science goes global**

The backstory on U=U

**Power dynamics**

The patient as healthcare partner

**What do poz women need?**

Women-centred research & care

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## Programs for Newcomers

BY SHAZIA ISLAM

Immigrating to Canada can be both an exciting and an exhausting experience. For many newcomers, Canada offers opportunities to improve the quality of their lives and, for those escaping persecution or hardship in their countries of origin, a safe refuge. But settling in a new country comes with its challenges: Newcomers must learn to navigate a maze of services—immigration, healthcare, education, employment, housing and social services.

While juggling competing priorities, many are also learning a new language, grappling with income insecurity, and discovering that their education or training isn't recognized here—often in the absence of family, friends and their cultural community.

An HIV diagnosis, either prior to or after arriving in Canada, can further complicate the settlement process. Many HIV organizations offer invaluable supports to help HIV-positive newcomers access care and connect with others. Here are just a few.



### Drumbeat

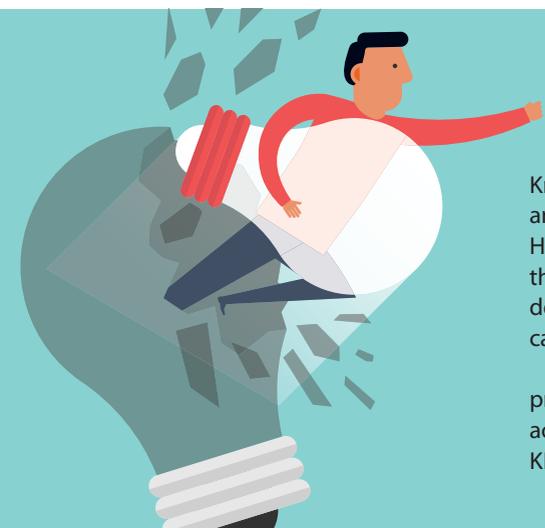
HIV Community Link, Calgary

This program was named Drumbeat to appeal to the African, Caribbean and Black (ACB) communities it aims to reach. The sound of a drumbeat is a call to listen and take action.

In addition to educating people at risk for HIV about HIV prevention, Drumbeat supports people from the city's ACB communities who are affected by HIV. It offers peer support to help newcomers settle into their new homes. It hosts informal talks for both HIV-positive and -negative people, such as "Brothers' Chats" at barbershops and local churches; discussions cover everything from HIV stigma to treatment to harm reduction. For African women living with HIV, events like Under the Mango Tree and In the African Kitchen provide an opportunity to socialize, learn and engage in craftmaking and cooking.

**For more info, call 403.508.2500, ext. 109 or visit [www.hivcl.org](http://www.hivcl.org).**

**You can also check out HIV Community Link's brochures, available in 8 African languages.**



### Knowledge into Action

Sexuality Education Resource Centre, Winnipeg

Knowledge into Action (KIA) is a program designed to raise awareness about HIV and hepatitis C, reduce stigma and improve the health of African newcomers from HIV-endemic countries. KIA runs a series of groups open to all newcomers, including those living with or affected by HIV. The sessions explore topics such as the social determinants of health, HIV 101, HIV stigma and how to manage your health. People can attend without disclosing their HIV status.

If you are a newcomer living with HIV, you can book a one-on-one session with the project coordinator beforehand to discuss your level of comfort participating in group activities where HIV is discussed. People living with HIV are also invited to facilitate KIA group sessions and are offered training to develop their skills beforehand.

**To find out more, call 204.982.7816 or visit [www.serc.mb.ca](http://www.serc.mb.ca)**

## Making Ends Meet & Systems Navigation

AIDS Coalition of Nova Scotia (ACNS), Halifax

To respond to the realities associated with income insecurity, Making Ends Meet offers people living with HIV access to personal hygiene products. Once a month, people can pick up shower supplies (soap, shampoo, shaving cream, razors) and dental hygiene items (toothbrushes, toothpaste, mouthwash) as well as other necessities such as scarves and gloves for winter.

"Making Ends Meet is one of our most in-demand programs for newcomers," says ACNS program coordinator Lori O'Brien. "Clients say that this program helps with the financial burden newcomers are faced with when starting over in a new country."

ACNS also offers newcomers referrals and help with navigating healthcare and social services.

The program coordinator informs clients of programs where they can access drug coverage, mental health resources, legal aid and housing, to ensure that newcomers have the tools and supports they need.

**To learn more, contact the program coordinator at 902.425.4882, ext. 225 [pc@acns.ns.ca](mailto:pc@acns.ns.ca) or visit [www.acns.ns.ca](http://www.acns.ns.ca)**



## Legal Services

HIV and AIDS Legal Clinic Ontario (HALCO), Toronto



HALCO is the only organization in Ontario that provides legal services specifically for people living with HIV. This includes summary legal advice, referrals and legal representation. These services are available to people with HIV who are financially

eligible and whose legal issue relates to HALCO's areas of legal practice (income security, housing, immigration/refugee, employment, health, human rights, privacy, powers of attorney and wills, prison law and family law).

HALCO also holds free educational workshops. Newcomers may benefit from going to workshops on the Ontario Disability Support Program (ODSP), Ontario's Drug Benefit Program, and HIV Disclosure and the Law.

For people looking for a lawyer at another organization or in private practice, HALCO makes referrals to lawyers who are knowledgeable about HIV and offers assistance with disclosing their HIV status to immigration lawyers.

**To learn more, visit [www.halco.org](http://www.halco.org)**



## Ethno-racial Treatment Support Network (ETSN)

Committee for Accessible AIDS Treatment, Toronto

This intensive training program is for racialized newcomers who are looking to meet other people living with HIV, learn how to talk to their doctors about their health concerns, increase their knowledge of HIV, and develop their counselling skills to support their peers living with HIV.

ETSN is divided into two parts: Level 1, "Helping Ourselves," is a four-day training that equips people living with and affected by HIV with knowledge about HIV treatment, how to manage medication side effects and talking to healthcare providers. Level 2, "Helping Each Other," as the name suggests, is all about taking care of others—participants learn active listening and peer support strategies.

CAAT reports that 90 percent of ETSN graduates subsequently become actively engaged in pursuing their life goals—through employment, further education and training, volunteering, sitting on boards and strengthening their support networks. One graduate commented: "Taking ETSN Level 1 helped me regain my self-esteem and confidence in the face of a recent HIV diagnosis. I learned about HIV drugs, how to take care of my health and what questions to ask my doctor. When I took Level 2, I learned how to hold space for my peers and support them. The training was very holistic and helpful."

**For more info, call 416.364.3030, ext. 2318 or visit [www.hivimmigration.ca](http://www.hivimmigration.ca)**

Research shows that ethno-racial minority newcomers bear a disproportionate burden of HIV in Canada: In 2014, ethno-racial minority newcomers accounted for approximately 13.9% of new HIV infections while making up only 2.5% of the population.



## PrEP Talk

We asked 3 people—HIV positive and negative—for their thoughts on PrEP. Here's what they had to say.

INTERVIEWS BY RONNILYN PUSTIL



**ALEXANDER MCKENZIE, 32**  
Sexologist, CRCHUM and REZO  
Montreal

I first heard about PrEP in 2013, when I began working at REZO as a counsellor in the IPERGAY study that proved the effectiveness of PrEP on an on-demand basis among men who have sex with men (MSM). PrEP seemed to be the way of the future with regards to HIV prevention for MSM. I was surprised that more people weren't talking about it. It seemed like something that everyone should be talking about.

About a year later, I started using PrEP myself. The participants I was counselling for IPERGAY were all men who have condomless sex. When hearing their stories, I thought, "How can I sit here listening to them and counselling them when I could be in their seat?" I realized that I needed to protect myself from HIV and that PrEP could be the best way to do that.

As a man who has sex with men, and as a person of colour, I grew up with the idea that I was the target population for HIV. When I came out to my parents, my mother's biggest

fear was that I was going to get HIV and die of AIDS. Always having that in the back of my mind kind of poisoned my sex life.

For years, even when I used condoms regularly, I felt very anxious waiting to get my HIV test results. For me, the secret side effect of PrEP is that you slowly stop living in fear of HIV.

Now I'm comfortable having sex with people who are HIV positive. I'm more open. First, do I find someone attractive? Let's go from there. I know that I've taken my sexual security into my own hands. I have a much more fulfilling sex life.

PrEP has also made discussions about safer sex easier. I let people know that I use PrEP, which opens up a discussion. That means I get tested every three months. It means that if I choose to not use a condom, I don't have a fear of becoming HIV positive. It means that I can choose to have more closeness with my partners.

PrEP has made people more open and willing to share with me as well. Often when you're trying to negotiate a hook-up, if you just go at a person with "when was the last time you were tested?" it can feel like you're attacking

or judging them. But if you say, "here's how I live my life and this is how I take care of my sexual health," it's more of an invitation to have a discussion and it allows the other person to feel more comfortable sharing these things with you. It allows you to make informed decisions about what risk-reduction strategies you can use together.

