

## Lending Medical Knowledge and Hope to Others



## Transplant UNWRAPPED

### Kayla Pfab self-educates and manages the day-to-day hardships of Intestinal Transplant.

**From a young age**, Kayla Pfab faced a series of health complications. Kayla and her parents constantly found themselves at the hospital to manage her pain and adjusting her medications to put off big surgeries that could alter her life. Doctors discovered she was experiencing chronic pain in her stomach resulting from a low functioning digestive system. In 2007, at the age of 14, Kayla was diagnosed with global dysmotility and an autonomic nervous system dysfunction at Johns Hopkins. The nerves to her intestine did not function properly, leading to impaired movement of food, fluid, and air through the digestive tract. Many years later, in 2014, Kayla was officially diagnosed with Chronic Intestinal Pseudo Obstruction (CIPO) at the Cleveland Clinic. After multiple visits at the clinic, Kayla was told she would need an intestinal transplant in the future.

As Kayla got older, her condition continued to worsen. The doctors tried various treatments to help relieve the pain such as a G-tube insertion and Octreotide injections, none of which worked. At this time, Kayla was enrolled in college at Duquesne University in Pittsburgh,



Kayla and her dad, Terry

Pennsylvania, pursuing a master's degree in Physician Assistant studies when she became too ill to complete her degree. Reality struck hard when Kayla's doctor told her that it was time for an intestinal transplant. Both Kayla and her Mom relocated from Richmond, Virginia to Cleveland, Ohio where they started the transplant process at Cleveland Clinic. They had to live within two hours of the clinic to be

eligible for the transplant. "I wouldn't say the decision to move was difficult as we know it was required and necessary, and this transplant was giving hope to my family," said Kayla.

Six months after Kayla's referral and six days after she was officially listed on the UNOS waitlist, she was told she had a match for a transplant. This was extremely fast for a patient like Kayla, as the evaluation alone can take months to even a year. She was surprised, to say the least. "I was hopeful that the transplant could provide me relief from the symptoms and give me the ability to wean off of TPN." Kayla started TPN, Total Parenteral Nutrition, in August of 2015. TPN is a method of feeding through a vein to provide the body with the nutrients it needs without going through the gastrointestinal tract. "I was so sick and had no quality of life, so I was at the point that I would try anything to regain some quality back," said Kayla. Hopeful, Kayla prepared herself for her upcoming surgery. She received a small bowel transplant on November 11, 2015. Kayla spent the next month in-patient recovering from the transplant. She had many complications post-transplant including an issue with bleeding which resulted in three additional follow-up surgeries. When she got out of inpatient, Kayla and her mom lived in their apartment in Cleveland and went to the hospital on most days for bloodwork, clinic visits, and other tests to check from rejection. Her recovery in Cleveland carried on until November of 2016.

Kayla's mom and she moved back to Richmond, Virginia in hopes that it would be the end of long hospital stays for the time being. However, more complications followed her transplant. Kayla was still experiencing pain, nausea, and other CIPO symptoms. When she went in for checkups every few weeks, doctors found that her stomach and intestines were dilated, abdomen extended, and rectal function was impaired. She had to stay at the hospital 1-2 times per month for NG tube placement and blood transfusions. Moreover, she was



Kayla sitting in the SICU after her transplant



Kayla and her parents at her white coat ceremony while she was in PA school.



Molly, Director of Patient Experience, Kayla's brother, Kevin and Kayla together at Cleveland Clinic.

experiencing chronic rejection from the first transplant. In April of 2017, Kayla's doctors agreed that she needed a modified multivisceral transplant. This transplant involved more organs compared to her first transplant. She spent lengthy amounts of time in the hospital, upwards of 213 days, before she received her transplant. During this time, she developed strong friendships with other transplant recipients who were going through similar challenges. "When I was in Cleveland, I did a ton of baking for the staff at the hospital with fellow transplant patients and caregivers," said Kayla. Kayla goes on to say, "Seeing the perseverance and strength of many of these patients helps me keep going." While waiting, Kayla and her family had the chance to go on her dream vacation to New Zealand and Australia. "We had three fifty-pound suitcases filled with medical supplies and TPN, but we did it, and it was awesome!" Despite the difficult situation Kayla is in, she has always tried her best to stay positive and do the things she loves, one of those things is traveling. When she got back from her trip, she returned to the hospital. After a year and a half of waiting, Kayla received her modified multivisceral transplant on February 3, 2019. This transplant included a stomach, duodenum, pancreas, and small intestine. Like her first transplant, Kayla faced a series of health challenges following the surgery. She had to receive four follow-up surgeries to stop internal bleeding and washout various infections within her body. Yet again, Kayla showed great resilience and a positive mindset during this difficult time.

