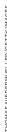
# The MAN With A PLAN

U=U is redefining how people living with HIV view themselves and their bodies, and it's become one of the biggest developments in HIV since antiretrovirals. But **Bruce Richman**, the man who crafted the message and helped push it to the world, says there's still more work to be done.

By David Artavia



THOMAS NIEDERMUELLER/GETTY IMAGES





Bruce Richman (right) with Sam Stone at the LIFE+ Solidarity Gala prior to the Life Ball 2019 in Vienna, Austria, last June.

ruce Richman, the renowned activist and founder of the Prevention Access Campaign, the organization that launched the undetectable equals untransmittable (U=U) message, is on a return flight from Greece where he joined local advocates in sharing the news that when you're living with HIV, on meds, and undetectable, it is impossible to transmit the virus to others.

For the last several years, Richman has united activists in efforts to end both the HIV epidemic and the stigma that many people living with HIV face. A growing network of health experts, professionals, teachers, siblings, spouses, parents, and friends have changed perspectives on what a positive diagnosis means. Through hard-hitting research and tenacious activism and lobbying, U=U has become a global consensus, recognized by the Centers for Disease Control and Prevention and numerous other agencies, doctors, and organizations around the world.

But despite the immense impact U=U has already had on the esteem, relationships, and overall wellness of those living with HIV (and the people who love them), the rest of the country's general perception of HIV is still outdated. This is what drives Richman's pursuit to change hearts and minds.

"U=U is my calling," Richman, a lawyer-turned-activist, says. "It grabbed me by the gut and yanked me forward. I've never felt such a compulsion and clarity. I knew that undetectable equals untransmittable, but millions of people were suffering because they were not being told and people in positions of great influence to alleviate that suffering were sitting on their hands. I had no choice."



## Mr. Jones

"We have a powerful voice collectively," says Bryan Jones about HIV-positive people. Now he's harnessing it to share the U=U message.

It's been over 10 years since Cleveland native **BRYAN JONES** walked out of his prison cell, having survived stage 4 cancer chained to a prison bed. But even while he was hitting rock bottom, Jones knew this wasn't the end. Something much larger was in store for his life.

"I had come to prison to die because I didn't want my family to take care of me in this ugly death, [but] something was in store for me," the long-term survivor who has been living with HIV for over 30 years reflects. "When I got out, I said I was no longer going to sanction my words. I was going to speak out about HIV. I took back my power."

Jones is one of the pillars in the undetectable equals untransmittable movement, which began with a simple Facebook conversation in 2015 with its creator Bruce Richman. Jones took the U=U message to Canada with the help of numerous other activists, including the HIV community in Ottawa, and in 2018 he was present when Canada became the first country to sign on the consensus.

"It's funny to be part of history because you don't know that when you're in it," he says. "Bruce made a point of being inclusive. I've been on stages I probably wouldn't have got on if it weren't for Bruce helping me. Most of the U=U ambassadors are people who don't fit into the mold, we're all people who are strong and opinionated, who don't agree with the status quo of what's been going on. I think U=U is the most important piece [of the movement] since ACT UP."

As U=U continues to shatter HIV stigma, Jones argues that if we're truly going to serve those who need the most help, we must have a larger conversation about privilege and how it impacts care and treatment.

"I think it's important for the CDC [Centers for Disease Control and Prevention] and our government to start funding smaller organizations and community-based organizations," Jones says. "As an advocate, I found that many providers, ASOs [AIDS service organizations], have their own agendas because so much is required of these organizations to include what the national agenda may be—and the national agenda I think looks very different in different communities."

"The CDC and other organizations have to be careful with the branding they use," argues Jones. "They lock people of color all under the same umbrella. Black, Latino, Pacific Islanders, and Native American people all have our [own] issues. But as it relates to funding, they have us under one umbrella. Then, there's white people. So white people are getting their funding, but people of color, we have to fight for our funding."

Jones has founded The Dirt Advocacy Movement, whose primary goal is to reach the most vulnerable and at-risk in his community, including hosting a food pantry that serves 15,000 people a month.

"There are no single-issue fights because there are no single-issue lives," he says. "The government has to stop treating HIV like a single-issue fight, because there are more important things such as survival, feeding your kids, having shelter, things like that. People have enough to worry about."