The thing I see the most in the guys in my practice who use PrEP is a sense of relief. One of the main things people talk to me about is the anxiety they have about sex. Everything about STIs (sexually transmitted infections) freaks them out to the point where people aren't able to maintain an erection or emotionally connect with someone because they're not sure if they can trust their partner.

PrEP allows people to feel that they're doing everything they can to protect their sexual health—not only with regards to HIV but also STIs. People on PrEP who weren't getting tested for STIs regularly now are. This means that STIs are caught and treated more quickly, which ultimately helps lower the incidence of STIs. As a result, people feel more confident and able to live the sex lives they want.

### WHAT IS PREP?

PrEP (pre-exposure prophylaxis) is one of the power tools in the HIV prevention toolbox. PrEP involves an HIV-negative person taking a pill that contains certain HIV drugs to prevent transmission. In 2016, Health Canada approved the use of the HIV drug Truvada (tenofovir + FTC) for PrEP. Less expensive generics are also now available. When a person takes PrEP consistently as part of ongoing medical care, they dramatically reduce their chance of getting HIV through sex. PrEP is also highly effective at preventing HIV transmission between people who share drug equipment.

Things have also changed drastically in the sense that people used to have strong judgments about what kind of people take PrEP. Now, it's becoming more and more accepted.

Although PrEP is becoming more accessible, the cost remains a barrier. Here in Quebec, even with our health insurance, a person can still end up having to pay \$85 to \$90 for a month's worth of medication, if not more. Many people cannot afford that. Studies have shown that having people on PrEP is far more cost-effective than having people become HIV positive.



**ABHIRAMI  
BALACHANDRAN, 24**

Women's Sexual Health Coordinator,  
Alliance for South Asian AIDS  
Prevention (ASAAP)  
Scarborough, Ontario

When I first heard about PrEP, my initial reaction was that it sounds like a great idea in theory but I was wary of how accessible it was, especially to people of my demographic group—South-Asian women.

I have never used PrEP myself, mainly because I had never heard of it prior to my working in this role. Unless you are a cis white gay man or part of the HIV sector, PrEP is rarely even brought up.

I inform the women I work with that this option exists, which almost all of them are unaware of. But most women say that they're not interested in trying it, perhaps because they're uncertain about the impact it could have on other aspects of their health. Women are also concerned about the

stigma they might experience if they ask their doctors about PrEP; they worry they could be seen as engaging in "risky behaviour."

Healthcare providers need to create safer spaces for women to speak openly about their sexual health, especially PrEP. Access to PrEP needs to be improved substantially, which entails better relationships between service providers and the communities they serve.

There are many barriers to PrEP access—the low usage rates among women, particularly women of colour, are evidence of this. Because PrEP is marketed predominately to gay men, many women are not even aware that this option exists. When you have funders implying that women's sexual health isn't a priority, we are left with the misconception that women are not at significant risk, when in reality they are.

PrEP is a feasible alternative for those experiencing intimate partner violence. Sexual violence is commonly overlooked as a significant risk factor and not all women are able to negotiate condom usage. This is not to suggest that PrEP is a solution to their problem, but it can be a good option that they should be aware of.



**CHUCK OSBORNE, 67**

Community researcher  
New Westminster, B.C.  
Diagnosed with HIV in 2002

I first became aware of PrEP in 2012, when I was a treatment outreach worker at Positive Living B.C. People were calling it revolutionary and comparing it to the birth control pill.

This was talked about for quite some time before Truvada was approved as a prevention strategy. People were struggling to get hold of it. But only a few doctors were willing to prescribe it as a prophylaxis before it was approved for PrEP. You know, the gay community is ahead of the curve!

In a very important way, PrEP soon became something I was talking about as a sexually active single gay man who had relationships with positive and negative guys. I like having more options to protect myself and my partners.

PrEP doesn't protect against other STIs, but it is easy to use. Because it's a pill, there's no need for sloppy starts and stops like when using a condom. At this time I have a positive partner, but there's always the possibility that one day I will be with someone who is HIV negative and PrEP may be needed.

In urban centres, PrEP has now become established conversation, at least among gay men. Since it was approved by Health Canada there seem to be many places where you can access it, but not everyone can afford it.

As a poz person, I take HIV drugs to keep my virus in check and prolong my life. When HIV drugs suppress the virus, they also prevent transmission. In a similar fashion, an HIV-negative person can use PrEP to prevent infection and protect themselves. How can people not see that PrEP is a realistic way of subduing the virus, and that there's no need to make PrEP users feel shamed and stigmatized?

Do we know the long-term impact of taking PrEP? No, but research shows that it dramatically reduces the risk of contracting HIV.

Studies are also being done on intermittent use, and injectables are in the pipeline, which might prove easier to deal with than pills.

Why not make PrEP available to all those HIV-negative people who consider themselves at risk? With treatment as prevention and U=U (undetectable=untransmittable) for HIV-positive people, we would be better able to reach our goal of ending the epidemic by embracing PrEP. +

# The Women of CHIWOS

3 women talk about the power of peer research and women-centred care.

INTERVIEWS BY RONNILYN PUSTIL AND DIEYNABA DEME

**W**omen living with HIV face unique issues related to their health and are less likely than men to be engaged in care, yet relatively few studies focus on the health and well-being of women with HIV and how their quality of care can be improved. Working to fill that gap is a national research project called CHIWOS (the Canadian HIV Women's Sexual and Reproductive Health Cohort Study).

In the spirit of community-based research, CHIWOS breaks down the hierarchy between the researchers and the researched. Research is done *by, with and for* women living with HIV, in partnership with academic researchers and clinicians.

Instead of simply consulting with women with HIV, the women are meaningfully involved in every stage of the research. These women, known as peer research associates, or PRAs, play a key role in setting priorities, developing surveys, collecting data and disseminating results (using both traditional avenues like academic publications and non-traditional peer-led community events).

Launched in 2011, CHIWOS enrolled a total of 1,422 women living with HIV in B.C., Ontario and Quebec, who completed a PRA-administered survey. From 2015 to 2017, 1,252 participants completed a second survey. The third wave, currently underway, is set to wrap up in September 2018. Saskatchewan and Manitoba joined the CHIWOS cohort in 2015, using Indigenized arts-based events to collect data and learn about the perspectives and priorities of women with HIV in those provinces.

## Meet the PRAs

Claudette, Stephanie and Brigitte are three PRAs who are working to dismantle the barriers and pave the way for women to be meaningfully involved in Canada's HIV response.

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### CLAUDETTE CARDINAL, 49

British Columbia PRA  
Social work student  
Living with HIV for 22 years

#### Why does CHIWOS matter to you?

After I was diagnosed, I was invited to participate in a qualitative study for newly diagnosed people, which involved speaking to a nurse at the University of Alberta. It was supposed to be a two-hour interview, but it ended up lasting more than four hours. That nurse was the first person

I really talked to about having HIV. It was a big relief to pour out my heart to her.

Now I'm on the other side of that research relationship. I've been on the CHIWOS Community Advisory Board for over six years. When CHIWOS first recruited PRAs in B.C., I applied for the job and was hired in 2013. I've now conducted more than 20 in-depth interviews with HIV-positive women.

It's like I've come full circle. To now be the one asking questions and supporting women is a great honour for

me because there are so many people out there who don't have someone to talk to—that person who will listen and understand what they're going through, like that nurse in Alberta did for me years ago. To have that connection only happens when you have something significant in common—in this case, being women living with HIV.

#### What motivated you to become a PRA?

My grandmother. She passed away in 2002. If she were still alive, she would be 103. She believed that we're supposed to take care of the sick and those who are suffering. That's one of her values that I carry forward. Now it's my turn to give back to the community and look after others who have HIV. I've come from being an ex-drug user, prostitute and alcoholic to abstaining and being drug-free and healthy. Now I'm a positive role model for others and walking that path.

#### What makes this work meaningful to you?

Seeing the smiles on the faces of the women who are there to give their input. By participating in CHIWOS, women discover a sense of self-worth and self-empowerment. Having a peer take the time to ask them personal questions and encourage them allows them to engage with the HIV community and challenge themselves in new ways. They're not stuck at home doing the same old, same old. One participant asked me, "How can I get to do your job?" It shows these women



**Claudette Cardinal**

that they just have to get out there and try something. Once they do, doors will open.

When the women come back for their follow-up interview 18 months after the initial interview, it's so great to hear about them making positive changes in their lives and to witness their accomplishments—if they've stayed out of trouble, haven't used or had a drink or gone to jail since the last interview—those good things that keep lifting them up. I feel like their role in the research helps them keep track of the positive stuff they've done since their last interview. Those are the triumphs I celebrate.

#### **Has there been a standout moment?**

The Indigenous Women Data Transfer Ceremony in Montreal, in 2017. We transferred the data gathered from 453 Indigenous women living with HIV over to leaders Carrie Bourassa and Renee Masching. It was a very heartfelt moment. Following a water ceremony, I spoke on behalf of the Indigenous women in the study. That

was a big moment for me, standing up and representing the women who had passed on and saying my piece about the importance of the data we were transferring over. We had a moment of silence for all the women who had passed and then we proceeded to drink water in the ceremony.

