Magazine

MAGAZINE

The gift

Without new lunges, Spencer Bean would die. His mother and his aunt, whose organs were healthy, knoew what they needed to do.

Spencer Bean and his mother, Jean Bearor, in 2008.

By Laura Pappano

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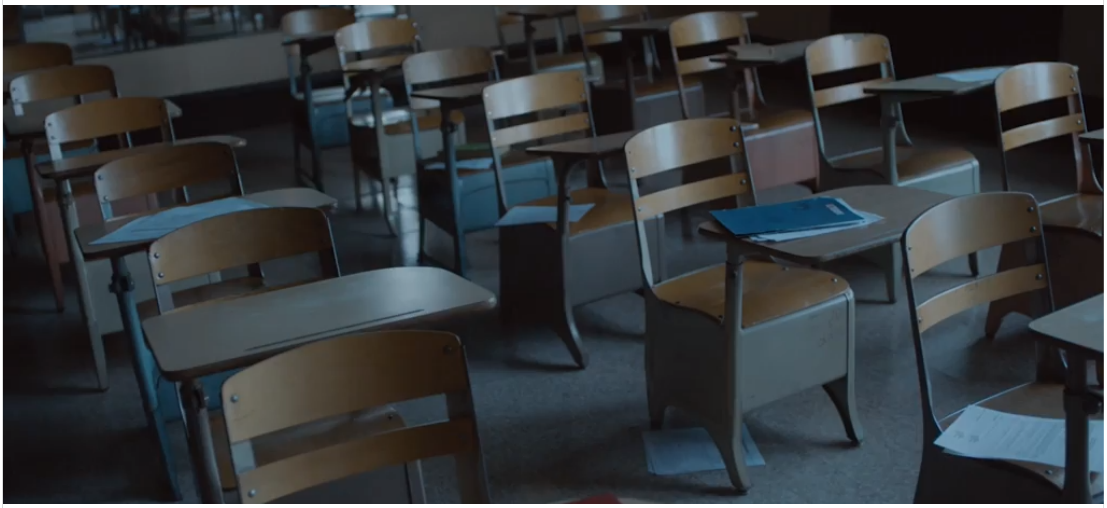
It is a chair no parent ever wants to occupy. But Sharon Bearor was there, sitting in a doctor's office at Massachusetts General Hospital, listening to him carefully outline her son's options.

As she sobbed and blew her nose into a brown paper towel, the only substitute for a tissue she could find, Sharon thought, "This is my son's life we are talking about -- and right in front of him!"



Secrecy, of course, had never really been an option: Her 19-year-old son, Spencer Bean, was born with cystic fibrosis, and Sharon, who is a nurse, had always known that someday the disease -- as much a part of him as his penetrating blue eyes -- could snatch him away. But she and her son had focused on life, not limitations. Spencer had played in Little League. He'd skied. Skateboarded. Now in college, he was a computer whiz who drew the less expert for tips to his dorm room at the University of Maine at Orono. He was a low-key young man who liked Mountain Dew and had an Internet home page, a love of bass fishing -- and a life's worth of aspirations.

Certainly, those who suffer from cystic fibrosis -- and there are 30,000 in the United States -- know that, today, the median life expectancy of those with the disease is just over 30 years. But it is one thing to hear such general projections and another to admit that they apply to you. It is easy to feel the invincibility of youth, easy to put off thinking about treatments that might be required -- or even new therapies that might be available -- in the future.

Now, as they sat in the office of the pulmonologist Dr. Allen Lapey on the first day of summer, 1995, the future had arrived: If Spencer were to survive for more than a few years, Sharon learned, he would need a lung transplant. It appeared to be her only child's only hope.

It was a hope laden with uncertainty. Dr. Lapey said that Spencer would probably qualify for the waiting list for a so-called cadaveric transplant. In that case, someone's death -- most likely from a stroke or a car accident -- could give him a shot at survival. But the shortage of donors meant it could take two years to get a pair of lungs. And the long wait carried dangers: About one-third of those on the list die while waiting for a donor organ or are too sick to undergo the operation by the time they reach the top.

But there was, Dr. Lapey said, another, experimental, option.

A few weeks earlier, doctors with the Massachusetts Consortium for Lung Transplantation had gathered at MGH and performed a relatively new procedure, one that had been refined only two years earlier in California. A normal pair of lungs contains five lobes, three on the right side and two on the left, that fit snugly together. The MGH doctors had taken one lobe from each of two living relatives and used them to replace diseased portions of a patient's lungs. So far, it seemed to have worked, with both the recipient and the donors -- their lungs, diminished by surgery, nearly back to capacity -- thriving. If Spencer chose to pursue this route, however, he would need to have both lungs removed entirely and would rely on the two lobes -- one on each side -- to expand and fill the space.

