



Joint Venture

By Stephen Gauer

On the day of the transplant, I woke up at 5, a few minutes before the alarm. I got out of bed, put on a pair of jeans and a black t-shirt, took the dog out, and carried the garbage cans out to the curb. The morning air felt warm and humid. My bag was packed and I was ready and there was nothing else to do so I sat on the front step and waited for the cab.

The cab was early too. The driver drove quickly, as though keeping time with the South Asian rock and roll playing on his radio. The streets were empty and every light seemed to turn green as we approached. I walked into Toronto General Hospital at a quarter to six and took an elevator up to the surgery admissions office on the second floor.

I was in the hospital on the last Tuesday in June because I was donating my left kidney to my 26-year-old grand-daughter, Amelia. My last encounter with a surgeon had been in 1965 when I was 12 and had my appendix removed. But I wasn't scared or nervous. I felt intensely alive and full of purpose. For five months the drama of the transplant and the anticipation of how it might change our lives had filled my heart to overflowing. If at that moment someone had turned and asked me why I was there I would have burst into tears.

There were fifteen of us waiting in the office, all middle-aged or older. A young clerk took our health cards and then clerk called us in two and threes, and another clerk led us to a yet another waiting room. Then my name was called and I changed into a hospital gown and put blue cloth booties on my bare feet. I handed my bag to someone, and walked to the prep room, a large open space holding about 20 beds, and got up onto a bed.

A nurse brought me a warm blanket. "How are you this morning?" she asked.

"Actually," I said, "I feel very excited."

She smiled. "Oh," she said, "that's a bit different."

How could I even begin to explain what I was feeling? Lines from a poem kept running through my mind, *I wake to sleep and take my waking slow / I feel my fate in what I cannot fear*. How could I explain that to her?

The nurse took my temperature and blood pressure. The junior surgeon appeared and introduced himself and smiled, and then carefully raised my gown and took out a pen and wrote his initials on my skin under my bottom left rib. He made a small arrow above his initials.

"Just so there's no mistake," he said.

"Yes," I said. "We want to make sure you and Dr. Mike take out the right – I mean the *correct* – kidney."

More people showed up to ask me questions about allergies and how I was feeling and to reassure me that everything would be fine. Then they left. I lay there very comfortably under the hot blanket. The lines of poetry ran through my head again.

Then suddenly I was in motion. The clock on the wall said two minutes to eight and there was no time to waste. They wheeled me down one hall, around a corner and down the next hall. A fierce headwind was blowing in my face. Then a door opened and I was in an operating room lit brilliantly by a constellation of overhead lights. A nurse appeared on the right and helped me move from the gurney to a narrow table covered with a turquoise foam pad. A man standing to my left, the anesthesiologist, put an IV into my left arm. He asked me if I was comfortable and I said yes and we talked and then suddenly, with no warning, no countdown from 100, everything went black.

Amelia Bruce came into my life 25 years ago because I met and fell in love with her grandmother, Judith, at a party in Toronto. Judith and I danced until 4 am. She told me she'd once been a nurse but now ran a luxury wool store in Yorkville and I thought she was rich and she told me later she thought I was gay, and as it turned out we were both wrong. A week after we met she told me she had a son named David and a daughter named Alison and that Alison had a two-year-old daughter named Amelia. All of this seemed sophisticated and interesting, exotic even. I was 30. Judith was 42.

I met Amelia a few months later when Alison brought her to Judith's apartment. I was painting the baseboard a bright pink when they arrived. Alison said hi. I said hi. Amelia said something like "Garble garble GOOGIE garble", Googie being her version of "Judy".

"I don't remember any of this!" Amelia says now. "I mean, I was only two and a half."

"I remember it very clearly," I say.

"What I do remember is that you were always there," she says. "You were always my grandfather."

Actually, I was Amelia's third grandfather because Judith had two ex-husbands. Being number three reduced the pressure. This was good because my 30-year-old brain knew absolutely nothing about being a grandfather. A few years later, after Judith and I had moved in together, and after Amelia had become a regular Friday night sleep-over guest, the three of us were having dinner in a College Street restaurant after a movie. The waiter assumed I was Amelia's dad and made a comment to this affect.

"He's not my dad!" she piped up. "He's my THIRD grandfather."

The waiter quickly apologized and withdrew.

Amelia was a sunny kid, almost happy go lucky in a way. She was also smart, resilient, at ease in any social situation, and somehow innocent and practical at the same time. She had a strong side; she was never afraid to voice her opinion, or ask for something she wanted. She was surrounded by friends and family, including the multiple grandfathers. Everyone loved her. Philip

Bull, who lived with Alison for nine years when Amelia was growing up, adopted her as his daughter. (Amelia has had very little contact with her biological father, who now lives in France.) These relationships are important, because life wasn't easy for her mom, who went back to school in the mid-1980s and finished an undergrad and master's degree at U of T while raising Amelia and supporting herself.