#### **What does women-centred care look like to you?**

It's care that is led by women from start to finish. That means having HIV-positive women working in all departments, involved in everything you would experience at a medical clinic.

When HIV-positive women speak about our issues, we understand one another and can openly talk about our feelings and experiences. It's about having a place for women where we can have those discussions, without being judged because we come from downtown or we're homeless, without having to fear those stereotypes that put us into boxes. Once we're allowed to speak freely and openly to

whomever we see as part of our HIV care—the nurse, the psychiatrist, the person who does your blood work—we're not stigmatized and are treated like regular people. It's just nonsense that we are stigmatized because we live with this disease.

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#### **STEPHANIE SMITH, 39**

Ontario PRA

Operating room attendant

Living with HIV for 14 years

#### **Why does CHIWOS matter to you?**

Women are under-represented in HIV research, and in most studies where women *are* included, we're treated like men, even though we have different needs. With CHIWOS, we hear the point of view of women—what we want, how we feel, how things affect us. We have different life experiences, so it's important to hear the women's side, in all its complexity.

I find the diversity of the positive women I interview astonishing—how they got HIV, what they've



Stephanie Smith

PHOTOGRAPH: BEN WELAND

accomplished in their lives, how being HIV positive has made them stronger.

Also, I get to connect with some women who aren't otherwise involved with the HIV community. Just because they don't want to be out about their HIV status doesn't mean they don't want someone to talk to. It's nice to sit and talk with a woman who's going through the same thing.

#### **What motivated you to become a PRA?**

I got HIV from my partner at the time who had cheated on me with men. After my diagnosis in 2003, I wanted to use my skills and do something good with the situation.

I was already working in the healthcare field as a homecare worker. I told my boss, who knew I had HIV, to send me to the homes of HIV-positive people. I realized that as a peer, as someone who could relate, there was so much more I could offer those clients. Being a PRA seemed like a good opportunity for me to do more in my life as a person living with HIV.

When I met Dr. Mona Loutfy, the principal investigator who told me about a new project called CHIWOS, I was intrigued because there weren't many studies out there specifically about women with HIV. I was one of the first PRAs to get involved: I did a test run of the survey and now I interview women living with HIV in Ontario.

#### **What makes this work meaningful to you?**

I know that it will help change things in the long run—policies, programs and, hopefully, the way healthcare professionals talk to women. I hope that it will help doctors ask the right questions about what women need. Take, for example, side effects and how HIV medications affect our bodies. Women are sometimes prescribed the same doses as men. A woman who weighs 120 pounds can be taking the same dose as a 300-pound man who is 6'4". What about the toxicity, the difference in side effects, the different ways that medications affect women's bodies?

#### **Has there been a standout moment?**

I interviewed a woman in Ottawa who was just starting to turn her life around. She wanted to stop using drugs, become a better mom and go back to school. We met at a coffee house and the interview lasted three hours. She had never met an HIV-positive woman who was working, had her life together, had a good family life. She saw that I was dating and in a relationship. We sat there, drank coffee and had a really good conversation.

"Things can change," I told her. "I make the HIV a little part of my life—it's not my whole life." She said she had never thought of it that way; she thought of her life as little and HIV as huge. When I explained that I saw it the opposite way, she was able to see things in a different light.

When we met a year later for a follow-up interview, she was in college, had her own apartment and had stopped using. It made me feel like I helped someone improve her life by spending just three hours talking

to her. This is what's so good about community-based peer research—in addition to collecting important information, you get to connect and sometimes help people.

### What does woman-centered care look like to you?

I recently changed family physicians. It's so great to go to a clinic where my doctor and the nurses are women who understand my needs as a woman who has HIV. I can get everything—blood work, X-rays, ultrasounds—done at this one clinic. It's so woman-centered compared to where I went to see my former family doctor who didn't really understand the needs of an HIV-positive woman. Having woman-centered care has changed the whole experience of going to the doctor for me. Now I ask my doctor sensitive questions that I didn't feel comfortable asking before.

### What does MIWA (the meaningful involvement of women living with HIV) look like to you?

I think of Dr. Mona Loutfy, who is amazing at this. As a principal investigator, she treats us as though we're at the same level as she is. She involves us from the beginning of the process so we can provide our expertise. We know what it's like to live with HIV, so it's meaningful to be involved like that from the beginning.

#### **BRIGITTE**, 55

Quebec PRA

Living with HIV for 33 years

### Why does CHIWOS matter to you?

Twenty-two years ago I was living in an AIDS hospice. I had to put my daughter in foster care because I was dying. But, as you can see, I pulled through—effective antiretroviral treatment saved my life and turned everything around for me—and this greatly motivated me to advocate for the rights of HIV-positive women.

Now I don't hesitate to share my experiences with others because I know it has a positive impact on other women living with HIV. It's like we

have a natural unspoken understanding of each other. This is why CHIWOS matters so much to me.

### What motivated you to become a PRA?

I connected with CHIWOS via a CTN (Canadian HIV Trials Network) committee of people living with HIV that I was on. That committee reviewed and made recommendations on HIV-related research.

I fell in love with this research work from the get-go. I wholeheartedly embrace CHIWOS' vision and mission of optimizing the health and well-being of women with HIV. As far as I know, there wasn't any research of this kind happening when CHIWOS started. This was a first. I was, and still am, delighted to be part of it. It's about time that people take into account the realities that women with HIV face!

### What makes this work meaningful to you?

I have now conducted approximately 60 interviews with HIV-positive women in Quebec. Each woman has a unique story. My goal is to have an impact on the people I meet and help women tap into their strength.

At the end of their involvement in the research, women often say that even though there isn't time to go into detail on many topics, it gives them an

opportunity to talk. Their participation makes them feel useful and needed.

### What does women-centred care look like to you?

Everything that has to do with women. It is important to address biological issues that are specific to women—such as pregnancy, menopause, PMS, menstruation—as well as women's mental health issues and social issues. These all affect women's overall health.

### When you hear the term MIWA (the meaningful involvement of women living with HIV) what do you envision?

MIWA is very important to me because there are still many battles to fight for women after they receive an HIV diagnosis. It's important to reassure women and help them integrate socially—for example, help them find employment. We are making progress, thanks to the involvement of people living with HIV. For example, U=U (undetectable=untransmittable) is a huge step forward. The fact that people with HIV who have an undetectable viral load don't transmit HIV to their sex partners and can prevent transmission to an unborn baby is really changing things for people living with HIV.

Thanks to CHIWOS and its essential and indispensable research, women feel heard. It's high time! +

## Women & HIV by the Numbers

Globally, women make up more than half of people living with HIV.

In Canada, 23% of people living with HIV are women. Black and Indigenous women are over-represented among women living with HIV in this country:

- 37% of women diagnosed with HIV in 2016 identified as Black.
- 36% identified as Aboriginal.
- 21% identified as White.

One large B.C. study, which analyzed the quality of care of 3,600 participants living with HIV, concluded that women generally receive "poorer quality of care" than men.

Data from CHIWOS reveal that gaps in care are real: About 1 in 3 women with HIV are lost to HIV care at some point following their diagnosis, with significant differences across different groups. For example, older women and Black women are more likely to be virally suppressed, whereas women who are younger, use illicit drugs, face food insecurity or have recently been incarcerated are less likely to be virally suppressed.

# Lovin' with HIV

It's no secret that when it comes to sex, an HIV diagnosis has been known to throw a wrench in the works. But navigating this new landscape is possible— with the right information and support. **Allison Carter** talks sexual satisfaction with two HIV-positive women.

PHOTOGRAPHS BY STASIA GARRAWAY AND KAMIL BIALOUS

*“To have something lifted, instead of another concern added on top, felt really good.”*

**Margarite Sanchez**



**M**argarite Sanchez, a self-described artist, activist and agriculturist who lives on Salt Spring Island, was in her mid-30s when she was diagnosed with HIV. She was newly married at the time, with a partner who was HIV negative. Today, at 60 years young, she is still in that relationship, and her partner is still HIV negative. He is also a loving and caring husband and father to their two children. Their life is good, Margarite tells me. And sex is a very important part of their relationship.

This is not to say that Margarite didn't face challenges after being diagnosed. "I went through all those things women go through," she says. "At first I felt like I was damaged goods. I told my husband to leave. I figured I would be alone for the rest of my life. I just didn't think there would be much more of that." Sex, she explains.

But her husband wouldn't hear of it. "Why should I leave the best relationship of my life?" he said. Margarite goes on to reveal something that many women with HIV have experienced as a barrier to achieving a pleasurable and satisfying sex life: her huge fear of transmitting HIV.

A small but growing number of studies document such feelings and the impact of HIV on women's sexuality and sexual well-being. A 2017 review of surveys involving 11,552 women living with HIV around the world found that after being diagnosed, it is common for women to experience reduced pleasure during sex. Fear of transmitting HIV to their partners, anxiety and depression, and broader societal stigma and discrimination are just some of the factors that can put a damper on the deed. Never feeling safe enough, it seems, is a common theme.

