GIFTS OF LIFE

Mom donates a kidney; daughter receives a kidney

BY ANDREA JACOBS
I n December, 2017, Hannah Hepner performed with a special needs cheerleading team at the state high school cheerleading championship. Everything was fine — until it wasn’t.

“When we got Hannah home, her legs were super swollen,” says her mother Michelle. “Her ankles were super swollen. However, we never had any idea . . . We’d just been to the doctor a week before and she was doing fine.”

It was a Friday night, when sirens blare through emptied streets and physicians’ offices are shuttered.

Michelle and her husband Michael phoned the doctor, who advised them to put Hannah’s legs up and watch her.

Not long after arriving at the office the next morning, they were sent to Sky Ridge Medical Center.

“Hannah was in the intensive care unit for the next four or five days,” Michael says as Michelle and Hannah relive the narrative in their eyes.

“At that point, everything changed drastically,” he says. “Hannah was put on a low-sodium, low-potassium diet. Medications kept her level. But when the kidneys aren’t working, the heart can’t function and blood pressure goes up.”

Her BP was so high that cardiologist Dr. Richard Jantz of Kidney disease is not a straight line. It fluctuates wildly.

Happy ending for the Hepner family

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Aurora Cardiology and nephrologist Dr. Michael Rocklin of Colorado Kidney Care were brought in. “I don’t what would have happened without them,” Michael says.

Hannah, then 26, was diagnosed with kidney disease — specifically, interstitial nephritis — a few weeks after attending that cheerleading championship.

Her physicians said her kidneys would deteriorate. The only viable hope was a kidney transplant.

More than two years after diagnosis, Hannah received a kidney from an anonymous donor and Michelle, despite being a close match for Hannah, gave hers to an anonymous recipient.

It sounds like a complicated arrangement, but it worked.

Both of their surgeries were performed on May 2 — eight weeks ago — at the Mayo Clinic in Rochester, Minn.

Hannah, who was born with a developmental disability that limits her speech and visual tracking, is quiet during the interview, although she’s much freer with friends.

Her parents translate her words for clarity — but it’s obvious that she understoosh every phase of her ordeal. Her facial expressions are revelatory.

Michelle’s buoyant mood permeates the room. Hannah’s shyness gradually melts like ice cream (which she loves). And Michael holds them together.

Their story is one of fear, uncertainty, strength, setbacks, tenacity and amply rewarded faith in human kindness.

“We call this our miracle,” Michael says.

Kidney disease is not a straight line. It fluctuates wildly. You feel OK until the numbers spiral out of control. Doctors stabilize them, until chaos erupts again.

Somehow, Hannah remained active from diagnosis until the transplant. She continued her job as the class roommate at the Village Childcare Center near Aish Denver, where she has worked Monday through Friday for

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Michael Hepner reflects on the lengthy, complex transition from doubt to successful resolution. Photos: Aleksei Kolesnikov
the last six years.

The strict “super bland” diet she had to follow ruled out her beloved hot dogs, ice cream, potatoes. “Once in a while we had a little ice cream,” Michelle admits. “And French fries cooked without salt.

“Everything on that diet was super bland — but we all got used to it.”

In the early summer of 2018, Hannah’s creatinine levels, a measurement of kidney function, shot up. “Dr. Rocklin told us that he could buy us some time before a transplant, but he didn’t know how much,” says Michael.

Hannah’s numbers normalized in June. She prepared to go to Adams Camp for children and young adults with intellectual disabilities for a week. Optimistic, her parents planned a week-long trip to San Francisco.

“Her numbers started rising again,” Michelle says. “Dr. Rocklin said it was time to think about dialysis in case the transplant could not be accomplished quickly.”

The Hepners abandoned their travel plans and flew to the Mayo Clinic in Rochester, Minn. Hannah underwent four or five days of arduous tests to see whether she qualified for a transplant. She did, and was placed on the National Deceased Donor Waiting list.

But the prospect of a transplant upset Hannah. “She wanted to keep her kidneys,” Michael says. “She didn’t want to hear that they weren’t working; she thought they would get better. It was a difficult time.”

