

Saving Dru

HOW THE U-M NETWORK HELPED
A YOUNG GIRL THRIVE

Dru Hendricks, now 7, has endured and survived more than many people do in their entire lives. At three months, she was found to have AT/RT brain cancer, a diagnosis that is virulently grim in children so young. Treatment included a bone marrow transplant. At 5, she underwent a lung transplant — one of a very few children her age to do so that year or any year.

BY DAN SHINE
PHOTOGRAPHY BY JEFF GROOTERS



But, here she is, bouncing around Ann Arbor with her family in a video her father, Brad Hendricks, made last year around Christmas. In the video, Dru walks a remote-controlled toy horse across the kitchen floor. She sleds down a snowy hill, giggling the entire way. She and her little brother, Winston, rip through presents on Christmas morning, making their parents laugh the way only children can. She is a buoyant little girl being nothing more than a happy, goofy kid. To arrive at these carefree moments, though, Dru and her parents have spent hundreds of nights in hospitals from Utah to Michigan to Missouri.

It's the kind of triumph that can spur reflection, and Brad began thinking over the biographies of his daughter's many doctors and a pattern emerged. Physician after physician, he discovered, had trained at the University of Michigan Medical School or in U-M hospitals. Still others who helped along the way were somehow connected to the university.

Brad has referred to Dru's story as a "testament to the Michigan network."

For Dru, that network is the doctor in Utah who treated her cancer; the doctors in Ann Arbor who monitored her remission and who first managed her lung trouble; the pulmonologist in St. Louis, and the business school faculty members at Washington University in St. Louis who helped her family find comfort in their temporary city. The connections reach into the future, too. A U-M Medical School graduate, now a pulmonologist at the University of North Carolina, will monitor Dru's lung health when the family moves there this summer.

FINDING MICHIGAN, IN UTAH

Like many, Brad Hendricks' initial connection to the university was as a sports fan. Growing up in Bountiful, Utah, Hendricks' first hat was a Michigan one. (Brad was so fond of the university that he chose to write about Michigan for a state report project in fourth grade, receiving extra credit for including so many articles about U-M Athletics.) "I wore that hat all of fourth grade," he says. "Then one day they wouldn't let us wear hats. It was a traumatic moment in my life."

Brad and Heather Robbins married in 2003. Dru was

born in January 2007, one month after Brad received his master's degree in accounting from the University of Utah. The family was growing and marching forward.

A bit fussy as a baby, Dru had a hard time eating but otherwise seemed normal. One April evening – "the longest night I've ever had," Hendricks says – Dru was inconsolable. The Hendricks had already been turned back by a physician as "overly worried first-time parents," when Dru screamed and cried on the way out of another doctor's visit. The pediatrician, upon hearing the pain in the baby's screams, referred Dru to Primary Children's Hospital in Salt Lake City.

A CT scan, given as a final precaution, revealed a brain tumor the size of a plum. The results surprised doctors, Brad says, because Dru had not shown any of the typical symptoms of a brain tumor, such as seizures or vomiting.

"I was shocked, and deeply saddened," Heather Hendricks says. "My very first initial reaction was that the tumor would take her life. I found myself mourning what her life could have been."

The day after the brain scan, Friday the 13th, Dru had surgery to remove the tumor. All but a small portion of the tumor that was wrapped around the brain stem was removed.

Carol Bruggers, M.D., was Dru's oncologist in Utah, and the first of many U-M connections for the young girl. A Michigan State University medical school graduate, Bruggers grew up near Ann Arbor and her parents were both University of Michigan doctors. Brad Hendricks remembers Bruggers saying they could either make Dru comfortable with medication until the cancer overtook her body or pursue treatment.

"She told us that she thought all kids deserved a chance. It meant a lot to have her say that even when we all knew how bad the prognosis really was," Brad says.

Dru and her parents spent almost 200 nights at the hospital that year. Her treatments included several rounds of high-dose chemotherapy and 30 consecutive days of radiation treatment. She later underwent a bone marrow transplant.

The Hendricks slept and showered at Primary, knowing their daughter's prognosis was not good. Dru was weak and had a hard time sitting up. She couldn't play on the floor or even leave the room because her immune system was suppressed. Other effects of Dru's therapy included a reduced ability to swallow, so she was given all of her nutrition through a feeding tube. "It was life in a 12-by-12 room," Brad says. "Hopefully you're not making her go through all this for nothing."

By Christmas, the family was able to go home, though Dru had brain scans every three months. Doctors told the



family that, based on statistics, the cancer may return in the first few months. Dru was cancer free at three months, at six and into her second year of life. “You start to wonder if you’ve won the lottery,” Brad says.

Even though scans remained clear, the Hendrickses never completely exhaled. Brad decided to go into academics so he would have the flexibility to help care for Dru, understanding that her health could be an ongoing concern. After applying to several doctoral programs in accounting, Brad chose the U-M. Michigan, Brad says, was the best program that also happened to come with the best insurance — a vital consideration considering Dru’s health. Bruggers assured the family they would be in good hands at the U-M.