As Dr. Lapey talked, Sharon's tears continued to flow. What would it be like to have doctors open up her son's chest and remove the only lungs he had? "Do they really know what they're doing?" she asked herself. Her tears, however, were also prompted by a sense of exhilaration: Because this new procedure could be scheduled in advance, Dr. Lapey was saying, Spencer's medical team could plan the surgery, making sure that Spencer was in top form to undergo it. They could also choose donors with healthy lungs. In her mind, Sharon ran through the blood types of potential donors. Spencer was O-positive. She was O-positive. But Spencer's father and her former husband, Brian Bean, was not a match. Sharon thought of family members. She thought of her sister Jean Bearor.

Spencer, meanwhile, simply listened, taking in everything Dr. Lapey said and silently turning it over.

As Sharon and Spencer drove home to Cape Elizabeth, Maine, the headlights of their silver Ford Escort pierced the dark of the Maine Turnpike. Dr. Lapey had laid it out: Spencer could do nothing and die; he could wait, perhaps too long, for an organ donor; or he could try an experimental procedure that had been performed just 30 times in the United States. Sharon saw Spencer wipe his eyes. She felt overwhelmed by the uncertain road ahead. As she later summed up the trip: "We were given three choices, and I didn't like any of them."

It's true that organ transplantation is no longer the wild gamble it was a few decades ago. But lung transplants have been reliably performed in this country only since 1983. At MGH, cadaveric lung transplant recipients have an 88 percent chance of living for one year and a 75 percent chance of living for three. The long-term survival rate is still unknown; one of the first people to receive a cadaveric lung transplant will celebrate 10 years of survival in January.

The procedure of transplanting lungs from living donors is too new to offer any odds at all. Despite the unknowns, however, the doctors at MGH, among the best in the world, said they were confident that the operation would work.

But there is much more to an operation of this magnitude than the odds of medical success and failure. For Spencer and his family, the transplant also would be about coping, about fear, about being a patient, and about having faith in something you cannot fully fathom. Spencer's story is as much a chronicle of these emotions as it is a window into the cutting edge of medicine.

For doctors, too, the procedure would raise larger issues, ones that swirl around transplants using an organ from a living donor: How could they be sure someone wasn't being pressured into donating? Is it ever reasonable to put a healthy person at risk? And how could they proceed cautiously, ensuring that such issues are addressed, without delaying so long that Spencer became too ill to survive surgery?

Before Spencer was born, his parents, whose families both had histories of cystic fibrosis, worried that their baby might inherit the disease. Only about one in every 3,300 babies born in the United States has cystic fibrosis, which afflicts mostly people of European descent. But Spencer's extended family had all too often experienced the tragic early deaths that it inflicts. Four of Sharon's first cousins had died by the age of 19. Spencer's father, Brian, lost a sister and a newborn brother to cystic fibrosis.

Sharon, concerned about the possibility of passing on the gene, had asked about the risks they faced if she became pregnant. But in 1975, doctors didn't know what they do now: Given their family histories, Sharon and Brian had a 25 percent chance of bearing a child with the disease. At the time, experts thought the odds were small. Sharon recalls her obstetrician scolding: "You nurses are all alike. Sharon, you worry too much!"

Spencer weighed nearly 8 pounds when he was born, on April 7, 1976, and he looked beautiful, Sharon recalls. At the same time, she knew something wasn't right. He didn't nurse. He didn't clench his fists when he cried. He didn't seem "vigorous." Sharon and Brian took their newborn to Children's Hospital, in Boston, where he was diagnosed with cystic fibrosis. At that moment, they entered a world of doctors and hospitals that would be as much a part of Spencer's childhood as his school and friends.

Spencer, like others born with cystic fibrosis, suffers from a genetic defect in his body's ability to process salts, and therefore in its ability to move fluids across the lining of the body's tubular structures, including the lungs, bowels, and ducts of the pancreas. In the lungs, debris isn't washed away; instead, it becomes dry and sticky, allowing bacteria to grow and to destroy lung tissue. To battle this, Spencer was immediately put on daily doses of antibiotics and, later, a bronchodilator to help clear his airways.

From the time he was a baby, he had regular physical therapy that involved clapping on his back to loosen secretions. Over the years, there would be hospitalizations and "tuneups," during which he would get intravenous antibiotics and intensified physical therapy to fight infections.

When Spencer was 8, Sharon felt he was in trouble and took him to see Dr. Lapey at MGH. On December 11, 1984, surgeons removed a lobe from his right lung that had been destroyed

by bacterial infection. After the surgery, Spencer improved. But there were still periodic hospitalizations, stays that became more difficult for Sharon to juggle with work after she and Brian divorced, in 1986.

The disease was a burden, but Sharon was determined not to let it rule their lives. She had used the rhythmic clapping of physical therapy to teach Spencer the ABCs. When he was older, she had him handle his own care. By age 15, he was setting up doctor's visits for himself and calling the pharmacy for his medications.

Despite the hardships, Sharon, who is 42, says she is not angry about the disease. Spencer says there are "always frustrations" with his condition. Is he bitter? "Not at all. It has defined who I am."

Three weeks after the meeting with Dr. Lapey, Sharon called her sister Jean, in Cornville, Maine. The two women belong to a family of seven children, one that has remained close despite time and distance. But the idea of a transplant had been too overwhelming to discuss even with Jean. Indeed, "transplant" was a word that Sharon couldn't even bring herself to utter. Finally, though, she called with a question: Would Jean consider donating part of her lung, as she herself planned to do?

