

# My Transplant Journey

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SANDRA H., liver recipient, February 1997

My transplant journey began in April 1992. After several years of not feeling well, a new doctor ran every blood test that she thought might lead to a diagnosis. Those results came back showing high liver numbers and I was referred to the Toronto General Hospital Liver Disease Clinic.



It took several tests and some investigation, but in May I was diagnosed with Primary Sclerosing Cholangitis (PSC), a rare liver disease. I was told that by the time I was 40 or 50 I would need a liver transplant. At the time I was 28 and thought that's a long way off, and none of us really know when we're going to pass. In addition to being diagnosed with liver disease, I was also told I had IBD and that it was either Crohn's or Colitis. So here I was at 28 years old with a liver disease which most people thought would have been caused by alcohol or drug use. Add in my problems with my bowels, and if there were any conversations regarding poop and diarrhea in my future, I would be the life of the party!

It wasn't that difficult to find information on IBD as there was the Crohn's and Colitis Foundation of Canada and many doctors who specialized in this field. I was able to obtain a book written by Dr Fred Saibil who eventually became my specialist. However, when it came to my liver disease, I first reached out to the Canadian Liver Foundation. At the time there was no easily-accessed information on this illness other than a link to a research page and a recent article from the US speaking about it.

One day while waiting for bloodwork at the Toronto hospital, I sat beside another liver disease patient. He passed me a card for a coordinator of the "Living with liver disease" meetings that were hosted by the Liver Foundation of Canada. He mentioned that these meetings helped him and that he thought that they would help me as well.

My first meeting was in August 1995 and I remember to this day sitting beside a guy named Peter who ironically had the same liver disease as me and just had a transplant the previous year. Meeting him, alive and well, gave me hope for the future.

By 1996 I had an email address and had set up Internet access at home. At the time this was all very new and I mostly used it to check emails from people, and to use a form of Chat that was available then. I had a neighbor who was very good with computers and he was able to provide me with printouts of information on my disease and transplants. I still have those pages. I remember thinking how foreign it all was to me. Although I had heard about transplants, I never would've imagined that I would require one someday.

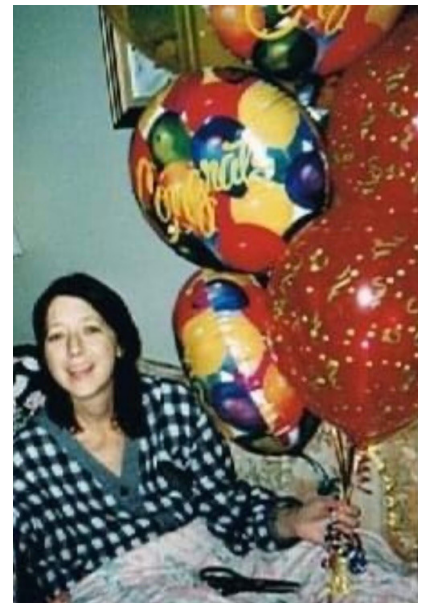


When it was time to be referred to the transplant team I received this big green binder that was to tell me everything I needed to know about receiving a transplant. The ironic thing is is when you have liver disease it's very difficult to focus and to retain information. You find yourself so tired and have no energy much of the time, so I confess I didn't read too much of that book. I did, however, make notes before each clinic appointment and brought along either my husband, my father, my brother or a friend to the appointment to make sure that I never missed anything. It also gave me an alternate point of view on the information being shared.

After being listed for a transplant in August 1996, I deteriorated really fast. There wasn't much time to prepare or think about what was going to happen. I was in survival mode, simply taking the medications provided and staying healthy enough to be ready for a call that would say they had a liver for me. There are a few things I wish I had known prior to the transplant, but in hindsight, what happened was just part of the process and I don't know if I could have prepared for it. I do remember watching this VHS video on a VCR in the patient room listing various outcomes and challenges following a transplant. While it was certainly revelatory, I found it hard to get over the acting.

After I recovered from my transplant, I wanted to do two things: I wanted to help "give back" by promoting Organ & Tissue Donation awareness so that more people like myself could have a second chance at life. I also wanted to help mentor people so they knew what to expect after a transplant as well and have someone to talk to about their feelings. I felt it was important to provide people with someone they could ask questions of, someone who had already been through the process.

I joined the liver mentor program at Toronto General Hospital and was trained on what I could and could not do to help people, such as not giving out medical advice, watching for red flags and knowing when it was time to have the mentee reach out to their medical team. Through this program I met several mentors & mentees, and although several have passed away, many are still good friends today.



One day I was in the transplant clinic and picked up a brochure about the World Transplant Games. Team Canada was going to Australia in the fall of 1997, the same year I had my transplant. I had also seen a poster in the hospital about Heather Fisher, a liver transplant recipient who was also an ER nurse working at London Health Science Centre. She was very athletic, had climbed mountains and was a member of the team. This brochure and poster encouraged me to register with the Canadian Transplant Association (CTA) in 1998. In April I met a majority of the co-founders of the association at a social gathering celebrating the 25th anniversary of one of the founder's kidney transplants. I also remember meeting Heather who had had her liver for 15 years by this point. I knew then that I had met amazing people who would become my friends.



Today I am fortunate to have attended many World, Canadian and American Transplant Games, Dragonboat Festivals, and other events over the years. I'm still connected to many members of this group today, although, sadly, over the years we have lost some wonderful people who passed away. Heather will be celebrating her 38th liver anniversary this year.

The CTA was a great resource for me as it helped me to connect with others who had transplants, were on dialysis or were simply waiting for an organ. As I continued to raise awareness I was able to meet some remarkable donor family members and transplant professionals who helped me have a better understanding of the organ donation and transplant field. The more I got involved, the more I learned, and the more connections I made so that I could become a resource for many on their transplant journey.

So much has changed since my transplant in 1997. Living donation officially started at Toronto General Hospital in 2000. This breakthrough really increased the number of recipients. New medications have been developed, as well as innovation and research leading to improved transplant processes and protocols.

For those on their Transplant Journey today, there is so much information available that it helps to have a centralized place to look for it. However, you also want to know what to expect along the way. Each person has their own way of learning and we need to look at how and when we provide this information. I think it's very important to have options for accessing information in a way that works for the recipient. For example, I'm a visual learner, but my husband and primary caregiver likes to read material and process the information that way. So multiple ways of delivering the information will make it easier for the person to absorb it.

All in all, together my husband and I have made a good team on my transplant journey. And for that I am forever grateful.

**Sandra H.**

Liver Transplant Recipient

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