"We as people living with HIV have an insight, we have a powerful voice collectively," Jones concludes. "U=U is another example that people with HIV are an intricate part of this fight. People with HIV are going to take it across the finish line."—DA



Richman was recently ranked an impressive no.15 in New York Pride's Power 100, a prestigious list of the state's "100 most powerful members of the LGBTQ community." It's always been in his nature to question injustice and stand up for others. When he was just 6 years old, Richman organized a bird club to protest the bulldozing of land for a new development that would destroy an essential bird habitat.

"We didn't win," he admits. But it was just the start of his activism.

By the time he reached his early 20s, Richman was reading a lot of Buddhist texts, specifically the mantra: "Be happy and help others be happy," an idea that goes straight to the core of U=U by encouraging us all to tap into our intrinsic value as humans, as activists, as people, rather than be defined by borders and terminologies.

"I must have been a guard dog in a past life, because I tend to protect people and be loyal to a fault at times," he explains. "I feel that loyalty to people with HIV whose lives have been clearly devalued in the field and in society. I am very committed to ensuring all of us are valued."

A Harvard Law School graduate, Richman worked in global philanthropy for two decades, developing foundations and programs around a variety of issues (including HIV). Long before U=U came Richman (center) discussing U=U at a recent community symposium in San Francisco



#### U & Dee

A courageous activist Found her calling with U=U.

After ending an abusive 10-year relationship, **DEE CONNER** learned she was living with HIV. Though she went through short waves of depression and alcoholism in response, she knew deep-down that her destiny was too strong to ignore.

Conner rose from the ashes not only for her then-6-year-old daughter, but also for the life she knew was



in store. Two years after being diagnosed, she married again and had another healthy baby girl. These days, Conner uses her platform as host of *Pozitively Dee's Discussion* podcast to address issues relating to HIV and stigma, to be a strong voice for those who need it most, and to continue spreading the message that when you are undetectable it is impossible to transmit the virus to others.

"Sometime in the mid-2000s I knew that I could not [transmit] HIV to my husband," explains Conner, who came out publicly about her status on Facebook in 2014. "We were married for about 14 years and there was a physician I had who basically let us know that I could not transmit HIV to him. Although the words 'You can't transmit' weren't said, I knew what the doctor meant."

But the full breadth of U=U didn't crystalize for Conner until she met likeminded HIV activists like Bruce Richman at the Positive Living Conference three years ago. It was here that the U=U message became articulated in such a way that it inspired Conner to join the fight more directly.

"I knew it was my purpose because I could feel it and it made me feel so good," she says. "My advocacy and U=U have become part of my life and I'm sure there are people who don't get what I am saying. I fall asleep thinking about what else I can do to make an impact to help others—so I don't sleep as much as I should since my brain is always working. My love for community and people leads me to want to educate, motivate, inspire, and encourage everyone."

Another layer of Conner's message is that, "[Community organizations] are the ones doing all the leg work in these vulnerable communities working tirelessly to get people in care who are out of care, working hard with access to care and getting individuals tested," she explains, adding that federal agencies should "stop funding the bigger organizations as much as they do and start looking at who is really doing the work out here in all these communities."

The U=U ambassador adds, "I know many small organizations that have to almost beg for help with funding and this leaves many people left behind who need them. Without the funding, how can any of the small nonprofits get the work done that is needed? That's what I think about resolving barriers, and Bruce Richman is doing just that by starting an ambassador's program for U=U with a panel of all people of color."

As for the future of U=U, Conner says it is "very bright right now as we speak and will continue to keep moving forward in other countries. Now, if we can get more people in the U.S. to do more when it comes to U=U that would be one of the greatest accomplishments for The Prevention Access Campaign and U=U. We can't say we care about those who are living with HIV and not give them this very important message. We all say, 'If you don't want to talk about it, then we'll do it for you.'"—DA





## Found in Translation

Victor Claros is helping other Latinx immigrants understand the U=U message.

**VICTOR CLAROS** knows the ugly realities of war. The El Salvador-born immigrant fled his country after being captured and nearly killed by guerrillas when he was 15. But the young man's spirit never died.