(Hannah was also accepted as a transplant candidate through an rigorous evaluation process at Presbyterian/St. Luke’s in Denver, to cover as many regional bases as possible.)

The next step was determining the availability of a living donor.

“They tested Hannah’s two brothers but they were unable to donate,” Michelle says. “Michael has back problems.”

Michelle underwent intensive tests in order to be evaluated as a donor. “I was the only one in the immediate family who tested as a close match.”

However, two red flags surfaced that concerned the doctors: the age of Michelle’s kidney, which would necessitate another transplant for Hannah in 25 to 30 years; and the Epstein-Barr Virus (EBV).

“My kidney is as old as I am!” Michelle explains. (A little prodding reveals that she’s 63.) “If worse came to worse and they needed to do a transplant they would have taken my kidney.

“But Hannah’s numbers were good enough to hold off.

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for a while."

“The doctors were troubled by something else,” says Michael. “Hannah is unique. She had never been exposed to the Epstein-Barr virus. This makes her EBV negative.”

One of the reasons the doctors felt that Michelle’s kidney was less than perfect was the fact that she had been exposed to the virus. “Doctors preferred a donor for Hannah who was EBV negative,” Michael says. “Otherwise that’s another infection that Hannah might get.”

But the probably of finding a live donor who was a close match for Hannah as well as EBV negative were very low.

Doctors then proposed the Paired Kidney Exchange, a national network of anonymous matched donors and recipients that has considerably enlarged the pool of available kidneys.

Under the exchange, Michelle could only give her kidney to an unknown recipient — but it improved Hannah’s chances of finding a kidney and enjoying a longer, healthier life. Touchdown.

Hannah and Michelle were entered into the Paired Kidney Exchange through the National Kidney Registry in January. This initiated the search for a live donor kidney for Hannah and a suitable recipient for Michelle’s kidney.

“Once we were on the list, I called every couple of weeks and asked, ‘What’s up?’” Michelle laughs. “They said, ‘When we’re ready we’ll call you.’”

Within four months, a kidney had been located for Hannah and a recipient for Michelle’s kidney.

Michelle submitted additional info as requested, and everything looked great — but the next day the Hepners’ hopes were shattered.

“Something happened in the chain,” Michael says. “All we know is something stopped the plan. Maybe someone declined, or the cross match didn’t work. We’re not sure. But the transplant was cancelled.”

On erev Passover, April 19, Michelle and Michael were shopping at Costco for last-minute items for their Passover seder when Michelle’s cell rang. “The area code was 507, which is the Mayo Clinic,” she says breathlessly. “I
grabbed it and stopped what I was doing. I was near the flowers. That I remember.

“I saw Mike, motioned him to come over and put my cell on speakerphone. ‘We can do both transplants — but it’s going to happen really fast.’ How fast? ‘May 2, but you have to be here by May 1.’”

Less than two weeks away.

“We didn’t know how we were going to get everything together because we were all a little crazy and just so happy it was going to happen,” she says. “We had our seder, the food was good and it all worked out.”

But Hannah needed time to digest a concept she’d heard about for more than two years and was now a reality.

“She still thought her kidneys were going to be fine and she didn’t need a new one,” Michelle says. But Hannah hated the thought of dialysis, an imminent necessity without a transplant. She had to choose.

“Hannah knew exactly what was happening from the beginning,” Michael says. “We had to explain a couple of times to make sure she was agreeable. We never imposed our decision. She had to be on board every step of the way — and she was.”

Hannah says she wanted to feel better. The desire eradicated doubt.

Michelle was fully prepared to donate her kidney.

“I just wanted to do it. I was going to do it. That’s where it was.”

Approximately 100,000 Americans are on a waiting list to receive a kidney annually, and over 3,000 patients are added each month. Twenty-two people die every day because the gift of life arrives too late, if at all.

Michael regards the two women he loves and says nothing. Awe has the

Hannah has three kidneys now, and she’s very happy
Michelle checked in at the Mayo Clinic’s kidney transplant department, which performs 700 transplantations annually, on May 1. Her surgery was scheduled for 5 a.m. the next day.

