Saving Chase / TEENAGER'S LUNG -LIVER TRANSPLANT REQUIRESFAITH, FAMILY AND SHEER WILL TO SURVIVE

By JEANNIE KEVER
Staff

THEY earned him a place in medical history, but to Chase McGowen, the events of Jan. 5 have been both more and less than that.

Finally he has a chance to get down to the real business of being a 13-year-old boy: going to school, riding his bike, counting the days until he gets his driver's license.

In some ways, though, what happened in an operating room at Texas Children's Hospital doesn't fit into any neat box.

How do you categorize a complicated tango of hope and loss, life and death?

In an operation lasting nearly 12 hours, a team of surgeons sliced through Chase's sternum, rerouted his blood supply to a heart-lung bypass machine, cut away his deteriorating lungs and replaced them with a healthy pair taken hours earlier from a person declared brain-dead in a West Texas hospital. As the new lungs were connected to his pulmonary artery, pulmonary veins and main airway, a second team of surgeons waited to remove Chase's damaged liver and replace it with a healthy organ from the same donor.

By the next day he was awake, aware of what had happened and "feeling kind of weird. I sort of had the heebie jeebies."

The lung -liver transplant was the first in Texas and the 14th in the United States. Most of the other patients, like Chase, had cystic fibrosis.

His new lungs and liver will remain free of cystic fibrosis, although his other organs are still affected by the disease.

Chase left the hospital on Tuesday, 1/20 a scary step but also a milestone in his quest to make it back to his real life as a teenager in Austin.

"I want to go home, but I just don't think I'm ready to go today," he told the medical team gathered in his hospital room Tuesday afternoon.

But the doctors insisted it was time.

"We fully understand being a little nervous about going home," said Dr. John Goss, the lead liver transplant surgeon at Texas Children's. "But we think it will be best to see Chase McGowen as an outpatient."

So Chase walked out of the hospital, accompanied by his father, Tom McGowen, and a box of 18 medications intended to keep him healthy and stop his body from rejecting the new organs.

He will remain in Houston for several months so doctors here can closely monitor his recovery.

For life after transplant , the only certainty is uncertainty.

Chase endured the painful removal of four drainage tubes inserted into his new lungs, the uncomfortable therapy to reduce the mucus accumulated there and the exhausting daily exercises to regain his strength.

His mother, Carol McGowen, came down with a cold on Jan. 16, and doctors sent her packing, insisting she stay away from Chase until she was well.

But there were amazing moments, too, as he came to realize that his new lungs really work, that he really can breathe without supplemental oxygen for the first time in almost

two years.
All in all, he's doing well, said Dr. George Mallory, a pediatric pulmonologist who is coordinating Chase's care. "Our only real, active problem is, he's accumulating fluid in his chest cavity," Mallory said as he released Chase from the hospital. "We're going to beat it, but it's going to take nutrition and exercise and time and prayer."
After a lifetime of waiting, Chase has his second chance.
Chase's time
Chase waited 8 1/2 months for the transplant , but in some ways he had waited forever. For his first 10 years, cystic fibrosis was a manageable if cumbersome disease, requiring daily breathing treatments, numerous medications and periodic hospitalizations. He was a little skinnier than most of the boys in his north Austin neighborhood, but he could still tear around on his bicycle, and jumping on the trampoline only helped knock the mucus loose in his clogged lungs.
But by May 2002, several years after he was forced to leave school and enroll in the Round Rock Independent School District's home-based program, his health was dramatically worse. For the next year, with collapsed lungs and other complications, he was in the hospital more than he was out.
"Chase was literally dying in front of me," his mother said.
Stuck in the hospital while his friends were playing football and complaining about homework, Chase ran the gamut of emotions: "Mad. Angry. Sad. I felt just about everything you can," he said. "I can't even put it into words.
"I was just so scared my lungs were going to collapse again, even though I wasn't doing anything rough."
He felt safe in the hospital, scared to leave it. "Whenever I left the hospital, I would cry."
Last winter, a pediatric lung specialist pitched a packet of information about lung transplants to McGowen as her son lay in an Austin hospital, struggling to breathe.
It was time, he said.
Improved treatments for cystic fibrosis have raised the median age of death to 33.4 years. Organ transplants carry their own risks, but without one, Chase seemed unlikely to reach his 14th birthday.
A family united, divided
Chase and Carol McGowen arrived in Houston in mid-May, accompanied by McGowen's sister, Kim Zimmermann, but leaving Chase's father, Tom, and two sisters at home in Austin.
The family had spent months researching logistics and financial realities, ultimately prevailing over their insurance company's insistence that Chase be treated in Los Angeles or St. Louis.
Both of those programs are big, with correspondingly long waiting lists. "I could tell by looking at my child, we don't have that long," Carol McGowen said.
The program at Texas Children's Hospital in Houston was new, started in July 2002. Chase's lung transplant was just the 10th performed there.
Despite the program's limited experience, the McGowens felt the shorter waiting list and the proximity fact that it was close to home made Texas Children's their best choice. Tom McGowen's parents, Paul and Norleen McGowen, live in Pearland, providing a built-in support system, and Norleen McGowen's mother's Museum District home had been empty since she entered a nursing home six months earlier, giving the family a place to