Despite having grown up in a religious and homophobic family, Claros found the strength to come out twice: first as gay to his then-wife, and later telling the world he's living with HIV. What happened next prompted him to take the first step towards becoming a staunch activist.

"I felt guilty, I was really afraid and ashamed," remembers Claros, who was working as an HIV educator at a nonprofit at the time of his diagnosis. "I think, sadly, it took me being diagnosed to realize how much stigma and discrimination people living with HIV face on a daily basis. What made it even harder is the fact that way too often the stigma came from individuals, providers, and workers who were helping people with HIV."

One of Claros's a-ha moments came when he overheard providers making negative comments about their own HIV-positive clients, an experience that made him realize he needed to fight harder for the people they were serving. So, he joined ranks with Bruce Richman and the Prevention Access Campaign to further promote undetectable equals untransmittable (U=U), a consensus that states when you are HIV-positive, undetectable, and on meds, it is impossible to transmit the virus.

Claros says, "The only way I was going to help others was by becoming vocal and openly start talking about these people I was testing on a daily basis. That's kind of the thing that pushed me to come out [positive]."

Being part of the U=U movement helped Claros zone in on the specific needs Latinx people face, which prompted him to cofound Impacto LGBT (ImpactoLGBT.org), an independent group developed and led by queer Latinx individuals from the Washington, D.C., area.

"One of the things we do is we accompany the client—sometimes we have to make two or three interventions—and we take them by the hand to their first appointment," he says of the organization. "Instead of having an interpreter over the phone, we do it for them."

Impacto LGBT, which is in the process of getting its 501(c)(3) status, also advocates for more inclusive language across the medical sphere, highlighting the negative impacts of naïve and stigmatizing language and how important it is for people to understand how it is detrimental to immigrants and monolingual Spanish speakers. While it's slowly bringing vulnerable Latinx communities together, Claros says the impacts are wide-reaching.

"We're sending people who they can identify with because they look like them, speak like them," he says. "They come from Central America like they do. People living with HIV who've experienced other issues like violence. That makes a big impact."—DA



to his attention, he founded Inspired Philanthropy Group, where he worked on initiatives for social change with everyone from Ellen DeGeneres to Archbishop Desmond Tutu, as well as brands like Sephora and Banana Republic.

Still, his personal climb towards clarity wasn't always easy. After being diagnosed with HIV in 2003, Richman spiraled into a cyclone of fear and shame, afraid of transmitting HIV to those he loved. Like many others, he became isolated and says, "[I] didn't allow myself to love."

"I was depressed, suicidal at times, because I'd really internalized the stigma and felt toxic, dangerous," he explained. However, in 2012, Richman discovered the scientific fact that when you are on treatment and your viral load is undetectable, it is impossible for you to transmit the virus to others. That's when he "started to see the possibility of love and real intimacy in my life without fear. It was like a new world."

But the realization turned into outrage when Richman realized that not only were health professionals and the HIV community failing to discuss this fact, but that millions of people living with HIV were not well-connected enough to the medical field to even know it.

"I was being told I wasn't infectious. They were being told they were infectious. Something wasn't right," Richman says. "I started collecting research and talked to clinicians, HIV-positive leaders, heads of medical associations, [and] journalists for input and found the general consensus was that U=U was true and accepted by many in the highest levels. People were so open with me about what was essentially a massive human rights abuse, and many in the field were participants or bystanders."

He adds, "I learned that some doctors felt it was okay to talk about U=U on an individual level, but

there was a great fear that if the information got out to the general public then some people with HIV would stop using condoms, which would contribute to the already rising STI rates. And some people with HIV wouldn't understand that they'd need to take their medications as prescribed to stay undetectable. Rather than educate about STIs and how to stay undetectable, it seemed like it was generally OK to withhold life-changing information from people with HIV."

Richman also found out that doctors who did know U=U were only telling patients who they deemed "responsible." That means that decisions were made through the lens of racism, classism, sexism, and all the other kinds of prejudice.

"People already marginalized by the system were being further marginalized," he says. "It is a human rights issue on a massive scale. I couldn't see that and not do anything."