Jean said she would think about it. And there was a lot to think about.

Jean wanted to make sure that this was right not only for Spencer but for her own children, too. She was, after all, a mother of three -- Rebecca, then 22, Jennifer, 21, and John, 14. She had also recently gone through a divorce. Jean had a good job as the director of the laboratory at a 92-bed community hospital in Skowhegan, Maine, but, with a teen-ager and two college students to help support, she felt the pinch of a single income. Would her insurance cover it? All of it? How much time would she have to take off from work?

"I had to think about how it would affect my family," says Jean, who is 47. "I had no problems with my health. But I was still putting my girls through college. It takes a whole period of time to process the situation."

And it was time that Dr. Leo Ginns, director of the MGH Lung Transplant Program, wanted to give her. Dr. Ginns, a deliberate man who listens more than he speaks, is familiar with

arguments against living-donor transplants. He wants every potential donor to weigh the issues carefully.

Opponents consider it unethical to submit a healthy person to surgery that provides that person no benefit -- only risk of harm. Dr. Thomas Starzl, a pioneering liver and kidney transplant surgeon who is affiliated with the University of Pittsburgh Medical Center, says that living donors helped him and others usher in the modern era of transplantation. But now he opposes the practice. "I have heard it said, and seriously, that one death every 2,000 patients, or whatever the figure actually is, is a statistical nonevent," Starzl wrote in a medical journal in 1987. "It is hard to really believe this since the death of a single well-motivated and completely healthy living donor almost stops the clock worldwide."

Opponents also argue that it's impossible to be sure that family members aren't pressured to donate. And while living-donor transplants are easier for doctors to schedule, critics argue that encouraging them could undermine efforts to encourage cadaveric organ donation.

"In my mind, the risk is too great for the benefit," says George J. Annas, an ethicist and professor of health law at Boston University School of Medicine. "You create a procedure where two people could die, when the whole point of organ donation is to make someone who would die live."

But Dr. Robert Keenan, head of cardiopulmonary transplantation and thoracic surgery at the University of Pittsburgh Medical Center, which started a living-donor lung program 18 months ago, sees the issue pragmatically: There is a shortage of organs. He has watched families devastated by the death of children who waited and then didn't get organs in time for transplant. "When you see this happening time and time again," he says, "you want to say, `Isn't there something else?' "

Today, about 48,000 people are listed on a national registry, hoping for an organ to give them a shot at life (2,165 are waiting for lungs). But just 19,136 transplants (including 871 lung transplants) were performed last year, says the United Network for Organ Sharing, which keeps a list of patients awaiting organ transplant. And in the five years from 1988 to 1993, a federal General Accounting Office report says, about 10,000 people died while waiting for organs.

The ideas for solving the shortage are wide-ranging, from paying families of cadaveric donors to moving to a national policy of "presumed consent," in which a dead person's organs are donated unless a family opposes it. Some, though, believe the best hope is with so-called living-related donors.

Dr. Ginns believes in the procedure, but he cautions against moving too quickly in a given case, before there is time to consider all the issues. After some time consulting with doctors at her hospital in Skowhegan and weighing the potential risks to her own health, Jean decided to donate part of her lung. Dr. Ginns, though, wanted her to feel free to reconsider. "The process is designed to be deliberate rather than rapid," he said when he met with the family. "Part of that is to permit the donor time to contemplate this and back out."

On December 19, 1995, the grounds of the University of Maine at Orono wear a hardened coat of snow. It is 10:30 a.m. -- dawn for many students -- but Spencer is awake and opens the door of his Oxford Hall dormitory room to a soft knock. "Hi, there," he says. "I'm just in the middle of my meds."

His "meds" have been part of his daily routine for years. Although Spencer is loath to discuss it, the disease is imposing more limits on his life. He loves sports and was a member of high school tennis and ski teams, but now he can only play soccer -- on the computer.

His room is like thousands of dorm rooms, too small for comfortable living by most adult standards and decorated in a way that mixes creative expression and practicality. There is the ubiquitous mini-fridge. Pearl Jam posters. Spencer's computer. A TV, tuned to Jerry Springer, on which sits a can of Spam.

It is exam week, and Spencer's roommate sleeps in a tangle of bed linens. Spencer stretches out on the lower bunk with a plastic inhaler in one hand and an empty beer can in the other. Every day, he takes antibiotics to keep the growing infections in his airways in check and an enzyme to loosen secretions so he can cough them up -- which he does, and spits into the beer can.

His doctors want him on oxygen all the time. And for about 18 hours a day, while in his room, Spencer is hooked up to a machine that concentrates the oxygen in the air and pumps

it in nearly pure form through a line of clear tubing, which fits over his ears and feeds into his nose. But Spencer refuses to bring a portable oxygen tank to classes or to meals. He wants to be like every other sophomore. And to watch him with his friends, he is. When fellow students drop by and ask about final exams, Spencer reports that he "rocked Strength and Materials."

