

## Amelia Part Two

By Stephen Gauer

On the morning of Tuesday, June 26, 2007, I went into hospital to donate a kidney to my 27-year-old grand-daughter Amelia. The operation went well, and six weeks later the Globe and Mail ran my story, Joint Venture, about Amelia and me and the kidney transplant.

Exactly 284 days after the operation, on Saturday, April 5, 2008, I was driving to Amelia's house to pick up the keys to the apartment she was planning to move into that afternoon. I'd started painting two Saturdays earlier and had one more session to go. Amelia was excited about finally moving out of her mother's house and into her first apartment. We'd talked on the phone at 7 pm the night before; she'd left work early because she was throwing up. She didn't think she'd feel well enough to come with me and help with the painting. She was disappointed but she sounded okay.

I'd already dropped Judith, my partner, at the St. Lawrence Market to buy halibut for dinner. I pulled into Amelia's street and parked the car half a block from her house. It was ten minutes to nine. I was early. Would Amelia be up? I saw a firetruck and police car parked near her house. I looked around but I didn't see a fire. I got out of the car.

Then I heard a woman's voice. A terrible crying and screaming voice. I kept walking. Then I recognized the voice and I began to run, and as soon as I came to Amelia's house I saw her mother Alison in front, crying and screaming, collapsed in the arms of a neighbour and with such a horrible tortured expression on her face. I knew what had happened. I knew that Amelia was dead.

"My baby is gone," she said. "My baby is gone."

There was a policeman on the front porch. I explained who I was and said I would go and get Alison's mom, Judith, and that was she was Amelia's grand-mother and I was her grand-father. Then I ran back to the car and started the engine and drove back to the market, cursing every red light, driving down University very quickly, across Adelaide, down Church and along Front.

There were hundreds of people in the market. I tried to scan every face. Where was Judith? I cursed the idiots who blocked my path. I ran across Front and into the north market and then back across Front into the south market, still scanning every face, like a cop searching for a killer in a crowd. And then I saw Judith. I ran to her and grabbed her arm. "Don't argue, don't say anything, just come with me," I said.

I dragged her along. We knocked people over. She got angry.

Finally we were outside in the sunshine. I took her in my arms and held her and said, "Amelia is dead."

We drove back and Judith went into the house to comfort her daughter. Other people had arrived. Philip, Amelia's dad, and his wife Erica. David, Amelia's uncle. They explained that the coroner was on her way. They explained that Alison had woken up to the sound of Amelia's alarm. When the alarm kept ringing, she went up to Amelia's bedroom on the second floor to investigate and found her dead in bed.

The rest of the day is a blur.

I remember Alison crying in my arms. "This is wrong," she said. "This is completely wrong. This is bullshit."

All I could say was, "We did everything we could, didn't we? We did everything we could for her." I was crying too.

For a time after the transplant, Amelia seemed to be doing okay. The new kidney was working fine. But by September the symptoms that had started a year earlier, before the operation, had come back. She was nauseous and vomiting. There were new problems and new symptoms: dizziness, slurred speech, speech, fainting, memory lapses. All through September and October and November she was in and out of emergency at Toronto General Hospital, sometimes for a day or two, sometimes for a week or two.

At one point she was in intensive care suffering from septic shock.

There were no beds for her in the transplant unit so she spent a lot of time in emergency. Emergency wards are designed for people with broken arms and bleeding heads, not for chronically ill patients like Amelia. The doctors couldn't pinpoint the cause of her problems. We were all puzzled and alarmed. She'd recovered quickly after the first transplant, back in 1997. Why was this round so much harder?

These were very difficult months for everyone. But Amelia never gave up. I'd go up to the hospital after work and visit her. She always greeted me with a big smile, followed by a detailed description of her plan for getting out of the hospital and back home again. She never despaired, she never raged at the universe. The only time I saw her cry was the afternoon she'd been kicked out of her room in emergency and forced to lie on a gurney in the hall for eight hours. I held her hand, and she cried and said, "I just want to go home. Please."

She was home most of December. She came to our house for Christmas dinner and seemed better. She went back to work in January, got fired when she missed too many days of work, and promptly started looking for another job. Through January and February and March she

still seemed better. She went looking at apartments and continued the job search. Judith no longer phoned her every day. We relaxed a bit, thinking and hoping that finally the worst was over for Amelia.

But she must have been far sicker than she appeared. The coroner's report said the autopsy revealed no visible cause of death. Further tests will take three months and may tell us whether her heart gave out sometime during the night of April 4, or whether Henoch-Schonlein Purpura, the chronic disease that caused the kidney failure in the first place, had attacked and weakened other parts of her body. HSP is a type of vasculitis which destroys the functioning of blood vessels and therefore no part of the body is immune or safe from it.

We held a memorial service for Amelia on Sunday, April 13, 2008 in the Debates Room at Hart House, at the University of Toronto. More than 130 people showed up. When Alison stood up to speak, she gasped when she saw how many people had come to support the family and celebrate Amelia's life.

Seven of us spoke. We all cried. We all remembered Amelia with love, affection, humour and sadness. "I learned openness, optimism, and where to get the best sushi and handbags," Alison said. "I learned that her generosity of spirit inspired the outpouring of concern and kindness everyone has shown me over the past week – the same kind of care and kindness Amelia possessed." Philip, who adopted Amelia while he was living with Alison, made us laugh by admitting that "Grumpy ironists both, Alison and I would actually have been more at home with a bitter child." We laughed again when her friends Marc and Kate reminded us that Amelia still owned a plush killer whale named Frank 'n' Bob that Judith had bought her in Vancouver 12 years ago; that she had a Hello Kitty TV

set; that she liked to eat popcorn in the bathtub while talking to her friends on the phone.

We told different stories. I tried to explain how because of the transplant I got to spend time with Amelia and get to know her and how she got to know me. "It's easy enough to say you love someone in your family," I said. "What's rarer is to say you honestly like them. I liked Amelia. I've never met anyone as appreciative and thoughtful."

And each of us, in our own way, stated the obvious: that Amelia was one of the bravest people we had ever met. And that she was, in the words of her dad, "the most insanely positive person I'll ever know."

After Amelia's death a few people asked me whether I regretted donating my kidney to her. This was a tactless question, at best, and at worst a rude implication that what I did last June was futile. People sometimes say tactless things when they don't know what to say and death renders many people speechless and some people stupid. (Trust me, all that is required is "I'm sorry for your loss.>"). It is, of course, a terrible terrible thing to outlive your grandchild.

Some of you may be wondering whether I regret my decision to donate a kidney, I will repeat my answer. Please pay careful attention.

I believe with all my heart and soul that if donating a kidney to Amelia made her life better, easier, less painful, more hopeful for even one day out of those 284, then it was worth it. Many people mistook me for a hero last year. I was no hero. I was just the right person at the right time doing the right thing. Amelia was the true hero for putting up with so much and never losing hope. She was always hoping for a happy ending.