

THE ROOTSHTAIN BROTHERS - LIVING DONOR LIVER TRANSPLANT



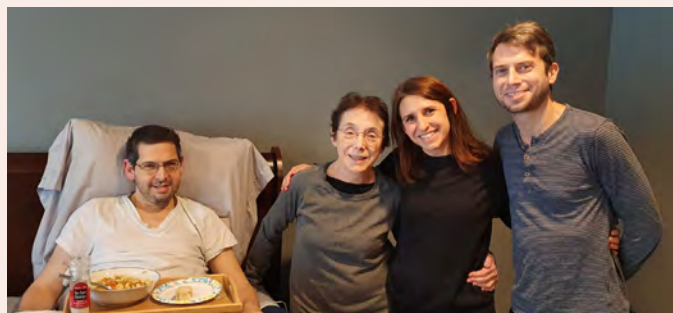
Gavriel (left) and Uriel (right) in the hospital the day after living donor liver transplant

On April 4th, 2022, Uriel Rootshtain became the 26th person to have an adult-to-adult living donor liver transplant at UW Medicine, a program that was revitalized in 2020 and serves the entire Pacific Northwest. Uriel's medical journey began several years prior, when he was diagnosed with primary sclerosing cholangitis (PSC), a rare disease that causes the bile ducts in the liver to become inflamed and scar, eventually blocking the flow of bile and causing irreversible damage to the liver. In September

2021, Uriel's condition deteriorated so quickly that he was admitted to the hospital and placed on the liver transplant list. That's when he met liver transplant surgeon Dr. Mark Sturdevant and learned about the living donor liver transplant program. *"When I went onto the transplant list my MELD score was in the mid-20s, and for someone with a B blood type, a MELD score of 20+ puts you pretty high on the list. The initial thinking was there could be a deceased donor relatively soon, but then my labs stabilized and my MELD score dropped quite a lot although I was still feeling very fatigued. I ended up much farther down the list as a result, so it looked like it was going to be a much longer haul."* Initially, Uriel didn't tell his family about the option for living donor liver transplant as he did not want to put them in harm's way, but when two of his siblings eventually learned of the option, they jumped at the opportunity to be tested to see if they could help their brother. Due to the COVID-19 travel restrictions, both siblings began initial testing at home in Johannesburg. Uriel's brother Gavriel shares, *"The tests came back positive for both of us in terms of being good candidates. My sister has four children and I said I would prefer to go if it was between us. From there they did additional testing to make sure I didn't have PSC as well, because it would be no point in giving him a sick liver."* Gavriel arrived in Seattle on March 4th and the next day began another round of testing to verify the tests done in South Africa. A month later, it was surgery day. Gavriel shares, *"The work, organization and*

effort felt like climbing a rollercoaster. Once operation day came, it felt like we had made it to the very top and now the different rush of the actual operation and recovery was one of relief that we both came out ok and were stable. Very grateful to the entire surgical team and care team for everything they achieved for us." Gavriel's donor operation took seven hours, and Uriel's procedure took ten hours, longer than expected due to the extensive damage the disease had caused on his body. Uriel shares, *"We were up and about walking the next day, getting our laps in in the hospital. Physically and from a labs point of view we were making very good progress. We were checked out of the hospital after a week – we were told initially we could be in for as long as two weeks."*

Uriel and Gavriel are now more than two months post-transplant and doing well. *"General awareness about this option is very low. It comes as a surprise to almost everyone that you can take a portion of someone's liver and transplant it, and that both halves will grow back to full size,"* says Uriel. Gavriel is quick to add, *"Initially, we didn't even know as a family that it was an option to be a living donor... especially for people with PSC, it's a good viable option to be aware of."* Uriel notes, *"I was fortunate that I had family members that took matters into their own hands and decided to get themselves tested to see if they were eligible. Living donor transplant has helped me tremendously in terms of giving me a path from where I previously wouldn't have had one – at least for a long time."*



Uriel, Leonie (mother), Ayelet (sister) and Gavriel, the day after they arrived home post-transplant



Top: Gavriel, Uriel and Leonie (mother) at discharge, one week after the living donor transplant surgery.



Bottom: Uriel, Angela (Uriel's wife), and Gavriel at SeaTac airport as Gavriel flies home to South Africa

JUDITH RAPP, ASSISTANT DIRECTOR
ACADEMIC & STAFF HUMAN RESOURCES,
DEPARTMENT COMMUNICATIONS

Why I am writing this: to tell the other side of the transplant story—the donor side from personal experience. To help others understand the healing nature of doing something for others.

