

Transplant Unwrapped

Intestinal transplant patient provides support and education

By Kayla Pfab

My name is Kayla and my journey began seventeen years ago, when I was ten. I have stayed positive throughout my medical journey by continuing to live life and doing the things I love: staying active, baking and cooking, traveling and helping others.

Over Reaction

When I was ten, I hit my feet on the diving board. I contracted complex regional pain syndrome (CRPS) in my right foot. My nerves sent signals of excruciating pain even though there was minimal injury. Months into my treatment, the CRPS mirrored into my left foot, leaving me wheelchair-bound. After an epidural catheter block at Johns Hopkins, my CRPS was cured, but I had to work to regain strength.

Over the next couple of years, I had bouts of dizziness and felt like I would pass out. Then my gastrointestinal symptoms came: abdominal pain, bloating and nausea. Initially, we just thought it was a stomach bug, but my symptoms persisted.

Just Constipation

I remember my first trip to the emergency room. After ruling out appendicitis, the ER doctor just brushed me off as being a teenage girl who was being over dramatic and that I was just constipated. I knew in my heart that this was not just simple constipation.

We saw a gastroenterologist at Johns Hopkins who diagnosed me with an overall autonomic nervous system dysfunction, postural orthostatic tachycardia syndrome (POTS) and global dysmotility of my digestive



tract. Essentially, the nerves to my entire digestive tract were not working correctly.

First Treatments

I didn't want surgery, so I came up with my own "protocol." I took massive amounts of laxatives. I wore a scopolamine patch to help with nausea. I did physical therapy. I regulated my diet and nutrition to minimize nausea. I used deep breathing and guided imagery to help manage pain. This regimen worked for my high school years.

I went to college at Duquesne University in Pittsburgh. I became so sick that in June 2013 I received my first ileostomy. Unfortunately, within 24 hours it became necrotic and I needed emergency surgery to make another ileostomy.

As the months went by,

I continued to have increased symptoms and frequent bowel obstructions. Throughout this time, I continued to go to school, taking finals early, making things up and working hard on my studies to distract myself from the way I felt.

First Intestinal Transplant

In May of 2015, I was officially listed for an intestinal transplant. My mom and I relocated to Cleveland. The most challenging part of the whole process was being away from our family back in Virginia. Luckily, I had the surgery only six days later..

My first transplant did not go well from the beginning. I had lots of bleeding from my ostomy and other transplant-related complications. I then began exhibiting signs of chronic rejection and my team decided I would require a second transplant. This time I would

receive a modified multivisceral transplant that includes a stomach, pancreas and small intestine.

In July 2017, I was relisted for my second transplant. During the wait, I had the pleasure of meeting many other transplant patients and we formed our own 'transplant family.' I used my love of baking and would hold parties for various holidays to bring transplant patients and caregivers together. I also spent a lot of time in the hospital. I had a 213-day hospital stay during which I continued to bake! My mom would bring in my KitchenAid mixer and all of the ingredients. I believed that continuing to do the things you love to keeps you positive and going.

Second Transplant

My second transplant was very rough. I had four additional surgeries within three weeks. I also contracted Epstein-Barr virus, post transplant lymphoproliferative disorder and cytomegalovirus and spent 100 days in the hospital. When I was discharged, I was the weakest I had ever been after surgery. I walked every day and slowly regained my strength.

At home in Cleveland, I slowly recovered. Because of all my complications, we remained in Cleveland for a long time after my transplant. My team finally released me from Cleveland last May. Once released, my family and I moved to Dallas.

Just recently, I had another surgery, which shows I am back in chronic rejection. Because of this, my surgeons created two ostomies and gave me short bowel. I have had numerous ostomies throughout my life, so having

two doesn't bother me. I have accepted that I will live with an ostomy forever. I often find it easier to have an ostomy versus always having to run to the bathroom worried that I might not 'make it,' which I often felt after an ostomy closure.

With my intestinal transplants, I traded one set of problems for another set of problems. I have to take numerous medications, including high doses of anti-rejection medications and steroids. In particular, the steroids have had a significant effect on me. From the steroids, I have developed avascular necrosis (AVN), which is death to the bones in the joints. I have AVN in both of my ankles, knees, hips, wrists and hands. This is one of the many life-limiting side effects that come with these medications and is an important reason why people must be well-informed about intestinal transplant before making decisions for themselves on the course of treatment.

Fulfilling A Need

From talking to so many transplant patients and caregivers, I knew that there is a lack of information and support for the intestinal rehabilitation and transplantation community.

This was my catalyst for starting the 501(c)(3) nonprofit organization *Transplant Unwrapped*, www.transplantunwrapped.org. No patient or caregiver should go through this journey alone. Whether it be living with an ostomy, or only learning about dietary modifications, everyone should have access to quality educational materials on intestinal transplants. 🌈

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