There is no doubt, though, that his life is different. A few weeks later, on January 4, 1996, while classmates relax during winter break, Spencer checks into MGH for tests to see if he's healthy enough to handle a lung transplant. So far, he's had a pulmonary-function test, stress test, chest X-ray, CAT scan, and, as he puts it, a "mess of blood drawn."

As Spencer sits in bed doing his meds with his mother nearby, Anne Mahaney, a social worker with the lung transplant unit, drops in. She talks about transplants, mentions a good book, then asks Sharon: How does she feel about living-related donor transplant?

"If my lungs fit and work, and I'm healthy enough to do it, let's go," says Sharon. Her chief concern: How can she be mother and nurse to Spencer after surgery when she must recover herself? "Right after surgery, I need to touch him and see him," she says.

Spencer rolls his eyes. His mom can be so, well, motherly that it's enough to embarrass a guy.

Sharon says she's an extrovert, open about her emotions. Mahaney glances at Spencer. How, she asks, does he deal with his emotions? He doesn't have to, he quips: "My mother does it for me." Mahaney laughs, but she's not satisfied. She wants to know more about Spencer: What is he like?

"What do I like to do?" Spencer asks. "I don't know. Do everything 19-year-olds like to do -- party, pick up girls, work on the computer, be creative, school."

They talk about his computer and his use of oxygen. He raises a paper cup to his lips and spits. She asks if he's religious.

"No, I guess not," he answers.

"Are you spiritual?" she asks.

"Somewhat. Not religious-spiritual. I don't know how to explain it. I don't believe there is a higher power. Everyone is their own power, and they have to rely on their own soul to heal them. That's how I think of it."

"When you go through difficult times, does prayer help?"

"No," Spencer says thoughtfully. "I haven't had difficult times."

On January 25, Spencer is listed with the New England Organ Bank as a patient awaiting a lung transplant. He will also be listed automatically on the national registry, providing an option if for some reason they cannot -- or choose not to -- go through with the living-donor transplant.

The focus shifts to Sharon and Jean. If they are to move ahead with a living-related lung transplant, they must show they are physically and mentally able to handle it.

The first tests of their lung capacity are scheduled for February 9. At midday, Sharon, Jean, Spencer, Brian Bean, and Dan Barker, Sharon's fiance, sit in the cafeteria at MGH. They planned to eat in the car, but it's too cold, even for people from Maine. Dan gets the peanut butter and marshmallow-fluff sandwiches they made for lunch.

The mood is tense. Spencer has the flu. Sharon is anxious about whether she'll pass the test. She used to smoke. She slept fitfully all night. "I'm so afraid I'm going to fail something," she says. Even Jean, whose composure is legendary in her family, seems a little nervous. "What if they find something wrong?" she asks.

In the pulmonary-function lab, Sharon and Jean sit with clips on their noses and blow into fat plastic tubes. Technician Barry Callahan, who banters with them, extols the "fresh Maine air" that has given them such robust lung capacity. He declares them "disgustingly normal," and other tests confirm his assessment: Their lungs are large and strong.

After lunch, Spencer and his family file into a conference room in the Wang Ambulatory Care Center. There, nurse-practitioner Susan Zorb, lung transplant coordinator, introduces them to two women: Jennifer Querusio, who is 32 and had the first living-related lung transplant at MGH, the previous June, and her sister, Mary-ann Mills, who donated a lobe.

Sharon and Jean ask about the pain, the scar, the recovery. Spencer asks about the ventilator, the intensive care unit, and when he can eat -- he figures he'll be "wicked hungry" after surgery.

The two paint a rosy picture. Sure, there is pain, grogginess. But Querusio, of Somerville, who suffered from a lung disease called pulmonary fibrosis, describes her quick recovery. Before the procedure, she says, it was so hard to breathe she couldn't read to her children. Now, she reads, climbs stairs, whistles, does everything she did before she got sick. Mills, of Malden, says it hurt to laugh and to cough after the surgery, but now, eight months later, she is herself again. For Spencer, Sharon, and Jean, the talk is a real high.

The families exchange phone numbers as Querusio and Mills leave, and Dr. Ginns, director of the MGH Lung Transplant Program, enters the room. He sits at the end of the long table. "So," he asks, in a professorial tone, "what did you learn?"

"That it works," Sharon responds eagerly.

Yes, there seem to be advantages to living-related lung transplants, says Dr. Ginns. They can make sure Spencer gets a "good lung." The operating rooms are next to one another; as soon as a lobe is removed, it can be transplanted. A cadaveric transplant provides a whole pair of lungs -- not just two lobes -- but, Dr. Ginns says, "if we have to go to Chicago, there is a certain amount of time taken up in travel" in which the donor tissue could be damaged.

Then Dr. Ginns raises the potential danger to the donors. He looks at Sharon and Jean: "I don't think there is any way to escape the fact that you are putting yourself at risk, and you have something to lose."

He explains the risks and the ethical problems. He emphasizes the "opportunities to withdraw." He goes over the procedure in detail -- the chest tubes, the incisions, the medications, the pain. Don't, for one minute, think this is going to be easy, he seems to say.