“She said she was very cognizant of Michigan’s abilities,” Brad says. “And she told us how a school teacher used to have her class march around singing ‘The Victors.’”



Brad Hendricks with Dru, just before her lung transplant (top); Brad holds Dru after her brain surgery (above).

THE MAGNITUDE OF IT ALL

The family moved to Ann Arbor in the summer of 2009. The first year was normal, Brad Hendricks says. Dru was healthy and hitting all her milestones, and the Hendrickses decided she could use a sibling around the house.

During Heather's pregnancy — son Winston was born in February 2011 — Dru's breathing became increasingly labored. She would ask to be held after running, but Brad and Heather thought she maybe just wanted attention. Considering Dru's health history, though, they took her to

C.S. Mott Children's Hospital.

"We had been around enough kids to know a lot of them get a secondary cancer," Brad says. "So we always suspected there would be something. We never imagined it would be of the magnitude it ended up being."

Pediatric lung specialists at the University of Michigan found that Dru's lungs showed evidence of injury, most likely a side effect of the life-saving chemotherapy she received. Dru still struggled to swallow, and doctors were concerned that she was inhaling saliva into her lungs. Various interventions helped for a short time, but Dru's lungs got progressively worse. Over the span of about nine months, Dru went from being an active preschooler to a little girl who lost her breath while walking. Dru was in constant need of supplemental oxygen and needed high doses of strong medicines.



Heather, Winston, Dru and Brad Hendricks in April.

Dru's lung doctors performed a lung biopsy to better understand what was happening with her lungs. The biopsy confirmed that there was scarring (fibrosis) in the lung.

During recovery after lung surgery, a small tube is often placed into the space between the lungs and ribs — the pleural space. The tube helps remove air that escaped from the lung into the pleural space, helping the lung stay inflated until it heals. But Dru's lung tissue wouldn't heal. Even after several interventions — including another surgery — the lung kept leaking air into the pleural space, a condition called pneumothorax. After a brief respite when Dru's lung could function without a tube, the pneumothorax returned and Dru was back in the hospital needing another chest tube.

"Because of the constant need for suction, she couldn't leave the hospital," says Toby Lewis, M.D., a pediatric pulmonologist at Mott and an associate professor of pediatrics. "The only chance at being able to ever leave the hospital was to get new lungs through a transplant."

Dru's parents struggled with what to do next, while her doctors worked to repair the lung damage. As doctors counseled the Hendrickses about a possible lung transplant, Dru settled in for another months-long hospital stay.

"It was difficult watching her slowly get worse and worse," Heather says. "We had suspected that lung transplant was going to be an option, but we hoped that it wouldn't come to that point. We also became fearful of the future. What would happen if we did or didn't do the transplant? How can we keep Dru as happy as possible?"

THROUGH EACH DAY

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ventually, this was the family's choice: a lung transplant for Dru or prepare her for hospice care.

"It was absolutely terrible, probably the worst thing that we have ever been through," Heather says. "The last thing that we wanted to do was buy Dru more hospital time. But if we did the transplant, there was a chance of a more 'normal' life. We went back and forth, and back and forth, and back and forth. There was no right answer. Then Dru's pediatrician — by far one of the best doctors we have ever dealt with — also told me that there was no wrong answer either."

Heather Burrows (M.D. and Ph.D. 2000, Residency

2003), Dru's pediatrician at Mott, says this case is "very, very rare." At Mott, physicians care for many children with rare cases, and that care is difficult because so few, if any, cases are at all similar.

"The challenge for Dru from having such a rare condition is that it's hard to get information on what to expect," says Burrows, also a clinical assistant professor.

Lung transplants are recommended when someone has severely damaged lungs due to an irreversible condition that won't recur in the new lungs, Lewis says.

Because such transplants are so uncommon in children, there are only a handful of pediatric lung transplant programs in the country, according to Lewis. Mott is not among the four medical centers in the country that routinely perform lung transplants on patients younger than 6 — and so the Hendricks knew they would have to travel for Dru's lung transplant.

"It is also true that there are also very few organ donors who are children," Lewis, the Mott pulmonologist, says. "And children who do need a lung transplant may have to wait for a long time to get matched with donor lungs that are the right size and immunologic match."

Though they decided to try for a transplant, the Hendrickses worried that Dru wouldn't receive donor lungs and her last months would be isolated from friends and family "in a strange city."

MICHIGAN IN ST. LOUIS

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t. Louis Children's Hospital has one of the few pediatric lung transplant programs, and it is led by another Michigan graduate, Stuart Sweet (B.S. 1981, Ph.D. 1989, M.D. 1990). In November 2011, Dru was transferred from Mott to St. Louis Children's on a specially pressurized medical transport plane. While waiting for matched lungs, the Hendrickses lived at the Ronald McDonald House in St. Louis. In early January 2012, they got the call that a set of donor lungs was available.

This is how Brad describes the moment when they knew the transplant would happen: "I don't know that I've ever been physically shaking like I was at that point. Even at that point, when the lungs are being offered and she is so sick that we have to carry her in our arms from room to room, we were unsure if this was the right decision. It was, and still is to us, absolutely terrifying to contemplate the scope of a lung transplant."