Judith also changed direction in the mid-1980s. She went back to nursing, first at a seniors home and then at Casey House, the palliative AIDS hospice. In 1990 we moved to Vancouver to care for her elderly parents. Amelia came out for yearly visits. We took her on trips to Vancouver Island and Seattle. One year we went whale watching off Ucluelet on a cold day in March. I have a photo from that trip: grandmother and grand-daughter, pale and unsmiling with the damp and windy cold, standing together, arms around each other, in the ship's passageway. Amelia never complained; she was game for any adventure and any experience. Every year she seemed to arrive from Toronto with a new and fierce enthusiasm: the violin, the Game Boy, Hello Kitty, sushi, mental arithmetic, blue cheese hamburgers, plush toy animals, the novels of John Grisham.

Everything changed for us in April 1997. Judith and I were spending Easter weekend at a resort in the Gulf islands. Judith called our Vancouver number to check for messages. The first one was from Alison in Toronto. "Don't freak out, Mom," she said, "but Amelia's in the emergency ward at Sick Kids. They think it's massive kidney failure."

Amelia had woken up that morning with swollen ankles. She was having trouble breathing. Alison took her to a walk-in clinic, where the nurse wisely took her blood pressure. It was well over 200. They called 911 and got her to Sick Kids as quickly as possible. Her kidneys had failed. She was on dialysis before the end of the day.

Her disease is called Henoch-Schoenlein purpura. It's a form of vasculitis and in most cases it's not serious. Amelia has a rare form that attacks kidney function and therefore is lethal. Within a year, she had a transplant from a deceased donor. Those were terrible months for everyone. Judith went to Toronto for the transplant in the fall of 1997. She monitored Amelia's

care, made sure her pain was managed properly, applied pressure to the system when required, and reassured her daughter and grand-daughter that all would be well.

And everything went well for several years. Amelia was on various medications and a controlled diet, but her life went on. She finished high school, did an undergrad degree at U of T, worked at a law firm and eventually landed a good job as a junior policy analyst with the provincial government.

Then, cruelly, the disease came back. By late 2005 the transplanted kidney was beginning to fail. We moved back to Toronto in the spring of 2006. By fall it was clear that Amelia would either have to go on dialysis or get another transplant. The wait for a kidney would be at least eight years. Through all of this Amelia never complained, even as her energy level fell to zero and her fingers began to tremble. Between December 2006 and April 2007 she was admitted to hospital five times.

Judith wanted to donate but she was over 60, the cut-off age for donors. Philip was the wrong blood type. Alison was next in line. She began the testing program at Toronto General Hospital. Then early in February she phoned Judith to say she'd been rejected because of a medical complication with her kidneys.

Judith called me at work and asked, "Will you get a blood test?" A donor doesn't have to be a blood relative of the recipient, but usually must have the same blood type. If the blood type matches, a long testing process begins. At the end of this process, the donor gets a thumbs up or thumbs down from the transplant team kidney specialist. At any time, though, the donor can change his mind and back out.

Judith's words sent a chill up my neck. I said yes, I would get a blood test.

Before the results came back, Judith went out of town to visit a friend and I said I would spend the weekend deciding whether or not I would donate a kidney. In fact, I spent all of fifteen minutes thinking about it.

I was healthy, I knew that. Donors lead perfectly normal lives with one kidney, I knew that too. The kidney is a complex organ, but you don't need two of them. The transplant surgery would mean two or three weeks recovery at home with no pay (I'm a freelance technical writer and have

no benefits) but I was well paid and would quickly earn the money back. The odds of dying were 3 in 10,000; to my mind this represented no great risk than what I'd faced single-handing a small sailboat across the Strait of Georgia a dozen times or more when we lived in Vancouver.

The truly important thing was that donating a kidney was a good and ethical thing to do. I didn't need a weekend of reflection to come to the conclusion that this was a rare opportunity in my otherwise easy and rather self-centred life to help someone who needed my help. Amelia was my family, not by blood, but by choice and by love. And in helping Amelia, I would be helping Judith too. So in my mind there was no moral ambiguity to this decision, and how often in our lives can we say this? To be honest, I thought that in helping to save her life I might in a very small way redeem the purpose and value of my life.

On February 14, the results of the blood test came back: I was A positive, the same as Amelia. She was happy. So were Alison and Judith. So was I.

