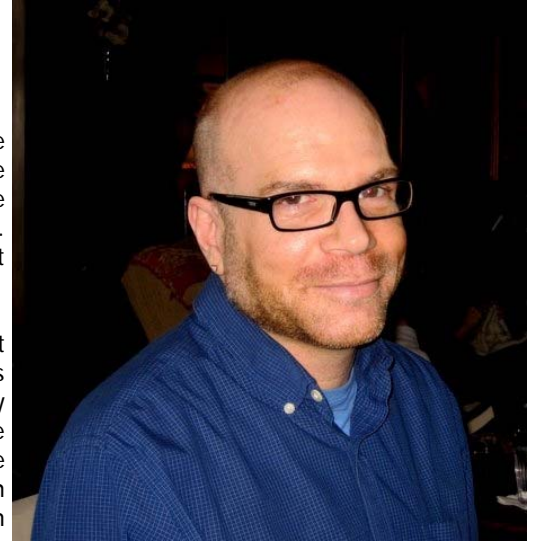


Living To Tell Our Stories: Minnesotans and HIV/AIDS



Diagnosed in his early 20's, Rob has been living with HIV/AIDS for 25 years. When he was first diagnosed, he experienced the denial many people deal with after receiving the news of an HIV positive diagnosis. He was certain there was a mistake; a false positive perhaps? He continued to work and kept his diagnosis a secret from friends and family. Asymptomatic and feeling invincible for many years, he became involved in his first meaningful relationship and felt pretty good about his life.

In 1994, Rob had to face his first opportunistic infection and the ensuing battle that would accompany his life with HIV. Losing the ability to walk and talk, Rob was diagnosed with progressive multifocal leukoencephalopathy, or PML, a rare and usually fatal viral disease that is characterized by progressive damage or inflammation of the white matter of the brain. PML occurs almost exclusively in people with severe immune deficiency; transplant patients on immunosuppressive medications or people living with HIV disease. Rob wondered why his first opportunistic infection could not have been something more manageable like thrush. Because very few people survive PML, Rob was given 9 months to live when diagnosed.

Surviving PML requires a boost to the immune system. Fortunately for Rob, his PML diagnosis occurred around the time several new antiretroviral medications were approved for use in humans. He had been in clinical trials for these medications which quite possibly saved his life. Now he looks back on his struggles through PML and feels very fortunate that he survived a disease from which most people never recover. PML also meant that Rob's family would learn of his struggles and he was able to talk about his HIV disease with them for the first time. As he looks back on that experience, he says, "It was a relief for all of us." As he was now able to communicate openly with his family, relationships improved.

Although he thought he had been given a death sentence, Rob was determined to fight PML and HIV. He accessed homemaker services and his doctor eventually "kicked him off of hospice services." Rob proudly states, "To this date, I am the only patient she has removed from hospice services."

A voracious reader and involved in his own healthcare, Rob did his research and discovered a long-term survivor group member who lived in the Twin Cities. Rob was impressed with the care system in Minneapolis, particularly the HIV medical specialists. After moving to Minneapolis, he started seeing a Speech Therapist and his speech gradually improved. He says, "It was a gift to get my speech back. Before, people looked at me when I struggled to communicate and I felt slow and extremely self-conscious."

Rob also accessed other Ryan White services including Case Management which helped him feel well connected to the Ryan White system of care. Services such as food delivery from one of the Ryan White service providers are crucial to Rob's continued good health. He says, "The home-delivered meals are vital to me. I would not eat without those deliveries." Rob confesses that he tried to "fix himself." He desperately wanted to live life as he did before PML. Although his speech and his gait are not exactly as they were before the disease changed his life, Rob has accepted the fact that PML is real, a part of being alive. "This is the hand I was dealt."

Rob readily acknowledges that he did not have to struggle alone. In addition to the professional services he received through Ryan White programs, he also developed a support system of friends that helped him through his struggles. He speaks of one friend in particular. Wanting to get involved, Rob attended the Minnesota AIDS Walk. When he could walk no more, a friend carried him along the route. This friend continues to push Rob to get involved.

Rob's resolve to defeat PML further strengthened him in the fight against HIV disease. He believes he has things to say and he is learning to make sure his opinions are heard. Wanting to be involved in the Ryan White Community as an advocate, Rob joined the MN HIV Services Planning Council where he serves as a voice for his community.

For World AIDS Day 2007, Rob submitted an entry in the Planning Council's writing contest. His submission was selected as the winning entry and he read his own story on the stage at Intermedia Arts during the World AIDS Day Ceremony. In the spotlight on that stage he said, "It has been a very long & sometimes scary journey. I have never considered myself to be a leader; most of the time I feel broken. But if my story can influence just one young gay man...or if I can erase some of the stigma, ease some of the shame, educate someone who thinks of HIV as a 'manageable' disease, then I become one of the leaders. And sometimes that is all that keeps me going."

Rob is indeed one of the leaders. He is an example to all of a life lived well.