Brad and Nicole’s Story

The Perfect Match

The following story is the true story of Brad and Nicole (not their real names), a married couple from Saskatchewan. In February 2016, Brad donated a kidney to Nicole, who was at the time was his fiancée, and this is their story in their own words.

Photo by Ryan Holloway

NICOLE:

In my late teens and early twenties, I began feeling tired and low on energy. I was up many times throughout the night to go to the bathroom, and something just seemed off. I went to my family doctor, and after some bloodwork, he sent me to see a kidney specialist. My kidney function was down to 30% as a result of being born with abnormal kidneys. Shortly after the diagnosis, I had surgery to fix the problem and worked with a team of doctors and nurses and dietitians to adopt a kidney-friendly diet to preserve my kidney function. My kidney function stayed around thirty percent for a while, then would drop, then remain steady for a while and then drop again. Finally, I got to the point where I was feeling exhausted and played out all the time. This was reflected in my kidney function tests, and it was time to start dialysis.

I started peritoneal dialysis in my mid-twenties. This involved putting 2 to 4 liters of special fluid into my abdomen through a special tube then draining the fluid a few hours later, taking the wastes with it. I remember clearly doing my dialysis training with the team at St. Paul's Hospital. It was the end of April, and I was working in North West Saskatchewan in the agriculture industry. Seeding was about to begin in May – so I focused on learning how to do this dialysis and getting back to work! Sure, I had my moments where I started to realize that this would likely be very inconvenient. Still, I am not one to dwell on the negative – so I set to work becoming the best dialysis patient I could be!

I was fortunate enough to be able to continue working while on dialysis, hooking up to a dialysis machine in my home for 8 hours a night as I slept. I did my best to keep a positive attitude, and many people didn't even realize that I was on dialysis. I told myself that I would not spend my days moping because of dialysis, but instead, I would be thankful for it. I know that may sound a little odd to you, but to me – dialysis was keeping me alive. If the alternative was death – dialysis was WAY better than the alternative.

I decided early on in my dialysis life that I was not going to have a boyfriend while on dialysis. I did not think it was fair to drag anyone into my situation, and I was just fine to look after myself. My friends all sternly disagreed – saying if I found the right guy – it really wouldn't matter…. but I wouldn't listen.

I was always hopeful that one day I could get a kidney transplant and move on to the next stage in my life.

I had many people offer to be kidney donors, but somehow it always seemed like I would get my hopes up to get a kidney transplant, then something would halt the process. Maybe the donor would not have a compatible blood type, or they would have an underlying medical condition that would make them ineligible, or simply they changed their mind. Each time someone volunteered to donate, I would get so excited – that maybe this was my chance…..inevitably this would be followed by immense disappointment, as the kind offer fell apart. I would do my best to brush it off as no big deal, as I wanted to protect the potential donor of any feelings of guilt.

As any parent likely would, my dad went through testing to be my donor. His blood pressure was too high to donate, so he started a stringent exercise regime and worked to improve his diet to be healthy enough to donate. He was given the green light to continue with testing, and with just a few more tests, we would be booking the surgery!

A few months later I got a call from my dad that he had been diagnosed with cancer, and it had spread to his kidney. He would be having surgery in a few weeks to have his kidney removed. He was devastated; he wanted nothing more than to give his daughter a kidney. Neither of us could really believe it or accept that all the testing and hard work he had done had come to this.

A few months later, my dad suffered a stroke due to the cancer and passed away shortly after. This was a hard time for our family.

After my dad passed away, Brad and I reconnected. Brad and I had met a few years prior, and he had worked with my dad at the College of Agriculture, so we had lots to talk about when we went out for coffee.

Brad and I were talking and texting more and more, and it was starting to feel like there was potential for a relationship here. I still hadn't told him about my kidney failure and dialysis. I was very hesitant to get my hopes up and even think for a minute that he would be interested in dating me. After all, I had told myself, "No dating till I get that kidney"!

I finally got the courage up to tell him. One evening out of the blue I said: "Tell me something I don't know about you…" He thought for a minute and said, "I still believe that if you step on a spider, it will rain…"

"Oh." I replied nonchalantly, "That's interesting. Well, you probably don't know that I have kidney failure and I am on dialysis".

I think he was a little taken aback, so I said he could think about it, and I added: "but I understand if you don't want to get involved with someone who is sick."

