Savvy Survivor

Eric Sawyer is the first recipient of the AIDS activism award given by Housing Works, an organization he cofounded in 1994. In 2011, he marks 30 years of surviving HIV while fighting for the lives of others. He shares his story of survival, thoughts on his current role at UNAIDS and a look at his future.

December 28, 2010 By Oriol R. Gutierrez Jr.

How does it feel to be honored by an organization you helped found?
I became symptomatic for HIV in 1981 and tested positive for HIV in 1985, the first year the test was available. In those early days prior to treatment, you felt you were on a conveyor belt leading to your grave. I didn't plan more than a couple of months ahead. So, it feels a little strange to have survived long enough to get an award for my work.

I was honored to receive the award [in December 2010] from Housing Works because the organization epitomizes the spirit of the HIV response, which is based on the concept that every life matters. To be honored by [Housing Works] for doing work that I feel I have an obligation to do is icing on the cake.

You also cofounded ACT UP. Were the groups connected?
I got involved in ACT UP primarily because of my friend Larry Kramer. In 1987, Larry called me when he was getting ready to give a call-to-arms speech at the LGBT community center in New York City. There had finally been a $100 million allocation [by the U.S. government] for AIDS research, but he discovered almost nothing was being spent. He wanted the media to know the government wasn't taking action to find treatments or a cure for HIV.

His plan was to start a civil disobedience organization to draw public attention and put pressure on the government to take appropriate action.

I had just lost my life partner to HIV and was really angry there was no way to help save his life. So I agreed to come to his speech and be a plant in the audience and to give a cheerleading spiel—a pledge of support to organize the first HIV/AIDS civil disobedience action. The rest is history.

Despite ACT UP's success, HIV continued disabling people, particularly poor people, and no one

was providing them with housing or other needs. Many people faced horrible discrimination from their own families; AIDS groups didn't offer housing; and no housing groups wanted to take on people with AIDS.

So, the housing committee of ACT UP organized to advocate for medically appropriate housing and access to entitlement programs. We challenged the government's policy of housing people with AIDS in shelters with people who had tuberculosis and got a court order for people with AIDS to be housed in medically appropriate housing. That opened the door to get capital funds to build AIDS-specific housing. In 1994, Housing Works was born.

You also cofounded Health GAP. How was that group born?
The situation in the United States was bad in the early days of the HIV epidemic, but it was much better here than in the developing world. I decided the bigger need was ensuring access to treatment in the developing world.

In 1996, I was asked to speak at the opening ceremony of the XI International AIDS Conference in Vancouver. There was a lot of hype about new treatment that year. David Ho, MD, was named "Man of the Year" by Time magazine that year for helping to develop highly active antiretroviral therapy. There was even talk that combination therapy involving protease inhibitors could constitute a functional cure.

But the truth was the cure really wasn't here and the treatments we had were highly toxic, really expensive and out of reach for 97 percent of the world's HIV population. So in my speech, I gave a wake-up call to the media and the public health establishment saying we needed an "access to treatment movement."

My message resonated. "Bridging the Gap" became the theme of the XII International AIDS Conference in Geneva in 1998. As a result, Alan Berkman, MD, asked me and a few others from ACT UP to create an ACT UP–styled movement for access to treatment in the developing world. In 1999, Health GAP was created.

Tell us about your current role at the Joint United Nations Programme on HIV/AIDS (UNAIDS).
For many years, I had been a collaborator from the nongovernmental organization (NGO) side with the HIV program at the World Health Organization and then UNAIDS.

After a brief stint in a think tank project called AIDS 2031, I was hired as a civil society partnerships advisor for UNAIDS in 2008. I moved from being an outside organizer of NGO efforts to being an inside facilitator of NGO involvement.

I'm currently facilitating NGO involvement in the 2011 high level U.N. meeting on HIV, which will be a review of the world's progress with regard to obtaining universal access to treatment. I'm also working on a campaign called "Light for Rights." It's a World AIDS Day commemoration project designed to highlight the need for human rights protection for all people with HIV.

How does it feel to be a long-term survivor of HIV?
I'm obviously really happy to have survived HIV for 30 years. The alternative of dropping dead still isn't very attractive. Many long-term survivors experience the joy of continuing to enjoy life, but they also have a certain level of survivor's guilt.

One of the questions that I've always asked myself is, "Why is it that I have survived a fatal disease like HIV and more than 26 million others have not?" It's because I was able to access the latest medical technologies as soon as they were developed. I feel because of my privileged access to care and treatment, I have an obligation to fight for the people who don't have that privilege.

Where are we in terms of fighting HIV/AIDS today?
The economic crisis is creating formidable challenges for obtaining universal access to treatment. We've made progress. We've increased the number of people on ARVs from 1 million in 2006 to almost 5 million in 2010. But, we have another 9 million who need treatment immediately.

We know how to stop the spread of HIV. We have effective treatments that can help people with HIV live a long time. But we don't have either the human or financial resources to provide people with prevention education, condoms, clean needles or ARVs. To win the battle against HIV/AIDS, we need a massive scale-up of human resources and money.

What's your assessment of the current state of AIDS activism?
We've seen AIDS activism drop off a great deal partially because of our successes. When people with HIV in the United States were dropping like flies, there was a lot of motivation. When effective treatments arrived, many activists went back to their daily lives.

We have to find a way to encourage young people to enter the HIV response for the long haul. We need to develop a sustainable mechanism to fund activism, to fund advocacy campaigns and to fund human resource development and capacity building.

We're going to have huge challenges in mobilizing the activism needed to effectively combat HIV until we find such funding. We may have to draw on PEPFAR [President's Emergency Plan for AIDS Relief] funds or bilateral aid or develop special funding mechanisms to develop programs and build capacity in NGOs.

Until we reform laws that criminalize behavior, and until we ensure that people at risk for HIV or living with HIV have equal rights, and until women have equal rights, we're going to have trouble. The absence of human rights protections undermines the HIV response.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/Savvy-Survivor-HIV-19652-8355