Understanding Undetectable Equals Untransmittable

A growing global community builds a movement.

February 18, 2019 By Olivia G. Ford

In 2018, in a packed hall at the biennial International AIDS Conference, the world's largest HIV-related meeting, a tall, earnest man asked a question of Alison Rodger, MD, lead investigator of the PARTNER2 study.

The study had delivered yet more unequivocal proof that people living with HIV who are on treatment and maintain an undetectable viral load do not transmit the virus during sex. The monumental discovery is often referred to as Undetectable Equals Untransmittable, or U=U.

"Today is marking a revolution in what it means to live with HIV," the man said, thanking Rodger for her research, before asking how she would respond to HIV information providers who persist in finding excuses to withhold the facts that her study and others prove.

"I think the time for excuses [is] over," she quickly replied, to loud applause. "It's very, very clear that the risk is zero. We very much have to promote this: If you're on suppressive ART [antiretroviral therapy], you're sexually noninfectious."

Rodger made sure to acknowledge the global campaign whose mission is to amass support for this message—especially since the man asking was Bruce Richman, founder and key force behind that effort. "I just want to pay tribute to the U=U campaign," Rodger told Richman. "It's been astonishing."

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The campaign's title—and the strong science now available to back it up—is a resounding yes to a question first posed publicly about 10 years earlier: Does undetectable mean uninfectious? Following extensive discussions and a literature review, a 2008 consensus statement by Swiss HIV experts was the first to assert that it does. The "Swiss Statement" inspired heated discussions, and more than a few objections, in the HIV research and advocacy communities.

The Swiss Federal Commission for HIV/AIDS was called "naughty" for releasing the statement without stronger evidence. The statement's authors were taken to task for its irrelevance to gay

men (all the evidence the writers cited in support of the statement concerned heterosexual transmission) and to those living in areas without access to treatment, viral load testing or screenings for sexually transmitted infections. There were concerns over stopping condom use. Caution reigned. Aside from coverage in HIV community media, discussion of the statement continued largely apart from those who stood to benefit from it.

The Swiss Statement was released on January 30, 2008—the day before Venton C. Hill-Jones's birthday, his first following his HIV-positive diagnosis in 2007. "At that time in my life and career, everything was really new," says Hill-Jones, now chief executive officer of the Southern Black Policy and Advocacy Network.

Hill-Jones was also in graduate school and relatively new to the HIV field in Texas. The statement's release did not register with him. "Working in public health, the messages I was seeing coming out of the field were not reaching the people they needed to reach the most—particularly Black communities in the South," Hill-Jones recalls.

Later that year, at a gay men's health summit, Hill-Jones heard a speaker living with HIV share the notion that a person with a suppressed viral load was unlikely to sexually transmit HIV, offering as evidence his own experience in a long-term serodifferent relationship—meaning his partner was HIV negative.

As a public health educator, Hill-Jones wanted to spread the good news. However, when he searched the Centers for Disease Control and Prevention (CDC) online and other primary sources to find references to support the claims made by the speaker he had heard, Hill-Jones found precious little information on the topic.

"It was kind of the wives' tale of HIV," he remembers. "You're not going to pass the virus on, but there's nothing proving that."

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In 2011, proof began rolling in, first by way of a study known as HIV Prevention Trials Network (HPTN) 052. HPTN 052—a randomized trial, the gold standard of clinical studies—found that treatment for the partner living with HIV reduced HIV transmission in serodifferent couples by at least 96 percent.

At that time, JD Davids, a communications strategist and longtime HIV activist, was serving on a federal working group that helps guide the U.S. HIV research agenda. Davids heard the preliminary results directly from HPTN 052's principal investigator after the study was halted years early "because it was so overwhelmingly successful that it was unethical to keep doing it," Davids marvels, meaning that the benefits of treatment were so great that it was unethical to keep participants from taking meds as part of the study. Advocates had hoped for, but not counted on, favorable results; few expected quite so clear a home run.