Brad, always a quick thinker, responded: "Well, you know, kidney function is really not high on my list of requirements for a girlfriend."

BRAD:

Just four months after dating Nicole, she became quite sick at a family wedding with an infection called peritonitis, something that can affect dialysis patients. This is ironic because she had just spent four months playing down dialysis as no big deal and nothing that would ever hold us back. Coincidentally, around that same time, she had also asked me to help with some computer stuff, and I noticed a note called "If I don't make it – what to do with my possessions." Now here was a young woman, 29 at the time and whom I had known for 5 years, full of life and with the whole world ahead of her, and she was making plans for the unthinkable. I decided at that moment I would get tested to see if it would be possible for me to donate one of my kidneys to her. I could not live with myself knowing I could have done something to help.

NICOLE:

Our relationship grew, and soon I was moving to Saskatoon. Brad was extremely supportive, each day hauling my dialysis boxes from our storage area in the basement, up three flights of stairs to our room so I could hook up to the machine for the night.

Unbeknownst to me Brad began getting tested to see if there was any possibility he could be my kidney donor.

BRAD:

My journey to becoming a kidney donor was relatively short and completely unexpected. I am, perhaps, the world's most unlikely kidney donor. I knew nothing about organ donation just two short years ago. I hate needles, I don't particularly like blood, I cringe at the thought of being in the hospital, and, well, who really likes surgery! In fact, to be honest, I am not even sure I had an organ donor sticker on my Health Care Card until I met Nicole. However, hearing her story immediately changed that. I firmly believe there are many more people out there like me who would donate in a heartbeat after being touched by someone's story.

For me, admittedly, the decision was swift.

Knowing virtually nothing about the process (other than that, the chances of being a match were probably pretty low), I awkwardly went about getting tested. The rest, in the most ironic twist of fate, is history. Test after test came back a perfect or near-perfect match, from blood type to tissue typing and cross matches. I even had great kidney function! I was quickly moving from thinking there was almost no chance a complete stranger could be a match to "wow; this is getting real!" This could actually happen. And then, after a few months of testing, I got the call that all was a go, and I was cleared for surgery. What a feeling; I think I was honestly speechless. I still get goosebumps thinking about it.

Now, I had the chance to do something I had wanted to do so badly since meeting Nicole, despite the incredible odds.

NICOLE:

A few months after our engagement, Brad told me that he had been getting tested to be my kidney donor, and we were a near-perfect match – against all the odds.

It was hard for me to accept his offer – because it is hard not to think about the risks. From my perspective, I wanted to protect the one I love and not have him undergo surgery just for me. But Brad had made his mind up. And for anyone who knows us, the only person more stubborn than me is Brad. He had done all his research, evaluated all the risks, and decided that this is what he wanted to do.

BRAD:

I can't say that I was ever scared through the process, but I was definitely unprepared for the emotions involved. Maybe it's just a guy thing, but I can count on one hand and probably with two fingers, the number of times I have cried in my life. However, the night before the surgery, once they had admitted Nicole for the night and I arrived home to an empty house, I broke down. On the coffee table she had left the most touching note and a present. The gift was a small collectible statue of a couple on top of the moon because we always tell each other, ‘I love you to the moon and back.’ I couldn’t hold it in anymore, I missed her terribly already, and I knew tomorrow she would go through very major surgery. Maybe there is a bit of donor’s guilt to that, I don’t know, but it was probably also the realization that I could no longer protect her or help her, and that scared the heck out of me.

The morning of the surgery was one of the hardest moments of my life, emotionally speaking. I hadn’t slept all night, I get there at 6 AM, ready for battle in a couple of hours. And then, as you wait, there comes your loved one down the hall, all hooked up to IV, fluids, and other meds, in tears because she is scared for you. Moments like this truly test the strength of love, and I learned a lot in those few moments about just how strong of a couple we were. As she walked me into the Operating Room, I knew I could not show one bit of fear or emotion; I had to be strong for her. Then came that final kiss and hug goodbye, which was perhaps the most challenging, most emotional thing I have had to do because what do you say to someone in a moment like that? I calmly let her know I was prepared for what I had chosen, and that no matter what the outcome, I wanted to help, and I desperately wanted to give her back what fate had taken away.

