Lung transplants save lives of two teenagers with cystic fibrosis

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Emma Greene (with cap) and Tiffany Senter recently met for the first time to share their experiences of undergoing lung transplants at Packard Children's. "It's nice to have a friend who understands," says Greene. Credit: Lucile Packard Children's Hospital

"There's nothing like having a bond with someone else who knows exactly what you're going through."

Eighteen-year-old Tiffany Senter is discussing her good friend, Emma Greene, also 18, with whom she has much in common. Both California natives are 5 feet tall; both graduated high school this summer with perfect GPAs; both have spent hours each day — for years on end — gulping down dozens of pills and relying on machines to help them breathe. And both received recent calls that gave them a new chance at life.

Senter and Greene both suffer from cystic fibrosis, a life-shortening congenital disease that renders the body unable to regulate salt transport in and out of cells. Over time, CF leads to destruction of the lungs. It also affects digestion, preventing the body from breaking down and absorbing food.

“Imagine trying to breathe through a straw,” said Carol Conrad, MD, director of pediatric pulmonary medicine at Lucile Packard Children’s Hospital. “Mucus has clogged up the airways, and the work required to get even a small breath is painfully high.”

Senter and Greene were diagnosed with the disease in early childhood and, for a period of time, managed CF with medication and treatment, leading relatively normal lives. Senter made straight As in school in Shasta Lake and was an award-winning jump-roper. Just over 200 miles away in Lodi, Greene was also a star student, plus a soccer player and a black belt in tae kwon do.

But eventually, life for both teens revolved around heavily scheduled treatments. As the years went by, they each found themselves sitting on the sidelines, literally trying to catch their breath.

By her freshman year, Greene’s lungs were working so poorly that she was evaluated for a lung transplant. Later, she became too sick to go to school. After she was referred to the medical team at Packard Children’s, it was discovered that CF’s thick secretions were damaging her liver. Even after a lung transplant, her liver function could be problematic. So, in November 2009, Greene was listed for a unique double-lung and liver transplant.

“It’s pretty rare to see a patient — especially in pediatrics — requiring both a new set of lungs and a new liver. There may be only one of these types of surgeries performed each year nationwide,” said Conrad. Even

though Packard Children's has one of the largest programs for pediatric transplants in the United States, this would be the first-ever double-organ transplant of this kind here.

Meanwhile, in Shasta Lake, Senter's daily treatments, including hour-long sessions of therapy to clear her lungs, progressed to four times a day. By the time she was a sophomore, she was being hospitalized frequently for lung infections.

"I couldn't even go out with friends — I'd be too tired and couldn't breathe," Senter recalled. She was listed for a double-lung transplant at Packard in March 2011.

Transplant prep is intense. "It's like an athlete preparing for an event: maximizing nutrition, and maintaining muscle tone and strength by keeping up their activity level," said Conrad. These are herculean tasks for cystic fibrosis patients.

Conrad worked to keep Senter and Greene's lung function stable with a rigorous schedule of lung clearance, medication, exercise and careful monitoring. Both girls were hooked up to feeding tubes before bed for high-calorie, overnight feeds.

Through it all, remarkably, both girls were able to graduate their respective classes with honors, with Greene even being named valedictorian.

It was shortly after this time, in June 2011, that Conrad gave the two girls a long-distance introduction to one another.

"Lung transplantation is extremely rare," said Conrad. "That's why I always try to connect patients pre-operatively to provide support for one another." The girls began emailing and texting their stories and words of

support even though they hadn't met in person.

Finally, one evening in early October, Greene received the call she had been anticipating for nearly two years: Thanks to the gift of organ donation, Packard's first double-lung and liver transplant awaited her. After a grueling but successful 12-hour surgery by Hari Mallidi, MD, and Carlos Esquivel, MD, PhD, she spent several weeks recovering nearby the hospital, and returned to Lodi in time for Christmas.

Senter's new lungs came in November, just before Thanksgiving. Richard Ha, MD, completed the 6.5-hour surgery. Tiffany had confidence going into the OR. "It's like working with God's hands. I knew I was in the best place I could possibly be," she said of Packard. She is now recovering at the Ronald McDonald House at Stanford.

Post-surgery, both girls were afraid to remove their oxygen masks. But the teens are now breathing on their own, gaining weight and, so far, have clear airways. While the transplants may not be a lifelong fix, Greene and Senter can now look forward to a much better quality of life, plus the energy and strength to pursue their dreams.

Inspired by the nurses who have taken care of her, Senter wants to become a pediatric nurse. Greene has plans to attend UC-Davis to become a zoologist. Both feel blessed, and are grateful to their donors for giving them a second chance.

It's a chance that promises a lifelong bond of support and friendship. They finally met in person after Senter's November surgery. Greene brought her friend a homemade pie. "It's like having a CF twin," she said. "We both have a lot of the same fears and questions, but it's nice to have a friend who understands."