Stories of Hope and Recovery

A National Kidney Registry Resource for Microsite Patients

Contents

Thank you for embarking on your search for a living donor with help from your transplant center and the National Kidney Registry.

We know the search for a living donor can feel overwhelming. This booklet was created to offer hope, encouragement, and real-life examples of what's possible.

Inside, you'll find stories from kidney and liver transplant recipients who once stood where you are now.

Their journeys are diverse, but they all share one thing: the power of perseverance and the life-changing impact of living donation. You will also find stories from several donors who offer insight into why they chose to donate.

We hope these stories bring you strength and remind you that you're not alone. A successful transplant *is* possible—and we are here to help you every step of the way.

Sincerely,
Samantha Hil
Samantha Hil

Living Donor Kidney Transplant Recipient
Microsite Product Manager & VP of Marketing
National Kidney Registry

The Voucher Program Turns a Poor Match into a Successful Transplant

By Lindsay Frusciante

Hadley's journey to transplant started pretty much at birth. Because she was born with a skin tag on her ear, the pediatricians recommended having an ultrasound of her kidneys to assess any potential complications. Sure enough, the scan showed Hadley's kidneys were enlarged, so she was referred to a nephrologist.

Over the next several months, Hadley had various appointments, blood work, and genetic testing, and it was eventually determined that she was positive for a WT1 gene mutation. After further genetic testing, it was determined to be a spontaneous mutation that was not in any family history.

In the few months prior to her admission to the hospital, Hadley underwent monthly blood work and regular oncology scans to monitor her kidney function and look for possible Wilms tumors, a known risk of the WT1 mutation.

Once Hadley's condition was identified, I was told she may face cancer and/or kidney failure within her first several years of life. However, I never expected it to happen when she was just nine months old. A day before we left for Hadley's first beach vacation, she had routine blood work. Just 24 hours later, I received a call from the nephrologist saying that Hadley's blood work was abnormal, and she needed to be admitted to the hospital as soon as possible.

Within a week of our admission to the first hospital, she was no longer producing urine, was placed on multiple medications, and had at least two surgeries to put in a central line to take blood and complete any necessary infusions. According to the doctors, if she had not been monitored over the previous few months, or if we had still been at the beach, her situation would have been much worse.

After a week, we were transferred closer to home. Hadley was admitted to Maria Fareri Children's Hospital Westchester Medical Center in late August 2023, where we stayed for the next year-plus. Within days of her admission she underwent another surgery, during which a gastric tube was placed to help with medications and feeding, as well as a peritoneal dialysis catheter and hemodialysis catheter so she could start receiving dialysis treatments. With practically every surgery, Hadley had to be in the Pediatric Intensive Care Unit for multiple days.

We would have gone home about two weeks or so after starting dialysis; however, due to circumstances out of our control, we were informed that we would not be able to go home until Hadley received a kidney transplant.

At that point, we worked with the doctors to determine the best course of action. She did not have the weight, height, or health she needed to be put on the transplant list until the end of February 2024.

During this time, Hadley would receive blood and iron transfusions, injections, and various other scans and procedures. In December 2023, a few days after Christmas, Hadley underwent surgery to have her kidneys removed because the doctors had found possible tumors. Unfortunately, after the procedure, there were complications with peritoneal dialysis and she was transitioned to hemodialysis treatments, which she received four days a week for five hours a day until her kidney transplant.

Hadley had various other procedures and ongoing infusions, and with time she became stronger, taller, and livelier. She was able to come off her blood pressure medication, and infusion treatments began to decrease.

Throughout all of this, my family and I began getting the word out about Hadley's need for a kidney. We worked with the transplant team's living donor coordinator, who helped us navigate through the NKR process and informed us how things could be streamlined. This collaboration was extremely helpful.

We were posting on social media, getting posters up, getting the news, radio, and TV stations involved, and directing potential donors to our NKR microsite. There were so many people who went to the microsite, and many filled out the information to see if they could be Hadley's donor. My sister wound up exploring her options to donate, and although she didn't have the same blood type as Hadley, she was given information about the Voucher Program and eventually decided to become a donor.

Within a week of being activated on the NKR, she matched with someone who didn't match with the majority of the country, and on July 18, she donated her kidney to a complete stranger. This gave Hadley a voucher for her kidney and within about two weeks of being activated on the NKR, she matched with a voucher donor.

Hadley had her transplant on August 9, 2024. It was such a whirlwind of an experience. If you were to ask any of her medical team, they would tell you that Hadley does things her own way, which is a little outside the norm—they were always left guessing. She always made things interesting, and the day of her transplant proved no different. Despite a tornado warning, bad weather, and the power going out during her transplant procedure, all was successful, and on September 3, we were able to return home.

Hadley has such a sassy personality, and her personality has really flourished since the transplant and being out of the hospital. There has been no regression in her attitude. All the love and support, socialization, therapies, and overall compassion and care from the medical staff as well as my family have truly set her up for success. Since the transplant, she has continued to flourish into such a spunky little toddler who will be two years old in just a few weeks.

I Didn't Know I Could Donate a Kidney—Until My Brother Needed One

By EJ Tamez

Back in 2016, I learned that my brother's health was deteriorating. I asked my mother about it, and she told me that he was in kidney failure and was already doing dialysis. I immediately went to see him and found him stuck in a chair, barely able to walk. He was only 42 years old back then, with a young family, and seeing him like that really broke my heart.