NICOLE:

I am not sure when it truly set in that this was actually happening. Maybe it was Feb 4th, 2016 as I tearfully kissed him before he went into the operating room, or maybe as I waited with anticipation to hear that his surgery had gone well.

My transplant was a success, and I attribute that to the amazing team at St. Paul’s Hospital and the fact that my transplant was from a living donor. To this day, it is still hard for me to believe that this all has happened and that I have indeed received the gift of life.

BRAD:

Thankfully, all went extremely well, due in no small part to the highly professional team at St. Paul’s. I am down a kidney, but I feel great, my heart is full, and after all this, she married me! There is no doubt we have grown closer from the experience, and we now share a unique emotional bond that many people in life never get to share. We consider ourselves some of the luckiest, most privileged people around because we know for so many others, their journey is much more difficult than ours, their wait far too long, their lives much too interrupted.

The kidney transplant has forever changed our lives, and we hope our story will inspire others to contemplate organ donation and to consider becoming a living organ donor. I have found that the beautiful thing about becoming a living donor is that you have the opportunity to see the difference in someone's life that your gift makes, and that truly is priceless.

I must also admit that I find it quite humbling to have 'kidney donor' in my biography and not just my obituary! I am so glad I didn't wait! Growing up, one of my favorite songs was "Heroes" written by David Bowie and redone by the Wallflowers. Many of you will know the song, but I am most fond of the chorus, proclaiming that "we could be heroes, just for one day."

On that point, I always tell people I would do it again in a heartbeat if I had another kidney to give and that I may again get that chance someday. Without hesitation or regret, I can state that donating a kidney is the most humbling and rewarding thing I have done in my life, and I am thankful to have been able to do so.

NICOLE:

We hope our story can inspire others to learn more about kidney health and to put that little sticker on your Health Care Card. More importantly, talk about your wishes with your family, and perhaps even consider living organ donation.

BRAD:

I want to share with you a text message I sent to Nicole after telling her that I was a match:

"Nicole, when we first met, you said something that touched my heart, and I will never forget it. You told me you were reserved to finding a boyfriend after you got a kidney. And that you never wanted to get married while on dialysis. It seemed as though your life was on hold. That has always stuck with me and affected me deeply, but I feel like we can change that together. Maybe, just maybe, we can get lucky and make those dreams of yours come true. Such is my hope, and life itself is nothing without hope. You changed my life, and maybe, if it all works out, I can help to change yours. Here's hoping...."

- Anonymous, as told to and edited by Christine Spetz, Sheila Chad, Phil Gleim, Alex Senger, and Mike Moser.

Three stories about organ donation and transplantation told by a transplant surgeon

Dr. Mike Moser grew up in Edmonton and went to medical school at the University of Alberta. He first developed an interest in transplantation as a medical student when he had the opportunity to spend a month on the Multi-Organ Transplant Program in London, Ontario. Eight years later, after completing his General Surgery training, he would join the London team for two years to train in liver and kidney transplantation. He is currently a transplant surgeon in Saskatoon at St. Paul's Hospital.

Running out of time

In the time I've worked in transplantation, I have encountered many memorable people and their stories, and there are two people that I met right around the same time when I was finishing my transplant training 15 years ago in Ontario that I will never forget.

The first is a woman in her mid-30s who had a condition that caused scarring to her bile ducts and eventually would cause her liver to fail.

She was the picture of health in her 20s; she had been a long-distance runner, a hockey mom, and she loved her job. However, when I met her, she was tired all the time and could no longer do the work and leisure activities that she loved. The liver disease caused her to turn yellow, lose half her muscle mass and even throw up blood. She was put on a liver transplant waitlist. Over the next year and a half, while she waited for a transplant, she was hospitalized over a dozen times and wondered if a liver transplant would ever come.

Finally, after a year and a half, she got the call she was waiting for. A donor liver had become available, and she received a liver transplant later that same day. Within only three days after her transplant, she told me that she felt the best she had felt in years. Within six months, she was back at work, running again and travelling the world with her family. To this day, I still hear from her, and it's clear that she is not just surviving. She is thriving and living a very full and active life.

The other story from around the same time is about a young woman, a mother of 2 kids, and she was born lacking an enzyme, and this disease caused her liver to fail by the time she was 28. Like in the previous story, she was put on the liver transplant waitlist. While waiting, she was admitted to the hospital repeatedly over the next 9 months.

