Young mother, teacher needs kidney transplant

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BY ANNE ADAMS • STAFF WRITER

MONTEREY — She made history a few years ago in a painful, frightening way. Courtney Kimble of Blue Grass was Virginia's first small bowel transplant patient. And its second. And last.

Now, at age 36, she needs a new kidney.

She's known for 10 years the day would come to start looking for one, and now she's on two transplant lists with a three- to five-year wait.

Given her medical history, though, waiting that long would be brutal on a body that's already fought numerous times for survival from an early age.

She and her husband, Chad, are hoping she can avoid dialysis — a typical eventuality for people whose kidneys are losing function. The procedure requires three hours of filtering blood, three days a week, plus the long drive to a hospital.

To understand how this young mother came to need a third transplant, it's important to know that Courtney's life is one full of faith and miracles that got her this far.

Genetic role

Courtney has a genetically inherited disease called FAP — familial adenomatous polyposis. Her father has it. Her grandfather died from it.

Her parents, Zack and Ellen Phillips of Blue Grass, had Courtney and her twin brother, Zack, in a Johns Hopkins University research study on FAP, and the medical team determined Courtney had the FAP gene, but her brother did not. Courtney participated in studies from the time she was 12, and for about four years, she had no problems.

But in December 1999, when she was 16, doctors found her large intestine riddled with polyps — polyps that would probably, eventually, cause cancer, like they did in her grandfather. So the summer between her junior and senior year of high school, Courtney's entire large colon was removed. That was July 2000; Courtney was 17.

She recovered, finished her senior year at Highland High School in 2001, and went on to Bridgewater College, preparing for a career in special education.

The summer of 2003, Courtney was experiencing pain, and saw a doctor in Richmond who determined scar tissue from having her large intestine removed had built up inside her fallopian tubes. Both tubes were blocked. A surgeon managed to get only one tube cleared, and at the age of 20, Courtney was told she would probably never have children. She took it hard.

She went on to marry Bill Wagner in May 2005. Because patients with FAP are normally unable to have children, the couple didn't know that with pregnancy, Courtney's disease could result in tumors. By February 2006, Courtney was pregnant and the couple was excited. She was considered high-risk, however, and referred to specialists in Charlottesville. But during her pregnancy, she felt something wasn't right. Bill decided to get her to the University of Virginia Hospital, where doctors found a massive desmoid tumor.

Desmoid tumors are not cancerous, but they are common in people with FAP. The higher estrogen levels in Courtney's body that are normal in pregnancy were feeding the tumor, and it was growing exponentially, pushing against the baby, and her spine, and every other organ. The baby needed to be delivered so he'd have a chance to survive, the couple was told, even though he would be nearly six weeks premature.

John William Wagner was delivered by C-section Oct. 10, 2006.

But both John and Courtney almost lost their lives that day. The plan was to perform a C-section, then immediately remove the tumor. That turned out to be impossible. Once surgeons realized how much of Courtney's insides had been taken over by the tumor, they called a specialist. That specialist told them: Don't touch it. Courtney's blood vessels were feeding the tumor, and it was intertwined with her small intestines. If they removed it, she would die. Surgeons were forced to close her up, tumor intact, and figure out another plan.

After two weeks, mother and child were allowed to go home — John on a feeding tube, and Courtney's tumor continuing to grow. All the usual feelings of new motherhood were compounded by Courtney's pain and sickness. She could barely do much but hold baby John when she had the strength. She was unable to eat. She was getting TPN — total parenteral nutrition — through a central-line IV. That gave her the essential nutrients and fluids to stay alive, but it was only safe for about six months.

Eventually, her doctors recommended chemotherapy, hoping that would reduce the tumor enough to remove it surgically without killing Courtney. It was the all-out, heavy-duty chemo treatment with all the worst side effects, including heavy vomiting and hair loss. It was right before Thanksgiving in 2006.

Chemicals were delivered intravenously for 72 straight hours. She could not keep any food in her stomach and continued to lose weight. The chemicals attacked the tumor, but also caused a lot of painful swelling, and the bowel to stop working.