But times are changing, and so is Margarite. Science now shows that it is possible for people living with HIV who take their medication as prescribed and maintain an undetectable viral load to have condomless sex without risk of passing HIV. This reality is captured by the slogan U=U (undetectable=untransmittable). After 15 years of using condoms religiously with no viral breakthrough, Margarite and her husband decided, as a couple, to do without them. Margarite was also fully menopausal at that time and in a long-term, monogamous relationship, so she wasn't worried about getting pregnant or getting other sexually transmitted infections.

"It was really nice, for once in our relationship, to have one less obstacle between us," Margarite says. The problem wasn't so much the physical barrier of the condom, but what it signified. "To have something lifted, instead of another concern added on top, felt really good."

Now Margarite describes her sex life as more relaxed and spontaneous, free from her previous worries about passing HIV. This medical strategy of treatment as prevention, she points out, has de-medicalized her sexuality.

**V**alerie Nicholson is 62 years old and lives in the Downtown Eastside of Vancouver. She is an Indigenous woman

and a proud grandmother. Like Margarite, Valerie describes the scientific discovery of U=U as liberating—not only when it comes to her ability to have close relationships with an HIV-negative partner but also for how she feels about herself as a sexual being. But the changes she went through to get to this point—the kind that happen internally and externally—didn't happen overnight.

"When I was first diagnosed, I don't think my sexuality changed at all," Valerie says, "because I wasn't really dealing with it." She was in a relationship at the time, and it was in that relationship that she acquired HIV. She was also struggling with substance use. She describes her sex life back then as routine: "Do drugs, have sex, do drugs, have sex." The drugs, she says, numbed any feelings she had about her diagnosis and about her sense of sexual well-being.

Valerie decided to stay in that relationship because she felt it was easy even though, she says, "it was an abusive relationship." But the risks of having to disclose her HIV status to someone new, which could open up a whole host of different harms, felt greater to her at the time than the dangers of staying with her partner. "It's kind of a weird feeling," Valerie says, reflecting on the tensions she faced. And, unfortunately, it's one that far too many women have to grapple with.

Of the 1,422 women who participated in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), 80 percent reported having experienced some form of violence and 67 percent said they believe that most people with HIV are rejected when others learn of their status. Over 50 percent reported suffering from depression. These social factors—violence, stigma and depression—can increase stress levels and greatly affect women's sexuality, reducing both sexual desire and arousal as well as increasing pain and anxiety with sex. On the flip side, this means that women's sexual well-being can be improved if their social context is improved.

**W**hen I ask Valerie about her experiences with sex and sexuality today, she replies, with joyful laughter, "Well, that's changed a lot." For many years after leaving her abusive relationship, she immersed herself in her HIV research and advocacy work and became known and much loved for her activism and her teaching as an Elder. This work led her to re-evaluate what it could look like and how it could feel to be single, HIV positive and happy with her sex life. "I had my toys, of course," Valerie says confidently, "because it was easier to have a toy than a man some days."

Valerie has since started dating again and has enjoyed a few meaningful relationships, with both HIV-positive and HIV-negative men. Currently, she is rekindling a romance from her past. Whether it's because of a new partner, a broader range of sexual activities or her reduced self-criticism and shame, she finds it much easier to climax during sex nowadays. She also attributes her newfound sexual freedom to U=U. And she's not alone. Many women



*“You’re a woman first. HIV is just something that you’re living with. And we have to honour ourselves as women.”*

**Valerie  
Nicholson**

PHOTOGRAPH: KAMIL BIALOUS

she has spoken to describe “getting a piece of their sexual life back.”

What’s clear in both Valerie and Margarite’s stories—and likely those of many other women—is that women are on a sexual journey. From coming of age to the golden years, dating to marriage to divorce, diagnosis to today, women’s experiences of love, sex and relationships are diverse and always evolving. There is not one path, but rather, many paths.

**W**hat advice do Margarite and Valerie have for other women who are newly diagnosed and struggling with their sexuality?

“It will get better,” Margarite says assuredly. “When you’re first diagnosed you go through all these feelings—you feel that no one is going to want you, that you’re never going to want to have sex again. But once you start to regain your confidence in living life, get your health straightened out and become stable on your medications, there’s absolutely no reason why you can’t live a complete and fulfilling life in every facet, including your sexuality.”

Valerie, reflecting on her journey, says: “You’re a woman first. HIV is just something that you’re living with. You could be living with a cold, cancer or the flu—it doesn’t matter. You’re a woman first. And we have to honour ourselves as women.”

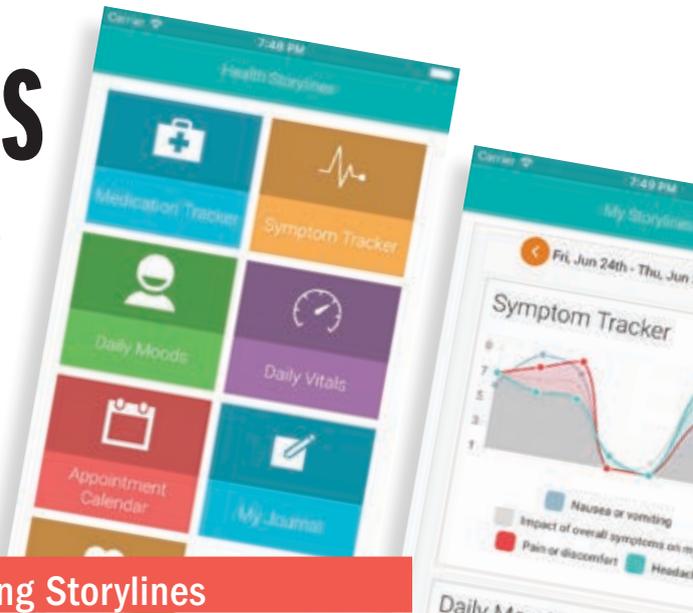
In terms of supports, both women emphasize the importance of having a safe place to talk with other women about sex and sexual pleasure. “I really envy gay men,” Valerie says, “because they often talk more openly about sex.” This contrasts with traditional female roles in which women are taught to keep their experiences and issues related to sex a secret, behind closed doors. Such talk is necessary, Margarite and Valerie say, for women to know that they’re not alone and to chart the course of their own sexual fulfilment. +

Allison Carter is an HIV-negative ally conducting sex-positive research with Margarite, Valerie and other women living with HIV. She is also working with them to create a new online resource dedicated to building conversation and community around sexuality and relationships for women and couples living with HIV: [www.lifeandlovewithhiv.ca](http://www.lifeandlovewithhiv.ca).

# Adherence Apps

If you could use some help remembering to take your meds, try one of these free apps.

BY NATHAN GIBSON



**H**IV treatment has changed radically—it is more effective, simpler to take and much easier to tolerate than it once was—but one thing that has not changed is the need to take HIV medications every day.

Experts recommend an adherence rate of at least 95 percent. That means if you take your medication once daily, you should not miss more than one dose per month; if you take it twice daily, you shouldn't miss more than three doses per month.

Why so strict? Because when you miss doses, the level of antiretrovirals in the blood can fall below the amount needed to suppress the virus. HIV begins to multiply in the body again, and new drug-resistant HIV can emerge. When the HIV in a person's body becomes resistant to the treatment they're taking, that treatment no longer works for them and a new treatment regimen must be introduced to get the virus under control again.

The fact is that adherence is key to the success of your HIV treatment: Maintaining an undetectable viral load is essential in order to protect your health and prevent transmission.

The good news is that there are many online tools that can help you stay adherent without much work! If you have a smartphone or other mobile device and you need some prodding, consider trying one of these free apps, which can also help you manage your health in other ways. +

Nathan Gibson is a student at the University of Toronto, studying neuroscience, health and bioethics. He is passionate about LGBTQ health and spends his time volunteering for LGBTQ and peer-support organizations in Toronto.

## Positive Living Storylines

Developed by the Vancouver-based Positive Living Society of British Columbia, with the input of people living with HIV, this app was designed to help users gain a sense of control over their HIV journey. In addition to reminding you when it's time to take your HIV treatment, it offers you a daily mood tracker and journal, as well as a tool for tracking any symptoms you may be experiencing related to HIV or other health conditions. You can also track your weight, blood pressure and other vitals. This app also gives you the option to share information with your doctor.

*Available in English. Compatible with iPhone, iPad, iPod touch and Android.*



## Every Dose, Every Day

Created by the U.S. Centers for Disease Control and Prevention (CDC), this app alerts you when it is time to take your medication. It also allows you to keep track of your medical appointments and test results and notifies you when it's time to refill your prescription.

The app has motivational tips, as well as the option to add a "reason picture" to help you stay adherent—for some people, that reason is their child or partner; for some, it's knowing that when they're undetectable, they can't transmit HIV to their sex partners; for others, it's the goal of staying in good health and being able to run the marathon next year.

