

My Left Kidney (Donation), an extraordinary experience



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Almost one year ago, I donated my left kidney. It was the most extraordinary experience of my life and one for which I'm incredibly grateful.

My beautiful wife, Joanne, lived with kidney disease for thirty years, first diagnosed at aged four. She had her left kidney removed as a five-year-old and carried on with a compromised right kidney, which slowly lost function due to the disease. We always knew that at some stage her remaining kidney would fail and that she would need a transplant. Five years ago her remaining kidney began deteriorating at an accelerated rate—the clock had started ticking on failure.

I never doubted that I was going to donate my kidney to Jo. Our goal was to absolutely avoid dialysis or the need to rely on “The List”—the deceased donor list. Mortality rates on dialysis are higher than cancer on average and transplants after extended dialysis treatment are often medically less successful—not one of the more broadcasted facts in the treatment of kidney failure. Similarly, wait times on The List can be very long in Canada—in Jo's case up to 8–10 years.

In late 2015, Jo's kidney function fell below 15%, making her a candidate for dialysis or transplant. Jo was relatively asymptomatic so, in consultation with her team at University Health Network's renal management clinic, dialysis was not immediately pursued. Instead, we began the transplant assessment process with physical, blood and genetic testing. At first, the tests progressed well and compatibility looked good—I would donate to Jo, on our own terms, long before dialysis became necessary. However, the picture changed upon the second round of immunologic testing. Jo's immunological profile showed she was no longer a match to 85% of potential donors, now including me. I was no longer a viable candidate.

Our carefully laid plans were typically thrown in disarray, and we considered alternatives as the prospect of dialysis hurtled towards us. While Jo's kidney function continued to deteriorate, Jo's family stepped up to be tested, but none were suitable candidates due to Jo's high antibody levels. She was provisionally placed on The List and we reluctantly toured a dialysis clinic.

That's when we were presented with the Kidney Paired Donation program run by Canadian Blood Services. KPD is a national sharing program in which a recipient and their prospective living donor (to whom they are not a match) register within a pool of other incompatible recipient/donor pairs. A sophisticated matching algorithm finds new compatible pairs within the pool, establishing transplant “chains” of up to six pairs.

Through research and consultation with the transplant doctors at UHN, we learned that the KPD program could likely provide Jo with a kidney and potentially a much better match than we could otherwise have anticipated, even despite her highly sensitized profile. I would donate to a recipient in the pool and Jo would receive a kidney from it. It's simple math: having access to a pool of over 150 donors improves the opportunity to find the best match.

By January 2017, Jo's kidney function had slipped to 6%...

On Friday of the third week of January 2017 we both received calls: a sudden match opportunity had arisen within the KPD program—Jo and I were the perfect match to complete an existing transplant chain. Surgery rooms had been booked for February 15th and 16th. Only three weeks later.

For a half-hour we wondered: “Three weeks’ notice in the busiest time of the year for our businesses? Can we do this right now?” Then, of course, common sense and the state of Jo’s health kicked in as we recognized the chance to get a matched kidney for Jo and, as icing on the cake, contribute to a transplant chain helping even more recipients waiting for transplant. It was a no brainer.

On Valentine’s Day, Jo was admitted to hospital for her transplant the next day. My donation surgery was scheduled for the 16th.

Jo’s surgery was a tremendous success. Her new kidney started working immediately and her kidney function went from 4% to over 80% quite literally overnight. Her blood was no longer toxic. It’s true what they say—transplant is a medical miracle. Now, 11 months following the transplant, Jo’s energy is boundless and her new normal is far beyond 150% pre-surgery.

For me, the donation surgery and recovery was really pretty easy. Two weeks off work, a few PDAC meetings in the third week and back at work full bore by the fourth. Swimming and squash after six weeks, and travel after two months. A nice scar and a little bit of discomfort along the way, but never a moment’s cursing, never a second’s thought: why did I do this?

Because now I get to see my JoJo burning brighter than ever before, every day.

My donated kidney now lives on somewhere in Canada. I will never know who the recipient is, but the thought of Jo’s return to full health while having the honour of transforming a stranger’s life is a rare gift and blessing. Jo and I are truly the lucky ones.

But then I think of those suffering from kidney disease who weren’t fortunate enough to have a donor. We met many of them through our journey. The terrible loneliness of not having a loved one to offer this simple gift haunts me. That loneliness cannot be acceptable in our Canada.

So, we challenge Canadians to think differently about organ donation. We truly have one of the great healthcare systems in the world, with the UHN’s Transplant Program performing more successful transplants in 2017 than any other hospital in North America. But we need more living organ donors and we need to start thinking of living organ donation *as simply the Canadian thing to do*.

You already know (or invariably will know) people in desperate need of a kidney. Please, consider being a living organ donor if you are given the special opportunity to do so. Think about it now, so when the opportunity arises, you’ll put your hand up without needing to be asked. Believe me, there is no greater gift you can give, no greater small sacrifice you can make.

If you’re interested in further perspectives on living organ donation or how you can help, please contact us at joanneandbrendan@gmail.com

Below: Two days post donation, three days post transplant February 2017