After 38 straight days in the hospital, doctors declared Courtney would either turn around on her own, or not. Courtney was released to go home right before Christmas.

In January, it was time for a third round of chemotherapy, but there was a new problem. The chemicals had created a hole; Courtney's small intestine had ruptured, leaking toxins into the tumor, which made it more dangerous than ever. If the tumor ruptured, Courtney would die in seconds. One doctor told Courtney she had 6-12 months to live. John was only three months old at the time.

Then one day in the hospital, Dr. Timothy Schmitt bustled in. He had done small intestine transplants at the Nebraska Health System in Omaha, the place with the most experience doing the procedure. He recommended she move out west for a transplant.

U.Va.'s Charles O. Stickler Transplant Center was one of the best in Virginia, performing transplants for more than 40 years, but intestinal transplants were rare. Neither U.Va., nor any other facility in Virginia for that matter, had done one before. Only about 150 such transplants a year were performed in the U.S. at that time. It has only been since the 1990s that surgeons became comfortable enough to perform them.

U.Va. had brought Schmitt on board because of his transplant experience, including small bowels. He performs roughly 50 intestinal transplants a year.

The program for that specialty wasn't ready yet at U.Va. but the hospital offered to expedite its training for Courtney, and she agreed. The hospital got in high gear over the next 3-4 months.

Courtney was home over that period, still on TPN. She was in and out of the hospital all the time, fighting infections, blood clots, and getting monitored by physicians regularly. All manner of tests were conducted to make sure her body could handle transplant surgery, so she could get on a waiting list for a new organ. Making matters worse, there was a battle with their insurance company, which didn't want to cover her surgery because U.Va. had not been approved for the procedure.

First new organ

One Monday in April 2007, Courtney was finally placed on the waiting list. Five days later, an organ was found. There was no time to get affairs in order, and no time to collect her thoughts. She got to see baby John only briefly that morning.

Surgeons had to remove the tumor before Schmitt harvested the small intestine in Roanoke, to make sure no time was wasted. There was a limited window of opportunity to take the new organ and get it back to U.Va., and they seized it.

That tumor they removed from Courtney weighed 13 pounds — three times the size of the child she gave birth to just weeks earlier.

The surgery had gone smoothly, and it was over. Courtney now had a new intestine.

It was April 28. U.Va. had just done the first successful bowel transplant in Virginia.

There was a very real risk Courtney's body would reject the new organ, but things progressed, and she was instructed to try eating. At that point, Courtney had not had any food or liquid by mouth for seven months. She had to learn to eat again, which was not easy. Her stomach protested mightily, first against liquids and near-liquid food, and then against solids. Even after being allowed to go home, eating was an impossible, messy task. The new intestine, however, seemed to be working; it would just take time for her stomach to remember what to do. After three weeks of recovery, Courtney was allowed to go home. She was told that being so long on TPN could have serious side effects on her liver, and she might need a liver transplant at some point. And because anti-rejection medicine is hard on kidneys, she might need a new kidney some day, too.

But the new bowel did its job — for a while.

That October, the mix of chemicals Courtney was exposed to caught up with her new organ. A cancerous lymphoma was discovered on the bowel six months after it was installed. The anti-rejection medication is carcinogenic, and this was a possibility.

Yet another surgery was in order. Doctors removed the spot on Courtney's new bowel in November. A week later, they opened her up again to make sure no cancer remained, and she was put on a low dose of chemotherapy. She suffered one infection after another, and the chemotherapy was causing low blood levels. Everything seemed to cause more damage to Courtney's body.

In July 2008, a viral infection caused the new bowel to fail. It was backing up. She was septic, and again close to death. So after 15 months with her new organ, Courtney's surgeons agreed it had to come out.