*Available in English and Spanish. Compatible with iPhone, iPad, iPod touch and Android.*



# The Patient as Partner

The idea that a person should be an active participant, not just a recipient, of their own healthcare has deep roots. Feminists, people living with HIV and people with hemophilia have been making the case for decades: People should have control over their own bodies. We introduce you to one man who speaks from experience about the life-changing benefits of being a healthcare partner. Nine years ago, **Vincent Dumez** set out to transform the healthcare system so that it harnesses the skills and expertise of patients.

BY JENNIFER MCPHEE

ILLUSTRATION BY CHRISTINE ROY  
PHOTOGRAPH BY SARAH MONGEAU-BIRKETT

**T**he concept of “managing your health” has been central to the Canadian HIV movement. From the earliest days of the epidemic many people with HIV pushed to actively participate in their own care because of experiences with a stigmatizing and paternalistic healthcare system that appeared unprepared and unwilling to care for the marginalized people first affected by AIDS. Gay men and their allies built on the feminist experience of reshaping healthcare for women that had emerged in the '60s, as well as from a growing post-Stonewall sense of gay identity and solidarity. People with HIV took healthcare into their own hands and sought an equal and respectful partnership with their healthcare providers.

This revolutionary approach to managing your health arose in the hemophilia community at least a decade earlier in a different way—a story that is largely untold. The concept of the patient as healthcare partner—first pioneered in the world of care for people born with the genetic blood-clotting disorder hemophilia—has been central to the development of an internationally recognized model of healthcare delivery in which the patient and provider learn from each other about how best to manage a chronic disease.

Vincent Dumez, who was born with hemophilia, knows firsthand the benefits of this model of care. He has made it his mission to use the lessons he absorbed managing his own chronic diseases—hemophilia, HIV, and hepatitis C (of which he is now cured)—to champion the critical role that patients can play as healthcare partners.

As co-director of a patient-partnership program at the University of Montreal's Faculty of Medicine, his goal is to teach patients and healthcare professionals to collaborate, learn from each other and improve the healthcare system together. Often referred to simply as the "Montreal Model," the university's approach has become a catalyst for real change at hospitals and universities in Canada and other countries such as Belgium, Switzerland, Italy and France. With 50 percent of North American adults now living with at least one chronic condition—and many older adults, especially people living with HIV, living with several—Dumez points out that this need for patients and care providers to work in partnership is as crucial as ever.



**G**rowing up in the 1970s with hemophilia, Vincent Dumez was constantly in the hospital for blood transfusions to stop his bleeding. When someone with hemophilia falls or cuts themselves or bumps into something, it can take much longer for the blood to coagulate. And common surgeries, to remove tonsils or appendices, for example, can be life-threatening. "To stop the bleeding, we need transfusions," Dumez explains. As a child with severe hemophilia, he would visit the hospital 150 to 200 times a year to deal with his bleeds.

To help Dumez live a more independent life, his healthcare team taught him and his family to give blood transfusions and to analyze his symptoms to decide whether they could transfuse at home or seek professional help. This was part of a broader trend in the '70s whereby hemophilia clinics provided ongoing training and education to people with hemophilia and their families and made this an integral part of the care process.

By the time he was six years old, Dumez could self-transfuse. His parents, grandparents and extended family all participated in coaching and supporting him. "I gained autonomy and a sort of transfer of power," Dumez says. "If I've been able to develop a normal life, it is because I have benefitted from this system, this avant-garde philosophy of care." Eventually, he even felt confident enough to take up downhill skiing, despite the risks for someone with this condition.

**D**umez was one of thousands of people with hemophilia who became infected with HIV and hepatitis C in the '80s after receiving transfusions with blood products containing the viruses. Some 2,000 Canadians were infected with HIV and an estimated 30,000 more were infected with hepatitis C in the three years it took the Red Cross to remedy this disastrous situation. Most were

hemophiliacs. More than 90 percent of people with severe hemophilia were infected with HIV or hepatitis C and more than half died of these diseases. Justice Horace Krever, who headed the inquiry into Canada's blood system in the wake of this tragedy, called it a "nationwide public health calamity."

The "tainted blood" tragedy destabilized the close, collaborative relationship between hematologists and their patients. People were angry about being infected with what was then a deadly, incurable virus; they were equally upset that many doctors (including Dumez's) knew about their patients' HIV status and chose not to tell them, in some cases for up to a year and a half following their infection. Dumez describes the advent of AIDS as "a new world" for people with hemophilia. Now this community was suddenly confronted with a fatal disease about which little was known.

Dumez experienced a sense of "profound loss" as he realized how much the partnership had been broken during that time. This sense of loss and the need to rebuild his confidence in the healthcare system spurred him to write his master's thesis on the doctor-patient relationship and later inspired his work at the University of Montreal. He wanted to understand why so many hemophilia experts failed to communicate with their patients at the exact moment when patients needed it most, and he wanted to make sure that partnership wouldn't fail again. "At an emotional level, I wanted to rebuild something that I lost in order to rebuild myself," he says.

The lessons of the patient-partner model were not lost on the hemophilia community. Hemophiliacs and family members continued to come together to trade information, tips and experiences on living with these new diseases.

Meanwhile, in the larger HIV community, the need for self-care models was also becoming apparent. It didn't take long for people living with HIV to mobilize and find ways to share critical information—on everything from which drugs were managing their symptoms to which doctors were



**“Doctors are specialists in the disease, and patients are specialists in living with their disease.”**

willing to treat them. AIDS phone lines and organizations like Toronto’s Treatment Information Exchange (TIE) Project—which would later become CATIE and would publish *Managing Your Health* in partnership with the Toronto People with AIDS Foundation (the “bible” of the patient-partner movement)—were created to address the need for patient education. People with HIV pushed for a patient-partner model that is at the heart of HIV management today.

Dumez sums up this achievement: “We demonstrated that people living with HIV could become competent at self-care based on the experiential knowledge they acquired living with the disease every day.”

Until 2010 Dumez was so focused on his work as the co-owner of a successful strategic management company that he hadn’t given the patient-partner concept much thought for some time. But that year, he met the management team of the University of Montreal’s Faculty of Medicine and realized that they shared the same vision of what needed to change in the education of medical students. Soon afterwards, the dean proposed that Dumez spearhead a new patient partnership program.

Dumez quickly left his career as a consultant behind and took up the challenge. At the University of Montreal’s Faculty of Medicine, he founded and co-directs the Centre of Excellence on Partnership with Patients and the Public.

This program recognizes that a person’s experiential knowledge gained from living with a disease is of equal importance to the healthcare professional’s scientific knowledge. “Doctors are specialists in *the* disease, and patients are specialists in *living with* their disease,” Dumez says. “Doctors need to understand that the patient isn’t someone you push care on; the patient is someone you partner with.” The program engages patients at all levels of the healthcare system, including in the training of health professionals.

Dumez successfully pushed the University of Montreal to integrate the concept of patient partnership into courses that teach healthcare professionals how to collaborate with each other. He convinced the university to allow experienced patients to co-lead these courses, a worldwide first. Today at the university, 300 patients pair up with healthcare professionals to train students in 13 different healthcare programs how to partner with patients.

The centre first teaches experienced patients to recognize and understand the skills they’ve acquired in the course of being patients. In addition to their experiential knowledge (knowing what it’s like to live with their illnesses), some experienced patients possess highly developed communication and collaboration skills, Dumez says.

These patients then use examples from their own lives to help train students to develop these skills themselves. For instance, patients in the program help medical students debrief after their first challenging experiences working with patients in clinical settings. “Patients give them feedback and help them realize that teamwork is complex,” Dumez says. “There’s not one specific behaviour that works to deal with various complex human situations.”

Medical students not only learn to communicate and work synergistically with patients, they also learn to appreciate the perspectives of patients. They come to understand, for example, that a patient’s goals for their own treatment may be different from the goals of their healthcare providers.

After graduating from the university, med students trained in the Montreal Model enter the real world with a completely different understanding of how to work with patients. This is a revolutionary change because, in Western medicine, doctors have traditionally seen themselves as the experts who tell patients what to do, and their patients as people who should largely follow—and not question—their instructions.

Additionally, the Centre of Excellence has worked with 30 hospitals in Quebec on initiatives that give patients a seat on hospital quality-improvement committees. “Healthcare providers are discovering that patients and family members who experience the healthcare system on a day-to-day basis can have good ideas about how to improve it,” Dumez says: “It’s about time.” The Centre has also supported the Canadian Institutes of Health Research (CIHR) on how to incorporate the patient-partner concept into its strategy for patient-oriented research (SPOR). SPOR researchers are now required to engage patients to define what research should be done and how best to accomplish it.

Hospitals, universities and decisionmakers in Canada and abroad have sought the expertise of Dumez’s team in replicating or adapting the Montreal Model for their situation. “The model has been a catalyst for systemic change in healthcare delivery—change that began in the hemophilia and HIV communities,” Dumez says. “Patients have huge things to bring to the healthcare system. It’s working.” +

Jennifer McPhee is a Toronto-based writer who contributes regularly to *The Positive Side*.