His son wanted to play football with his dad and my brother couldn't even get out of the chair to play with him. That was wake-up call number one. When I saw that, I said, "you need to go to a transplant center and I am not asking you, I'm telling you." He hadn't been to a transplant center yet because there was no transplant center in the small Texas town where he lived.

My brother and I are very close, and he always listens to me, so he said OK. I told him I was going to meet him at the transplant center in San Antonio in two weeks.

Before we went to the center, we shared the same hotel room for the night, and I witnessed him performing peritoneal dialysis in the room. When I saw that, that was wake-up call number two. I said, "Brother, you do that every night?" He said yes, "every night." He had to disinfect the whole room and sleep like that until morning. When I saw that, I wanted to do something else for him, but I didn't know what.

In the morning, we headed to the transplant center together. He was talking to the nephrologist while I was in the waiting room. It took hours because they did a whole workup to try to get him on the waitlist.

A nurse saw me waiting there, just sitting looking down at the floor. She said, “Sir, is everything OK?” I told her I was very sad because my younger brother needed a kidney and there was nothing I could do for him. She looked me up and down and said, “Well, you look healthy enough to be a donor.” My eyes went wide and I said, “Ma’am, how can I donate a kidney if I am still breathing?” She laughed and said “come with me.”

She explained that I could donate as a living donor and I completed the initial questionnaire at the center. They said everything looked good and they would probably call me in a few weeks for more tests. They told me I could either tell my brother now that I was being evaluated as his donor or wait till I was approved. I decided to wait because I didn’t want to give him any false hope.

Two to three weeks later, they called and said they needed to do more blood work, but I didn’t have to go back to the center, I could do it near my home. After another few weeks, they asked me to come in and have a full workup. About a month later, the coordinator called me and said, “Mr. Tamez, you are approved to donate to your brother.”

I said “Wait, let me tell my wife!” I hadn’t even told her yet. I was a little concerned about what she would say. The first thing that came to mind was what if one of our sons ever needed a kidney, or my wife? This is what she told me: “Honey, we don’t live by what may happen tomorrow, we live by what happens today, and if your brother needs a kidney, we’re going to help him.” I called the transplant center and told them I was ready.

I set a date for the surgery: March 1, 2017. My wife had a great idea for how to tell my brother. We got the families together and wrote on a birthday card “Good for one living donor kidney.” When we gave that card to him and his family, they started crying. They couldn’t believe it.

Then, to my astonishment, my brother wanted to convince me not to do it. He said, “I don’t want anything to happen to you.” I told him my mind was already made up and nothing he said would change my mind. I told him, I have done my homework, and you know me, when I make up my mind, no one is going to convince me not to do it.

This is all too common, and when I was the NKR’s director of patient coaching, my team and I saw it all the time. Patients don’t want their family to donate. They don’t even want to ask them to get tested. This is the wrong mentality. It is the donor’s choice. More often than not, like me, family members want to help in whatever way they can, they just don’t know how.

That whole month he called me almost every day trying to convince me not to do it—up to the day of the transplant when we met at the center. We were in the pre-op room and he told me again that I don’t have to do it, I can still back out. I said “I’m not backing out, I am ready.”

In the recovery room, I asked the doctor how my brother was doing. He said, “it’s funny because your brother has been asking about you. Before he asked about himself, he asked about you.” A few hours later, we all got together with the families. His youngest son came and gave me a little silver pendant that is half a kidney and he said, “Uncle, thank you for saving my father’s life.”

Once he recovered from the surgery, my brother told me, “you know, I had forgotten what it felt like to be healthy.” Dialysis is a way to survive but not a way to live.

My Son's Life Was Saved by a Stranger Who Saw His Microsite

By Donna Viau

In 2021, at his annual physical, our then-23-year-old son's lab work came back with too much protein in his urine. He was referred to a nephrologist and had a biopsy. We were shocked to learn he had Stage 3 chronic kidney disease, with a GFR (glomerular filtration rate, a measure of kidney function) of 58.

Greer felt fine and had no symptoms. He was eventually diagnosed with collapsing FSGS (focal segmental glomerulosclerosis), and they had no idea how he got it. They thought it was most likely a virus that settled in his kidneys, perhaps undiagnosed COVID, strep, mono, or Epstein–Barr. They decided to put him on meds and monitor him. Life went on, and he continued feeling fine.

In January 2023, his company abruptly closed, so I urged him to get a physical while still insured. He said he was fine and would be seeing the nephrologist in March. I said no, get a physical now. He did and was told to see his nephrologist right away. He called me crying, saying his GFR was plummeting and he needed a transplant.

On February 22, he called to say he was really sick. His girlfriend rushed him to Brigham and Women's Hospital in Boston with vomiting and swollen legs, and he was admitted. They discovered his GFR was down to 17. He was released on February 27, 2023—my 63rd birthday. At home, he just stared into space, asking, "Who is going to give me an organ out of their body to save my life?"

My heart sank. I could only say, someone WILL. We learned that the wait for a kidney from a deceased donor could be seven to 10 years, and it was up to us to search for a living donor.

