

Shannon

*November 7, 1984 "She is diabetic."*

*November 29, 2018 "She is a former type 1 diabetic."*

*November 7, 2020 "Hi, I'm Shannon. Just Shannon. How are you?"*

## My Story

*November 7, 1984 - I was rushed to the doctor because I was listless, throwing up uncontrollably, and completely delirious.*

*I remember being curled up on the floor in the back of the car. My mom and dad were with me and someone was watching my brother at home. We got to the dr. office about 5 minutes from home and the doctor was closing up. "Bring her back tomorrow if she's still sick."*

*My dad peeled out of the parking lot "no way - she's going to the ER". They took me to Strong Memorial. After some tests and one frantic ER doc who said to "cover the rest of my patients, I'm staying with her", he told my dad I was type one diabetic.*

*"Check again"...my father's words repeated 3 times until the head of the pediatric department at the hospital met with him to confirm that yes, "your daughter is diabetic".*

*I was 4 and a half (or it might've been a year later and I was 5? It's a bit hazy). I'd had a healthy annual physical the month prior. But there I was, with a blood sugar of 1652 (normal is 80), diagnosed as type 1 diabetic.*

*The next 3 decades were anything but "normal". I take that back. I was the typical "normal" diabetic child-defiant, to put it mildly, and though I knew right from wrong, broke every possible rule in the book as far as how to take care of this disease. My parents did the best they could but I was "too smart" for my own good. Sadly, defiance and non-compliance led to complications as I grew up. Retinopathy and cataracts led to laser treatments. Neuropathy led to pain and medicine to try to help it. The "take care of yourself or this could happen" caught up with me full force.*

*I was able to go college, get a degree, and work, but there were many interruptions in daily life, most often brought on by poorly controlled diabetes. I had 2 toes partially amputated. I developed Charcot foot, requiring casting and braces, and finally a Velcro brace that I wear every day, and as such am limited in footwear and feeling in my foot. The complications made many things tough, but my perseverance and strong-will kept my hope alive. Hope I'd be able to rise above my "too smart" mind and realize I wasn't being smart at all. I was ruining my life all because I was in denial of being diabetic...still.*

*I woke up one morning and said "I don't want diabetes anymore. I went to the Internet - searched for diabetes advancements, and learned about clinical trials. One caught my eye - islet cells. The cells that make insulin in the pancreas were being placed into the liver and working. I called all around - Australia, Canada, Italy, Georgia, and I found out either the studies were not accepting new patients or you had to be a resident. I actually looked up how long I would have to live in Australia to become a resident. I then found a trial right here in Massachusetts. I emailed them and was excited to find out they were taking new patients! I started the process, filled out the forms, even had an appointment set up to meet with*

*the team. Then I got a phone call..."we are sorry, we have lost funding for our trial, we can no longer accept new patients." I was sad but I quickly said "ok, who's next". I went to Facebook. Facebook CHANGED MY LIFE. I found a support group for islet transplant and posted my plea "I've called all around, I'm not making progress, help!" As luck would have it, a now dear friend would see the post and share information about the trial at the University of Chicago. I emailed and started the process. I had to be in a certain range to be accepted and so I found my motivation to kick my own butt into gear, exercise, watch my diet super close, just to get within a range of blood sugar where I could possibly have my life changed for a clinical trial. I went to Chicago for testing. On the last day in Chicago I was accepted into the trial! Then the phone call came "Ms. Kessler, you are allergic to Bactrim, that is one of the medicines used, we cannot accept you." I cried - on the phone - still talking to the doctor. I didn't understand - that was on the form from the very beginning. Why was I brought here and tested and given hope if all along it was no? He said "please don't cry, let me see what I can do. It may take a little time, I have to call Italy."*

*The doctor cared so much that he called Italy, to the global headquarters of the trial drug that was being used, to get an exemption to take a different antibiotic for one of the supplemental drugs that were used in the clinical trial. This was just a glimpse into the heart and mind of him, and his entire team.*

*Italy said ok.*

*I was accepted and waited only 2 weeks after the transplant groups designated vacation for my first "transplant" (islets are cells versus an organ). Most of you know the rest of the story...I had 2 more islet transplants after that, and while I was considered a success for the trial (the ultimate goal was to not have diabetic unawareness-the lack of indicators that diabetics get when they have low blood sugar), I was still taking a bit of insulin, despite having had times where I was able to go off of insulin completely, and was eligible for a pancreas. When I was first told that being part of the trial was also going to make me eligible for pancreas, I had said no, I couldn't go through that. I've never had such a major surgery like that. After having the taste of life without diabetes, when it came up again, I immediately said "yes!".*

*Amazingly, I was listed on the waitlist for a pancreas on the same day I was diagnosed - November 7 - just 34 years later. I had no idea that only a few weeks later, someone who I now know and consider a friend and even my family, would be saying goodbye, and become connected to me in a way I never expected. It's the hardest part of transplant. My gift of life is someone else's saying goodbye to the person who would selflessly give me a pancreas, and I can never say thank you, show her how my life has changed for the best. Every day I think of her, how she saved so many-I think 5 or 7 people received transplants thanks to her, countless others too received gifts from her as well. She and her family, along with Tim and our families are my big why for taking care of myself, cherishing life everyday NOW instead of always wondering about the future, seeing things the way I had never seen them before (both my view point and how I appreciate things that I actually see), and making the most of everything.*