*"U=U." Life4Me+ launched a major awareness-raising campaign in Russian-speaking countries in Eastern Europe and Central Asia*

Groundbreaking, game-changer, revolutionary. These words have all been used to describe the discovery that undetectable HIV is sexually untransmittable. But what good is groundbreaking science if people don't know about it? **Bruce Richman**, the driving force behind U=U, describes how the once-unpopular campaign gained critical mass.



# U=U

## THE BACKSTORY

### WHEN

my HIV doctor told me in 2012 that I could not sexually transmit HIV because I had an undetectable viral load, it changed my life. I was elated. For years I'd been so afraid of passing on HIV that I hadn't opened myself up to love. Now I felt free. But it struck me that nobody seemed to be talking about this earth-shattering news.

HIV information sites were saying that there was a risk of transmission—even when you're undetectable. I started talking to researchers, heads of clinics and some HIV-positive community leaders. They knew about the research but it seemed to be a big secret in the field. Most people weren't being told that when you have an undetectable viral load, you cannot transmit HIV sexually. It was known to only a privileged minority. Millions were left in the dark, especially people already marginalized by the healthcare system.

I felt that I had to do something to get the word out. So, in the summer of 2015, I began organizing with other activists and researchers to launch the Undetectable=Untransmittable (U=U) campaign, to make sure that the breakthrough science of HIV transmission would reach the people it was meant to benefit.

I had developed cause-related campaigns for high-profile people and brands before, but this was the first time I was to embark on something so close to my heart, with so much potential to help people and the field. I gave up my income from previous clients, moved into a studio apartment in New York City, and had absolute faith that truth and science would be my guides.

## LAYING THE GROUND

It's mind-blowing to look back at how much the global U=U community accomplished in a short time. Just over two years ago a small group of us started drafting the U=U consensus statement with researchers from groundbreaking treatment as prevention studies—HPTN 052, PARTNER, Opposites Attract and the Swiss Statement. We planned to use that statement as an advocacy tool to secure influential endorsements to support the overwhelming evidence confirming U=U. When we issued the consensus statement in the summer of 2016, we felt we had the holy grail. It was a life raft in a sea of HIV stigma.

We needed to find champions. U=U was brought to life when the pioneering Dr. Demetre Daskalakis from New York City's Department of Health signed on that summer and Terrence Higgins Trust led the way in the U.K. But even after New York City and several powerhouse U.S. organizations joined a few months later, there was a frustrating lack of acceptance of the science, or even an understanding as to why the message was so important. Quite often, I felt that life raft sinking.

## RESERVATIONS AND RESISTANCE

The initial response was mixed. Few recognized that U=U was true. We found visionaries who stepped up, but most of the established HIV organizations worldwide were telling our advocates that we were wrong, and even a danger to public health.

People worried about the Pandora's box that might open up if people with HIV stopped using condoms and about the rise in STIs that could ensue. Some worried that people might not realize that they need to take their meds every day to stay undetectable. In other words, they worried about whether people living with HIV would understand that meds only work if you take them. We were told this would be a disaster in places where people don't have access to treatment and regular viral load testing. People who doubted the science felt we were being unethical and dishonest.

Essentially, we were told to stay silent.

## THE CANADIAN CONNECTION

The campaign picked up momentum in January 2017, when CATIE's executive director Laurie Edmiston was unequivocal in her support of U=U:

*All of us here at CATIE, and indeed around the world, are celebrating the most significant development in the HIV world since the advent of effective combination therapy 20 years ago: People living with HIV with sustained undetectable viral loads can confidently declare to their sexual partners, "I'm not infectious!"*

When Bob Leahy, the leading Canadian U=U advocate and publisher of [positivelite.com](http://positivelite.com), sent me CATIE's endorsement, I couldn't speak. I was sobbing. CATIE's credibility

and reach helped set the message on an international trajectory.

CATIE's statement and ongoing advocacy and education have paved the way for other organizations in Canada and abroad to embrace the message. These organizations now recognize that U=U must be a headline, not an asterisk. This builds on the years of work of Julio Montaner, director of the B.C. Centre for Excellence in HIV/AIDS, and colleagues promoting HIV treatment as prevention in Canada and internationally.

Canadian organizations are engaging in open and challenging dialogue to explore the complex issues related to U=U—such as the social determinants of health, the criminalization of HIV non-disclosure and women's reproductive health. U=U is a leading topic at Canadian HIV and sexual health conferences that set the priorities for the field and at conferences led by and for people living with HIV throughout the country.

Every time I've gone back to Canada, I'm moved and inspired by the trailblazing work of our Canadian partners.

**MORE THAN 600**  
pioneering community  
partners, including  
research associations  
and public health  
bodies from  
**75 COUNTRIES**, have  
joined the campaign.

## INTERNATIONAL MOMENTUM BUILDS

Soon after CATIE signed on, other globally respected HIV research and HIV/AIDS service organizations joined, and we started gaining critical mass. It was a glowing validation that the message we were shouting from the rooftops was not only factual but a game changer for the field.

In September 2017, history was made at the United States Conference on AIDS (USCA) when one of the world's preeminent immunologists, Dr. Anthony Fauci, declared that "the science really does verify and validate U=U." Later that month, the U.S. Centers for Disease Control and Prevention (CDC) confirmed that there is "effectively no risk" of sexual transmission of HIV when undetectable. That update to the CDC's messaging had a transformative impact not only in the U.S. but around the world.



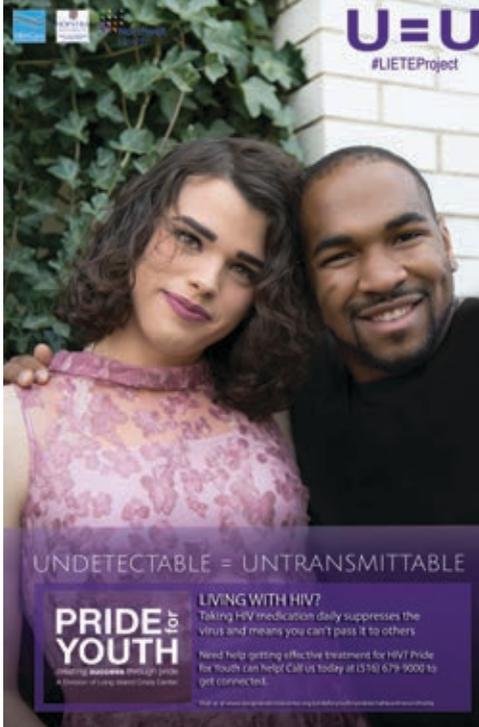
"I have HIV. It is not contagious. Scientific evidence shows that people with HIV who take treatment regularly and have an undetectable viral load cannot transmit the virus." Part of a social marketing campaign launched by LILA (Italian League for the Fight Against AIDS) in Italy



Screenshot from a video produced by the Gay Men's Health Charity in the UK



"HIV-positive people on treatment have many things to transmit. But not the AIDS virus." Part of a campaign from the French organization AIDES



In the United States, Pride for Youth brought the "Undetectable=Untransmittable" message to Long Islanders and people throughout New York



"Mission: #undetectable. HIV-positive. No longer infectious." A poster from the Swiss AIDS Federation

U=U and similar messaging is now being integrated into policy and communications in many parts of the world, including China, Uganda, Kuwait, Malaysia, England, South Africa, Australia, Guatemala and Vietnam.

I was overcome with joy to be in Toronto when the Canadian Government declared its support of U=U on World AIDS Day 2017.

U=U has been featured in national and global media and was even lauded by the editorial board of the leading medical journal *The Lancet*:

*U=U is a simple but hugely important campaign based on a solid foundation of scientific evidence. It has already been successful in influencing public opinion, causing more people with HIV (and their friends and families) to comprehend that they can live long, healthy lives, have children and never have to worry about passing on their infection to others. The clarity of the message will make it easier to promote the undeniable benefits of treatment, which will encourage more and more people with HIV to seek treatment, bringing the HIV community one step closer to achievement of the UNAIDS 90-90-90 target by 2020 and to complete elimination of the entirely unfair and outdated stigma still faced by many people living with HIV today.*

U=U has now been widely accepted by the global medical and scientific community. More than 600 pioneering community partners, including research associations and public health bodies from 75 countries, have joined the campaign. In Eastern Europe and Central Asia: H=H; in Vietnam: K=K; in Brazil: I=I; in the Netherlands: N=N; in Turkey: B=B.

## THE TRANSFORMATIVE IMPACT

Saying U=U, or any version of it, is still revolutionary. The message is the most radical challenge to the status quo since we learned 22 years ago that antiretroviral therapy can keep us alive.

U=U is transforming the social, sexual and reproductive lives of people with HIV. Our partners are using the message as a powerful public health argument for access to treatment and viral load testing, and to promote treatment uptake, adherence and retention in care. They are dismantling stigma in an unprecedented way by changing what it means to live with HIV.