Getting a call no parent wants to get – ever – that your child (in this case, grown child) is in the hospital neuro-ICU and has suffered a brain trauma. He is alive, but in serious condition.

I will never forget the long drive to Tacoma General Hospital on January 2, 2020—one day after the start of the new year—not knowing much, fearing the worst; hoping “alive” meant he’ll be OK eventually; confused about what happened; nor what we would face when we got there. I kept holding on to the “he’s alive” phrase – where there is life, there is hope.

We were met by a small group, the nurse in charge of that unit and the neuro-trauma doctor attending him. We were taken to see Nicholas, our 35-year-old son and only child. He was on a ventilator and his eyes were closed; otherwise, he looked normal and peaceful. We learned he had suffered asphyxia and his brain had been deprived of oxygen for an undetermined amount of time. EMTs had been able to re-establish a heartbeat, but he was on a ventilator. The doctor was kind but gave us the straight facts: Nicholas’ brain had been deprived of oxygen for long enough that at this point the outcome was uncertain, but it did not look good.



Judith and Nick at Christmas

Then a most important thing happened. The doctor (I believe he was a neuro-ICU hospitalist) took us to a private space and discussed with us the kinds of brain trauma and how they are determined.

I cannot emphasize how important this conversation was. I am sure medical staff do realize these are sensitive conversations, but I emphasize that handling these well was crucial for our understanding, important decision making, and a vital step in our grief process. The doctor and the other caregivers treated us with respect, honesty, compassion and agency - people, though in shock and grieving, could handle painful information. Another important quality was the doctor and the rest of the team provided us time and space for questions, many repetitious.

We came to understand what brain death was, how it was distinguished from other forms of brain trauma, such as **Coma, Vegetative State and Brain Death**, which we learned was an irreversible cessation of all functions of the entire brain, including the brain stem. A person who is brain dead is dead, with no chance of revival.

I asked if or how they knew what state Nicholas was in – was he brain dead? I learned that pronouncing someone’s brain death is not a simple yes or no. There are criteria that are met or not met over the course of a couple of days that would determine whether he was brain dead. Our doctor explained that tests would be conducted, and he would be meeting with other doctors experienced in evaluation of the data. That was the process to determine Nick’s brain status. He did say that tests so far did not reveal any reactivity to pain, and he did not have a gag reflex – both indicators of brain death. At this point, he was not hopeful there would be recovery.

Stunned, I asked a lot more questions. “*You hear of people waking up from comas, might that not happen in this case?*” I had seen one of the fingers of his right hand move slightly and that gave me hope.

The doctor again told us that he did not think Nick was in either a coma or vegetative state, but more tests – over a period of hours or a couple of days – would need to be done for them to pronounce Nick as brain dead – which is dead. The heart and lungs were now functioning by artificial means and would stop when those were removed.

It was during these conversations that we discussed organ donation. I have always been an advocate of organ donation, as I knew Nick was. But in those moments, you want to make really sure that there is no chance of recovery before you give permission.

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THE HEALING POWER OF TRANSPLANTATION

Much as we wanted to hope, it became harder and harder to believe he would recover. We watched them perform some of the tests, which I am grateful they allowed us to witness - tests like the pain and gag reflexes. We gradually accepted our son was brain dead, and on January 4, 2020, he was pronounced brain dead – which is dead.

We gave permission for organ transplantation and the Life Center Northwest¹ (LCNW) organization took over. It was comforting to me to know that the transplantation team operated independently from the team that pronounced Nick brain dead. Separation of interests is an important concept to me – and allowed and allows me to trust these systems.

The LCNW nurses and organ donation coordinators were extraordinary – they explained every step of the process, provided comfort, and made sure Nick was well taken care of during his final days. The process of determining what organs

could be donated, finding and preparing the recipients, and getting the transplant teams ready to go takes several days. I found these days a grace granted to us. We were able to be with Nick – in a hospital room – but it was peaceful in its own way. LCNW provided a personalized quilt. Nick appeared peacefully asleep. I was grieving as were my husband and our son's fiancée, and we all took extraordinary comfort in our granddaughter, who reminded us of new life.

In the end, though Nick could have donated six organs in total (lungs, heart, liver, pancreas and two kidneys) for various reasons, four organs found new life in recipients that were very sick. His heart, his liver and both kidneys were transplanted.