We were told Brigham was affiliated with the National Kidney Registry and participated in the Microsite program, which meant Greer could get a personalized donor search microsite. I wrote his microsite page and added photos, submitted it for approval, and it was immediately made live so we could start the outreach.

My husband was out as a potential donor due to Type 2 diabetes. Our younger son was eliminated because of their genetic connection and not really knowing why our older son was sick to begin with. I began my testing immediately but was devastated to be disqualified two months into my testing due to my GFR being lower than Brigham's requirements.

My husband designed and had 150 magnetic bumper stickers made with a QR code link to Greer's microsite. We were featured in our local paper, on the city website, local Boston news, radio, theater programs, and in publications and on websites connected to our friends and families. We used flyers, social media, joined more than a dozen city and town pages and groups in our area and our hometowns, and had family and friends share with everyone they knew—we were relentless.

We were told NEVER to discuss blood type. If you disclose the blood type of the person who needs a transplant, people might think, "Oh, I don't match," and not come forward. This can prevent the possibility of a paired exchange or voucher donation, which has the potential to save multiple lives—including the person you're trying to help. We were also advised to tell anyone with medical questions that if they came forward to be tested, all their questions would be answered by the transplant coordinator.

In March, Greer had to go on emergency hemodialysis. He had to go every other day. The clinic was a dreary place, but the nurses were wonderful. I kept him company at his treatments, and I can't tell you how hard it is to see your child hooked up to a machine for hours and see his blood being pumped through tubes.

Greer was amazing. He never, ever complained. He was also training on home peritoneal dialysis and switched to that on Easter of 2023. It was difficult, as it is usually supposed to be for eight hours a night while sleeping, but he had to be on it 13 hours every night.

He couldn't work. I made him special foods for his no-sodium, low-potassium diet. He lost weight, and we had many emergency room visits. We masked constantly and kept our contact with crowds to a minimum. His life was in total upheaval. It was awful.

His microsite got over 4,350 views, and 65 people came forward for medical evaluation. In August 2023, he was notified that he had an altruistic anonymous living donor. We were told not to share anything yet, as the team doesn't consider a patient officially transplanted until the surgery is complete—unexpected issues can arise even moments before the operation.

He had his transplant at Brigham on September 14, 2023. We were told the donor was doing well and had given Greer a great match. Greer was in the hospital for six days and was like a new person. He now had a post-transplant team. We had to go in two to three times per week for labs/checkups and medication adjustments. He needed rest and light walking, and someone would have to be with him at all times for at least the first three to four weeks. He had to monitor his weight, urine output, temperature, and blood pressure.

By the first week of November, he could go back to his apartment (he had been living with us so I could look after him), and drive, but he could not go to restaurants, large indoor venues, buses, planes, or trains for six months. He was allowed light exercise, mainly for circulation, and no lifting.

As the months passed, his appointments became less frequent, but still regular. His meds are for life. He can't have raw sushi, grapefruit, marijuana, or ibuprofen, has to avoid deli meats and salad bars, and limit alcohol. Most of those things were easy to give up because they were never part of his lifestyle, except he loved sushi.

We had all written the donor and sent letters through the transplant office right after the transplant. Within a few months we received a letter back from his donor. It was amazing. She was a wife and mother who had seen one of my posts on social media through a mutual friend and felt what she called a "heart tug" to come forward. She had been standing right beside us in the hospital when she and Greer were both called for pre-op. She recognized us from Facebook but said nothing.

We called her and thanked her. We started talking, texting, writing, sending her Christmas and birthday gifts, etc. She came to our home in May 2024 to meet in person. Greer baked her scones and cookies. He was nervous to meet her. He said, Mom, what do I say to her? She saved my life. I said, just say thank you, she's a mother, she knows. It was an incredible day, and she is part of our family forever.

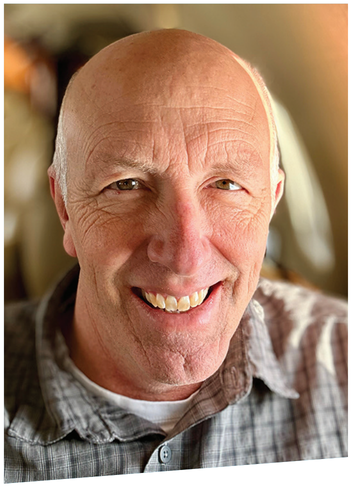
Greer now lives a healthy lifestyle, quietly appreciating the lifesaving gift he received. He is back to some of the things he used to do, like snowboarding, indoor rock climbing, playing ping pong, and cooking. He is moving forward with life and LIVING IT. Thank you to everyone who comes forward for evaluation, for helping save the lives of people in need through living kidney donation.

In an effort to raise awareness about living kidney donation, Greer has chosen to keep his microsite active as a post-transplant microsite, an NKR program that allows transplant recipients to continue sharing their journey. A transplant offers a second chance at life, a precious gift of time, but it's not a forever fix. Greer is still young, so there's a possibility he may need another kidney one day. Keeping his microsite live shares his story, inspires others to donate, and may provide Greer with a voucher for a future kidney transplant.

Low Eplet, High Impact: How the NKR Revolutionized My Transplant Journey

By Matt Freund

When I was diagnosed with PKD at 15, I knew a transplant was in my future. Decades later at age 52, I found out how much I didn't know about the process. Now, looking back, I'm amazed by how much the National Kidney Registry (NKR) transformed my experience.