The study was heralded by HIV media and celebrated at clinical conferences; HIV treatment as

prevention (TasP), as it was now more widely called, was the 2011 Breakthrough of the Year in the journal Science. Yet the TasP message was still not breaking through to most people living with HIV, especially not via their providers.

“You would hear about it in passing,” says Gina Brown of Southern AIDS Coalition, “but it didn’t really resonate.” Though her viral load had been undetectable for years, no provider had ever offered Brown information about her lack of risk of transmitting HIV.

“We continually hear from providers [and] public health officials that sometimes they are uncomfortable giving [U=U] information,” said Naina Khanna, executive director of Positive Women’s Network–USA (PWN-USA), the nation’s largest advocacy network of women living with HIV, during a recent webinar exploring racial and gender justice in the U=U movement.

This is a troubling, persistent trend in medical systems: health professionals acting as gatekeepers, withholding information people need in order to make decisions about their lives and health. Racial and other biases compound these conditions. For example, research shows that health systems are less likely to share decision-making power with Black clients than with their white counterparts.

In 2013, PWN-USA conducted a sexual and reproductive health and rights survey of women living with HIV, most of whom were on successful treatment and highly engaged in care. Less than half of them had been told by a provider that having an undetectable viral load was a form of prevention. PWN-USA revisited the question in a 2016 community-based participatory research study; close to two in five of those women had not been made aware of TasP.

“That discomfort is frequently grounded in this idea that people living with HIV can’t be trusted with this information,” commented Khanna. “At its core…that narrative is racist, homophobic, patriarchal, misogynistic.”

In 2012, Richman, the founder of the U=U campaign, was told by his physician that he could not transmit HIV while undetectable. Richman had lived with HIV—and in fear of transmitting it—since 2003. It had been nearly a decade since he felt so free.

“This was incredible,” Richman told fellow U=U activist Davina Conner on her radio program, Pozitively Dee Discussions, in early 2017. “I had always heard and been continuously hearing from social marketing campaigns and clinics and doctors and governments and federal health departments that I was a risk, that all of us were still a risk, even when we were virally suppressed.”

Richman began collecting research, eventually quitting his previous career to launch the Prevention Access Campaign (PAC) in early 2016. PAC’s signature effort, “Undetectable Equals Uninfectious,” became “Undetectable Equals Untransmittable” after members of PWN-USA, who had been running campaigns to change stigmatizing language in HIV communications for years, brought to Richman’s attention the fact that a term like “infectious” was problematic in a campaign meant to fight stigma. The PAC founding task force ultimately agreed.

“Bruce wanted us in communities of color to have this information that he, as a white man, was freely given,” says Brown, who joined PAC’s steering committee after meeting Richman at a conference in 2016, researching the facts he shared with her and becoming a key bullhorn for U=U. “He brought the message to the masses in such a clear and concise way that it was easy to buy into.” While numerous leaders in the U.S. HIV community have traditionally matched Richman’s own gay white male demographic, Richman knew that the U=U message would have true power when U=U advocates more closely mirrored the epidemic.

PAC’s founding task force included advocates like Hill-Jones and Davids as well as the lead authors of HPTN 052, the Swiss Statement and two other trailblazing TasP studies, PARTNER and Opposites Attract. The group drafted a consensus statement to gather endorsements from institutions—including service providers, advocacy organizations, national and international policy bodies, publications, government entities and medical associations. The statement’s message was clear and direct: The risk of sexual HIV transmission from a person who has had a suppressed viral load for at least six months is “negligible to nonexistent.”

Cofounder and director of the African-American Office of Gay Concerns (AAOGC) Gary Paul Wright signed his longtime HIV testing and prevention agency in Newark on to the PAC consensus statement after he encountered Richman shortly after U=U’s launch. “You need to bring this to New Jersey,” he remembers telling Richman. “[Bruce] said, ‘Oh no, they don’t want me, they need you.”