In 2015, Richman formed a founding task force for PAC to help get the U=U campaign off the ground, today it includes many notables such as Housing Works founder and CEO Charles King, National Black Justice Coalition's Venton C. Jones Jr., chief medical officer of the San Francisco AIDS Foundation Dr. Robert Grant, and HIV activists JD Davids, Carrie Foote, Peter Staley, Sean Strub, and Kamaria Laffrey.

Richman also reached out to Dr. Pietro Vernazza, the author of the Swiss Statement, a proclamation published in 2008 that stated people living with HIV on effective treatment cannot sexually transmit the virus. PAC also worked with respected researchers to create a consensus statement clearing up mixed messages and to confirm U=U was true.

"We created an advocacy video of people with HIV explaining why U=U is important to all of Richman with famed performer Conchita Wurst us," Richman remembers. "Our idea was to use that scientific statement, the video, and our voices to change the narrative about our bodies. We would engage influential people and organizations to join us in confirming what we knew to be true."

The campaign launched in July 2016. Within a few weeks, New York City signed on as the first city, public health department, and group of public health officials in the world to officially recognize the truth in the U=U statement. It was the birth of a movement.

"During the first few years, I was a machine," reflects Richman. "The movement was much bigger than me, and I felt that my personal life didn't matter. I was intensely driven because I knew how people with HIV were suffering, and then I'd see how U=U was changing lives. And I was full of outrage that people in influence were doing nothing about it, especially in the U.S."

Something shifted at the 22nd International AIDS Conference in Amsterdam in 2018. "U=U was everywhere," he says. "It was truly global. When Dr. Alison Rodger [of the PARTNER studies] said from the stage, "The risk is zero' and 'The time for excuses is over,' and acknowledging our campaign, I felt I could relax more. I felt tremendous gratitude."

It's clear that U=U is a torch for the HIV community as it steps into the future. It's also a reminder of where we come from. As Richman puts it, "Systems need to be challenged, or else they become monsters that thrive on keeping things the way they are."

"We can say U=U now because of activism dating back to the '80s. We also can't get complacent now that we know U=U. We must continue to hold accountable not only our government, but also the community organizations and people who are meant to represent us and have our backs yet are still not sharing the message."

Richman adds, "Before U=U, so many of us never imagined being able to love, to have sex or to conceive children without fear. That fear was present in the most intimate moments of our lives. After U=U, people are having social, sexual, and reproductive lives they never thought would be possible."

For example, "There is a well-known activist in the U.S. who hadn't had sex in 15 years. Now she's in a relationship with a woman," Richman says. "Another activist had attempted suicide after diagnosis and felt his semen was toxic. Now, he's married to an HIV-negative man. A woman living with HIV in Canada had been afraid a condom would break every time she and her husband had sex for over 20 years. The day she learned U=U, she went home and had sex without a condom for the first time. I've met people who point to their babies and say they're because of U=U, or show me their engagement rings."

A major piece of the movement is sparking a larger dialogue between community organizations and federal agencies, like the CDC, which is often criticized by HIV activists for not including people of color and transgender representatives on initiatives that impact these communities most.

However, despite numerous protests and demonstrations, which Richman admits are sometimes necessary, ultimately we need to get to a place where we change the world together.

"I think if we point fingers at the feds, we also need to be looking at the nonprofit and activist role," he says. "Are we doing enough to address the barriers to care? There are powerful people and organizations in the U.S. who have done essentially nothing to share the U=U message. They talk about stigma being the greatest barrier





#### Truth Teller

This Louisiana-born activist had enough of the official HIV narrative, so she decided to change it.

**ALLEEN KING-CARTER** has used her life to spark change and dialogue about HIV. She is the founder and CEO of Living in 3-D, an HIV education organization that produces anti-stigma initiatives across communities. A state-certified HIV counseling, testing, and peer facilitator, King-Carter began her career at the Philadelphia Center in Shreveport, La. But while her life has been widely centered on activism, she's the first to tell you that finding her voice took effort.

Even while King-Carter was working in the HIV sphere, she tells *Plus* that she was still closeted about her status. It wasn't until she attended the DREAM Symposium Retreat several years ago that a fellow advocate helped her realize a larger calling.