The mood in the room grows subdued. By the time they leave for Maine, the whole family is physically and emotionally spent. There it was: the dazzling success of high-tech medicine side by side with the inherent dangers of rearranging the contents of the human body. And now it would be happening to them.

By early May, Sharon is impatient with "the process." "I need a number," she says. "I need a date, now." Sharon and Jean have had test after test, met psychiatrists, independent pulmonologists, the chairman of the hospital ethics committee. They have met Spencer's surgeon, Dr. John Wain, and their own surgeon, Dr. Cameron Wright.

Jean makes her first trip ever to London and plans a major hike for June. Sharon, invited by Jean on the England trip, doesn't go. She feels stressed. She has started relying on a daily glass of wine for what she calls "the wrong reasons." Her family doctor prescribes an anti-anxiety medication. "I cry a lot," says Sharon. "I am having a hard time with this."

Finally, in early June, the date for the transplant is set: July 17. A Wednesday.

Spencer's health is getting worse. He is on oxygen all the time. Still, he hopes to be best man at his friend Aaron Williams' July 6 wedding. As Sharon plans her leave from work and a vacation, it bothers her that Spencer cannot travel beyond the 50-foot radius of his oxygen line. She's fed up with the trail of clear tubing that gets stuck in doors, runs up the stairs, and catches stuff in its path. She sees her son's vulnerability. "Last week," she says, "I went to the beach, and he couldn't come with me."

Although she is a donor, Sharon focuses on Spencer. She becomes philosophical and considers that his life may end with surgery. "There are no guarantees. This may not work," she says. "Sometimes I can't believe Spencer lived to be 20."

Spencer, though, is not thinking about death. "I picture the whole day of events," he says. "I'm excited. I just picture myself doing what I used to do, which was everything."

Spencer talks about returning to school in January 1997. He wants his own apartment. He asks Sharon to save old pots and pans and silverware. She is struck by his confidence. "We were sitting downstairs the other day, and I did ask him, `Are you scared about the surgery?' " Sharon says. "He said, `Nope.' "

On July 11, one week before surgery, Spencer, Jean, Sharon, Dan, and Brian are at MGH for final preoperative tests and meetings, including one with Dr. Wain, Spencer's surgeon. Spencer's oxygen tank is zipped out of sight in a blue L. L. Bean backpack. Almost everything

has become an effort. His shoulders appear bonier as his chest muscles work even harder to help him breathe. When he speaks, he stops between words for air.

Sharon has photos from his friend's wedding the previous week. Spencer is handsome as the best man, dressed in a tux with a pink bow tie. But in one photo, he sits at a round table covered with a white table cloth, the wedding festivities out of the frame. In this picture, he is not smiling or talking with friends. He wears a tired expression. He rests, alone, with his oxygen tank and a Mountain Dew, a snapshot that captures the dark power of disease to separate a person from life.

In Dr. Wain's office, Spencer asks to hear about the surgery, even though he already knows much of what will happen. How long will it take? Where will the incision be?

"There will be a scar along the base of the pectoral muscles," Dr. Wain says, running his index fingers across his rib cage. "It looks like a big mustache."

Dr. Wain goes over the plans. He will remove Spencer's right lung first, because it is the worst, and replace it with Jean's lower right lobe, because the lower lobes are easiest to remove. Then he will remove the left lung, replacing it with Sharon's lower left lobe.

PART 2

After surgery, to halt organ rejection, Spencer's immune system will be suppressed, making him vulnerable to infection. So, at first, visitors may only peer through the glass of his room in the surgical intensive care unit. Later, a limited few may enter, but only wearing gowns, gloves, and masks. At first, a ventilator will push oxygen into Spencer's new lungs, Dr. Wain says. Later, he will breathe on his own.

There is laughter and joking by the pool at the Holiday Inn, in Boston, where Jean and Sharon are holding court with friends and family. It is a warm, breezy night on July 16, the eve of surgery. There is an odd mix of anticipation and fear in the air. Among the group are Jean's two daughters, Jennifer and Rebecca; Sharon and Jean's brother Stephen Bearor, who gave his late daughter Chelsea a kidney and an extra year of life; sisters Joyce and Joanne; friends of Sharon and Jean from high school, including Janelle Seazey and Wendy Liberty,

who will care for the two sisters after surgery. Later, a second cousin, Rev. Jon Martin, arrives, in Sharon's words, to "bless us and bless the surgeons."

Jean sits beside her daughters. Rebecca will handle the bills and care for their younger brother, John, while Jean recuperates. Jennifer is proud of her mom, but she admits, "I'm anxious for it to be over."

Inside, in Brian Bean's hotel room, Spencer, attached to his oxygen line, rests on a bed, playing with his step-siblings, Adrian, 4, and Olivia, 2. His father reminisces about taking Spencer to hear Hall & Oates, his son's first rock concert. The previous night, he'd found an old tape and played it. He's brought a good-luck charm: a photo from his 1989 wedding, of Spencer in a suit and red tie, the ring bearer.