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A key battleground for U=U advocates is the language used to convey HIV risk. The launch of the consensus statement coincided with the publication of interim PARTNER study results, which famously logged more than 58,000 transmission-free condomless sex acts in serodifferent couples. Richman and other campaign supporters were charged not only with correcting misinformation about the study from community members, providers and media but also with encouraging the reframing of risk messaging—from cautious to celebratory, from vague to direct.

“The message about the transmission risk from someone living with HIV has a profound impact not only on HIV stigma…but also on HIV prevention, testing and treatment,” wrote Richman in his inaugural blog entry on POZ.com when the campaign launched. “It is essential that message about risk be accurate and meaningful.”

“Accurate” meant stating the truth—that in light of increasing evidence, risk of sexual transmission while undetectable was not “extremely low” or “greatly reduced” but rather negligible, as in so small that it is not worth considering. In other words, the risk was zero. Information sources needed to reflect that.

The campaign developed discussion guides and trainings to equip supporters to respond to and resolve incorrect or biased communications whenever they encountered them. The language that PAC champions has itself evolved over time, leaving behind terms like “neglible” in favor of more

direct, easy-to-understand expressions such “no risk” and “cannot transmit.”

“It’s up to us to change the narrative about us,” read the tagline of one of PAC’s media training programs. The program was successful in correcting language in several national publications that exaggerated transmission risk or otherwise stigmatized people living with HIV.

“We are up against more than 35 years of fear of people living with HIV,” says Richman of the challenge of communicating these truths. “I think that people fear change, especially a change that involves people living with HIV not using condoms.”

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Jennifer Vaughan’s story of becoming ill, finding out in early 2016 that she had HIV and then returning to health is emblematic of the modern era of HIV treatment and hope. She believed she would be all right. She found an HIV medication regimen that worked, and her virus quickly became undetectable.

Vaughan shared her diagnosis with her children, family, friends and a growing audience of YouTube followers through regular video blogs sharing her journey, and responses were supportive. When someone connected her with Richman, he was the first to tell her that now that her virus was undetectable, she couldn’t transmit it to her boyfriend.

“I remember saying, ‘What?!’” shares Vaughan. “My second reaction was why: Why had I not been informed by my doctor or anyone about this information? Why was I left to feel that I was still a risk to my boyfriend?” Vaughan’s doctor had encouraged her partner to use condoms and pre-exposure prophylaxis, or PrEP.

When Vaughan spoke with this same doctor about U=U, the doctor discouraged her from sharing the campaign’s messages via her growing platform. “[My doctor] agreed with the science but felt people wouldn’t be responsible with it,” Vaughan says. As those who have learned about U=U from Vaughan’s videos know, she could not stay out of the campaign for very long.