live rent-free.
Tom McGowen and Chase's sisters visited most weekends, and friends poured in all summer.
Still, the separation hurt.
"Not seeing my sisters every day is hard," Chase said. "Not seeing my dad is the hardest thing."
Tom McGowen, training coordinator and safety manager at Newmark Homes in Austin, accepted it stoically. He had to work, not least because his job provided the family's health insurance. He had also become the day-to-day parent to Tara, a high school honors student and volleyball player, and Casey, a fifth-grader who swims competitively and plays basketball.
But throughout the summer, his only son grew steadily weaker.
"Chase calls, and you can tell he misses his sisters and dad. You can hear it in his voice," Tom McGowen said last fall, his own voice betraying his emotion. "That's tough."
For Carol McGowen, a stay-at-home mom since Tara was born, being with Chase was both a luxury and a mind-numbing 24/7 responsibility, but only occasionally did she acknowledge the difficulty.
It didn't matter. They did this, or Chase died.
But they didn't do it alone.
Zimmermann, 34, turned her own life upside down and came to Houston to help.
She and her husband, Mike, had just moved into a new custom-built home in Georgetown, where she taught at a private Lutheran school down the hall from the classrooms of her children. It was a comfortable life, but her sister needed her.
"There just wasn't a choice," she said. "I won't let my sister go through this by herself."
Michael, 9, and 6-year-old Shelby Zimmermann spent the summer in Georgetown with their dad, then moved to Houston in August.
Carol McGowen and Zimmermann had moved in together to care for their mother in Austin before her death almost three years ago of non-Hodgkins lymphoma.
"I thought that was going to be the hardest thing I ever dealt with," the 39-year-old McGowen said. In retrospect, those months were a final gift from their mother, teaching them to work together for Chase.
They came to Houston for new lungs. In July they discovered that the liver disease that had plagued Chase since he was a baby - a complication of cystic fibrosis - meant he also needed a new liver .
So they waited, never straying far from the beeper that would alert them to a potential match.
It went off on Aug. 14.
Tom McGowen, 42, raced to Houston with Tara and Casey. Chase danced around the house, calling friends with the news. McGowen and Zimmermann watched in amazement, exulting that he was so fearless.
Several hours later, the verdict was in. Waiting families seldom learn why a potential match didn't work out, but lungs are easily damaged and often rejected for transplant after testing.
False alarm No. 1.
Waiting and worrying
Life went on - Zimmermann's kids began school at Poe Elementary School, and Chase's

friends returned to school in Austin - but Chase's life remained on hold.
Anytime he left the house, and the oxygen generator to which he had been tethered since April 2002, he toted an oxygen tank. Thanks to Houston's triad of heat, humidity and ozone, he was unable to be outdoors for much of the summer and fall, prompting McGowen and Zimmermann to scrounge for entertainment that was both cheap and air-conditioned.
By fall, Chase had gone for a test-drive in a Hummer, toured Reliant Stadium, watched the Astros and met many of the players, and been to a Texans' game. He'd been to museums, restaurants and movies, even the neighborhood fire station.
But what they took to calling their "Houston adventure" wasn't really about sports and good times. It was about beating a ticking clock.
In a process that took many of his waking hours, Chase required three daily breathing treatments, each time inhaling three medications to break up mucus and fight infection. Afterward he slipped into an inflated electric vest, which vibrated to shake the mucus loose so it could be coughed up.
He was often on intravenous antibiotics, and he spent every night hooked to a feeding tube in an effort to keep his weight up. He saw Mallory, who runs Texas Children's lung - transplant program, every week.
Starting in September, he met twice a week with a teacher from the Houston Independent School District's homebound program to keep up with his eighth-grade classmates back home.
Everything revolved around Chase, even though he sometimes found it all maddeningly boring. "I sit down and get another breathing treatment," he said, describing a typical afternoon. "I watch TV. Michael and Shelby come home, and I help with their homework. If I have time, I'll play Nintendo."
If a household with two mothers provided a bit too much attention for a thin and pale teenager who, all in all, would rather be playing video games and listening to rap music, he also grew increasingly dependent, feeling truly safe only if McGowen and Zimmermann were around to oversee his therapy and medications.
"I'm sick of it, a lot of the time," he said. "Sometimes I finally just cry."
Not that he didn't struggle against the rules.
Chase wanted to stay up late, while his mother insisted he be well-rested and ready for a transplant at a moment's notice.
"Normal kids stay up late," he argued.
"You're not normal," McGowen answered, hating to say the words but fighting to keep him healthy.
Three times a week, Chase and Zimmermann headed for the fitness center at First Presbyterian Church. Chase had received physical therapy at the hospital, but McGowen quickly realized that was costing his insurance policy between $900 and $1,200 a week. By then, the $1 million insurance cap was looming closer.
"It sounds like a lot, but it's not," Carol McGowen said. Years of treatment for cystic fibrosis already had taken almost half, and the transplant would take the rest. Costs not covered by insurance had long ago eroded their savings.
McGowen and Zimmermann handled the IV's and feeding tube to limit home health-care costs. When they moaned about the expense of hospital-based physical therapy, Mallory mentioned that his church had a nice gym.