One night she was admitted to the hospital because she was vomiting blood and nearly in a coma. She was in bad shape. We worked hard to get the bleeding to stop, but unfortunately, it would not stop, and she passed away at the age of 29 because she wasn't able to get a life-saving liver transplant in time.

These true stories illustrate the current reality that, in Canada, one in three people waiting for an organ will die before that organ becomes available. Transplantation has been called a miracle of modern medicine, but without donation, there are no transplants.

A donor family

Several years ago, I was travelling through Europe on a group bus tour, and I met a couple from Canada. When they found out that I was a transplant surgeon, they recounted the story of what happened in their family just a few years before.

Their son, an energetic 26-year-old university student, was a track star and did a lot of volunteer work. One day, without any warning, he collapsed while at school. He was taken to the hospital, where they did tests, and he was found to have a blood vessel in his brain that had burst. The medical team did everything they could, but unfortunately, he deteriorated further over the next 24 hours and was declared brain dead.

This was a terrible day for his parents. Still, when they were approached regarding organ donation, there was no doubt in their minds that this was something that their son wanted. He had discussed his wishes years before. So, they had no hesitation in making the decision to donate his organs.

This could not have been an easy story for them to tell me as it had happened only a couple of years previously, so what impressed me the most about them was the pride they had as they told me their son's story. The loss of their son would forever leave a void in their lives, but the fact that his organs went to save the lives of 5 people was a source of great comfort and pride to them.

Their story is also a reminder that we all need to have an important discussion with our family and friends. By making it clear to my family that I want my organs donated when I pass, I make it easier for them to make that decision at a difficult time.

The moment of truth

There are a lot of aspects about transplantation that I am passionate about. But I do have a favourite moment that I'll get to in a minute.

When an organ is taken out of one person and prepared for transplantation, it is essential that we flush the blood out and cool the organ as soon as possible. This leaves the organ looking almost grey in colour and looking kind of deflated, in fact up to 50% smaller than it usually is when the blood is flowing into the organ. This is true whether it's a kidney or a liver or even a heart.

The organ is kept at 4 degrees Celsius in this way, and eventually, when it's time for the surgery to put it into the recipient, it is brought out of the cold and into the opening in the recipient. While we make the new connections between the person receiving the organ and the new organ itself, clamps are placed on the blood vessels to stop the blood flow to the area where we are working.

When we are all done sewing the new connections from artery to artery and from vein to vein, the clamps are removed, and the recipient's blood starts flowing into their new organ. This is what we call the "moment of truth," and in less than a minute, the new organ swells to get back to its normal size and changes from gray to red -- it's as if the organ is coming back to life or being re-born. I have seen this "moment of truth" over 500 times for different organs, and I find it just as amazing now as I did the first time I saw it.

What I find even more rewarding is seeing the change in patients after they have received a transplant and seeing how quickly this change occurs. Patients will often tell me they feel the best they have felt in years, typically around the third day after their transplant surgery, and you must remember that they have this fresh incision and are hooked up to a bunch of tubes and machines. It's an unbelievably quick reversal of the disease that caused them to deteriorate for years and then sometimes wait on the list for years. Because of these patients and their donors, I feel privileged to be part of the transplant world.

- Dr. Mike Moser, with edits by Christine Spetz and Sheila Chad.

Before and After

Connor's journey with kidney disease, dialysis, and transplantation:

The following is the story of Connor (not his real name), a young man who was in excellent health and even played professional hockey. Over two weeks, his life changed dramatically, and he developed kidney failure. He required life-saving dialysis three or four times a week, 3-4 hours at a time. This is the story, in his own words, of his experience on dialysis and the difference that receiving a kidney transplant made in his life.

My name is Connor. I'm a farmer and former professional hockey player.

When I was 25, I was diagnosed with kidney disease. Basically, my kidneys – the two-bean shaped organs that keep waste from building up in your body – were shutting down.

This came as a shock to me because I was always a healthy guy. I would get up early in the morning and work on the farm for 12 hours a day before returning home to my wife, Katie, and my young son. But in the months before I was diagnosed, I started getting a lot of headaches and would often come home from work early to nap.