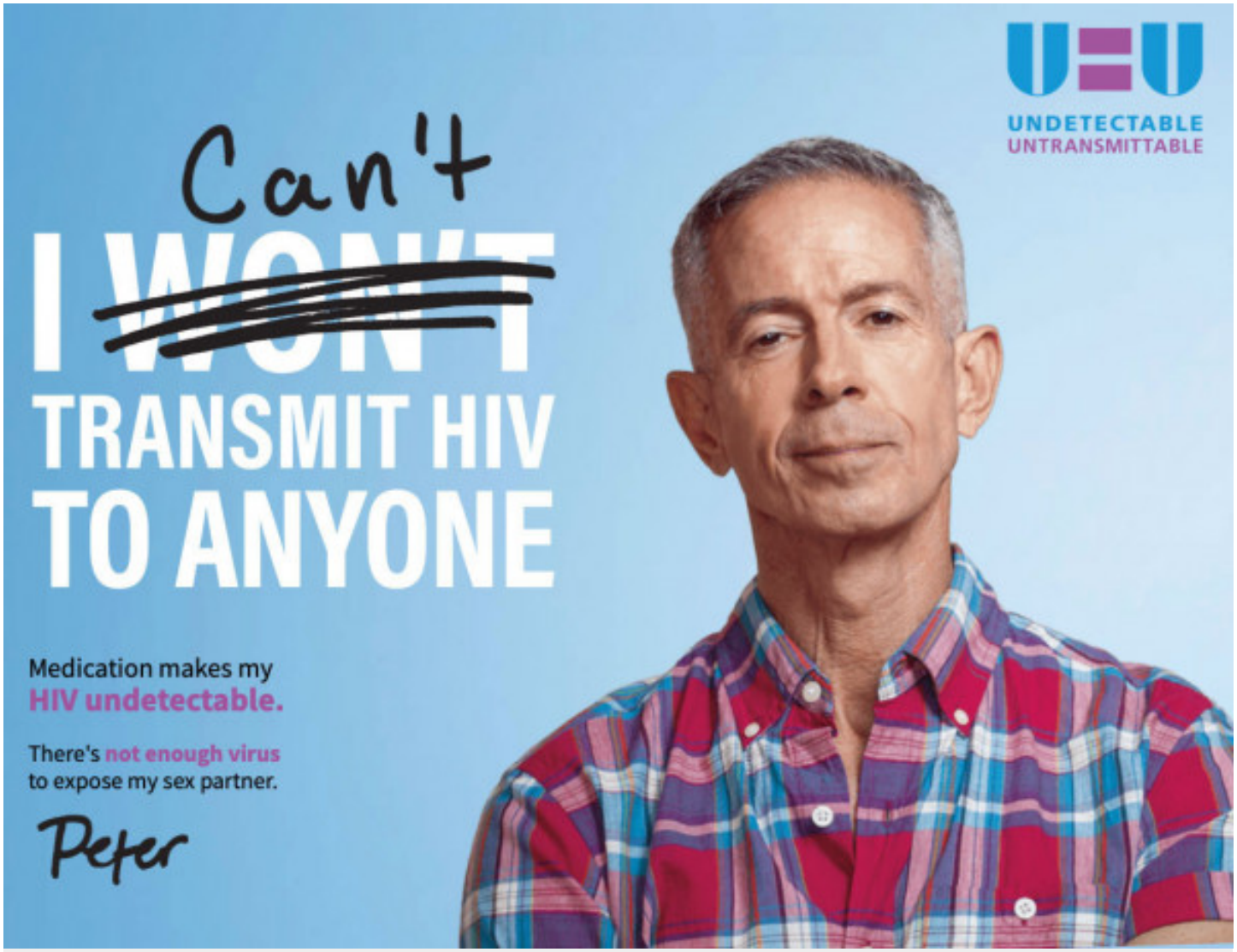
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“The science wasn’t the problem,” says Richman about his efforts to convince prominent HIV leaders to sign on to PAC’s consensus statement. “They were worried about being the first.” Richman recounted this process to longtime advocate Nelson Vergel in a 2017 interview.

Early adopters amassed: Demetre Daskalakis, MD, a pioneering physician from New York City’s Department of Health and Mental Hygiene, signed on to the campaign the month of its release, making New York the first city public health authority in the United States to do so. Housing Works was the first U.S. HIV service organization to sign on. Then NASTAD, the coalition of U.S. directors of state HIV programs, came on board as well. But like Hill-Jones, many advocates on the ground were hesitant to take up the message until public health information sources like the CDC stood beside these declarations.

A series of watershed moments came in September 2017 when Anthony Fauci, MD, longtime head of the National Institute of Allergy and Infectious Diseases, said from the stage at that year's United States Conference on AIDS that "the science really does verify and validate U=U." Soon after, the CDC made its first statement featuring its updated HIV risk messaging, the result of a months-long process to develop new language incorporating TasP: People who are virally suppressed have "effectively no risk" of transmitting HIV.

After the CDC and other federal agencies came around, says Richman: "Then we felt like we could breathe."



The New York State Department of Health U=U campaignCourtesy of The New York State Department of Health

More than 800 organizations, from nearly 100 countries have signed on to PAC's consensus statement and agreed to spread the campaign's message and values. The simplicity of the U=U message is among its greatest assets—and most vexing challenges.