When I started the transplant journey in earnest, I had the misconception that I think a lot of transplant recipients do. I knew that I needed a good kidney match, and I thought the best way to do that would be with a relative. I thought that surely relatives would be more closely matched than the general population.

What became clear as the process unfolded was that the relative advantage only applied with siblings, which offered a one in four chance of a perfect match. Well, one of my siblings was prediabetic, so she was out. Another proceeded through the screening until they found a tumor in his intestines, so that ruled him out too. My wife and my mom also made it through the initial screening but were eliminated during the onsite evaluation.

I chose the Mayo Clinic as my transplant center because of its reputation—I had no idea they were part of the NKR network, or how that would improve my chances of finding the best match. During my first meeting with my surgeon at Mayo, he explained how the NKR's matching system gave me better odds—that it was a doorway to a national network of donors, recipients, and centers all working together to find the best possible matches.

He also gave me a primer on eplet matching and why it was the new frontier, and a newer, higher resolution way of looking at how donor kidneys are matched to a recipient. He said that with a low eplet mismatch, I'd have a lower chance of rejection and graft failure, meaning the kidney I receive would last longer. That piqued my interest.

As we went through the process, my sister-in-law was cleared as a donor. Her blood type was A and mine was O, so we were not a match, but the NKR's Voucher Program turned out to be an incredible option. Not only did it give me the chance to find a low eplet mismatch, it also allowed my donor to be fully recovered by the time my surgery happened, which is a big benefit for family members.

At first, we were shooting for a zero eplet mismatch, but as time went on, we widened the criteria to low eplet mismatches, which expanded the opportunities.

The whole process worked beautifully. My sister-in-law donated in early 2023, and by fall, I had my new kidney—from a kind stranger in Utah who donated on behalf of her mom. My surgery went great—I had minimal pain and a quick recovery, and my low eplet mismatch kidney is working well.

Throughout my transplant journey, I was looking for a way to return to flying without complications. Flying is something I've always been passionate about, and I was fortunate to have it as my career.

While the eplet matching aspect didn't have a direct impact on my flying career, the difference is that my transplant will probably last longer. This definitely bodes well for my ability to keep flying in the future.

From a quality of life standpoint, my number one objective was to get a kidney that would last for my whole life. My career is important to me, but being alive is even more important. Getting a low eplet mismatch really improved my chances of a quality long-term outcome.

My Microsite Saved My Life

By Matt Hess

My kidney transplant journey started with an ATV accident back in 2019.

I was crushed between an ATV and a tree, which caused catastrophic injuries, including paralysis from the waist down, ribs through both of my lungs, and my left side being completely crushed. Luckily, there was another group of riders behind us that had a trauma nurse with them. She was able to keep me alive until the helicopter arrived.

I was flown to three hospitals before they found one that could handle my level of injuries. I ended up at the University of Kentucky. Both my kidneys were crushed, which caused kidney failure, and I had many other injuries. After the accident, I was in the hospital for 11 months.

When I got out of the hospital I was set up with rehab, but nobody taught me how to turn my body so I ended up with a bedsore that exposed my tailbone. That ended up infecting my spinal fluid, so they had to do surgery to remove, clean, and replace my spinal fluid. During that operation, I died medically a couple of times.

I was really put through the wringer. I am so much better now but I was in really, really bad shape for a while. I don't think I got out of bed for two years after the accident, and once I got home from the hospital, I was never home for more than five days before an infection caused me to go back. Then, because I was so frail and immune-compromised, they would keep me in the hospital for the full course of the antibiotics.

Meanwhile, the world was just finding out what COVID was, so I was lying in a hospital bed barely able to move and then my family was ripped away from me. It was very hard to stay positive, but I did.

The doctors were hoping my kidneys would recover over time, but that never really happened: one was functioning at 20% and the other at around 15%. I had torn my ureter on the right kidney, so for three years I had to have a nephrostomy, which is a tube that goes directly into the kidney to drain out urine.

In order to get me on the transplant list for a kidney, they had to remove my right kidney, even though it was functioning better than my left, because I had the nephrostomy tube running into it.

That surgery, in August 2021, left me with one kidney functioning at about 15%, causing me to be in end-stage renal failure. I was having dialysis three times a week to keep me alive.

I didn't really know the difference between transplants with deceased versus living donors. I was in line at the DMV with my mom waiting to take the test to get my driver's license back (it actually took a little over a year because now I drive with adaptive functions and I had to go through countless hours of training before I could even apply), when I got an email from the National Kidney Registry about one of their microsite trainings.

My mom had applied to be a donor but was denied in the very last test because her heart wasn't strong enough. We were literally standing in line racking our brains trying to figure out how to get the message out that we needed a donor when that email came in about microsites, with a link to join a webinar to learn more. We signed up, and that's where we really learned about microsites, including how to set one up, how to promote it, and the support the NKR gives you. The webinar taught us so much—it was really a godsend.

After the webinar, we got to work on my microsite right away. I remember working on it on Thanksgiving Day. By Christmas of 2022, it was approved.

We posted the link on my parents' Facebook page and within a month it had over 1,800 hits. Four people signed up to donate for me: two first cousins who I'm close to but who had no idea I was in kidney failure, one friend I hadn't seen or spoken to in 30 years, and one stranger—a nurse from Paoli Hospital. To this day I don't know who she is.