Over the next two months, I took a few hours off work once or twice a week and rode the subway up to Toronto General Hospital for testing to make sure my kidneys were in good shape and I was healthy enough for surgery. I donated two dozen vials of blood and 7.5 litres of urine. I was x-rayed. I was hooked up to ECG machines for heart tests. One day I ran a treadmill for 14 minutes, boosted my pulse to 165 and then posed for an ultrasound. Afterward I saw something miraculous on the technician's video screen: the internal chambers of my own beating heart, the mitral valves flopping up and down like overexcited minnows.

The strangest test was the CT scan, used to create a 3-D image of the kidneys. For this test, you lie down on a white bed in front of a huge, gray, donut-shaped machine. The technician inserts an IV into your left arm. A woman's voice coming from a speaker in the ceiling tells you to close your eyes and hold your breath. For a test run, the bed moves through the donut and back out again. If you peek, you see a sign overhead that says, "Close your eyes or the laser beam will blind you."

Then the technician activates the IV. A liquid dye, used to improve the contrast of the image, enters your body. You feel a tremendous surge of heat flow through your body from head to foot. Then you feel like you've peed your pants. Then a funny metallic taste fills your mouth.

None of these sensations inspires confidence. The bed moves into the donut and stops. You count to 50. Then the bed pulls back out again. The technician removes the IV. The test is over.

Later, the surgeon who performed the transplant, Dr. Mike Robinette, showed me the image from the CT scan. It was amazing: there on the computer screen, rotating merrily in 3-D glory, were my two kidneys, purplish and plump, like distended fruit, suspended from arteries branching from the skinny white aorta, the main blood vessel leading down from the heart. My kidneys looked beautiful. Dr. Mike smiled.

By early May, the tests were done. Both kidneys were in good shape and my heart was strong. Amelia, meanwhile, was on dialysis three times a week at TGH and suffering such intense abdominal pain that she needed morphine shots to finish each four-hour session. Philip, married now to Erica and with a son of his own, continued to play an important part in her life all through her illness; when she was in dialysis he picked her up at the hospital on the days she was too groggy from the morphine to make her own way home..

Before I was approved to donate, one of the transplant coordinators spent an hour explaining the risks associated with surgery: possible death, post-operative pneumonia, gas trapped in the lung cavity, blood clots, allergic reactions to the general anesthetic. She explained that I would spend the rest of my life with 75% kidney function, and higher blood pressure and higher protein concentrations in the urine could occur after the operation and would need regular monitoring.

The last interview was with a social worker, who assessed my motivations for donating and made sure that I wasn't pressured by Amelia or anyone else in the family. I had to describe my life while she took notes. I described my academic history, my girlfriend history, my work history. I described my relationships with Judith, Alison and Amelia.

At one point she said, "Does Amelia appreciate what you're doing?"

I paused. "Of course."

"How do you know that?"

"By everything she says and does," I said. "By the fact she called me one weekend when Judith was away because she thought I needed some company."

And then I started to cry.

Tell the world you're donating a kidney and the next sound you hear may be the soft whoosh of a halo moving into position two inches above your head. Even before I had the final go-ahead from Dr. Richardson, one of the kidney specialists on the transplant team, I told everyone I knew and almost everyone I met, and the halo effect worked about 95% of the time.

"You're my hero," said Amelia's mom.

"What a wonderful thing to do," said a friend in Vancouver.

"It's a beautiful thing to be able to give such a gift," said another friend in Vancouver.

"You're very courageous," said a co-worker.

"It is a very brave thing for you to take on," said another co-worker.

"You're doing a good thing," said my manager.

"It is inspiring to witness such an act of humanity," said my yoga teacher.

Of course it felt good to get praise. Did I need it? I don't think so. You have to separate the action from the actor. Of course I was doing a good thing. Did this make me a good person? Not exactly.

A few reactions were skeptical, or negative, or ignorant.

"What about the ick factor?"

"Why doesn't Amelia go to India and get a kidney there?"

"What if you get a kidney disease later on? You'll only have one left!"

I asked the skeptics whether they would donate to a family member who needed a kidney. If they said yes, they regained my respect.

I thought the worst part of the whole transplant experience would be the first hours after the surgery. I was wrong. When I came to, around noon, on the sixth floor of the acute care unit, I was in a bed in a room. I was connected to an IV line (via my wrist) and a catheter (via my penis to my bladder) and I had a nasal clip for oxygen.

But I felt fine. I felt better than fine. Thanks to the morphine I felt, well ... *euphoric*.

"How do you feel?" asked Alison.

"I feel great," I said, smiling. "I feel very *relaxed*."

She smiled.

"I think everyone should donate a kidney," I said.

She laughed.

Once the morphine wore off, later that day, I didn't feel quite so wonderful. The incision hurt and the bed wasn't comfortable no matter how I adjusted it. My throat was sore from the breathing tube used during the operation. I couldn't eat or drink. I had to sip tiny chunks of ice in a plastic cup. Every four hours, day and night, a nurse came and took my blood pressure and temperature. I had a little button for dispensing morphine into the IV feed. This is called a PCA (Patient Controlled Analgesic) and means the patient has complete control over pain management, in theory at least. But pressing it didn't seem to make a huge difference.