"The message was primed for this upcoming generation," AAOGC's Wright points out—a cohort accustomed to receiving information in quick bites via apps and social media. The pithy phrase could also be a jumping-off point for community members to further investigate the matter, he adds. However, what a hashtag-based message reaps in shareability, it may lose in complexity

and nuance.

“How this message gets translated to the wider world can be problematic,” says Andrew Spieldenner, PhD, chair of the United States People Living with HIV Caucus. The caucus brings together networks and other groups of people living with HIV to speak in a collective voice for the U.S. HIV community. While many of its member organizations have signed on to the U=U consensus statement, the caucus itself has not.

Both Spieldenner and vice chair Barb Cardell, as individuals and on behalf of the caucus, praise the groundswell of strength, self-empowerment and sex-positivity U=U has inspired among people living with HIV.

“We know that it is not the intention of the campaign” to relegate those with a detectable viral load to lesser status, says Cardell. However, U=U supporters cannot control all the message’s uses, including as a potential tool to punish people living with HIV through criminalization.

Spieldenner cites a recent revision to North Carolina’s HIV-specific law that lists a suppressed viral load as a reason not to criminalize HIV nondisclosure, leaving people with a detectable viral load vulnerable to prosecution. To address concerns such as lack of access to treatment and overpolicing, PAC developed the “third U”: “Unequal.”

“Our collective celebration of U=U is undermined if our access to HIV diagnostics, treatment and care is unequal,” states the page on PAC’s website devoted to the third U. Richman sees the third U not only as a reminder to be conscious in communications and not shame detectability but also as a tool to advocate for treatment access for all.

The caucus, according to Cardell and Spieldenner, continues to wrestle with questions of how the campaign can satisfy its own best intentions.

“How do we make our public health partners accountable to that message?” asks Spieldenner. “How many organizations [that have signed on to U=U] have done in-service trainings with their staff to change the way they talk about HIV?”

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With or without the #UequalsU hashtag, the facts behind U=U are reaching an ever-wider audience. Hill-Jones expressed excitement at the potential for the U=U message to spread more widely into communities of color across the country, citing the most recent season of the Fox series Empire as an example of an innovative, accessible approach.

In a tender, informative and markedly undramatic turn for the often over-the-top family/music-industry drama, a main character on the show and his boyfriend, two Black gay men in a serodifferent relationship, engage with disclosure, undetectability and efforts to assuage the fears of a mother who witnessed the worst of the epidemic’s early years. “Those are the messages that reach people in their living rooms,” says Hill-Jones.

Wright hopes that U=U will influence the basic messages young people today receive about HIV and that the focus on biomedical prevention approaches will not eclipse the need for behavioral interventions that can help people connect with care and treatment. Wright has seen funding for behavioral approaches flag in recent years, as PrEP and TasP have taken the stage.

Vaughan, who is contacted by many newly diagnosed people as a result of her YouTube videos, has noticed that more and more of them, in many countries, are already aware of U=U. “That means our message is getting out there,” says Vaughan, “it’s working!” Like many involved in the campaign, she hopes the facts of U=U can be leveraged to improve treatment access for all.

Cardell’s suggestion to that end? Talk about systemic inequities first. “What if there were a T-shirt that had just one U on it?” she muses. “And the conversations started off with: ‘We acknowledge that there is unequal access in the United States and globally to these medications, to [viral load and STI] tests. We need to always be working around that unequal access—and we want to do that so we can reach this vision of people being undetectable if they choose to go on medications.’”

Longtime HIV activist JD Davids has also thought a lot about where the U=U movement might go from here. “Amazing, brilliant people have come together to call for this,” he says. How might those people work together to become an even stronger base of power in the HIV community, pushing for deeper systemic change?

He recalls and quotes from ACT UP icon Vito Russo’s classic speech “Why We Fight”: “After we kick the shit out of this disease, we’re all going to be alive to kick the shit out of this system, so that this never happens again.”

Then, Davids asks, “If we have ‘kicked the shit’ out of [the myth that] people living with HIV are dangerous to others, what shit are we kicking out of the system so that the stigma, the misinformation, the intentional underinforming of people—all of it—never happens again?”

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