More recently, Kayla has dedicated her time to helping patients like herself and clinicians learn more about intestinal transplantation. "Whenever I talked about my intestinal transplant with my primary doctor in Virginia, they didn't fully understand what an intestinal transplant was," explained Kayla. As a former student

studying to be a physician's assistant, Kayla dove into medical journals focused on intestinal transplantation, pulling important information from them, and combining it with her experience having gone through the process herself. This wealth of knowledge now lives on a website called Transplant Unwrapped. It is a newly certified 501©(3) nonprofit that educates people about intestinal transplantation. "I encourage people to investigate all possible treatment options and become well-educated before making any decisions," said Kayla. "Intestinal transplant is definitely not a cure, and you trade one set of problems for another." Kayla's fellow transplant friends also help with the Transplant Unwrapped, sharing their stories on the website, and using their talents to contribute to the overall organization. This has been a source of inspiration for Kayla as she continues to deal with various health challenges. She is the perfect example of a strong woman making a change in the transplant community with her work. Despite everything she has gone through, she keeps her spirits high by doing more of what makes her happy. "Staying positive is all about doing the things you love." ★



Kayla walking on Fernandina Beach, Florida with her two friends, Laura and Cindy



## Zero Hesitation...

### How Marathon Running Led Roger Castillo to Save a Life



*Roger poses at the finish line after his first marathon post kidney donation.*

**Running has always** been a reflective outlet for Roger Castillo. As a half and full marathon runner, the Filipino native has a lot of time to appreciate the world around him while he is on his long runs. In addition to running, he enjoys biking and hiking. “The fresh air, green trees, and sunlight lift my mood which is then reflected to how I face my daily routines and interactions with other people,” explains Roger. At fifty-two years old, he has an outlook on life that many people strive to obtain. He attributes his positive attitude to his healthy and active lifestyle.

Roger’s passion for running led him to save a life. Through a running friend, Roger met a couple, David and Greg, who belong to a LGBTQ+ Running Club called Frontrunners in Long Beach, California, where Roger resided. Over the next few years, the Roger and his spouse, Douglas became close friends with David and Greg. In the spring of 2019, David and Greg invited Roger and Douglas to stay at their house in Lake-wood, California to celebrate Gay Pride Weekend together. When they arrived at the house, Roger noticed an alarming amount medical equipment lying around the house. He asked Greg, who was the only one home at the time, what the medical equipment was for. Greg explained that David had kidney failure and needed home dialysis for seven hours every night. Roger was shocked, he had no idea that David had been going through all of this. Greg showed Roger and Douglas the home dialysis setup they had in their bedroom. Roger remembers this moment clearly, “I was at a loss for words and so overwhelmed with emotions.” In that moment, Roger offered to donate his kidney to David without any hesitation. “I just said it,” recalled Roger, with a shaky voice. While waiting for David to come home, Roger, Douglas, and Greg talked about the pos-

sibility of Roger donating his kidney to David. They discovered Roger and David were the same blood type. When David arrived at the house, Roger announced that he wanted to get tested to donate his kidney to David. To which he responded, “Thank you brother.” It was an emotional and exciting weekend for all of them as they celebrated gay pride and the possibility of Roger donating to David.

Not knowing how this would affect his running, Roger researched how kidney donation might impact his athletic ability. He discovered a Facebook page hosted by Kidney Donor Athletes, a nonprofit that connects living kidney donors across the country. Within this group are living donors who have continued to excel in marathons, ultramarathons, triathlons, and more athletic events post donation. He also connected with donors and asked them questions about their recovery, which gave him more encouragement to go forward with donating his kidney to David. Roger did all the necessary testing to become a living donor and a few months later in November, the transplant team told him that he was a match for David. “I had a gut feeling,” said Roger, who predicted he was a match from the start. After hearing this exciting news, Roger and David were informed that their surgery would take place on February 4th, 2020 at Cedar Sinai Hospital in Los Angeles. Roger’s family was supportive of his decision to donate. “A few were worried that I may not be the same as far as being active afterwards. I reassured them that I researched intensively,” said Roger. Moreover, he had a strong base of online supporters from Kidney Donor Athletes, who were cheering him on virtually.

In January, the month leading up to his donation surgery, Roger ran six miles every day to stay in shape. Not only did this running regimen help keep him as healthy



*Roger and David together after the transplant*



*Roger in the hospital after his donation surgery.*

as possible going into surgery, but it also helped Roger him process what he was about to do. The day before the surgery, Roger walked over 7.5 miles in his neighborhood and reflected about how special the gift of life is. “I thought about the good stuff, what I was about to do and how it was going to help David,” said Roger. This inspiring walk put Roger in the right headspace before his surgery. “The green trees and grass helped me focus and kept me in a positive mindset,” said Roger. The next day, he went into the operating room and successfully donated his kidney to David. Soon after the transplant, David’s new kidney began producing urine. Roger spent two nights in the hospital recovering from the surgery and then he was released, David was released from the hospital the following day. Both of them recovered well. Roger, eager to move his body after surgery, started walking around his neighborhood. Week after week, he began building up miles until he felt comfortable running. “I didn’t really feel any different,” said Roger. “I tell people that my experience was great. Following through with a goal to help another person was so fulfilling.”

Since donating, Roger and Douglas relocated to Portland, Oregon. They made sure to visit David and Greg once before they left town. “We are like brothers now after the donation and we’re planning on getting together soon when the pandemic situation gets better,” said Roger. Since settling into Portland, Roger built up his endurance and started running longer distances. More recently, he reached a huge milestone: completing his first marathon post-transplant. On October 14, he competed in a virtual marathon in Portland. “It was so rewarding that I cried at the end of the race,” recalled Roger. “I’m happy that I could show people that running marathons as a living donor is a possibility.” Throughout this process, Roger’s positive outlook and love for life never wavered. Today, he shares his donation story on social media and advo-



*Doug and Roger hiking on a trail in Oregon in October 2020*



*Doug and Roger before his donation surgery.*

cates for living donation. Roger’s donation reveals one can still be extremely active and dedicated to their sport after giving the gift of life. His story will inspire those who hear it and encourage all types of athletes to consider organ donation. ★