Spencer is astonishingly calm. "One of the reasons I am kind of mellowed out is that the last three or four months, I just, like, sat down and put myself in my position and imagined what it would be like. Whatever feelings I would have now," Spencer explains, "I've already had."

At 6:45 a.m. on July 17, a group of 14, including Spencer, Sharon, and Jean, walk from the Holiday Inn to the surgical reception room in the Wang building at MGH. The three say quick goodbyes, change into surgical gowns, and are wheeled on gurneys down a cluttered hallway to the operating area. Once they arrive, they are separated.

Those left behind grow serious. There are furrowed brows, wide eyes, concerned expressions, as transplant coordinator Susan Zorb announces that she will give them regular updates on the surgery.

Spencer will be in Operating Room 8, and Jean will be in Operating Room 7. The two rooms are connected. Sharon will be down the hall, in Operating Room 3.

As Sharon rests in her curtained-off room with a nurse at her side, she is weepy. "I want to be strong," Sharon tells the nurse, Patty Harris. "I just love Spencer so much. I want to be strong, because Jean is strong." She pauses. She is upset by her own outpouring of emotion. "Does fentanyl do this?" she says, referring to the pain medication she has been given. "Yes," replies Harris. "And having a son go through a big operation."

Meanwhile, Jean rests on the hospital bed in a room across from OR7. An anesthesiologist comes in. "Need anything?" he asks. "I need a cup of coffee," she says, "but so far, so good." Then she thinks of something: "Do you have another pillow?"

A few minutes before 9, Jean is wheeled across the hall and into the operating room. Spencer is awake in OR8. But a short while later, an anesthesiologist places a mask over Spencer's nose and mouth and tells him, "You'll feel some pressure in your neck. It will be over in two seconds, one second."

Over the next few minutes, within the confines of this room, a stunning transformation takes place. Spencer, in a sense, loses his humanness -- the qualities and presence that make him a person one would have a conversation with -- and he becomes a gleaming white chest under a surgical lamp. It is the only part of him that is visible once his arms are pulled above his head and his body is draped in green sterile cloths. Soon, the only sound in this room, with its milky-green tiles and rolling tables of shining sterile instruments, is the "bleep, bleep, bleep" of the heart-rate monitor.

At 9:50 a.m. Dr. Wain positions himself on Spencer's right side and makes the incision. Dr. Craig Lillehei, from Children's Hospital, stands directly across the operating table, assisting him. For the next eight hours, Dr. Wain will concentrate completely on the surgery before him. He will not leave to eat, to drink, to urinate, to stretch his legs. He will travel only from Spencer's right side to his left, walking in a tight U around the bottom of the operating table.

Dr. Wain is intense, focused. Despite his confidence that the operation will go well, he puts the risk of Sharon's or Jean's dying during surgery at .3 percent to .5 percent; the risk to Spencer, he says, "is closer to 10 percent." Spencer's risk of dying in the hospital afterward, Dr. Wain says, is "less than 5 percent."

Although the living-lung donor transplant has been done only once before at MGH, Dr. Wain has performed some 50 cadaveric lung transplants in his career as well as last year's living lung procedure. As a surgeon, Dr. Wain is a straight shooter. There is no cowboy ego, no pre-surgery ritual. There is no music playing in his OR. "My thing is, I think everyone should focus on the operation," he says.

When Spencer's chest is opened and Dr. Wain looks inside, he sees that the operation is going to be harder than expected. There is a lot of scar tissue around the right lung that must be removed before it can be freed and the new lobe transplanted.

In OR7, the radio is tuned to Magic 106. Elton John croons, "It's no sacrifice, no sacrifice at all," as Dr. Wright works through layers of Jean's tissue, then places a rib retractor between two ribs to reveal her chest cavity and the lobe he plans to remove.

At 11:10 a.m., Dr. Wright tells Dr. Wain: "We're ready to go."

Dr. Wain is still dealing with scar tissue. By 11:30, he calls for an argon beam coagulator, which helps cauterize large bleeding surfaces, to help finish the job. At 11:52, a nurse comes through the operating-room door. "They're all set up and ready to go next door, John."

"Tell them we'll give them the high sign and be ready to go in five minutes," Dr. Wain responds.

At 12:08 p.m., Dr. Wain cuts Spencer's pulmonary vessels and right mainstem bronchus, the tube that connects the lung to the trachea, lifts his right lung out, and places it in a square stainless-steel tray. He gives the go-ahead to remove Jean's lobe.

By 12:35, Jean's lobe is free, and Dr. Wright is flushing it with water and giving it a puff of air. It is a delicate pink. Even to someone unfamiliar with the process of disease and the workings of the human body, Jean's organ is a remarkable contrast to Spencer's, which is purplish red and laced with mucus: It has the rough, marbled look of corned beef. Jean's lobe is placed in a bowl on a bed of crushed ice covered with pale green plastic. Dr. Wright then gathers and ties the top of a plastic bag in which the bowl sits and gives it to another doctor to carry into the next operating room, warning: "Don't you dare drop it."

