



Long-Term Survivors and Youth Benefit From U=U

Gregg Cassin and Hernando Umana credit Undetectable Equals Untransmittable with helping them live fuller lives with HIV.

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An HIV survivor for almost 30 years, Gregg Cassin, 65, started his spiritual journey as a boy growing up on Long Island, New York. “As a kid, it was not in the days of Ellen [DeGeneres],” he said, “there were no openly gay people. I had no idea who I was or what I was.” Since there were no role models for him in his life, Cassin did what he calls “the Catholic boy thing.”

“I had a spiritual director who was a priest,” Cassin says. “He never came out of the closet; it was just understood that he was gay. I can remember at some point saying to him, ‘Do I have a vocation? Am I going to be a priest?’ And him saying, ‘Move to San Francisco.’”

It was 1980. Cassin packed up his belongings and made his way from his parents’ home to the City by the Bay, where, prompted by his own HIV diagnosis and to comfort people who are suffering, he has dedicated his life to helping people, specifically those living with and affected by HIV and AIDS..

Gregg Cassin
Courtesy of Gregg Cassin

“I never could figure out when I became positive,” Cassin says. “But I listened to this famous doctor in San Francisco, she mentioned flu-like symptoms with an unusually severe sore throat, and I’d never heard anyone say that before.” Cassin reflected on his own life experience and recalled a time in Paris when he was severely ill with a painful sore throat and slept for almost two days straight. “There was easily a week when I couldn’t take a sip of water,” he says. “It felt like there was a hole in my throat.”

Cassin does, however, remember the diagnosis. In 1985, a friend took him to a doctor. “I don’t

remember getting a test," he says. The doctor examined him and found swollen lymph glands. "You're probably positive," the doctor said, "nothing I can do for you."

There was no cure. At the time, there were no effective treatments. And the stigma surrounding the disease was soul crushing. Still is. Not knowing what the future held for him—or for the ever-growing numbers of people with the virus—Cassin found a way to help.

"There was something amazing happening in my life dealing with my own mortality, seeing so many friends die, trying to help," Cassin says. "I started this thing called the San Francisco Healing Circle."

Cassin began facilitating groups of people affected by HIV and AIDS, bringing them together for a kind of spiritual healing. He also founded the San Francisco Center for Living and has continued to host retreats and speak at conferences and events locally and nationally.

When Cassin first heard the news about Undetectable Equals Untransmittable (U=U), the fact that people living with the virus who have an undetectable viral load thanks to effective antiretroviral treatment cannot transmit the virus sexually, he was mostly excited for his community. "I work with a lot of long-term survivors," he says. "I work with a lot of women. I work with a lot of straight men. I work with a lot of trans women," he said. "U=U transformed people in helping to lift stigma."

"The people in our community," Cassin goes on, "carry so much stigma, it's like a 40-pound weight—like, ugh!—and U=U definitely lifted some of that."

"My best friend is a trans woman," he said, "and she deals with stigma all the time." U=U changed how she felt about herself. Cassin explains, "She told me, 'With U=U, I feel like I'm healed. I feel like I'm innocent. I feel like it's all washed away.'"

Cassin adds, "Every human being has to go on a spiritual journey to find out who you are and find out why you're here."

"I got [HIV] from the second person I ever slept with," says New York City-based actor and entrepreneur Hernando Umana. It was 2009, and he was 21 years old.

"I didn't have any sex education as a kid," he says. "My parents pulled me out of sex ed classes. So that, plus being gay. There are no sex ed classes for being gay. So I felt invincible."

At 20 years old, Umana was dating an older man: He was 28. "We slept together a couple of times, unprotected," he says, "and I found out [I had HIV] because I got crazy sick for months. It happened crazy fast. I slept with this guy in November, and by the end of December, I was crazy sick." This man was the only possibility, since he and his first sex partner had both been virgins.

Hernando Umana's August 20 Instagram post [Instagram/@hernandoumana](https://www.instagram.com/@hernandoumana)

The manager at the restaurant where Umana worked told him he needed to seek medical attention and recommended Ryan Health. "I got tested, even though I told the doctor I didn't think I needed to because I didn't think I was capable of getting HIV," he says. "I thought that HIV was only for certain kinds of people, whatever that means," he adds.

The diagnosis sent Umana's mind into a spiral. "My first question to the woman who told me was 'How long do I have to live?' because I truly knew nothing," he says. Luckily, she was sympathetic. "She said, 'Honey, I've been HIV positive for 15 years, and I can tell you you're going to be just fine.'" Still, Umana was in shock. "I spent the next few weeks crying. There was a lot of confusion," he says.

A few weeks after the diagnosis, two of Umana's friends made an off-the-cuff joke about his HIV to him. "I was really caught off guard," he says, "but it was the first time I realized that this doesn't have to be so terrifying." One of Umana's defense mechanisms has always been sarcastic humor. "Once I started making jokes with friends and people [about HIV], I realized that not only did it make me feel better, but them hearing me make a joke about it made them feel better about it too," he says.

Umana was started on medications right away and quickly regained his health. The singer-actor-dancer went on to great success, including being cast in the Broadway company of the 2013 musical *Kinky Boots*, which won the Tony Award for Best Musical, and the national tour of *School of Rock*. In 2018, Hernando made his HIV status public with a post on Instagram. "It was the most important, scary and liberating post of my life," he says.

Finding out about the science of U=U was another liberating moment. "That was life-changing," he says. "That was game-changing for sure." What he really appreciated was that finally there was a phrase for the science—the fact that HIV-positive people with an undetectable viral load cannot pass on the virus sexually—that was easily understandable. "Just being able to tell possible sex partners, like, 'This has been proven!'" he says. It has helped him to inform partners not only that he is positive but also that he is undetectable. "I've literally sent links to people," he says.

Today, Umana finds that there are days that he forgets that he's living with HIV. Still, he is very up-front about his status and enjoys being able to tell people about U=U. "I want to remind people that if someone doesn't know about U=U, consider taking a pause and making sure they do know," he says. "Your journey is your journey, and you are not responsible for educating everyone," he says, "but you could be the change you want to see."