Daughter and father came to the clinic at 8:30 a.m. May 2 for Hannah’s surgery. The exact time of the transplant depended on the kidney’s arrival from the tri-state area.

(Michael’s brother-in-law Gordon Rosen is head of the department but did not participate in the transplant due to his connection to the family.)

Michelle’s operation finished around 8 a.m. Minus one kidney and floating in anesthesia paradise, she doesn’t remember anything “except they put me out and here I am. I think it went very quickly.”

For Hannah and Michael, who stayed with his daughter in pre-op, waiting of Hannah’s new kidney was agony. “It was kind of scary being in pre-op, wasn’t it Hannah?”

“Yes,” she whispers.

(“We later learned that Hannah’s kidney was driven to the hospital,” Michael says. “The surgeon had an app that tracked the GPS attached to the frozen container with the kidney.”)

After what seemed like forever, Hannah’s kidney appeared wheeled into the operating room. The anesthesia did its job, the surgeon did his magic and Hannah awoke with three kidneys. (Surgeons prefer to leave the old organs in place unless they cause pain, are infected or can lead to complications.) Hannah points to her abdomen, where her power to silence.

‘There is a desperate need for donors out there’
new kidney rests right below the surface. She’s happy she has her old kidneys.

Hannah feels well now — and she eats whatever she wants. Asked whether the first thing she did after the transplant had something to do with food, she laughs.

“Yes” Michelle agrees. “Milkshakes. Ice cream. A knockwurst, a hot dog, cake. We really overdid it the first five days. Then they told us to cool it.”

Some time later, Hannah started feeling faint. Doctors increased her salt intake. “What?” Michelle exclaims. “After that low-sodium diet?” She even took salt pills as a supplement.

Hannah will take anti-rejection drugs for the rest of her life. Doctors will monitor her closely. But the anxiety initiated by that shocking diagnosis in 2017 has vanished.

The Hepner family is breathing again.

While Michelle was at the Mayo Clinic, people constantly told her how wonderful she was for donating her kidney. Regardless of their relationship to the case, they all praised her.

“The reason I did this is because Hannah needed a kidney,” she says. “I’m not a hero. You just do what you have to do. I think most parents in this situation would have done the same thing.

“But I heard how I great I was so many times that I just went with it!”

The Hepners intentionally withheld Hannah’s medical crisis from everyone except family, close friends and the clergy at Temple Emanuel, where Michael is a past president.

“We wanted to keep it private,” he says. “We didn’t want people rushing to be donors for two reasons.

“Once Michelle was accepted, we felt the parent-donor route was the best way to go.

“And donation is a massive undertaking. You’re talking about flying out to Rochester, staying there for three or four days and going through the most difficult physical examina-
tions you can imagine.”

Michelle, who had registered as an organ donor on her driver’s license years before Hannah developed kidney disease, never really considered being tested as a donor.

However, this experience has convinced her that despite the arduous process awaiting them, people must donate their organs.

“The truth is there is a desperate need out there,” Michelle says. “We have a friend who lives in Chicago and about three weeks ago he called to tell that he was in an Uber and the car in front of him had a sign: ‘My son needs a kidney, please call this number.’”

The Hepners, who were in the waiting room of the Mayo Clinic at least 30 times over the last two years, remember that after the transplant they saw countless people entering the room for the first time.

“Given the fact that there is a five-year wait for a deceased donor, it shows you that there’s an incredible need for living donors,” Michael says.

The Hepners posted their first Facebook account of the transplant on April 21. As he recalls the outpouring of love and support from the community, Michael’s voice chokes and his eyes water.

“Once we knew there was going to be a transplant, a resolution, we told everybody and posted regular updates. The support we received bolstered us, and it helped Hannah a lot.

“She heard from a lot of friends, some of whom she hadn’t been in touch with for a long time. They all offered such positive encouragement.”

Hannah has overcome many obstacles. Today she adds a kidney transplant to her triumphs. She faced the fear, weighed the odds and made the choice to persevere. This is the young woman across the table.

“We are so proud of her,” Michael says before joining Michelle and Hannah for a group photo.

“You asked why I teared up before. It’s the sense of relief. We’re exhilarated!”