In OR7, Dr. Wright begins closing the layers of tissue. By 2:15 p.m., Jean's surgery is over. An anesthesiologist is at her side. "Squeeze my hand," he says. "Good. You're doing great. You still have a breathing tube in. You're with it, aren't you?"

Jean is. He removes the breathing tube. "Everything's going great in the other room." Jean gives him a thumbs-up as she's wheeled out of the OR and up to a recovery room. Dr.

Douglas Mathisen, chief of thoracic surgery and part of this transplant team, calls downstairs and tells Jean's daughters that everything went well. Then Dr. Mathisen goes to OR3, where Sharon is under anesthesia, and makes an incision below her left breast and toward her back.

In OR8, Dr. Wain prepares to put Spencer onto the bypass machine, which will take some of the blood flow from the heart so it doesn't all rush into the newly transplanted right lobe when the left lung is removed. Dr. Wain makes eye contact with the technician operating the bypass machine, then asks the anesthesiologist for numbers. How is Spencer's blood pressure? He clamps the pulmonary artery going to the left lung and waits. Blood pressure now? All attention in the room focuses on Dr. Wain and the bypass technician. The question: Can the newly transplanted lobe handle some of the blood flow, so Dr. Wain can remove the left lung? The clear plastic tubing turns red with blood. Dr. Wain wants some blood flushed through the new lobe.

"Give us some up-and-down on the lung," he calls out. "The right lung."

There is a collective sense of joy as the pink-white organ that a short while ago was part of Jean's breathing apparatus now rises and falls in Spencer's opened chest cavity. It is a wondrous sight. An essential element of life has just been transferred from one person to another.

"It looks fantastic," Dr. Wain says, observing how Jean's large lower lobe fits well into Spencer's smaller chest. "It easily fills the thorax. I think it will be normal for him."

By 3 o'clock, Sharon's lobe is ready to go; by 3:25, Spencer's left lung is out, looking worse and more marbled with mucus than his right had. Minutes later, Sharon's lobe is flushed clean, packaged, and transported to OR8.

Then, some six hours after he made Spencer's incision, a few minutes before 4 p.m., Dr. Wain begins sewing in Spencer's second new lung. By 5:15, Sharon is upstairs in recovery. Not long after, Spencer is brought up to the surgical intensive care unit.

The next day, Dr. Wain gives his assessment: Removing Spencer's right lung was more difficult than expected because of the scar tissue. The actual implantation, he says, "went just as I had hoped."

If Spencer has, as he says, pictured the whole transplant operation in his mind, there is no image that could have prepared him for his recovery.

He will spend 33 days in the surgical intensive care unit, in a sealed room with a view of the reception desk but of little else. Jennifer Querusio, the previous living-donor transplant patient, spent only a short time in the ICU. But she had not been weakened by a life's worth of cystic fibrosis. Spencer, who is 5 feet 9 inches tall, weighs only 116 pounds. His weight will fall to 102 pounds during his hospital stay.

A week after surgery, Spencer cannot walk or stand alone. His life depends on a roomful of machines with lighted displays and lines and tubes that connect to his body at a dozen points. His father, Brian, visits each day for hours. He talks and moistens towels to ease Spencer's fever. Later, he feeds him tiny cups of apple juice.

In the ICU, a sign from Sharon is taped to the wall. It says: "Elephant Shoes" -- a phrase that Spencer years ago discovered sounds like "I love you" but that was always easier for a guy to say to his mom. Her message is there, but Sharon is in Maine, recovering in her home alongside Jean. At first, they have a great deal of pain and cannot shower without help, cook, or drive. Then they settle into a ritual of watching Rosie O'Donnell on TV and having their friend Janelle Seazey take them for a midday drive. Over time, they work up to longer walks and outings.

Spencer's recovery is not so easy. Early on, his doctors discover fluid in his lungs, which can interfere with the exchange of oxygen and carbon dioxide. If the fluid were left unchecked, Spencer could suffocate. Later, there are fevers. The fevers are troubling, because doctors don't know whether they are being caused by an underlying infection or by organ rejection.

This presents a serious dilemma: Treating one makes the other worse. Further suppressing the immune system to reverse organ rejection will fuel the spread of infection and make him sicker. Left unchecked, organ rejection could kill the new lobes. What's more, because Spencer is already so sick, he cannot undergo the tests normally done to find out which is the culprit. The doctors go with their hunch that the fevers are being caused by rejection and increase his anti-rejection medication. The fever goes down.

During this time, Dr. Ginns, the director of the Lung Transplant Program, finds himself focused on Spencer, thinking about him as he showers, drives, carries on conversations. He, like Drs. Wain and Wright, monitors Spencer's condition at the hospital; at home, he calls in for updates.

Dr. Wain has given Spencer a tracheostomy, cutting a hole in his windpipe and inserting a short tube to help him breathe. It is more comfortable than a breathing tube running into the mouth and down the throat, but the procedure takes away his voice.

When Sharon calls Spencer on the telephone, he taps on the back of the receiver, tapping quickly when he is excited or in agreement with what she's saying. Although Sharon and Brian have been divorced for a decade, Brian understands what she, as Spencer's mother, needs to know. As parents, together they appreciate Spencer's first laughs and cries after surgery, the first time he is able to sit up in bed, his first taste of applesauce.

