Why AIDS Must Be Cured

The executive director of AIDS Policy Project on expanding international cure advocacy.

March 15, 2011 By Kate Krauss

Winstone Zulu is the first person to publicly come out as HIV-positive in the African country of Zambia. Now in his early 40s, he has been an activist for 20 years. He has been commended by Nelson Mandela for his work. I worked with him in late 2009 when he contacted me to help him advocate for local children who had been cut off a PEPFAR-funded food program.

At that time, I mentioned that we had launched an AIDS cure campaign. He replied immediately:

Yes, yes, yes. We badly need a cure. Why is all the important research on treatments, vaccines and microbicides? What about me who is already infected? Please send us details of how you are pushing this agenda and we can take up here as well. The world will likely to react faster if it hears the same message coming from all corners of the earth. Time for a cure!

Since then, Winstone has written newspaper articles about AIDS cure research, shared information with his colleagues, and delivered speeches in support of cure advocacy. He is slated to fly to New York later this month for a meeting with Stephen Lewis.

I thought I would get to meet him in person at last year's Vienna AIDS conference. Instead, while I was talking to researchers and pushing AIDS cure research, Winstone was battling a gastrointestinal infection and fighting for his life.

From his email: *I very nearly died from the damn disease. I couldn't even attend Vienna on account of that, even though I was scheduled to speak at a panel. Three weeks ago AIDS almost orphaned my four children. I want to be assuredly alive when they graduate*.

He eventually recovered and he hasn't given up. "Without a cure it is death for many of us," says Winstone. Many people are becoming resistant to first and second line drugs. There is little money to pay for new regimens. Without effective medications, they can't survive, and wealthy countries are cutting back on treatment funding. Only five million of the 33 million people with HIV have access to AIDS medications. No one knows how many are becoming resistant to the drugs.

What it's like to have AIDS in Zambia:

I have been on treatment since 1996 and I am currently on one of the most expensive and inaccessible regimens in Zambia. I receive my drugs from a group of kind people in New York and I believe I am one of the lucky few--if not the only one--whom they are supporting with this regimen in Africa. And yet I am still having problems with AIDS.

We face perennial stock-outs of anti-retroviral drugs in several towns and cities of Zambia, including Lusaka. It is very clear that under this scenario even the argument that treatment is prevention is not possible. If drugs can run out in the capital city of a country, it is not difficult to imagine the horror in the rural and difficult-to-reach parts of the country. To compound the problem of drug stock-out is the issue of the poor nutritional support for many of those taking the medicines. Here many people on treatment are forced to take all their drugs on an empty stomach.

Winstone was ill again last week, and had to cancel a meeting during which he had planned to seek funding for cure advocacy.

He knows we are working to dismantle a myriad of obstacles for AIDS cure researchers--difficulties getting drugs into human trials, and lack of support for new ideas. And funding. He wrote to me a few days ago:

All around me I see all sorts of programs aimed at preventing HIV from entering people's bodies. We have male and female condoms; there is serious research into microbicides; there is a campaign to stop transmission of the virus from mother to unborn child and there is even scientific evidence that if one is on treatment and reaches undetectable viral load that there are fewer chances of infecting another person. The only person left out of the whole equation is me: the one already infected.

In the past 20 years since knowing my HIV status I have always believed that this was because it was extremely difficult to find a cure.

Then late last year I got hold of the AIDS research budget of the National Institutes of Health (NIH) in the USA. It was shocking to find that despite all the talk about striving to create an AIDS-free world, only 3% of the budget goes towards research to find a cure.

Now do not misunderstand me. We need new ARV treatments to keep us alive, and we need vaccines to protect those that are not yet infected. But, in my opinion, we need a cure that will also keep the 33 million people with the virus free from AIDS without any need to take drugs. Donor countries are getting fatigued with making contributions to what seems to be a problem without a permanent solution.

I was sick again from Monday to Thursday this week. As usual I look like a poster boy of the pre-ARV AIDS generation. I am sick and tired of missing important development meetings like the one I skipped on Monday [at a foreign embassy]. I am sick and tired of having to depend on my wife, Vivian to come down and look after me for even the most mundane of needs. I am sick and tired of

taking these drugs that do not seem to make a difference. I am sick and tired of hating myself so much when I miss a dose, even for just 20 minutes as I did this morning because I took Vivian back to the bus station.

Kate here: Back in DC, the National Institutes of Health is talking about spending $5 million more for new AIDS cure research. In contrast, California's state stem cell agency routinely hands out $15 million grants for a single AIDS cure project--some of which have made history, as we saw recently at the Boston Retroviruses conference. There is money at the NIH left over from two different institutes, NIDA and the NCRR. Unfortunately, there is not yet the will to spend it on AIDS cure research.

So here we are. Thirty years of AIDS, 25 million deaths. The United States has a million people with AIDS, along with most of the AIDS research money, many of the world's top scientists, drug companies, and media. Outside the US, in subSaharan Africa, 25 million people with AIDS are barely holding on. It's time for us to speak out together about the need for a cure.

Together, can we make this the first generation of people in 30 years to truly survive AIDS?

What can you do to advocate for a cure for AIDS?

1. The most important thing you can do is call up and make an appointment to make an appointment to meet the staffers of your US Senators and Congresspeople (if you are lucky, you will meet with the member of Congress herself). Bring a small group with you of good talkers: people with AIDS and their allies (the head of an AIDS NGO, an activist, a faith leader, a physician, a researcher, etc.) to visit your member of Congress and educate them about this problem--You can read and bring along fact sheets and reports from our web site, at www.AIDSPolicyProject.org.

Have a pre-meeting to plan what you want to say, be sure to ask for more money, and give each person a speaking part. It's easy, fun, and powerful. Activists are calling for an increase in AIDS cure research funding to $240 million, using funding left over from the NIDA and the NCRR. Email us at info@aidspolicyproject.org if you need help with this.

2. Spread the word about this situation to your friends and the leaders at your local AIDS service organization. Bring fact sheets to your support group and your doctor.

3. Read our report, "AIDS Cure Research for Everyone." Write letters to the editor about a cure; blog and tweet about it.

4. Come to our AIDS Cure Activist Conference! The AIDS Policy Project is organizing an AIDS cure activist conference on May 28, 29, and 30 in Philadelphia. Join us, as together we work in solidarity

with activists like Winstone. A cure isn’t just a research issue or a US issue. It’s a global health issue. For more information, contact kate@aidspolicyproject.org.

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