Zimmermann, a lean and lanky distance runner, took on the workouts herself, and First Presbyterian allowed them to use its facilities for $30 a month.
By mid-September, Chase was beginning to grow stronger. One day he and Zimmermann strolled into the gym, trailed by the portable oxygen tank. A North Carolina Tarheels cap topped his sandy hair as he climbed onto a treadmill.
Chase was determined to walk a mile. Zimmermann vacillated between encouragement and worry that he would overdo it. She promised that after the transplant they'd do a 5K race together. And she told him it was OK to stop. "Sometimes I go out to run 10 miles, and I only run five."
It wasn't OK with Chase, and after 21 minutes he flipped the treadmill off, his mile finally done.
One child dies, another lives
Lung -liver transplants are rare. Because of that, there are no reliable statistics on success rates, said Anne Paschke of the United Network for Organ Sharing.
About 80 percent of cystic fibrosis patients who have a lung transplant are still alive one year after surgery, according to the Organ Procurement Transplant Network. That drops to 61.3 percent after three years.
"We would all be glad if lung transplantation was the answer, but it's so difficult, and it's still a procedure fraught with problems," said Allison Tobin of the Cystic Fibrosis Foundation.
But Mallory, who coordinated three lung -liver transplants at St. Louis Children's Hospital before coming to Houston, felt it was the best hope for Chase.
His only hope.
Gene therapy may provide valuable treatment in the future; the gene that, when defective, causes cystic fibrosis was discovered in 1989, the year before Chase was born, and research is continuing.
Chase couldn't wait. But getting on the waiting list for a transplant was only the beginning.
More than 83,500 people in the United States are waiting for an organ transplant - kidney, pancreas, liver , intestine, heart, lungs or some combination. Slightly more than 19,000 transplants were done during the first 10 months of 2003. On average, 17 people on the waiting list die every day.
As a mother, McGowen lived with the knowledge that another family had to lose a child and agree to donate his or her organs in order for her own son to live.
"We have no choice," she said. "Either he gets a lung -liver transplant or he dies. But . . . I look at the other family, the potential donor's family. We can't lose sight of that."
When Mallory met Chase last spring, the lung specialist broached the subject other people had avoided. "Nobody is going to die for you," he told Chase. "It's just going to happen."
LifeGift, the organ-procurement agency that provided the lungs and liver for Chase's transplant , works in hospitals in Houston, Fort Worth, Lubbock and Amarillo. About 65 percent of families asked to donate organs and tissue agree to do so, said Catherine Burch Graham, director of communications for LifeGift.
Finding lungs suitable for transplant is especially complicated.
They are fragile and susceptible to damage and infections, Mallory said. Slightly more than 6,000 families agree to donate the organs of a loved one each year, but fewer than

