Health Care is a Human Right

The 30/30 Project seeks to bring affordable access to those most in need.

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Julie Lewis is the mother of Ryan Lewis, who is half of the Grammy Award–winning hip-hop duo Macklemore & Ryan Lewis. She also is a 30-year survivor of HIV. In 1984, she contracted the virus from a blood transfusion that she needed after she lost a lot of blood during the delivery of Teresa, her first daughter.

In 1990, Julie's doctor told her that he was informed by a blood bank the person who had donated the blood had AIDS. By that time she also had given birth to Laura, her second daughter, and Ryan. Her husband, Scott, and their three children tested negative for HIV, but she tested positive.

She was told she only had a few years to live.

To mark 30 years of living with HIV, Julie launched the 30/30 Project with the support of her family. The project aims to build 30 health centers around the world that will operate for at least 30 years for those who need it most. Construction for Change will build the centers, and groups such as Partners in Health will staff them.

The phrase “Health care is a human right” has become the slogan of the project. In addition to HIV/AIDS care and treatment, the centers will screen and treat tuberculosis and malaria, as well as provide comprehensive health care. The project already has raised more than $150,000 to build centers in Malawi and Kenya.

To build on the success of its Indiegogo fundraiser, the 30/30 Project has partnered with the producers of Mothers and Sons, the Tony-nominated AIDS-themed play by esteemed playwright Terrence McNally. After each on-the-road performance, a collection will be held with proceeds going to the 30/30 Project.

POZ caught up with Julie in New York City after she flew in from her home in Seattle to talk to the audience at the end of one of the final Broadway performances of Mothers and Sons. During her speech, she elaborated on the continuing partnership with the producers of the play and her perspective as a long-term HIV survivor. In our exclusive interview, Julie gives us more insights.

What happened right after you were told that you might have HIV?
We took our kids to get tested. They were 2, 4 and 6 years old. They took the test on a Thursday and the lab was closed that Friday, so we had to wait until Monday to get results. It was a really long weekend.

Monday came and this was supposed to be Scott’s first day in a new job in Spokane, so we already had everything in a U-Haul truck. There we are in an empty house just staring at the phone on the wall, because we didn’t have cell phones back then.

Finally the phone rang, and I could tell right away the nurse had a cheerful voice. She told us that everyone in my family was fine, except for me. Literally within hours we got into our car and moved. That was intense.

At the time, I knew enough to know that AZT was the only HIV drug. I was so sick when my doctor put me on it. I don’t think I would’ve made it through AZT without the support of my family, especially my brother. I took it faithfully, even though it really made me sick. Eventually my body got more used to it.

Scott and I decided to tell barely anybody because our kids were so little. We read about all the discrimination families faced, and we were new in town. I did get to know a few other women living with HIV in Spokane by getting into a support group for women. There weren’t very many of us, but we were a strong group.

In the summer of 1994 we told our kids. We told them individually because my 10-year-old Teresa would of course react differently than my 6-year-old Ryan in understanding. At that point, it became public information. Whenever it seemed interesting to him, Ryan just shared it. He told his second grade class and even a lady at a grocery store.

So, that was kind of fun. I mean it was kind of funny in a way. It was great that he didn't see why not. He wasn't afraid of people's reactions. He was trying to figure it out in his own mind and he wanted input, so he would tell people.

How did you cope with being diagnosed?
I joined a speakers' bureau and pretty much went to most of the high schools and colleges in Spokane. I was in the bureau from the fall of 1994 until we moved to Seattle in 2003. It had about 15 to 20 people in it at any time. I would say about 80 percent of those people have died, especially those from the early '90s.

As friends from the bureau died, I started not to socialize as much with new speakers to protect myself from losing more good friends. Plus, I went to work for the Spokane Regional Health District. The job was to manage the speakers' bureau, so it became more of a professional relationship with the speakers.

In 1998 I went back to college to get a health educator degree. I already had a degree as a science teacher, but I went back so I could do public health education. I worked as a health educator in bloodborne pathogens, so I did professional trainings not only for HIV/AIDS but also for hepatitis C.

I worked in HIV prevention in all of the juvenile systems, so I did all of the testing of the kids in the drug treatment centers that the court ordered. I taught classes everywhere, from high schools to universities, as well as the pharmacy school at Washington State University. I did a lot of them in high school assemblies.

As an aside, when I became a health educator—especially in those years when medications were still being developed, then protease inhibitors came out and combination therapy started—POZ was a resource for me. It was great seeing the advocacy and seeing inspirational people. POZ broadened my knowledge of HIV/AIDS.

How did you first get the idea for 30/30?
My family had been talking about wanting to do something that was a pay-it-forward project to share our good fortune, but I have a specific moment. Construction for Change had built a hospital in India. I saw a slideshow about how it was built. I hadn't realized until then that women had built this hospital.

Here are these women in their saris with tools in their hands and helmets on their heads building a hospital. The reason was the nearest hospital was several hours away. Despite these women having cars, their children were dying in transport to that hospital. I realized watching the slideshow if they can do that then we can do more.

Our first health center, which is in Malawi and is being staffed by Partners in Health, should be operational in January 2015. We have funding for a number of other clinics, but we are still vetting partner organizations. It takes a while. For any international construction project, it takes about a year from the idea to actually breaking ground.

When it comes to international development, I like to point out the model that Construction for Change uses. It isn't an organization that goes in with a bunch of people to just do their thing. Construction for Change has a community tell them their needs. The group wants to see great work being done for a long time.

We come in with one or two people to hire a local workforce and get local supplies to build a building, then we give it back to that community and we leave. We empower communities by building buildings. We want to leave as little of our own footprint there, other than the building.

I hope that through 30/30 there will be a greater effort from others to bring health care to those most in need for HIV/AIDS, but also for malaria and tuberculosis, as well as many additional diseases that people don't need to be dying from. We actually do believe that health care is a human right.

As for building health centers in the United States, to be honest it's way more expensive to build domestically. I would like to brainstorm ways to partner with local AIDS service organizations and related foundations. That's on my heart too, of course.

How does it feel to be a long-term survivor?
I'm happy to still be alive, especially when I've seen all the things in my life that I may have missed. Everything from my kids getting married to Ryan's career taking off and him living his dream to having two new grandsons this year and even being there for the delivery of one of them. My life has been rich for years.

I don't have a big fear of dying; I have a deep faith. However, when it comes to actually celebrating survival, it is just so sad. It reminds me of people who aren't here, who were so young, who left children without parents who were raised by their grandparents or friends. I do feel guilty sometimes that I lived. It's bittersweet.

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