

From *The Positive Side, Summer 2018*

## U=U: The Backstory

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." [Life4Me+](#) launched a major awareness-raising campaign in Russian-speaking countries in Eastern Europe and Central Asia

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.

## **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, because of the groundswell of data and our community's activism, 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.

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.



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](#)



“Mission: #undetectable. HIV-positive. No longer infectious.” A poster from the [Swiss AIDS Federation](#)





In the United States, Pride for Youth brought the “[Undetectable=Untransmittable](#)” message to Long Islanders and people throughout New York



“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

## 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 freedom and hope—and that means everything.

## U=U 2018: Celebrate, Activate and Implement

We’re sharing this message at the U=U pre-conference at AIDS 2018 in Amsterdam, on Sunday, July 22. The event will be hosted by the Prevention Access Campaign in partnership with AIDS United, Broadway Cares / Equity Fights AIDS, CATIE, Elton John AIDS Foundation, Housing Works, ICASO, International Community of Women Living with HIV, International Treatment Preparedness Coalition, NASTAD, Terrence Higgins Trust, and The Well Project. Attendance is free for AIDS 2018 delegates. For more info, visit [UequalsU2018.eventbrite.com](https://www.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*.

## Produced By:



Canada's source for  
HIV and hepatitis C  
information

555 Richmond Street West, Suite 505, Box 1104  
Toronto, Ontario M5V 3B1 Canada  
Phone: 416.203.7122  
Toll-free: 1.800.263.1638  
Fax: 416.203.8284  
www.catie.ca  
Charitable registration number: 13225 8740 RR

## Disclaimer

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

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

CATIE endeavours to provide the most up-to-date and accurate information at the time of publication. However, information changes and users are encouraged to ensure they have the most current information. Users relying solely on this information do so entirely at their own risk. Neither CATIE nor any of its partners or funders, nor any of their employees, directors, officers or volunteers may be held liable for damages of any kind that may result from the use or misuse of any such information. Any opinions expressed herein or in any article or publication accessed or published or provided by CATIE may not reflect the policies or opinions of CATIE or any partners or funders.

Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV, viral hepatitis and other infections. It is not intended to encourage or promote the use or possession of illegal drugs.

## Permission to Reproduce

This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit its content. The following credit must appear on any reprint: *This information was provided by CATIE (the Canadian AIDS Treatment Information Exchange). For more information, contact CATIE at 1.800.263.1638.*

© CATIE

Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.

Available online at:  
<https://www.catie.ca/en/positiveside/summer-2018/uu-backstory>