1,000 sets of lungs are suitable for transplant .
There are other hurdles, too.
About 60 pediatric lung transplants are performed in the United States every year, at six locations: Houston, Los Angeles, Philadelphia, Pittsburgh, St. Louis and Gainesville, Fla.
Most people have to move.
"That costs money. That costs emotions," Mallory said. "There are a number of really sick kids whose families just aren't crazy enough to do this."
The McGowens were crazy enough.
The cost of life
Organ transplants are about money as well as medicine.
Lots of money.
Clinic visits, medications and medical equipment continued to eat away at Chase's insurance policy. Although the bills haven't yet been tallied, Carol McGowen figures the $1 million policy ran out sometime during the transplant .
So few lung -liver transplants have been done that cost estimates of the surgery and follow-up care aren't available, but a 2002 Milliman USA report pegged the first-year cost of a lung transplant alone at $343,000. Transplant patients need expensive anti-rejection drugs and follow-up care for the rest of their lives.
Clearly, money was a problem.
Chase qualified for Medicaid, a federal-state insurance program that will cover at least some post-transplant expenses, because he lived apart from his dad, the family's sole wage-earner. Whether he will keep the coverage when the family reunites remains to be seen.
They can't afford to lose Medicaid coverage, so perhaps, the McGowens say, Tom McGowen will have to move out of the family home. Perhaps they'll have to get a divorce.
Everything is under consideration, they say, but there are no easy answers.
"What we need is to win the lottery," Tom McGowen said.
Most managed-care policies are capped, usually at $1 million or $2 million, said Donna Poole, director of business services at Texas Children's.
Eligibility for Medicaid and the state Children's Health Insurance Program is based on income and assets, and families of transplant patients have to see which programs, if any, they may qualify for if they lack health insurance or their insurance runs out. Without coverage of some sort, or an independent source of income to cover the cost, patients seldom make it onto the waiting list at all.
Poole said she knows of one case in which a young transplant patient's parents divorced so their child would qualify for CHIP.
Others raise money on their own.
The McGowens tried that, too.
They set up a Web site, www.helpingchase.com, cqand established two funds.
Information on both is available on the Web site.
Carol McGowen and Zimmermann also hit up everyone they met for a donation.
"It was really awkward at first," Zimmermann reported to her sister after making one approach. "But," she shrugged, invoking the mantra they adopted during the wait for a transplant , "it's all about Chase."
So she pushed on.

A veteran of eight marathons, Zimmermann had registered for last weekend's Houston marathon just hours before Chase's transplant began.
At first she figured that being with him at the hospital and with her own children after school would leave her no time to sleep, much less to stay in shape for a marathon.
Then she decided to make the race a fund-raiser, asking people to pledge $1 a mile for the 26.2-mile race. By race day, she was up to $225 a mile, and she's still accepting donations.
"It's all about you, sweetie," she told Chase before the race.
Back home, Chase's friends sold their artwork to raise money. They made cookies, mowed grass, held a swim meet and collected donations door to door.
Families that had watched Chase grow sicker were determined that money not be the stumbling block.
"The McGowens are wonderful," said Tracy Gilbert, a second-grade teacher at the neighborhood elementary school whose sons are among Chase's best friends. "The support system we have in our neighborhood is wonderful. It's a big family, and we take care of each other."
Those small fund-raisers showed Chase that his friends cared. But a lifetime of medical bills means his family needs more money than kids can raise singing door to door.
On Oct. 23, friends raised more than $65,000 with a golf tournament in Round Rock.
Tom Graf, quality-assurance coordinator for the Texas Legislative Council, knows the McGowens through his kids, 13-year-old twins Logan and Jolie, and came up with the idea of a golf tournament last spring.
"We've all lived through Chase's condition," Graf said. "We knew he had cystic fibrosis. Everybody knows the sentence for that."
Living on faith
Money worries aside, everyone's nerves were starting to fray by fall..
Chase's lung capacity dropped to 17 percent in mid-September, the lowest it had ever been. Everyone focused on the good news - he wasn't on a ventilator, wasn't in the hospital, was still working out regularly with Zimmermann.
Still, the dropping numbers could only mean he was getting sicker.
Mallory recognized the signs of stress.
"This is just getting old," he said. "I tell families, `If you've never lived by faith before, you need to learn how to do it now.' "
Pegg Dobmeier, lung -transplant coordinator for the hospital, silently took note as McGowen grew teary-eyed during one visit. "With Chase, they're working so hard to keep him healthy," she said. "That's one of the stresses. Is he going to stay healthy enough (for a transplant)?"
McGowen and Zimmermann had relied on Dobmeier for far more than medical information. Where could they get a good haircut? Which restaurants should they try? After all, people don't live by inhalers and pulmonary-function tests alone.
One of the more serious questions of the fall concerned Casey.
Chase had been sick for so long that, in some ways, the natural order of things had shifted. Chase, at 13, remained in the role of the youngest child, while Casey, three years his junior, assumed the role of the middle child.
She fretted about him, and he chafed at her hovering. Then she wanted to be coddled, but Chase needed more attention.

