

At 18 years old, he donated a kidney. Now, he regrets it.

By Michael Poulson October 2

When I was 18, my stepfather's brother had been on dialysis for just over a year. He was thin, he exercised regularly and he seemingly was in perfect health, but inexplicably his kidneys began to fail him. Although I was just about to leave for college, I'd heard enough about the misery of dialysis to decide to get tested as a possible donor. In the back of my mind, I knew that the chances of our compatibility were incredibly low because we were not related by blood. Perhaps that made it easy for me to decide to get tested.

When we received the results, I was stunned to find out that he and I were a match. The transplant team gave me plenty of opportunities to back out of the donation, and it put me through countless evaluations, physical and psychological. Much of my family was steadfast against my becoming a donor. Looking back, who could blame them? Their son-grandson-nephew was going to undergo a major operation with no benefit to himself.

However, I continued to be confident in my choice. I relied on the one fact that would be repeated to me many times: "The rate of kidney failure in kidney donors is the same as the general population." Why wouldn't everyone donate a kidney, I wondered.

My mother was the only one to — reluctantly — support my decision. She accompanied me to San Francisco, where the surgery took place, and we settled in for the weeks that I would spend recovering. On the day of the surgery, anesthesia flowed into my arm and the world swiftly slipped away. Then, just as quickly, it seemed, I awoke, nauseated and confused. So much preparation for such a short nap. The anxiety I'd felt about the surgery was now gone — as was one of my kidneys.

An uneventful recovery came and went. I returned to college and resumed a normal life. Likewise, my step-uncle did very well and is living a full and healthy life, as is my donated kidney.

Five years after the surgery, when I was 23 and getting ready to go to medical school, I began working in a research lab that was looking at kidney donors who had gone on to develop kidney failure. For that research, I talked to more than 100 such donors. In some cases, the remaining kidneys failed; in others, the organ became injured or developed cancer. The more I learned, the more nervous I became about the logic of my decision at age 18 to donate.

And then in 2014, [a study](#) looking at long-term risks for kidney donors found that they had a greater risk of developing end-stage renal disease. Another study that same year raised the possibility that they may face a heightened risk of dying of

cardiovascular disease and all-cause mortality (although this point remains controversial).

Other studies and surveys, though, suggest that the risk, while greater, is still fairly small.

The truth is, it is hard to get good numbers about what happens to donors. Hospitals are required to follow them for only two years post-donation, which does not catch such long-term complications as chronic kidney disease, cardiovascular issues or psychiatric issues. There is no national registry for kidney donors or other large-scale means of tracking long-term outcomes.

The result is that we know neither the denominator (the total number of kidney transplants that have occurred over the decades) nor the numerator (the number of donors who have gone into kidney failure). And what we do know is incomplete. Yet the need for donors remains great, as the number of Americans needing a kidney transplant has steadily increased — to more than 120,000 — while the number of transplants performed has remained relatively steady — at about 30,000 per year.

Donors are lauded for their altruism and bravery for what is promoted as a benign procedure with low long-term risk. We are told about neither the reality of donation risks nor the scarcity of data that's available.

As a medical student and soon-to-be physician, I've come to better understand the imperfections in the idea of informed consent. We work with the data we have, and patients aren't always told that it may not be that solid. At the time of my surgery, I thought the system was designed to protect me as a donor. Yet, now, more than eight years later, I am angry that I was never fully informed of the lack of research or the unknown long-term health implications for me.

Mostly I've come to terms with the increased risks of being a kidney donor. But I'd be lying if I said I don't get anxious about it. I feel vulnerable. Sometimes I can think of nothing but my remaining kidney. I'll feel pressure on my ribs, and I think, "Is that my kidney acting up, or simply back tension?" Or I'll wonder: "Should I be feeling this lump? Am I going into kidney failure?"

Being a kidney donor has become a part of my identity. Some people — particularly in medical school — have put me on a pedestal for my altruism and bravery. But often I find myself hiding the fact that I donated, which I'd like to think of as an act of modesty. The sad and difficult truth is this: Knowing what I know now, I regret donating in the first place.

Currently there are over 120,000 people in need of a kidney transplant; 3,000 are added to that list every month. Yet in 2014 there were only 17,000 kidney transplants performed with a third coming from living donors. The need is real, as is the push to attract more living kidney donors.