Dru Hendricks playing tennis in Ann Arbor

Driving to the hospital that night, the family was incredibly nervous. When Dru heard they would go back to their temporary apartment in a few weeks, and that she'd feel better, she asked, "Can we go back to Michigan?"

"We told her that we could and she didn't ask any more questions after that. That was enough for her. I think that is enough for all of us," Brad and Heather wrote on their blog.

According to Sweet, Dru's lung damage due to cancer treatment also is "one of the themes we see." He says the biggest challenge for young lung transplant patients is the chronic care needed after surgery.

34 Fifty percent of patients live five years, and, after a decade,

only 20 percent survive. "We're very up front. They know what they're getting into," Sweet says.

Dru was one of eight children younger than 6 to get a lung transplant in the United States in 2012. After her successful transplant, the Hendrickses stayed at the hospital for weeks and in St. Louis for about four months to monitor possible rejection. While there, Brad Hendricks continued his studies.

Brad's advisor at U-M's Ross School of Business, Gregory Miller (Ross Ph.D. 1998), connected the Hendricks with two Michigan friends at Washington University in St. Louis. A former Ross faculty member, Rich Frankel, offered room for the Hendrickses to stay at his home and volunteered his

children for babysitting duties. Chad Larson (Ross Ph.D. 2008) found Brad office space at the university and connected him with undergraduate research assistants.

“You know how difficult it is going through the Ph.D. program, then you add on top of that this incredibly difficult situation,” Larson says. “When you see that, anything you can do to help you’ll do.”

Heather says the family’s faith in God, help from family members, the Ronald McDonald House Charities and her husband’s professors at the U-M made it possible for them to endure this all together — as a family.

“I wouldn’t have survived this experience if Brad and I would have been separated,” she says. “I tried to just focus on the daily tasks at hand, instead of worrying about the future. I just did what I had to do, and made it through each day.”

PROTECTING DRU

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y summer 2012 the family was back in Ann Arbor “trying to figure out how to do life again,” Brad says. “You don’t feel stable anymore. You always keep a suitcase packed because you don’t know when you’re going to be

back in St. Louis. You live with a level of anxiety now that you never imagined could exist.”

Dru returned to St. Louis for lung checkups, including one in March. Through all of this, Dru has repeatedly impressed her doctors with a buoyant, fighting spirit.

Burrows says that Dru is a fun-loving girl with a great sense of humor. Dru loves Disney princesses, the movie “Frozen,” and anything pink or purple. Her infectious laugh starts high and finishes, joyously, even higher. Although shy around visitors, Dru’s silliness emerges with her parents. During a reporter’s recent visit, Dru fixed her father’s hair with frilly barrettes and happily showed off a new bathing suit.

Each day, Brad and Heather balance the health risks of taking Dru into the wider world against exposing her to outside joys. Dru is homeschooled to help insulate her from the long flu season rushing through school halls. She can’t risk getting sick while her body works to accept her new organ. Dru participates in some activities, including dance and swimming. Grateful for Dru’s care at Mott, the Hendrickses invited Burrows to their daughter’s Christmas dance recital.

“It reminded me why I love what I do,” Burrows says. “I

think back barely a year ago. She was on oxygen, not able to do anything. Her health is still something that requires a lot of effort and care, but she’s able to enjoy a lot of wonderful things.”

Brad says they have alienated people to protect Dru from germs. They have had family out visiting who, at the first sneeze, are sent on the next plane home. If the family is in public and hears a cough or sneeze, “We’re up and moving.”

“Our experience with cancer, and remission, was like winning the lottery,” Brad says. “It can be cured, it can go away forever. But with a lung transplant we knew we weren’t playing in that same area. You win, but you win years, you win conditions. But you don’t win a cure.”

TO A NEW TOWN, STILL WITH MICHIGAN

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he family moves to North Carolina in August, where Brad will teach and research at UNC’s Kenan-Flagler Business School (and where his dean will be another Michigan graduate).

When Brad and Heather were considering jobs, they focused only on universities with nearby pediatric lung transplant programs. It seems inevitable now, but that decision also led to Dru’s care being handled by another Michigan physician — stretching her connection to the university all the way from Utah to North Carolina. Terry Noah (M.D. 1985), a pediatric pulmonologist at the University of North Carolina and the North Carolina Children’s Hospital, will take over the monitoring of Dru’s lung transplant.

Noah says the succession of Michigan people taking care of Dru and her family is “quite remarkable.” He admits that Dru came to UNC “not because somebody from Michigan is here, but because of the transplant center. But it does speak to the national reach of the University of Michigan Medical School.”

Sweet, Dru’s pulmonologist in St. Louis, says the reach of the U-M network that the family encountered follows his experience over the years from being an undergraduate in Ann Arbor to leading a pediatric lung transplant program.

“Michigan is an extraordinary experience,” he says. “It attracts smart people who go elsewhere and develop their careers. It’s not surprising to me the family has touched Michigan wherever they have gone. The message of their story is that you don’t have to look very far to see Michigan.”

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