Pain is a big topic with nurses and doctors. It seemed like every five minutes I was asked, "How's your pain? On a scale of one to ten?"

"What's ten?" I asked on the first day.

"The worst pain you've ever experienced," they said.

"Well," I said, "if a ten would be two sharks ripping off my legs, I guess right now I'm a one or two." They wrote this down.

On day two, the gas began and got worse and worse. My belly swelled. Coughing and laughing were very painful. The gas is a function of the fact that the lower digestive tract does not like surgery and therefore shuts down. Gas is produced but not allowed to exit the body. You must walk to relieve the gas, even though walking is painful and when you walk you shuffle down the hall like a tired old man. You have raced ahead in time. You are an old man.

On day three, I farted at 11:03 in the morning. This was good news for everyone. Violet, the day nurse, smiled and said I would be allowed to eat. Eating? What was that? I couldn't remember. She removed the IV line taped to my left wrist. This was good.

Then she lifted my gown and said, "Take a deep breath."

I did.

She pulled the catheter from my penis. The pain of this action was sharp and immediate and indescribable to anyone who does not have a penis.

“Now then,” she said. “As long as you pee within the next five hours, I won’t have to put this back in.”

I was peeing within the next hour.

Walking got easier. I asked for sleeping pills and the night nurse let me sleep through the night. The patient in the next bed, a rather cranky man recovering from leg surgery who would loudly proclaim to the nurse “I want to die, I want to die” when asked how he was feeling at 4 am, was moved to another hospital.

I went up to see Amelia, who had her own room one floor up. She looked wonderful. She was sitting up in bed, a big smile on her face. “I feel 8,000 percent better,” she said. “How are you?”

“Oh,” I said, “bad gas, very bad gas.”

“Yeah, I know,” she said. “I get that too, sometimes.”

But she was smiling.

The gas passed eventually. I ate a bit of food and read my books. I was bored and ready to leave. On Friday morning, the fourth day, I got up and walked down to the lobby of the hospital and bought two newspapers. I came back to the room and tried sitting in the chair. It didn’t feel too bad. I got up and packed my bag. Judith arrived around noon. I got up again and put on my comfy yoga clothes and said goodbye to the nurses.

When we walked out through the hospital door back into the world, the first thing I felt was the warm June sun on my face. How lovely that was. I took a deep breath. The air was stinky. I loved it. The traffic on University Avenue was noisier than I remembered. I loved that too.

I spent two weeks at home recovering. Mostly I sat on the front porch reading novels and watching the neighbours come and go. I felt like James Stewart in Rear Window. Sadly, there

were no murders to observe. I couldn't drive or lift anything heavier than ten pounds. My body was still sore, especially the mid-section. I had to carefully ease into and back out of a chair, or the bed, or the passenger seat of the car. I moved slowly, not because I wanted to, but because I had no choice in the matter.

Three weeks after surgery, I went back to work. Downtown Toronto seemed noisier and more crowded than I remembered. I worked shorter days than usual and found I was tired by 3 and so I went home. But by the end of the week, something had changed. One morning I got off the streetcar at Queen and Yonge and walked down to Front Street, as I always did, and for the first time since the operation I had no consciousness of my body. I was thinking about music, and work, and what I would eat for lunch. I looked at the crowds of people rushing to work and felt no different from them. And then I realized, this is how you recover, and this is when you know you're going to be alright.

Six weeks have passed since the transplant. Amelia is doing very well. The Gauer kidney has made her healthy again. She has the energy of three grandfathers. She is still under quarantine but she's back on normal food and plans to return to work fulltime in September. Her doctor, Dr. Cardella, who's overseen her care at TGH since the late 1990s, hopes that a plasma treatment she will undergo soon will destroy the disease that attacks her kidney. She's still takes a galaxy of medications, 16 in total, but she feels better than she has in a long, long time.

I'm proud of what I've done. I feel a great tenderness towards Amelia that I find hard to express to her in person. In an email to her recently, I wrote, "When I think about what we've done, you and I, my heart is full to bursting."

She replied, "I don't know if I will ever be able to fully express how I feel about the events of the past few months but I know that I am extremely lucky to have someone like you in my life and that is very special to me."

On the morning of the day I left the hospital I got out of bed and went up to see Amelia. Her room was filled with soft light from the window. She was asleep, glasses off, her face neatly framed by tendrils of blonde hair. I didn't wake her. She looked very peaceful and much younger

than 26. She was a child and a woman at the same time. I stood and watched her for a moment, then turned and quietly walked away.