Two weeks later I got a random call from Stephanie—a friend I grew up with but hadn't spoken to in over 25 years. She said, "I saw your story on your mom's Facebook page and knew you were struggling, but I had no idea you were in kidney failure. I have a proposition for you. My husband was going to donate his kidney to our neighbor's son, but by the time Brian got approved, he already had another donor. Brian has done his research and is still fully committed to saving a life. He wants to complete the process of donating to someone in need. Would you like his kidney?" I said, "Uh, yes please!"

Brian had already been approved by Penn and I was approved through Penn as well, so that made it easy. It took the NKR just four weeks to find matches for both of us. His kidney went to a 50-year-old in North Carolina and I got mine from a 30-year-old in Pennsylvania. Paired exchange is just incredible—they made it happen so fast!

I had my transplant surgery on February 28, 2023. It's amazing that within two months of launching my microsite, I had a kidney. The NKR, the microsite, my microsite coach Debbie Parrish, and all the support I received made it happen.

Brian had his surgery two weeks after mine, and between the two of us we were able to connect two kidney donation chains. When Brian was in the hospital after his surgery, I went to visit him. It was the first time we met face to face. My microsite saved my life.

How the NKR Voucher Program Helped My Brother Save Two Lives

By Rachel Bress

Having been diagnosed with polycystic kidney disease (PKD) in 2011, I knew a kidney transplant was in my future, though the timing remained uncertain. PKD doesn't run in my family, making my case unusual, as I inherited it without a familial genetic link.

I have been closely monitored by my nephrologist since diagnosis. My kidney function began declining in 2019. Seeking to avoid dialysis, I pursued a transplant evaluation in 2021. My brother wanted to be my kidney donor. Despite his willingness to donate, he wasn't a compatible match.

I was fortunate enough to have found another suitable donor. However, they later withdrew their offer. In a remarkable turn, my brother stepped forward to donate his kidney to a stranger through the National Kidney Registry's Voucher Program, facilitating my own transplant.

Both my brother's donor nephrectomy and my transplant surgery took place in New York City, with my brother undergoing the procedure in October 2023. Mine followed in November 2023, which also involved a bilateral nephrectomy. While I'm unaware of my donor's identity, I've written a letter expressing my gratitude, hoping for a chance to thank them personally.

Above all, I owe an immense debt of gratitude to my brother, Michael, whose selflessness, courage, and love not only saved my life but also bestowed the same gift upon another. He epitomizes the true essence of a hero, and I am endlessly thankful for his extraordinary generosity.

She Wished to Be a Normal Kid—Three Donors Helped Make It Happen

By Lisa Tucker

"If you had just one wish…" Before the question was finished, Harlow Tucker was ready with the answer: "To be a normal kid."

Her angelic smile and quiet charm can make you forget for a moment that she has been in and out of hospitals since she was only two weeks old.

Harlow is a bright 14-year-old girl from Connecticut. She's very cute, a little shy, and lights up when she talks about Taylor Swift. She was born with a single, partially functioning kidney due to a condition called Branchio-oto-renal (BOR) syndrome. Doctors said her kidney would eventually fail altogether, and sure enough, at age six, it began to shut down.

A crisis was unfolding, and little Harlow needed a miracle.

All prayers are answered, and so were the prayers for Harlow. But when the answer came, it was bittersweet.

Heartbreaking news arrived that Harlow's older cousin, David, had just died in a motorcycle crash. Amid the tragedy and sorrow, Harlow was granted her miracle! The generosity of David's family and a successful kidney transplant allowed Harlow to resume a relatively normal life for the next seven years.

In August 2022, the transplanted kidney began to fail, and she was hospitalized once again. This time, there were no miracles. So Harlow underwent surgery to have a port implanted in her chest, allowing a tube to connect her to a dialysis machine for four hours a day, three days a week.

Then, disaster struck: Harlow had a heart attack during one of her first dialysis sessions. An embolism had suddenly developed, traveled through a blood vessel, and lodged in her heart. She was rushed from the dialysis unit to the operating room for emergency open-heart surgery.

Incredibly, only a few days later she experienced another embolism and another emergency surgery to clear it from blocking her dialysis port. Still fragile and recovering, she developed sepsis, a life-threatening infection that sent her to emergency surgery once again. After four surgeries and over a month in the hospital, she was finally able to come home to her family and her beloved "Baby Cat."

Harlow enjoys school and loves spending time with her friends. In 2023, her dialysis schedule was reduced to just Mondays and Fridays and she was excited about another day at school and less homework for those missed days.

On top of all the health challenges, the ongoing dialysis sessions, and all the school she'd missed, Harlow is also partially deaf (also due to BOR syndrome), so she wears hearing aids to compensate. But despite everything she was going through, Harlow made the honor roll that year.

The family's search for a living kidney donor got a boost in March 2023, when a reporter from WFSB-TV in Hartford contacted Harlow's grandmother, Lisa Tucker. He had seen Lisa's public appeal for a living donor on Facebook and wanted to do a story about Harlow. Soon, Lisa and Harlow's father, Kirk, were on the air, telling Harlow's story to 101,600 "TV households" in the Hartford metro.