"During a breakout session, my shero Monica Johnson said, 'I don't have time or T cells to stress about how someone else feels about my HIV status," King-Carter remembers. "She was the first openly positive woman I ever met. She was open in her truth and encouraging, confident, no filter. She helps so many, including me. I thought, If she can help people living with HIV by just being bold and telling her story, I want to be like her."

The next year, King-Carter had a huge HIV coming out party to celebrate her birthday. Little did she know that soon she would meet a man named Bruce Richman who would alter the course of her activism.

While attending the "HIV Is Not a Crime" conference, Richman posed this question to King-Carter and other attendees: "Did you know that if you become undetectable while taking your meds, science says you can't transmit HIV?"

That one sentenced struck a chord in King-Carter. "[Richman] told me where to find the research, and so I did," she says. "I became angry. Why hasn't anyone told me this before now? He asked after knowing the science, would I be willing to speak out on film and support the movement. So, I pulled out my smartphone [and] ranted about the B.S. of it all. Then I joined the founding steering committee for U=U. I thought, If they can't tell the truth, we'll tell it for you."

Now a U=U ambassador, King-Carter has pushed the movement to new heights, leading with the message that the quicker a person starts medication, the sooner they can become undetectable. She's also been a staunch critic of the Centers for Disease Control and Prevention for failing to do proper outreach to those most in need.

"The CDC and other federal agencies did PLHIV and all humankind a disservice by not supporting and promoting the true science of U=U," she says of the years prior to October 2017, when the agency endorsed the consensus. "Now, they have finally embraced U=U, but after years of not telling the truth. Many—on their watch—did not obtain access to care because who in their right mind would take meds, attend appointments, and take care of their health, when eventually it didn't matter because they could always down the line harm the people they loved? Although it is untrue, that's the myth their unwillingness to tell the truth promoted."

Looking to the future, King-Carter knows that things are changing swiftly. This time, poz folks are leading the conversation.

"U=U is for the people by the people," she says. "People living with and affected by HIV/AIDS said that since society won't tell the truth about our health, we will! I believe the future of U=U will reflect all people, be in all languages, in all regions of the world, told by people living with HIV."—DA

to ending the epidemic and aren't using U=U to dismantle it. They talk about having the tools to end the epidemic and mention PrEP, but forget to mention U=U, which [renowned HIV researcher] Dr. Fauci calls, 'The foundation of being able to end the epidemic.'"

"Roughly 500,000 people with HIV are not on treatment and in care," Richman adds. "Most are slowly declining in health and progressing towards an AIDS diagnosis because they are not getting the care they need. And there are also several hundred thousand people with HIV who are suffering from social rejection, isolation, depression, suicide, intimate partner violence, prosecution, and murder because they and others think they're infectious. The fact that PrEP continues to be the priority of too many of our leading HIV organizations shows us who is valued and who is not. I'm not knocking PrEP. We need PrEP. It is an extraordinary HIV prevention option, [but] access to PrEP should not be a higher priority than saving the lives of people with HIV."

Moving into 2020, the future is certainly bright for the U=U movement. But in order to fully grasp its potential, Richman says we need new minds and innovators at the table.

"We talk about disruptive innovation, but we're going back to the same well that has kept us where we are," he says. "We need the greatest minds to come together to work on the U.S. HIV response like it's a high-level consulting project. We need brains from other industries like the high-tech field to attack this issue from multiple perspectives. There are many entrepreneurial and brilliant leaders emerging in the U.S. field who could make an impact on a national scale if they were in positions of influence."

While he cares most about saving lives of those already living with HIV, Richman knows it's also critical to share the broader public health impact of U=U. In other words, broadcasting that getting all HIV-positive people on treatment and to undetectable viral loads is the best way to end the epidemic.

"It's important that advocates prioritize the U=U public health argument when asking for increased funding for treatment, care, and services; not just for the wellbeing of people with HIV but also to prevent new transmissions. That prevention argument will align with many policymaker's interest in HIV prevention. The concept is: if you



want to end the epidemic, invest in the wellbeing of people with HIV. Ensuring the people with HIV have the treatment, care, and services we need not only keeps us healthy, but it's the most effective way to stop new transmissions."

The campaign is also building its global communications division to better serve the nearly 1,000 official U=U partners in almost 100 countries that are seeking resources to get the message out in clinical, public health, and policy networks.