Kidney Disease

Eventually, I went to the doctor. The first thing he did was take my blood pressure, which came in at 220/130 – the highest risk category for heart attack, stroke and other life-threatening problems. Thinking the machine wasn't working, the doctor took my blood pressure again. After taking it for the third time with the same result, he sent me straight to the emergency department. That same afternoon I was admitted to the Intensive Care Unit, where I stayed for two weeks.

I discovered that having kidney disease meant I had to take medication every day. I had to start a restrictive diet that eliminated some of my favourite foods like red meat, cheese and even bananas, which are high in potassium (when you have kidney disease, your kidneys can't clear out potassium, and so it can build up to dangerous levels). I also discovered that I could no longer put in a full day's work on the farm or play hockey without feeling tired for a day or two afterwards. Some days I was so physically drained I could barely get off the couch. I'm the type of person who likes to be busy, so it was hard for me to feel so drained and unproductive.

I kept telling myself, “I’m going to beat this disease; it’s not going to beat me.”

But it got worse before it got better.

Dialysis

When my doctor realized that my kidneys weren’t improving through diet and medication, he put me on hemodialysis. For four hours, four times a week I sat in a chair at the hospital while a machine connected to a dialysis machine. The machine pumped blood out of my body, ran it through a filter, which served as an artificial kidney, removed toxins, and then pumped the clean blood back into my body. Right after getting dialysis, I always felt great. The next day I would be okay, but the day after that, I’d feel sick again and would go back to the hospital to start the process over.

After about six months of hemodialysis at the hospital, I found out I was eligible to receive peritoneal dialysis at home. Before I could even get started, I had to complete six weeks of training. I also had to have surgery to get a small tube placed below my belly button that linked my peritoneum (the lining of my abdomen) to a machine in my home office that pumped the clear fluid in and out of my abdomen. Every day, I hooked myself up to the device, which pumped fluid into my peritoneal cavity to draw out the toxins. The fluid, along with the toxins, was then pumped out. I repeated this process four times a day for nearly two years.

Sticking to my dialysis schedule every day – even though it wasn’t always easy – meant that I could live a relatively healthy lifestyle.

It also meant that I was a good candidate for a kidney transplant. There are many factors that go into determining if someone can receive a transplant and being able to manage your health before the transplant is a big one. That means a lifelong commitment to taking medications regularly, eating healthy, exercising regularly and not smoking and drinking very little or not at all.

Some people receive a kidney transplant from a deceased donor – someone who has died and donated their kidney. Other people receive a transplant from a living donor – someone who donates an organ like a kidney or part of their liver to another person in need.

I was extremely lucky to receive my kidney from a living donor who also happens to be my younger sister, Kailey.

From day one, Kailey has been by my side. When I was put on the transplant waitlist, Kailey was pregnant with her second daughter. Almost immediately after giving birth, Kailey asked to go through the testing to determine if she could donate one of her kidneys to me. Even though we are born with two kidneys, we only need one to live. Although you’re supposed to wait a year after having a baby before even thinking about donating an organ, she insisted on getting as many tests as she could within that first year. Once she cleared the first year, she had more tests to determine if her blood and tissue were compatible with mine.

We were thrilled to discover that Kailey was an excellent match.

After the transplant

A few months later, I received a kidney transplant from my sister. When I woke up from surgery, I instantly felt better. Within six days, I was back at home with my family. Six weeks later, I got the all-clear from my doctor.

The transplant has given me my life back. I'm working on the farm again and playing hockey – only now I wear a big foam protector on my abdomen to protect my kidney. My days are like anyone else's, except for the medication I take in the morning and evening to prevent my body from rejecting the transplant.

I was very fortunate to receive a kidney from my sister. But not everyone has a Kailey in their lives. Sometimes family members aren't able to donate because they're not a compatible match or have an underlying medical condition that prevents them from donating.

These people often rely on deceased donors for a transplant. And right now, there are many people on the waitlist and not enough donated organs to keep up. This means that most people who need a kidney wait years on the waitlist.

That's why it's so important for us to talk to our families about our decision to donate. In Saskatchewan, organs and tissue cannot be donated without your family's consent. If your loved ones know that you support organ and tissue donation, they can make this important decision on your behalf after you have died.

For the hundreds of people waiting for a transplant who don't have a Kailey, will you talk to your family?

- *Anonymous*
- *As recounted to and edited by Christine Spetz, Sheila Chad, and Mike Moser.*