Once the doctors removed it, Courtney's only choice was to go back on TPN to survive long enough for a second transplant. Of the normal 20-22 feet of intestine in most people, Courtney had 1.5 feet left. She needed another new organ, but her physicians decided Courtney needed to get off most of the medications that had racked her body, and gain some strength, before the procedure was tried again. They sent her home to do that, but it

would take more than a year in medical limbo before she had another shot at normal living, and the chance to be the wife and mother she longed to be.
Back on TPN she went. Doctors assigned a digestive team to help. Courtney was hooked to her central line 12 hours a night, and again five hours a day for fluids. For the first four months, every time she ate, she vomited. For 16 long months, the family stayed close to home. Courtney was at risk of infection. Caregivers for little John were not allowed in the home unless they'd had certain vaccines.
For her part, Courtney forced herself to eat a few choice foods on some days to remind her stomach of its purpose, but she was constantly nauseous. Traveling anywhere for the couple was difficult. Not only did they have to take along the usual necessities for a toddler, but also a cooler and all the bags, medicine, pumps and equipment Courtney required daily.
John, over the course of that year, became accustomed to his mother's routine. He liked to put on his own latex gloves, use a blood pressure cuff, and play doctor. He had the kind of skill set few children learn at that age.
Schmitt monitored Courtney's condition, and the digestive team watched her strength and weight.

Second time's the charm
Finally, on July 4, 2009, Courtney was put back on the waiting list for a new small intestine. Being on the list meant staying on-call 24 hours a day. There was only a window of 6-8 hours to get the surgery once an organ was donated.
That fall, Courtney got the call an organ had been found. Surgery would take place at 4 a.m. and would last 4-5 hours. That was Nov. 10, 2009.
Surgeons at U.Va. completed the second intestinal transplant ever performed in Virginia — on the same patient as the first.
But that night, Courtney became nauseous. Her brother, Lincoln, was with her at the time. "My heart was racing, and it wasn't calming down," she explained. Thirty minutes later, she was having serious problems breathing. Courtney was rushed to the ICU.
"There were suddenly like 20 people around me and I was so scared," she recalled years later. Her oxygen levels dropped precipitously. Doctors couldn't figure out what was happening to her.
It was at least the sixth time in three and a half years Courtney had come close to death. She was kept on oxygen all day. A CAT scan revealed no problems. Eventually, she returned to normal on her own. Physicians later attributed the problem to an allergic reaction to the anti-rejection medication.
Courtney was released in 10 days, on Nov. 20. She remained on TPN for a few weeks, until she started gaining weight.
Courtney had spent 229 days in the hospital over the course of four years. She gained her weight back, and worked her way down from 30 pills a day to 20.

New challenges
Since 2010, her life has changed a lot. She and Bill parted ways, but she was able to finally put her degree in special education to use, and now works at Pendleton County schools with a caseload of about 25 fifth and sixth-graders.
And about three years ago, Chad Kimble came into her life.

“I told him right away what he was getting into,” she said. “I told him he could turn away and walk right out the door and I’d understand.”
Chad smiled as she said that. He was unfazed. “Well, there’s lots of people dealing with all kinds of stuff,” he said. “We’re not going to let this get in the way. Love finds a way around every corner.”
The couple married two and a half years ago, blending a family that includes Chad’s children, Emily and Evan, and her son, John, 11, who now has a step-brother only a year older. They are in the sixth grade together, and get along like best friends. “Well, they certainly fight like brothers at times, though,” Chad laughed.
Life had settled into a far more normal routine for a few years, but now Courtney is gearing up for the next challenge.
All this started due to the hereditary disease that runs in Courtney’s family.
Courtney knew her son, John, had a 50 percent chancing of having FAP. She put off getting him tested longer than she intended, she said. “I was just terrified to find out. What if he has it? But I finally got him tested last spring.”
He is negative for FAP. “And I’m very happy for that!” John exclaimed last week, as his mother talked about her next steps.
Over the course of 10 years, the anti-rejection medication Courtney takes, for her lifetime, have taken their toll on her kidneys. “The doctors predicted I’d need a new kidney in 10 years, and this November it will be 10, so they pretty much got that right,” she said.
While there was concern early on about her liver, too, Courtney’s liver function returned to normal not too long after her second transplant, and has been fine ever since.
With a transplanted small intestine, Courtney’s body continues to make antibodies to fight off the organ that isn’t hers. She take two different drugs twice a day, and at one of the strongest doses.
For his part, Chad has gotten himself up to speed, ready to advocate for his wife.
“Did you know that anyone who goes for a kidney transplant goes in with two kidneys and comes out with three?” he said. “They just pop a hole in the bladder, tie the new kidney into blood vessels, and leave the old ones there.”
And that’s true — Courtney’s own kidneys still work some, and the new one will be added to make up for the work hers aren’t able to do. Chad likens it to tapping a new spring when an old one starts to lose its volume. “You get the new water line going, but you tie it into the old ones because they still have some water trickling into the system,” he said. “And, the other cool thing is that they don’t tie any nerves into her new kidney, so it won’t be able to feel anything.”
Courtney does not know when she’ll need the kidney. Her creatinine level dropped enough to get onto the transplant list, but she’ll need weekly testing to monitor her kidney function. At some point, it will be low enough that she’ll need the surgery, or dialysis.
Much is determined by a GFR number. GFR stands for glomerular filtration rate, and is a measure of kidney function. According to the National Kidney Foundation, that number is figured from one’s creatinine test, age, body size, and gender. The lower the number, the less one’s kidneys are doing their job.
Kidney transplants are relatively common these days. Chad said, doctors did four of them in the few days they were last at the hospital.