I am continually moved to hear about the impact this information is having on people's lives. A man who attempted suicide after his diagnosis now feels human again and has become an educator, letting others know about U=U. An HIV activist who isolated herself from relationships for more than 15 years because she feared passing HIV is now dating and open to love. A woman finally feels she can be intimate with her husband after more than 20 years of feeling unsafe and worrying that a condom would break. People talk about feeling hope rather than shame, fear and stigma. +

## U=U 2018: CELEBRATE, ACTIVATE AND IMPLEMENT

We're sharing this message at the AIDS 2018 pre-conference in Amsterdam, on Sunday, July 22. The event will be hosted by the Prevention Access Campaign, in partnership with the Elton John AIDS Foundation, CATIE, Housing Works, ICASO, International Preparedness Coalition, NASTAD and Terrence Higgins Trust. Attendance is free for AIDS 2018 delegates. For more info, visit [UequalsU2018.eventbrite.com](http://UequalsU2018.eventbrite.com)

Bruce Richman is the founding executive director of Prevention Access Campaign's award-winning U=U movement. He has worked in global philanthropy for over two decades developing interventions, grantmaking and social marketing campaigns on a range of issues including HIV stigma and prevention, sustainable development, childhood obesity, violence prevention and the empowerment of girls and women with people and brands including Donna Karan, Ellen DeGeneres, Archbishop Desmond Tutu, Bob Marley Foundation, Sephora and Cartier. He received both his master's in education and law degree from Harvard University.



To hear the powerful testimonials of people from around the world, check out #UEQUALSU / @PreventionAC and [www.preventionaccess.org/news](http://www.preventionaccess.org/news) For a Q&A on U=U and testimonials from Canadians, check out "U=U" in the Summer 2017 issue of *The Positive Side*.



ILLUSTRATION: IAN PHILLIPS

# Ask the Pharmacist

**Jennifer Hawkes** answers some commonly asked questions about HIV treatment.

**M**any of us think of pharmacists as people who dispense drugs, but they do much more than that: They can offer advice on how to deal with side effects and avoid drug interactions. They can work with you to figure out drug coverage. And they are often easier to get a hold of than specialists. We decided to tap into the HIV expertise of B.C. pharmacist Jennifer Hawkes.

## Do you have any good treatment adherence tips?

Keep your eye on the endgame! It can be a powerful motivator. Remember that taking your HIV medication every day is an important step that you can take to improve your health or stay healthy. And if you maintain an undetectable viral load, you can prevent HIV transmission.

Research shows that starting antiretroviral therapy early and taking it without treatment holidays or breaks leads to the best long-term health outcomes.

I like to have people play an active part in their own treatment adherence plans. This puts you in the driver's seat. When you do something because you *should*, it can end up feeling like

## YOUR PLAN FOR SUCCESSFUL ADHERENCE

Here are some things to consider when thinking about your adherence plan:

### Timing is everything.

- Think about your daily routine. When are you most likely to remember to take your medication—when you wake up in the morning or go to bed at night? Lunch or suppertime can be more difficult to remember but may be necessary if your meds have to be taken with food and you sometimes skip breakfast.
- If you take other medications and supplements as well, for the sake of convenience take your HIV meds at the same time (unless two of the drugs can interact).

### Use blister packs or a dosette box.

- Ask your pharmacy to blister-pack your meds. This typically free service is a convenient way to tell if you have taken your pills each day. You can cut a strip for each day so you have smaller pieces to take with you.
- If you're not a fan of blister packs, consider buying an inexpensive dosette box to fill yourself. This way, you won't have to wonder if you've missed a dose or worry that you've doubled your dose. When it comes to lifelong medications, the days can blend together.

### Set up reminders.

- What or who can remind you to take your meds? Maybe it's a visual reminder, such as where you put your medications—in plain view or near a bracelet or watch you put on every day. Maybe it's a note in your calendar or an electronic reminder, such as an alarm on your phone, a text or an app. Or maybe it's your partner, a friend or family member.

### Anticipate possible obstacles.

- Identify and discuss any negative feelings, doubts or concerns you may have about taking your HIV medications. You should always

feel like this treatment is the best choice for you. It is common to feel shame or internalize stigma around having HIV—many people do. Is there a supportive person you can talk with openly about it? Is there a group you can join at your local HIV organization? Once you feel more acceptance around living with HIV (getting to this place can be a process), this can allow you to shift your outlook to one of “I am doing a great job controlling my HIV.”

- If you are struggling with other health issues or social concerns—such as unstable housing, food insecurity, addictions or mental health challenges—seek support. These can all affect your ability to take your meds in the long term. It is often helpful to have a team of healthcare providers supporting you. If you are actively using street drugs, HIV meds will still work as long as you take them every day!

### Prepare for the unexpected.

- Always have more meds on hand than you need. If you're travelling, take extra. If you move around a lot, consider keeping a stash of a few days to a week's worth in the places you frequent.
- Know where you can get more medications if you lose them, go on a trip or end up in the hospital.
- Try not to get to that last pill before you call for a refill because some pharmacies do not serve many people who take HIV meds.

### Be your own cheerleader.

- How will you reward yourself for great adherence?
- What motivates you to take your medications? Is it a loved one, your pet, your care team, your desire to be healthy and live long? Make sure to remember these things on the tough days.
- Forgive yourself if you occasionally miss a dose every few months. You're only human!

a chore. Plus, you know yourself and what works for you better than anyone else does.

### What kinds of side effects will my drugs have?

Although most prescription drugs come with a long list of possible side effects, it's worth remembering that some people don't notice any side effects from their HIV meds!

If you do experience side effects, they will likely subside or go away over time (in a matter of weeks to a month) and can be managed. For example:

- Nausea can often be improved by taking the medication at a different time, taking it with food, ensuring you're well hydrated, avoiding constipation or taking an anti-emetic medication to prevent nausea before you take your meds.
- Decreased appetite can often be dealt with by eating small frequent meals or sometimes by taking a medication to stimulate the appetite.
- Diarrhea can be treated with anti-diarrheal medications.

If your side effects persist, you and your doctor might want to consider a new drug regimen.

### Do I need to worry about drug interactions?

Before you start or stop any medications, check with a doctor, nurse and/or pharmacist who has experience with HIV medications. Let them know about everything you're taking, including over-the-counter products (such as pain relievers, acid reducers and nasal sprays), vitamins, supplements and street/recreational drugs.

You can look up information about individual HIV and hepatitis C drugs and check drug interactions at [app.hivclinic.ca](http://app.hivclinic.ca).

### Is newer better?

A newer medication is not necessarily more potent or easier to take. Any guideline-recommended combination of HIV meds that you do not have resistance to and you feel well on can be a good choice.

**“Theoretically, if you are adherent to your treatment regimen, you could be on the same medications for the rest of your life and they could continue working for you.”**

For people who take some of the old drugs, such as didanosine (ddI), lopinavir-ritonavir (Kaletra) and stavudine (d4T), doctors typically recommend switching to a newer medication that is less toxic, has fewer long-term side effects and works better.

If you have bothersome or significant side effects or significant drug interactions, it is probably a good time to switch medications. If you feel worse after switching, the good news is you can switch back or switch again to another combination.

**My HIV treatment is working well—I'm virally suppressed—but I'm thinking of switching my regimen to take**

**fewer pills a day. Should I stick with my current treatment or switch to a simpler one?**

Taking fewer pills is certainly more convenient, especially with several single-tablet fixed-dose combination pills available. But it's worth noting that if you also take other medications (for example, for cardiovascular disease or kidney disease), when you switch regimens you might need to adjust the dose of those other drugs.

Let the doctor who oversees your HIV care, as well as your pharmacist and any other doctors, know about *all* the drugs you take (prescription, over the counter, street/recreational drugs and herbal supplements), so they can adjust your prescriptions accordingly.

If it puts your mind at ease to stick with what you know, especially if your current treatment is working well for you, there is no need to switch.

Another thing to consider: If you have problems swallowing pills, know that a single-tablet regimen will be a larger pill.

**Will my pills stop working one day?**

Ever since triple-drug combination therapy was discovered in the mid-1990s, people living with HIV develop drug resistance far less frequently. Theoretically, if you are adherent to your treatment regimen, you could be on the same medications for the rest of your life and they could continue working for you. If you are not sure whether you can take your pill(s) consistently every day, let your doctor, nurse and/or pharmacist know, as some drug combinations are more forgiving than others.

**If I have HIV and hepatitis C, should I get my hepatitis C treated?**

Yes. If you have HIV, your hepatitis C might progress more rapidly. People who are co-infected with HIV and hep C are one of the “priority groups” to receive the new well-tolerated and highly effective hep C treatments.

If you have good adherence to your HIV medications, you will likely have good adherence to hep C medications too—this is the most important part to having the treatment work.

To reduce or eliminate the chances of HIV and hep C drugs interacting, doctors sometimes switch people's HIV treatment to a newer combination, such as one containing integrase inhibitors.

**How will I know if my HIV treatment is working?**

You and the doctor who oversees your HIV care will work together to ensure that your treatment is working. There are two things that will be monitored regularly with simple blood tests: your HIV viral load (lower is better) and your CD4 count (higher is better). The results of these tests will tell you and your doctor if your medications are working. Ideally, your viral load will become undetectable and your CD4 count will rise.