On August 14, nearly a month after the surgery, Spencer looks fragile. A month in the ICU is, by any standards, trying; while he has not developed "ICU psychosis," in which patients hallucinate, he is on antidepressant medication. His demeanor is brittle. He is a young man overwhelmed by the road ahead.

In the early afternoon, a physical therapist enters. Spencer's eyes are glassy. He shakes his head "no" when he spies her. He mouths that he is "too tired." She says he is "strong as an ox," but the words hang there in painful contrast to his physical state. He mouths that he is not sure he can pull through. He doesn't see how he will ever be able to walk again. "I don't have the will," he mouths, tears dribbling down the sides of his face. "It's too much work."

Soon, Sharon appears outside Spencer's room. She has seen him twice since his surgery, but both times she could only gaze through glass. This is the first time she can enter his room, the first time she can touch him.

He is overcome with emotion. His lips quiver. His eyes overflow with tears. He needs her. She goes to the anteroom, hurriedly puts on a gown, gloves, and mask, and enters. She feels his forehead, pushing back his hair with her firm, sure hand. She strokes his arm, ignoring the tubes and the lines. She kisses him and tells him how wonderful he looks.

She has remembered to bring a new toothbrush, his favorite purple sweatshirt, and his L. L. Bean blanket from home. She won't allow his future to seem tenuous. Her presence is at once both a salve and a tonic.

Jean is in the waiting room. Although it will be months before their lungs feel absolutely normal and the pain along the scar subsides, Jean, like Sharon, looks no different than she did before donating. For Jean, always full of strength, the experience of surgery has brought an unexpected gift: She has relinquished much of her mothering role and seen the amazing competence of her own daughters. Rebecca and Jennifer, who always called her or came home when they needed support, are now doing the caring. "I let go," says Jean, "and let them take care of my son and take care of me."

On August 19, Spencer is transferred to Blake 6, the transplant floor. He begins eating on his own. Visitors need only wear gloves and a mask, no gown. Spencer tires easily. But he can walk the hallways, using his wheeled oxygen tank for support. He uses his lungs more and more on his own. The ventilator still helps him breathe, but he no longer relies on the machine for high concentrations of oxygen. He instead takes in room air, using the ventilator to provide the pressure he needs to breathe, pressure most of us create unconsciously with our chest muscles.

To get that air, Spencer no longer needs the tube in his windpipe and can get by with the help of a nose line, like the one he used before the operation. When the hole in his throat is closed, he regains his voice. His last challenge remains: getting off the ventilator altogether. He starts going off for several hours at a time; then overnight; then for 24 hours. Meanwhile, the tangle of other tubes and lines has been reduced to a mere few; a week later, all will be gone. On September 4, Spencer goes home to Maine.

Spencer has paid a hefty emotional and physical price for his recovery, but there are other costs as well. The hospital's total charge for the procedure comes to $390,000 -- $314,400 for Spencer and $75,600 for Sharon and Jean. It is covered by Spencer's health-insurance company, which gets a $30,000 prompt-pay discount from the hospital.

Back home, Spencer is, for the first time in years, free of his daily ritual of inhaled medications and coughing up mucus. But, as Zorb and Dr. Ginns are fond of saying, in

getting a transplant, one is simply "trading in one set of problems for another." For the rest of his life, Spencer will take anti-rejection medications and some of his cystic fibrosis medications. The disease will continue to afflict parts of his body -- but not his lungs.

Still, Spencer feels free. By mid-October, he is living again, relishing his freedom even in small ways: walking around the mall, walking around computer shows, walking downtown. Walking was something he used to dread. Now, he jumps in the car and goes out with friends without thinking about how far it will be from the parking lot to the front door of the pizza joint.

Sharon, who has returned to work, gushes with excitement when Spencer goes with a friend to a computer show in Portsmouth, New Hampshire, and stays out for 10 hours. "He's more independent than he's ever been," she says. "I almost don't know what to do with this good feeling."

On October 12, Jean, who returned to work just eight weeks after surgery, climbs Pleasant Pond Mountain, part of the Appalachian Trail in Maine, a rigorous 1 1/2-mile hike. She says there isn't anything she doesn't feel up to.

Spencer is, as always, focused on the future. He plans to return to school in January. But before then, he plans to do something he hasn't been able to do in at least three years: ski.

First, he's going to hit one of those "blowout sales they have at outlets around here, where equipment is dirt cheap," and get himself outfitted. Then, "as soon as the snow gets on the slopes," Spencer will ski.

Although he is not one to ruminate about what-if scenarios, Spencer feels lucky to have received what he calls "a gift." It is hard, he says, to be the one needing something so great. In another sense, though, it is all so simple. While medicine struggles with ethics and odds and how to address questions of life and risk, three people simply did what seemed right. Spencer says he's not sure he could have asked his mother or his aunt for lungs, if he'd had to. "I only received the gift," he says. "I never had to ask."

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