In late 2020, it plans to launch a U=U grant-making fund. After all, "it's important to cultivate the innovators," Richman says.

"Look at the people and organizations who got behind U=U early on when most folks were either afraid to say it or were fighting us. These are the bold innovators and early adopters who challenged business as usual. They risked their personal and professional reputations—some risked their lives—to stand with the truth. These are the kinds of people we need to be leading the U.S. and global HIV response. We need to look at the ones who fought [against] U=U and are still in positions of power. These are not the people who should be in power. They should never be allowed to make decisions about our HIV-positive bodies again." •

#### Meet More U=U Ambassadors

These activists have answered the call to share the undetectable equals untransmittable message.

The Prevention Access Campaign is the organizational force behind the consensus that undetectable equals untransmittable (U=U). Leading activists, growing voices, and renowned healthcare professionals have joined PAC in educating and empowering HIV communities and health care providers.

The U=U campaign's current ambassadors (some profiled in this issue and others listed below) have gone through extensive training in the science that proves those who have undetectable viral loads cannot transmit HIV, as well as in strategies for communicating and advocating around that stigma-busting message. To learn more or to connect with the ambassadors for community events, speaking engagements, and more, visit PreventionAccess.org/ambassadors.

Arianna Lint, Fort Lauderdale, Fla. An outspoken trans activist living with HIV, Lint is the executive director of Arianna's Center, a South Florida community-based organization providing advocacy, education, and training; case management; and linkage to care for trans people. Originally from Lima, Peru, she is also part of the National Board of PositivelyTrans and The Well Project.

Anselmo Fonseca, San Juan, Puerto Rico A long-term survivor diagnosed nearly 30 years ago, Fonseca is a gay Latino whose work was recognized by the Obama administration as one of the 350 Most Influential National Advocates during the launch of the National HIV/AIDS Strategic Plan 2010. With over 20 years in the field, Fonseca is also a Ryan White Part B Community co-chair where he mentors poz representatives. He is also the cofounder of the Coalition Cero HIV PR.

Deondre Moore, Houston, Texas Since being diagnosed at 19 years old, Moore has dedicated his life to help his community achieve a vital education on HIV and prevention. He has also served as ambassador for Greater Than AIDS as well as the SpeakOut advisory committee. Recently, he became the first out HIV-positive person in Texas to announce his candidacy for state representative.

Luis Mares, New York City As director of community mobilization programs at the Latino Commission on AIDS, Mares plans, develops, and implements national campaigns for National Latino AIDS Awareness Day and National Hispanic Hepatitis Awareness Day. He also plays a vital role for the New York State Department of Health AIDS Institute, the AIDS United Community Mobilization Subcommittee, and the NYC AIDS World Day Event Planning Committee, among many others.

Mania Mejia, Fort Laudendale, Fla. The current co-chair of the women and minorities outreach for Dab the AIDS BEAR project, Mejia also coauthored the book From a Warrior's Passion and Pain, a real-life account of her 30-plus year battle with HIV. She sits on the board of directors for CANN and Arianna's Center, and is currently representing the state of Florida as an advisor and consultant for Gilead's Compass Initiative.

Roscoe Boyd, New York City, N.Y. As executive vice president of external relations at SLAY Media House, a leading online entertainment destination for queer and trans people of color, Boyd is an expert in leadership, sales, public speaking, and education. A Detroit native, he has worked with various organizations like Callen-Lorde Community Health Center, the HIV Stops With Me Campaign, and New York State Department of Health.

Wanona "Nunu" Thomas, Atlanta, Ga. Thomas has used her HIV diagnosis to inspire people across the country through Live In Your Truth, a Milwaukee-based nonprofit she founded that focuses on empowering and inspiring individuals in recovery from diagnoses of life-changing conditions. A writer for the blog A Girl Like Me with The Well Project, Thomas is also an ambassador for Youth Across Borders and is an HIV expert consultant for Merck.

Yonce Jones, Bronx, New York A vocal trans advocate for nearly 15 years, Jones is part of Harlem United and AIDS United. She began her HIV activism as a teenager while working a summer job in the basement of a community center, and continues her advocacy today. "I am not a disease, I am simply Yonce from the Bronx." — DA