**What else can I do besides take my meds and monitor my bloodwork?**

For your physical self: If you are a smoker, consider quitting or cutting back. There are more smoking-related deaths among HIV-positive people than HIV-related deaths. If you're a substance user, consider cutting back. A healthy diet and adequate sleep and exercise are also important. Keep your vaccinations up to date, including the yearly flu vaccine.

For your mind, spirit and emotional self: Don't forget about these parts of your whole self! +



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*Being & Otherness, 2014*

## The Healing Artist

Darien Taylor in conversation with artist **Andrew Zealley**.

**A**ndrew Zealley is a queer shaman. He believes that art can heal. Through his art, and in the way he lives his life (his art and life can hardly be separated), he is constantly on the lookout for the ingredients of a magical healing compound that will soothe queer minds and bodies.

I first encountered Andrew in the late 1970s, when he was part of Toronto's Queen Street West scene, playing in the

queer proto-electro band TBA at the Beverly Hotel, the watering hole of art students and other disaffected youth at the time. I bumped into him again years later when he played with the band Greek Buck. As an audience member I thought, simplistically, that Andrew was a musician. But over time I learned that he is so much more.

First of all, Andrew is not as interested in music as he is in sound itself:

energy-filled, often jarring and awkward sounds—and silences—that do not come together in a way we traditionally think of as music. His sound work requires our ears to listen and our minds to hear in new ways.

Secondly, Andrew's art has evolved beyond his sound-based work to include ritualized performances, as well as conceptual art, which he often documents in photos, videos and art books. In these

works, he continually explores themes of sex, love and healing.

From the 1980s onward, Andrew's art has documented his relationship to HIV—first as a caregiver, then as a person living with HIV, and always, as a healer. He and his works present an integrated, compassionate and optimistic view of HIV as a journey to health.

**Darien Taylor: When did you first become interested in art?**

**Andrew Zealley:** My interest in music and sound reaches back to childhood. I could often be found in my bedroom closet, as a child, with my older sister's portable record player, moving the records backwards and forwards with my fingertip, exploring the strange sounds these gestures produced. So, I was always into sound and music.

My father was a professional artist with a studio in our home, and my parents always encouraged my interest in art. In 1970, when I was 13, my father bought me Yoko Ono's first LP with the Plastic Ono Band. Six months later, my mother bought me my first set of headphones for my birthday!

I remember buying a copy of *FILE Magazine* as a teenager, which had a big influence on me. *FILE*, published by the artist collective General Idea, documented the queer, subversive underground art scene that was shaking up Toronto and other international urban centres at the time. It completely altered my understanding of art, merging glam rock and punk sensibilities with references to Art Deco and 1940s nostalgia.

**DT: What sort of impact did HIV/AIDS have on the arts scene?**

**AZ:** It became a galvanizing force for the city's arts community. In the 1980s, crosstalk between the visual arts, music and performance worlds was exploding. When AIDS hit, the interdisciplinary arts scene was already vibrant. It was a wonderful time artistically speaking, and a fucking scary time in terms of sex and queer identity. Many queer artists in the city rallied around the AIDS flag as a survival strategy. We held on to each other. The arts community, the

queer community and the HIV/AIDS community were bound together in that moment.

**DT: Much of your work explores the medium of sound. Can you tell us a bit about the sound work you've done?**

**AZ:** Throughout the 1980s, I wrote music and played in successful pop bands like TBA and Perfect World. In the 1990s, I began to score for filmmaker John Greyson, and in 2000, I co-produced the theme song to the hit TV series *Queer as Folk*.

Listening is part of the environmental writing course I currently teach at York University. To me, listening is not limited to listening with the ear alone, it is also about "deep listening," which involves feeling the vibration and movement of sound.

**DT: You collaborated with visual artist Robert Flack. Can you describe that work and your relationship with Robert?**

**AZ:** In 1989, I started collaborating with Robert Flack, who tested HIV positive around the same time as I was confronting serious liver issues.

We researched alternative healing methods, visual and audio representations of body, mind and spirit, and histories of queer people as shamans and healers. This collaboration resulted in the exhibition *Empowerment*, at the Garnet Press Gallery, in 1991—a series of prints that depict the chakra points on the body accompanied by an ambient soundtrack. The images and sound installation from this show are now in the permanent collection of the National Gallery of Canada in Ottawa.

I was the last person to be with Robert before he died in 1993. He was in the old Wellesley Hospital.

An artist friend, David Rasmus, had arranged some of his beautiful photographs of flowers and sky on the wall, facing Robert. Robert was very quiet that evening. His copy of *The Tibetan Book of the Dead* was on the bed at his side. I turned my chair to sit abreast with him. We sat for hours in silence, gazing at Rasmus's blossoms, blue skies and white fluffy clouds.

**"The project is guided by a simple inquiry: What becomes possible when artists are visible and active in AIDS service organizations?"**

When I left, he quietly said, "Just keep working on your music." I have never faltered on that instruction.

**DT: And then you yourself became HIV-positive....**

**AZ:** Yes, I seroconverted in 2001. At that point, my art had already focused on AIDS-related issues for over a decade. So I thought I knew the issues, but I hadn't anticipated the challenges of HIV "on my own skin," so to speak.

**DT: Did the meaning of self-care change for you after you became HIV positive?**

**AZ:** When I tested positive, I doubled down on my self-care. I got serious about what I put into my body—clean water and good food, lovingly prepared. At first I had problems with the side effects from my HIV treatment and it wasn't until 2009 that I found a treatment combination that worked for me.



Andrew Zealley in front of “shadow prints,”  
photographed by Roberto Bonifacio, 2015

My AIDS-focused art and self-care have evolved side-by-side, and this connection deepened after I tested HIV positive.

**DT: Art-making offers a kind of healing for you. Can you talk about some of the work you have done post-diagnosis and its relationship to healing?**

**AZ:** Music can offer rich healing experiences. Look at disco music and the community-building that erupted in its wake!

In 2004, I worked on two significant sound pieces with AIDS themes. One is “Five Nocturnes for Electricity,” published as a vinyl-only edition of 100 with an edition of photographs by General Idea co-founder AA Bronson. The sound pieces explore dreaming and healing. They reflect on Bronson’s photos of gay men naked in their beds. Together, the sound and photos offer ways to reimagine the bed as a place of nurturing and love instead of a place of death, as it was in the pre-HAART era.

The second piece was a performance organized by Ultra-red, an artists’ collective working in sound and political activism. It took place at the Art Gallery of Ontario, as part of the

2006 International AIDS Conference. The artists recorded statements from conference delegates. As the layered sound was broadcast into the large space at the art gallery, the result was a massive, deeply energizing roar of sonic emotion. Remixes by the artists are available online for free download on Ultra-red’s site ([www.publicrec.org](http://www.publicrec.org)).

The processes involved in researching and producing artworks can be healing, and sometimes the works convey ideas of healing in and of themselves—for example, *Being & Otherness* (see pg. 28), a piece that is from a larger body of work titled *Black Light District*.

I started with a copy of Sartre’s *Being and Nothingness*, a seminal existential text that had a big influence on me when I was around 17. The photograph features a first edition hardcover copy gifted to me by a former teacher-friend, and a series of glass bottles with rubber stoppers. The bottles unambiguously suggest amyl nitrate, an inhalant used to enhance sexual practices that is now banned in Canada. The piece speaks to the othering effects of both the drug and the book as ways to achieve what I would call the “privileged position of outsider.”

**DT: You returned to school around this time...**

**AZ:** Yes, to the Ontario College of Art and Design University in 2011, after 32 years away. This decision was prompted partly by my HIV-positive status, as well as a desire to challenge myself and a goal to teach. It was a powerful moment for me, to draw together my creativity, my health concerns and my interests in queer people as healers and shamans.

**DT: How has your current work at York University continued to examine themes of healing and self-care?**

**AZ:** My PhD research involves a studio residency project at the Toronto People with AIDS Foundation, called “This Is Not Art Therapy.” My aim is to show that making and responding to art can offer healing that is different from the pathologizing tendencies of the art therapy model commonly offered to people with HIV. The project is guided by a simple inquiry: What becomes possible when artists are visible and active in AIDS service organizations?

I think it’s time to bring artists into community-based AIDS organizations in roles similar to complementary care practitioners.

**DT: How does this challenging work affect your own health?**

**AZ:** The challenges and rigour of graduate studies appear to be beneficial to my health. My HIV-related numbers have never been better. By focusing on my studies—which are related to HIV status, health and community, and are entangled with arts—I see and feel my body responding in positive ways. +

Darien Taylor is CATIE’s former Director of Program Delivery. She co-founded Voices of Positive Women, to empower and support women living with HIV, and is a recipient of the Queen Elizabeth II Diamond Jubilee Medal. Darien has been living with HIV for more than 20 years.

Check out more of Andrew Zealley’s work, including samples of his audio work, at [www.andrewzealley.com](http://www.andrewzealley.com).

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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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