Meanwhile, on the other side of the world, Michelle Allen from Queensland, Australia has just unexpectedly lost a close friend to an aggressive disease, which inspired her to look for ways to make a difference. She discovered the National Kidney Registry's Voucher Program, an innovative solution to the problem of matching donors to patients. With the Voucher Program, factors such as blood type, schedule, and even the distance between donor and recipient are no longer the obstacles they once were. Donors can give a voucher to a person of their choice, even if they are not a medical match. That sets into motion a process that enables two patients to receive transplants instead of just one.

Since Australia had no such program, Michelle registered with the NKR and was accepted as a donor candidate. So she got on an airplane, came halfway around the world, to a place she'd never been, to save the life of someone she didn't know. That place was Hartford Healthcare Center in Hartford, Connecticut.

It was through the hospital's "Living Donor Support Group" on Facebook that she happened to meet the Tucker Family. They exchanged text messages for a couple of months, and then on September 9, 2023, Michelle told the family that she had decided to give a kidney voucher to Harlow. The news brought the whole family to tears. What a relief!

But Harlow's story was about to get even more complicated. Two days after learning Michelle was going to be Harlow's voucher donor, Lisa visited the transplant office to meet Harlow's new social worker. She had only been in the room for a few minutes when in walked the transplant coordinator. Lisa was totally unprepared for what she was about to hear.

"A donor came forward in May after seeing Harlow's story on the local TV news," she said. Since the donor had chosen to remain anonymous, she couldn't tell Lisa much, but what she could say was that he was local and that he was "such a near-perfect medical match, he could have been her father!"

It was truly a painful dilemma for the family. Michelle had traveled so far and given them so much. They told her about this unexpected development, hoping she would understand. Not only did Michelle understand, but she decided to provide a voucher for Harlow anyway.

On September 18, 2023, Michelle underwent surgery at HHC to have her kidney harvested, generating a voucher for Harlow. Should Harlow ever need another transplant, Michelle's voucher is redeemable for a lifetime.

November 15, 2023, was the day that we had been praying for, hoping for, wishing for. Harlow had her second kidney transplant. She went into surgery at 9:00 that morning, and at 2:30 that afternoon, the surgeon came into the waiting room and told the family that the transplant had been a complete success! The doctor said that within minutes of connecting the donor's kidney, it started producing urine.

Three days post-op, Lisa posted this update to friends and family: "Her new kidney is working great, and she gets a little stronger every day. She has even been up walking even though she is still in some pain. But she is smiling and joking and talking about getting out of there!"

But recovery from transplant surgery is a marathon, not a sprint. In the six months after surgery, there were challenges and setbacks, but there were victories, too. Harlow recently celebrated the first anniversary of her transplant, sailing through her first annual check-up with flying colors. Today, she is back in school with her friends—happy, healthy, strong, and enjoying her life as "a normal kid."

All this is a clear reminder that "It takes a village." To Michelle, who gave her kidney, then stole our hearts; to the anonymous donor who selflessly gave Harlow the gift of life; to the miracle workers at HHC; and to everyone in "the village" who have offered your prayers, cheers and support since she was a little girl with big dreams—love and a heartfelt "Thank You!" from Harlow and her eternally grateful family!

From Curiosity to Compassion: The Power of Microsites and Donor Shield in Living Donation

By Jasmine Duplin

My kidney donation journey started one day in April. I was just scrolling on Facebook and two of my friends had shared Crystal's story, about how she was looking for a kidney. I read her whole story and felt so bad for her and was intrigued at the same time.

There was a link that said, "see how you can help," so I clicked that, and it went to another little mini site, with a mini health assessment. If you passed that assessment, it took you to another site that explained about Donor Shield and the National Kidney Registry, and from there it took you to a screen saying Crystal was working with Hartford Hospital.

I answered all the questions and within two days, someone from Hartford Hospital reached out to me. She explained the living donation process and answered all my questions. I was also connected to a living donor mentor, who really helped me through the process. The whole thing was so convenient.

I also did a lot of research on my own. I read about people's experiences, the good and the bad, because I am the kind of person who, if I am going to do something, I am going to be prepared.

I was so proud of myself for passing all the tests. They made absolutely sure I was healthy enough to recover well and continue being healthy after donation. I really appreciated how thorough they were.

I felt really prepared. I had no doubt at all. Going to the dentist really freaks me out but donating my kidney, no problem. My friends were all asking if I was sure, and I was like yup, I'm sure. When I have my mind set on something, no one can stop me.

I wasn't a match for Crystal, so when I finally got approved to donate, I decided to donate a kidney on her behalf through the Voucher Program. It's so great because with the Voucher Program, you are in control of when you have your surgery, which I think is a beautiful thing. I could choose when to do it and have time to tell my employer.

That was one thing I was nervous about, because I wanted to help Crystal, but I also have to pay my mortgage. They told me about Donor Shield, which reimburses living donors for lost wages, and that made a huge difference for me. I was able to take time off from work to recover, and I knew my lost wages were going to be covered so I would be OK.

I spent three days in the hospital after the surgery and I'm not going to sugarcoat it, it was painful. My son took a week off work to help me recover at home. He made me breakfast and helped me get out of bed and everything, so that really helped.