"It has been more difficult on Casey than we want to admit," McGowen acknowledged. She had received a reminder the previous evening, when a friend relayed a conversation between her daughter and Casey.
"My brother isn't coming home," Casey told her friend.
McGowen believes in positive thinking, and for the most part, that was her line: Chase will get the transplant . He'll be healthy. But she had to be honest, so she couldn't promise that Chase wouldn't die.
"Help!" she e-mailed Dobmeier.
Dobmeier alerted a hospital social worker, who appeared in the waiting room during Chase's next clinic visit, offering a sheaf of information on kids and stress and support groups near the family's home.
With Mallory, McGowen launched into another worry. With school under way and Chase's friends no longer free to visit as often, he was growing more depressed.
Mallory climbed onto the exam table to look Chase in the eye. "I know it's not easy," he said. "It's really about character, and you've got a great character. God isn't finished with you yet."
Nor was David Blanco.
Blanco was Chase's favorite respiratory therapist at Texas Children's, a therapist-cum-cheerleader who offered unwavering encouragement as he determined the state of Chase's lungs.
"Big, deep breath," he instructed as Chase clenched the test machine's mouthpiece between his teeth. "Blow it. Blow it. Blow it. Blow it. Now push. Push. Push. Push. Push. Push. Push. Push."
Blanco tapped at his keyboard to log the results.
"Everything's up," he reported. Chase's lung capacity was 19 percent, an unexpected improvement.
Chase brightened. "I want to do it again."
Blanco cheered him on again, sitting upright when he read the results.
"Whoa, man. Where did that come from? Twenty percent. You haven't seen 20 percent in a while. Very nice."
Chase leaped from his stool, leaning over to study the paperwork Blanco printed out.
"That's awesome. That's cool," he said.
"Can I have a copy so I can show my dad?"
False alarms
Weeks passed, and the usual caveat that accompanied all plans - "unless we're at the hospital for a transplant " - began to ring hollow.
McGowen missed her daughters and her friends. Zimmermann, energized by the people she had met in Houston, began wondering whether she wanted to return to teaching or try something new with her life.
The beeper went off twice more, on Oct. 1 and Dec. 6. False alarms Nos. 2 and 3 .
Chase felt stuck.
"Every time I think about it, it seems unreal," Chase said. "I want it to be over, but nothing ever happens. Just go to the doctor, go home, hope it happens.
"Everyone keeps saying, `Oh, it's going to happen.' But they're not the one who's sitting here."
He was clingy, sitting in his mother's lap or slumping against her during clinic visits, and

the numbers on his weekly lung -function tests began sliding back down.
"You're not a machine," Blanco told him when he couldn't nudge the meter above 18 percent. "You can't do the same thing every time."
Chase didn't say anything.
Mallory was quiet at that visit, too, reviewing Chase's test results and listening to his lungs.
"I think we're hanging," he told the family. "I'm making no predictions, but we're ready."
Then, a phone call
No one wanted to seem ghoulish, but everyone knew that the holidays, when traffic accidents usually increase, were the most likely time for a transplant .
But by Jan. 4, it looked as if nothing was going happen. Tom McGowen had returned to Austin with Chase's sisters after spending two weeks in Houston. Zimmermann and her kids were back from Georgetown.
At 11:25 that evening, the telephone rang.
They had a donor. Eighteen hours later, Chase had new lungs and a new liver .
His new life had begun.
. . .
FAMILY FUND RAISING
The McGowen family is raising money for Chase's post-transplant care.
The Web site, www.helpingchase.com, provides information on two funds. Donations via the National Transplant Assistance Fund (www.transplantfund.org) may be made to the Chase McGowen Restricted Fund for Lung Transplant Assistance by calling 800-642-8399.
Donations to the Chase McGowen Medical Assistance Fund, administered by the family, may be sent to Bank of America, 13435 U.S. 183, Austin, TX 78750. Mark donations for Account No. 0057 4500 9549.
Chase's aunt, Kim Zimmermann, asked people to pledge $1 per mile - $26.20 - as she ran the HP Houston Marathon on Jan. 18. Checks may be sent to the Chase McGowen Medical Assistance Fund, c/o Sherry McGowen Nelson, 4713 Highway 6 South, No. 140, Missouri City, TX 77459.
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ABOUT THE DISEASE
Cystic fibrosis is a genetic disease affecting about 30,000 people in the United States.
It causes the body to produce an abnormally thick, sticky mucus, due to the faulty transport of sodium and chloride within cells lining organs such as the lungs and pancreas to their outer surfaces. The mucus also obstructs the pancreas, preventing enzymes from reaching the intestines to help break down and digest food.
The disease develops when each parent carries the defective gene; 10 million Americans are symptomless carriers. When two carriers conceive, there is a 25 percent chance that the child will have cystic fibrosis and a 50 percent chance that the