To date, no other intestinal transplants have been performed at University of Virginia Hospital. In fact, the program the hospital worked so hard to get up and going for Courtney was eventually discontinued. Courtney said the hospital had to pay insurance on the program, but didn't have any other patients who needed her kind of transplant. She was the first and last to get one there — well, two.

Her transplant doctor left for Duke Medical and that's where her transplant team is now. That's also why, when Courtney wasn't feeling well recently, she was transported from U.Va. to Duke with symptoms doctors eventually concluded were the result viral infections.

This happened right before Christmas. She was nauseous. She recalls working only half days, coming home that last day and collapsing on the couch, sleeping all afternoon and evening. She got to the ER, and her lab work showed a drop in her creatinine levels. Creatinine is a waste product filtered through kidneys, and its levels indicate kidney function.

That was Dec. 20, 2018. She spent 11 days at U.Va., through Christmas, until doctors there decided she should be closer to her transplant team. Chad drove her to Duke on New Year's Eve, where she spent another 10 days.

"She actually felt pretty good," Chad said. "We walked around in the hospital, making things feel somewhat normal, and we Facetimed a lot with the kids on Christmas, and saw their basketball games. They basically left her on fluids, did some biopsies, and the intestine seemed fine, so they sent us home."

Courtney was added to U.Va.'s transplant list in August, when her GFR fell below 20, which qualified her to be added. When her GFR came back up to 23, they listed her as "inactive" but still on the list.

When she was at Duke, she got on that hospital's transplant list also. As it turns out, U.Va. and Duke use two different regions from which they receive donated kidneys, so being on both lists increases her odds, with a broader pool of potential donors.

Courtney really wants to avoid dialysis if at all possible. "They say doing that is like a whole other part-time job," Chad said.

In the best of all worlds, Courtney would have a donor about 40 years old or younger — a kidney that will take her through the rest of her life. The right donor will have her blood type, in the A family, too, although one person who called the transplant team was told they could sometimes work with a different blood type.

The couple said several folks in the community have already stepped up to find out if they qualify to donate, and Courtney's twin brother will get tested, too.

Chad has already learned he doesn't qualify, but he was quick to point out there's a "paired donation exchange" program, in which one donor gives to a different recipient, who has a donor that could be "exchanged" with another one.

Courtney's insurance will pay for the cost of getting tested.

To find out whether you can donate, call Duke Health at (800) 249-4884; or U.Va. at (800) 543-8814 (option No. 2). You will be asked to provide Courtney Kimble's name, and her birthday, Sept. 17, 1982.

Chad and Courtney both noted that agreeing to donate is a heavy decision for anyone, but their hope is that sooner rather than later, someone will be willing to help her survive.