The first two weeks recovering at home were the hardest. After that, I just focused on getting out there and walking. I couldn't drive, so people took me to the park. Every day I tried to get stronger.

Originally, I took six weeks off from work. But I do a lot of lifting in my job for the American Red Cross. I have to lift equipment, push heavy carts, and load and unload trucks on a daily basis, and I didn't want to come back to work and get a hernia. My medical team recommended taking an extra two weeks off just in case, and that extra two weeks was so important for me. When I went back to work after two months, I was fine.

In September 2025, it will be two years since my donation and sometimes I forget I did it. A lot of people ask me about it. I always share my personal story and reassure people that there is nothing to be scared of.

I tell them that you can have a sort of consultation about it if you have questions, and you can also sign up to do it and see where it takes you. You don't have to do it right now, and you can change your mind at any time. I don't regret anything. I would definitely tell people to be open to the idea and not to be scared.

We only need one kidney to live a normal healthy life.

Oliver's Transplant Journey: The Power of Community, Social Media and a Microsite

By Tammy Mayer

Oliver was diagnosed with chronic kidney disease when he was eight years old. His kidneys never really grew; the doctors don't know why. We are an adoptive family, and we don't have any information about the birth family. He didn't really have any symptoms, but he had short stature, and when they started to investigate why he was so tiny, they discovered his kidneys had not developed.

In April 2021, when Oliver was about 20, they decided he needed to have a kidney transplant. At that point, I was not at all knowledgeable about the transplant process. I just assumed that when you got on the transplant list, there was some sort of algorithm that made people go up and down the list, and when you got to the top of the list, poof, you get a kidney. It doesn't work that way.

I didn't even know there was such a thing as a living kidney donor. I learned that the stats are so much more in the patient's favor with a living donor versus a deceased donor. Once we realized we really needed to pursue a living kidney donor, we got educated on how to do that.

At first, we didn't realize we had to do anything. Our first aha moment was when we received the business cards for Oliver's microsite. We were like, "what is this?" They said, "that's for your microsite: you need to make sure your microsite is customized with your story." I was like, oh, WE need to find a kidney.

So our first task was to add the information we thought was important to have on the microsite. Our draft was approved, and the microsite went live in January 2022.

As important as the microsite was for us, at first we didn't realize that not every kidney patient gets one. We had no idea that it was a special thing offered by the National Kidney Registry. What a blessing that was for us. It made a huge difference. Not only did it have Oliver's story, it really walked potential donors through the process and had a form where they could register. Without the microsite, I don't know how we would have gotten all of that information to potential donors so succinctly and easily.

Before the microsite was even live, we and several family members registered as potential donors and got tested. Sadly, we were all declined for medical reasons. That was another aha moment: we came to recognize that the process doesn't happen in the blink of an eye. There are so many steps to make sure a candidate is the right candidate. The transplant team is serious about making sure donors are completely healthy before they can donate a kidney, which I respect.

Once the microsite was up, the next step was to get the story out on social media. I was never on social media: I never had a social media account, I had never even looked at a social media account. I had no idea what I was doing—I was like a deer in headlights. The first thing we did was set up a Facebook page and post a video asking for help. This was a big step for our family because we had been so private before that.

We had read on a kidney search website that we should ask others to help get the word out. So I enlisted two of my sisters, my best friend, and her daughter to help create social posts and share them. We had three goals: 1) have information about Oliver so that people understood his personal situation, 2) educate people about living kidney donation, and 3) make it clear that if donation isn't for you, we totally get that, but could you share his story and link? We knew Oliver's kidney donor was out there somewhere—he or she just needed to see the information and respond to it.

We also regularly updated his microsite with new photos and new information. Each time the main photo is updated and the microsite link is posted on social media, that new photo shows up on social media posts. This helps create "stopping power" because it's a new visual for readers to notice.

One of the most important things we did early on was create a vanity URL that pointed to the microsite. That was really key. People don't remember a website with a bunch of digits, but they do remember Kidney4Oliver.com. We put that URL in every single communication.

We did a lot of posts on Facebook and Instagram. I created an email list of hundreds of friends and family members and sent out emails with Oliver's information. We created flyers and put them on cars in parking lots and enlisted friends and neighbors to put them in mailboxes. We created a decal for our car. We went door to door in our town. I walked around our local town wearing a sandwich board. Every time I stepped out of my car with my sandwich board, I would think, ugh I don't want to do this. Then I would think of my son, and I would think, OK, I don't care if I'm humiliated.

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LEAVES NO STONE UNTURNED

MOM SEEKS A KIDNEY TRANSPLANT FOR SON

BILL RETTEW — MEDIANEWS GROUP

Mom Tammy Mayer seeks a kidney donor for her son Oliver.

By Bill Rettew

brettew@dailylocal.com

WEST CHESTER » East Goshen Township mom Tammy Mayer is leaving no stone unturned in her fight to find a compatible living donor to donate a kidney to her son Oliver.

Oliver Mayer, 22, was born with chronic kidney disease and his mother said he needs a kidney transplant to live. Dialysis is a temporary, and not a long-term, solution for the HVAC worker whose kidneys are now functioning at 11%.

At Jack's Plaza at 44 West on Wednesday, with a tear in her eye, Tammy Mayer said she would do anything for her son.

"I'd donate if I could, but I can't," she said. "Someone healthy has to donate a living kidney.

