We Can Change This

The former Peace Corps volunteer who helped change its discriminatory HIV policy reflects on five years of living with the virus.

January 11, 2013 By Jeremiah Johnson

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January 11 marks five years since I was diagnosed with HIV. Since then, I have undergone a transformative journey filled with highs and lows, peaks and valleys. Yet through it all—through every single challenge I have faced as a gay man living with HIV—I have had tremendous support. I had a father who was brave enough to stand by me even when he didn't understand me. I had friends who loved me when the negativity from others and from within myself felt like it would crush me. I had a loving and caring doctor who patiently listened to all my questions (even the ones I was afraid to ask) and helped me get on life saving treatment.

It is thanks to them that a situation which could have broken me has instead empowered me. I am stronger and more capable than ever before to fight for my rights and the rights of other people like me.

But, for me, it was very dark before the dawn. Before I could step into the light, I felt alone in the shadows, trying to find my way by myself. When I was diagnosed with HIV, I was halfway across the world; far away from my family and friends and serving as a Peace Corps volunteer in Ukraine. After serving for 16 months with 11 months to go, I was offered an HIV test as part of my mid-service medical exam. I took the test, not expecting that it would come back positive, and not knowing how much it would change my life.

That was how, thousands of miles from home, I found out that I had HIV. The virus that was at the center of so much worldwide discussion was inside of me - just under the surface of my skin. I knew the facts: I knew that I could live a normal life so long as I had medication, but still I felt despair in my heart. Every negative thing I had ever heard or thought about the virus or those who carry it seemed to suddenly flourish in me, and I internalized it. The shame, the fear, the despair all grew in and around me. I needed help, and I desperately needed support. But, even more than that, I needed empowerment. I needed to finish the last year of my Peace Corps service and prove to myself that my diagnosis would not define me. I decided, even in the dark haze of my diagnosis, that I would not retreat and not back down. I needed more than ever to feel valuable, to feel loved, and to feel powerful.

But instead of finding what I needed, I found opposition, isolation, stigma, and discrimination. Shortly after my diagnosis, I was contacted by Peace Corps administration and told that I would have to leave Ukraine - that the laws there would not allow me to complete my service. When I later asked them if I could finish my service in another country with less oppressive laws, I was told that I could not continue

as a volunteer. According to them, being HIV positive meant that I could not fulfill my duties as a volunteer and that they would be unable to take care of my medical needs in a developing nation. It did not matter to them that I was physically just as strong as ever, or that all I needed was regular blood work and possibly treatment to keep me strong. It seemed that Peace Corps saw me only as a burden - as a liability that needed to be returned home immediately.

The loss I felt was tremendous, and the obstacles ahead of me felt insurmountable. Instead of support, I was surrounded by people who seemed ready to get rid of me. Instead of empowerment I had been shown just how little worth I had. Instead of love, I felt despair—deep and profound and all encompassing. Behind me I saw only loss: The loss of the work I was completing in Ukraine, loss of the hopes I had for the projects started in the small town where I had been stationed, the loss of the friends I had made and the students to whom I had taught English, and finally, the loss of my perfect health. In front of me, I saw fear - the fear of being forced to tell friends and family why I had returned home, the fear of unexpectedly having to find a job and a place to live, the fear of finding a doctor and confronting my new diagnosis.

It took a friend—an amazing person in my life—to remind me that I was not powerless and that I was just as valuable as ever. In my darkest moment, my friend lifted me up so that I could see the path forward- so that I could see my way back from the brink of destruction. It is because of that support that I felt strong enough to contact a lawyer about my dismissal from Peace Corps. That lawyer then connected me with the American Civil Liberties Union, who took my case and helped me challenge the legality of what Peace Corps had done. From there the support around me grew - as I felt more empowered, more friends and family rallied to my side and gave me the love I needed to fight the negativity that was invading my life. I found a job where I could be out about my HIV status. I found a doctor who treated me as a peer and gave me confidence in managing my own health. Things still felt dark, but the warmth around me let me know that night was almost over - that I was headed back to a better place.