I was especially thankful his heart was able to be transplanted. Partly because it was a heart, and also because I knew the odds were that one of the surgeons I worked with every day – and had for over 15 years – was likely to perform the transplant. Hearts do not stay viable as long as other organs, and therefore can't travel as far to be transplanted. In the state of Washington there are only a few places it could be transplanted, with UW Medical Center doing the most heart transplants in this region. So, though I don't know for sure since that information is not shared with organ donor families, the odds were one of our surgeons would likely be performing the transplant. This thought was comforting to me. I know our surgeons; I know their skill and compassion. It felt to me like my family was taking care of my son. This is a unique circumstance – knowing and working with cardiac transplant surgeons – but I know that skill and compassion are present in every transplant they do.

I know that his organs went to people who really needed them – a mother with three children received one of his kidneys, another woman got his other kidney; a man got his liver, and his heart went to a 40+ man who has a family that very much needed him. We know that all the recipients are alive and doing well; made it through the worst of COVID. In that I take comfort.

The death of our son was surely the hardest thing we have ever been through. The grief is real and it hits you unexpectedly, and is triggered by the smallest things; but there is grace, too. An important part of walking through the grief toward healing was the knowledge that our son had given the ultimate gift, the gift of life for others.

¹ Life Center Northwest is the federally-designated organ procurement organization and AATB-accredited tissue recovery organization serving communities throughout Alaska, Montana, northern Idaho and Washington. <https://www.facebook.com/lifecenternorthwest/>.



Top: Nick and Natalie around her 1st birthday - 2018

Bottom: Nick and Natalie a few months before his death - 2019

DR. DAVID CAMP - ALTRUISTIC KIDNEY DONATION

In February 2020, Dr. David Camp, a chiropractor from Lacey, WA, traveled to Germany to have two lumbar discs replaced, a surgery that he hoped would finally resolve his debilitating back issues caused by a car accident in 2015. Little did he know, this would be the start of a long and very painful medical experience.

While under anesthesia, Dr. Camp's spine surgeon found a rupturing abdominal aneurysm. Without a vascular surgeon on staff, Dr. Camp was rushed to another hospital for an aneurysm repair. Recovery was complicated, and Dr. Camp was in and out of the intensive care unit, his abdomen swollen with fluid. The hospital team thought this was a post-surgical seroma, but the gallon of fluid they drained from his body was never sent for testing. As days passed, Dr. Camp's condition continued to deteriorate, and a week later his abdomen was swollen with fluid again. *"They had put a port in my jugular vein, and they were giving me fentanyl and morphine at the highest doses that were safe, and that never lowered my pain below a seven,"* said Dr. Camp. *"I got a cold while I was in the hospital and I coughed one night. I coughed and my ureter exploded ... that was like a 15 out of 10 pain."* An MRI revealed a ruptured ureter and the abdominal fluid was drained and sent for testing, which came back as urine. The surgeons laid out five surgical options, but Dr. Camp wasn't interested in another open abdominal procedure and asked about transplant. *"They said under German law, they don't allow living kidney donors unless you're donating it to a close family member. They basically said they would take my kidney and study it, which means they would put it in formaldehyde and it would be useless. In my mind losing a healthy kidney and no one getting the benefit of that didn't make any sense."* Dr. Camp decided to look into altruistic kidney donation closer to home and emailed Dr. Ramasamy Bakthavatsalam. *"I appreciate Dr. Baktha probably more than he knows. Two days after I sent an email, he called me in Germany to ask about the situation. And, you know, that was an important part of my outlook on having this kidney donated."*

In March 2020, 46 days after being admitted, Dr. Camp was finally discharged from the hospital with a nephrostomy tube. He was far from good health and couldn't walk 10 feet due to the 56 pounds of muscle mass he had lost while inpatient. Dr. Camp and his wife rented an apartment and spent the next four months recuperating so Dr. Camp would be strong enough to travel.

Finally in July 2020, five months after the initial surgery, Dr. Camp was back in the United States and began testing for kidney donation. In November 2020, it was time to donate. *"I've got a lot of adhesions from having my organs bathed in urine for so long, and instead of doing a traditional four-inch scar to remove my kidney, they had to split me almost a full 12 inches because my kidney was encased in scar tissue."* Dr. Camp doesn't know who received his kidney, but he does know that individual is in excellent health. *"I assume that they're doing well because I've always tried to stay healthy. To me, it was just a natural thing that I wouldn't want to just get the kidney out just to be done with it. I've been in chiropractic practice for 29 years and I've served people, and to me it made sense to at least allow somebody the opportunity to utilize the kidney that was healthy."*



Dr. Camp on a fishing trip post-donation