"Only the transplant team can tell them if they are healthy."

As part of the push, Tammy recently organized a trip, along with the National Kidney Foundation, for 300 well-wishers, to attend a Wilmington Blue Rocks game. She has sent "lots and lots" of emails, gotten the word out through social media and said she has made "lots and lots of prayers."

For the past 26 days, mom has even worn the same green T-shirt that reads, "Oliver Needs a Kidney."

Oliver talked about his mom's battle to get him a kidney.

KIDNEY » PAGE 10

CHESCO COURTS

New sentence issued in home invasion

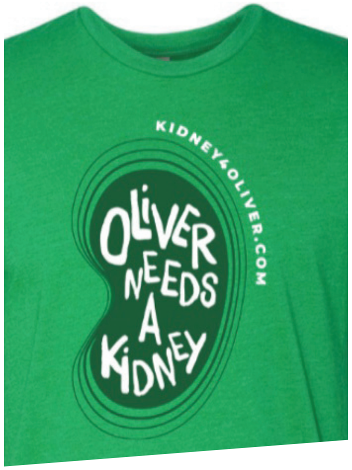
Kar'Ron Smith gets 19 to 38 years for felony burglary, robbery charges

By Michael P. Rellahan

At one point I said, "I think we have to go broader because it seems like this is going to be a harder task than we thought." We decided to see if we could get some media attention. We invited 150 friends and family members to a minor league baseball game in our area. We paid for the tickets and just asked them to come be an encouragement to Oliver, make a lot of noise, and be a visual reminder.

Another friend designed green T-shirts that said Are You My Match?, which we handed out to everyone who came. We took up an entire section: all you could see was this sea of green T-shirts. It got a lot of attention. I called the ballpark ahead of time, and the team asked how they could help. They put Kidney4Oliver.com on the Jumbotron, they announced Oliver's situation several times throughout the game, and they had him do the first pitch with the mascot. It was very attention-getting and encouraging to us!

I had reached out to local TV stations and newspapers, offering them a free ticket to the game and asking them to write about Oliver's story if they found it interesting. After the game, someone from one of the local TV news stations reached out and said she was sorry she couldn't come to the game, but to let her know if we had another event. I sent her a picture of me wearing a sandwich board and asked if this counted as an "event." She responded by asking where and when. She interviewed Oliver and me, along with a previous living donor and a kidney transplant recipient—two people I never knew before we started this journey but who rallied with me and became Oliver's advocates! The interview aired on the station's health segment. The local newspaper also ran an article. We tried to pull every lever we could.



All the while, our church congregation surrounded us with love and attention and help. They were delivering flyers to their neighborhoods and holding prayer meetings to pray for our family and Oliver's health. It was a young man from our church who ended up giving his kidney to Oliver. Apparently, being a part of that sea of green T-shirts at the baseball game somehow impacted him. He was there to support and encourage us as a church member—he wasn't necessarily thinking he was going to be a donor. But it turned out that he was tested and approved before we ever knew he was thinking about donating. You never know what blessings are happening behind the scenes!

It really takes a special person to be a living donor, and their family as well. Oliver's donor has a wife and a young son, and they were all in on this idea of donating! For me, the entire family having no hesitation about the donation was almost as much a blessing as Oliver receiving a new kidney. Our church rallied around the family and provided meals, rides and childcare for their son. It was a beautiful picture of humanity at its finest.

Oliver received his new kidney in January 2023. He is doing great, living an awesome life. And his donor and family are doing great too. We are in awe! God has truly held us in the palm of his hand!

For anyone with a microsite, I suggest keeping it live even after the transplant. It can serve as a helpful example for other patients building their microsites and as a resource to help potential living donors learn more about donation. It could also help the recipient get a voucher if another kidney is needed in the future.

My Kidney Donation Went So Well, I Decided to Donate Part of My Liver Too

By Kristie Sue Hathaway

I donated my kidney in February 2021, and that went so well that I just felt like I wasn't done yet. I knew that if I had more kidneys to give, I would give more kidneys. So I decided to move forward with liver donation.

I went through the process to get approved in December 2023. I knew that I had a vacation and a wedding coming up, so I told them I would be available anytime after mid-April.

They found me a well-matched recipient pretty quickly, and I donated on May 23, 2024.

My recovery was more intense than the kidney donation. I was off work for 12 weeks, so I didn't have to rush back into anything, which was really nice. I didn't end up using Donor Shield because as a longtime Minnesota state trooper, I was lucky to have enough sick time. If I worked an office job, I could have gone back within a month and my lost wages would have been covered by Donor Shield and the NKR.

They cleared me to run after six weeks, but I still had a lifting restriction. I was back to 100% by September, and in October, I ran a 10-mile race.

After my donation, Mayo did an article about my donation that was shared internally with the state patrol. They had gotten the recipient to comment in the article, and through that I found out that my liver recipient was the wife of a cousin of one of my coworkers.

I am friends with her on Facebook, but she's not super active. I'm not in close contact with the person who got my kidney, either. I knew going in that that was a possibility, and that's fine. I wouldn't want the recipient to feel any pressure to communicate with me or feel that they need to disclose to me why they needed a transplant. That's a very personal thing—they don't owe me an explanation.

For more stories and information,
please scan the QR code or visit
www.findakidney.com

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