Just six months after being kicked out, the dawn came. The Peace Corps stopped defending their policy and announced that volunteers with HIV would be able to continue their service uninterrupted. It was a victory not only for the rights of volunteers living with HIV, but also for me, personally. It showed me that no matter what others said about me, I could stand up to anything so long as I had support. With the help of my friends, my family, and my doctor I would not only survive—I would thrive.

It hasn’t been all smooth sailing since that time. It is never easy to be part of such a highly stigmatized group of people - but with every bump and every fall, I have had a network of people to help catch me- to help me find my way back to where I belong.

The support that helped me fight back against discrimination is the kind of support that every single person living with HIV should receive. Every. Single. One. I don’t care how they got HIV, where they live, who they love, what ethnicity they are, how much money they have, or what gender they are. We all deserve to be loved, embraced, and empowered. We should all have the right to access the best medications that don’t produce side effects. We should be protected by our governments, not prosecuted by them. We should all have healthcare from nonjudgmental doctors who treat us as equals. We should have friends and family who stand by us and help us continue to reach for our dreams. We should all be treated as amazing, beautiful, sexy, and very capable individuals. We should all be treated as more than a virus.

But right now for the 34 million people living with HIV there is no guarantee for support, no guarantee for

love, no guarantee for safety, and no guarantee for medical care. Right now there is so much work that must still be done to protect the rights, dignity, and dreams of HIV positive individuals. And we can't wait because right now millions of people still need life-saving treatment. Right now, 45 countries still have laws that undermine the rights and well-being of people living with HIV. Right now millions of people, human beings just like you and me, are dying every year because medications are too expensive, too inaccessible, too far away. Right now the dreams of millions of people living with HIV must take a backseat to fear: fear of violence, fear of financial insecurity, fear for their health, fear of being rejected, fear of being alone.

We can change this. You and me. We and our friends. We can raise awareness through social media. We can write our legislators. We can learn what efforts are being made to stop injustice and support them. We can empower people living with HIV with our words and never make them feel limited - never clip their wings. We can demand that governments, international organizations, pharmaceutical companies, medical doctors, AIDS service organizations, and HIV prevention organizations place the wellbeing and quality of life for people living with HIV above ALL other priorities.

Support and justice is obtainable for all those with HIV, but we must all work together to demand for change. It will not be given freely. We cannot keep the status quo; we must look at existing systems, organizations, and policies with new eyes and learn to question what can be better. We will have to think outside of the box and ponder what makes people living with HIV feel like victims, feel helpless, feel stupid, and feel abandoned. We will also have to consider our own role in the stigmatization of people living with HIV. How do we speak about HIV when we think no one around us is infected? How do we deal with the possibility that a sexual partner might be living with HIV? How do we truly and honestly feel about people who are HIV positive?

How do we change ourselves? How do we change the world to be a safer, more empowering place for people living with HIV? How do we stop stigma and discrimination?

Today, five years after my diagnosis, I am thankful that I feel safe, strong, and healthy. I dream of a day when all people living with HIV can feel the same way.

Jeremiah is currently a 2nd year MPH student in the sociomedical sciences department at the Mailman School of Public Health. Diagnosed with HIV in 2008, Jeremiah has firsthand knowledge of the impact that stigma and discrimination have on people living with HIV. Since his success in changing Peace Corps' discriminatory policy on HIV, Jeremiah has continued to raise awareness for the detrimental impact that stigma has on the spread of HIV and the lives of those living with the virus. Most recently, he spent two years in northern Colorado working as a case manager and prevention specialist at the Northern Colorado AIDS Project. There, he learned that there is still much work to be done to improve the quality of life for people living with HIV. To read the 2008 POZ article on Jeremiah, click here. This article was originally published at MSMGF.

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