Making Transplant History

Advocate John Tenorio could be the first HIV-positive person to receive a kidney from a living donor with HIV.

November 15, 2018 By Alicia Green

Editor's Note: Unfortunately, John passed away before he was able to receive a transplant.

John Tenorio has been involved in HIV advocacy ever since he tested positive in 2006. The Colorado native has worked to improve the lives of Native Americans with HIV as executive director of the National Native American AIDS Prevention Center.

Tenorio, who was just named to our 2018 POZ 100 list, was recently diagnosed with kidney disease and may receive a new kidney by the end of the year.

He recently spoke with POZ about his potential transplant, which could be the first ever from an HIV-positive living donor to an HIV-positive recipient.

When were you diagnosed with Stage 5 kidney disease?

I was diagnosed right after Christmas last year. But I have known my creatinine [a waste product in the blood caused by the normal wear and tear on muscles of the body] was rising [an indication of kidney damage] for about two years.

I was on Atripla for eight years. Atripla could be what caused my kidney damage, but it also could be that I'm a type 1 diabetic and I've been on insulin for 30 years.

I've only been listed on the kidney transplant list as an official candidate since September. I was told it would be a three-to five-year wait for my blood type.

Can you talk more about what Stage 5 kidney disease means?

Stage 5 is end stage, which means you are ready for dialysis or a transplant. It means exactly what it is. If I don't do something, I will die.

My [glomerular filtration rate], which is my kidney function, is 13. You cannot live with your kidney function under 10 and be OK. My creatinine is 9. Somebody with no issues whatsoever would be 0.1 or 0.2. My potential donor doesn't have any issues with her kidneys. She's been HIV positive her whole life.

So what is the exact cause of your kidney disease?

Doctors are saying three different things. It could be the Atripla. It could be the insulin. I'm somebody who doesn't take a lot of insulin, and I have a CD4 of 1,800.

When I lost my leg, I was on pain pills for two to three days. I can't even tell you the pain of losing a leg. It's just uncontrollable. You just live miserably. Then, it went away.

While most people stay on a heavy narcotic for about two months, I only took it for three days, maybe four. After that, I took ibuprofen for probably three months. But not a lot, just a little bit. Ibuprofen is horrible for you. It can ruin your kidneys. Leading up to losing my leg, I had to two to three foot surgeries. I was on ibuprofen then too. So it could have been the ibuprofen.

Now that you have a potential donor. Have you removed yourself from the transplant waiting list?

I'm still on the list, since I don't have a new kidney yet, and there could still be an issue. I've had previous donors that were rejected due to a health problem.

I moved up on the waiting list. My blood type is O. If somebody comes in and has a car crash or drug overdose, the doctors could call me and say, "Get here now." If that happens, I'll be jumping ship because someone else will be giving me a kidney. I don't have to be the first living positive-donor recipient. Yes, it's kind of cool. But I want to live.

This is supposed to be the first living-living transplant involving two people with HIV.

Doctors have transplanted [cadaver organs] to a positive person. They do these transplants all the time. In 2013, the HOPE [HIV Organ Policy Equity] Act was passed, which allows [people with HIV] to get a transplant [from an HIV-positive donor]. But they haven't had [an HIV-positive] living-living transplant.

What's your life expectancy with a kidney transplant?

If I had a live donor, doctors say 15 years. But I know people who are going on 30 years right now. With a [cadaver organ], the life expectancy is about 10 years.

Right now, my donor is being scrutinized to make sure that she is healthy enough to give me her kidney. With a [cadaver organ], I'd get a call and I'd have to be there in two hours to get the kidney.

Where is your transplant supposed to take place?

It's supposed to be at Johns Hopkins in Baltimore. The University of Colorado at Denver has a transplant program, but Johns Hopkins's program is a little bolder.

Johns Hopkins is not just choosing anybody for this. They are being as safe as possible. They knows that I have never been under 1,300 CD4 cells and I have 1,800 today. I could afford to lose 500 or 600 CD4 cells and still be healthy.

You created a GoFundMe account to raise $50,000. What exactly will that money go toward?

Doctors are telling me I will need to stay a month in Baltimore and [my housing] is not covered. I'll need to be in the hospital for five to eight days. I'd have to stay in a hotel or something. Denver would be so much cheaper for me. I have relatives I could stay with.

Doctors don't want me to stay far away. I'm going to start out with a number of medications because they don't know which ones I'll need. Then, it's a process of elimination until they find a regimen that is right for me. It takes times to wean me off those medications. I have to be right there. I can go into rejection overnight.

So that is what the GoFundMe is all about. To help me support myself, buy food, transportation, etc.

How long will recovery take?

My doctors said about three months.

How do you remain positive through this?

I have faith because I came through all this other stuff. I lost my leg. I never let it bother me. I became HIV positive. I couldn't feel sorry for myself. I got diagnosed and I moved on because I didn't have a choice. I made it work. I kept working. I never missed work. I had two children to take care of. I raised my children alone. They are grown now.

Is there anything else you would like to add?

Everything I've done has made me a better person. I think things happen in your life for a reason. Hopefully there will be hundreds of HIV-positive to HIV-positive transplants after me. But doctors won't do more of them until they know the outcome. It's worth it. This isn't just about me.
