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Published: September 21, 1998

Breath of Life

**Section:** Health and Science

**Edition:** Final

**Page:** B1

**Caption:** (Color) Dale Daniel recently donated a lung lobe to his niece who has CYSTIC FIBROSIS.

(Color) After many years with cystic fibrosis, Lindsay Fitzpatrick now has one lung lobe from her 49-year-old uncle and one from her 21-year-old boyfriend. This photograph was taken soon after the ventilator was removed and she was breathing on her own for the first time with her new lungs.

The right lung consists of three lobes and the left lung - slightly smaller and indented to make room for the heart - has only two.

(Drawing) Rey Pineda News-Sentinel staff

**Illustration:** drawing; photo (2)

**Wynne Brown News-Sentinel staff writer**

**By Wynne Brown, News-Sentinel staff writer**

Technically, it's called a "double lobar lung transplant from living-related donors." But for Lindsay Fitzpatrick, it's called "a chance to be normal."

Three days after her lobar transplant the medical staff at Childrens Hospital Los Angeles removed the ventilator. After many years with cystic fibrosis, 17-year-old Lindsay was able to breathe on her own with her new lungs.

The right one is a lobe donated by her 21-year-old boyfriend, Brad Kawamura. The left was donated by Lindsay's uncle, 49-year-old Knoxvillean Dale Daniel.

And what's the first thing this teenager will do when she leaves the hospital?

"Go to Taco Bell," she responds promptly in a telephone conversation from her hospital room. "The food's terrible here."

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Dale Daniel is a quiet, gentle-spoken man, not one to seek out glory.

"I'm really not the story," he insists. "The emphasis should be on the disease, not me."

Cystic fibrosis affects about 30,000 children and young adults in the United States. The disease causes the body to produce a thick, sticky mucus, which affects the pancreas, where it prevents effective digestion, and the lungs, where it prevents normal breathing.

Daniel says Lindsay has been able to take medications to moderate the disease's effect on her digestive system. But, he says that in people with CF, "mucus builds up and hardens in the lungs, and they deteriorate. That's what usually kills young people." Rarely do patients with cystic fibrosis live beyond their 30s.

The effects of CF vary from being quite mild to devastating. Lindsay's symptoms abated for a long time -- in fact, so long that Daniel says that many of her friends didn't even know she had cystic fibrosis. In elementary school she did some distance running in her hometown of Manhattan Beach, Calif., and in high school, she was on the flag team.


"She did very well for a long time," her uncle says, "but in the last 18 to 24 months, her lung capacity dropped like a ski jump. She basically got to an end state."

Lindsay had to drop out of school but still managed to get her GED. She says one of her favorite books is Amy Tan's "The Joy Luck Club."

While searching for treatments her mother, Donna, learned about Dr. Vaughn Starnes, a cardiothoracic surgeon in Los Angeles who repaired Arnold Schwarzenegger's defective heart valve. According to Bob Spieldenner, spokesman for the United Network for Organ Sharing, a national transplant database, 85 living lobar transplants have been performed.

Starnes has done 40 of those.

Lindsay became one of his patients, and the hunt began for likely donors. Lindsay's father is dead, and while no one in her immediate family were matches, both Dale Daniel and Brad Kawamura were.

  
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Lindsay and Brad discussed the surgery at length, Daniel says, and it was something the young man wanted to do. "He said that even if the relationship wasn't a long-term thing, he still wanted to do it for her."

And Daniel himself?

"I considered it a real privilege to be able to help my niece," he says quietly.

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The surgery was Monday, July 23, and took place in three surgical theaters with three separate teams of surgeons.

While two of the teams removed lung lobes from Daniel and Kawamura, Starnes removed Lindsay's diseased lungs completely. Then he stitched each donor lobe into Lindsay's chest cavity, carefully connecting all the airways, veins and arteries.

Humans have two lung lobes on the left side and three on the right. Losing one lobe only drops a person's air capacity by 20 percent, says Michelle Caudill, cystic fibrosis case manager at Vanderbilt University Medical Center's Heart and Lung Center.

"Most people wouldn't even notice the drop in their breathing capacity unless they were used to running marathons," she says, adding that two lobes from adult donors will just about fill a pediatric chest cavity.

"Cystic kids are usually small and underweight," Daniel says. "Lindsay's healthier and larger than most. But I'm enough larger than she -- and so's her boyfriend -- that our lobes are about the same size as her lungs."

Donating a lung lobe is a bit more arduous than giving a pint of blood. Dale Daniel was in the hospital for 12 days and says matter-of-factly, "Well, they cut you open, pry your ribs apart and take a chunk of lung out -- it's pretty rough.

"But -- you go in healthy and highly motivated. You're not going in sick, so your recovery's a lot faster."

"It's really a remarkable procedure. It's not a cure, but it will allow her to have a normal way of life."

Lindsay has had cystic fibrosis since she was a small child and says she feels "a lot better now."

But "I hate talking about CF," she says flatly. "I spent years dwelling on it, and now I never want to think about it again."

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Lindsay's new lungs won't get CF or as many infections, but she probably won't be able to completely stop thinking about the disease.

Her digestive problems will continue, and she'll have to be on anti-rejection and immuno-suppressant drugs for the rest of her life. The side effects may include a puffy face and some complexion problems, says one person who's been there.

In 1993, Kristi Willis, another Starnes patient, was the fourth person in the world to have a living lobar transplant. "I spent my 21st birthday in the hospital," she said by telephone from Brewton, Ala. "It was the best birthday I'd ever had -- it was the first time I could actually breathe!"

Willis has had cystic fibrosis since she was an infant and was about two months from death when she had the transplant. Her parents read about Starnes in their local Birmingham, Ala., newspaper.

Some people have trouble adjusting to the idea of living with someone else's organ. "I didn't have any trouble -- mostly because I was still alive," says Willis. "It gave me a new lease on life."

"I think it's a great thing they developed this surgery because there aren't enough donor organs, and people, especially people with CF, die waiting."

Now, Kristi Willis says she has a normal life, a full-time job working at a newspaper and -- "I'm living on my own three hours from my parents.

"It's been a real miracle. Words are inadequate -- and words are my venue -- but sometimes they just aren't enough to describe the miracle."

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Dale Daniel, Brad Kawamura and Lindsay Fitzpatrick have agreed that wherever they all are next year, they have a date.

Daniel says that Lindsay's hometown, Manhattan Beach, holds a 10-kilometer run every year. The two of them, uncle and niece, ran in it about 10 years ago.

"She and Brad and I have agreed that we'll meet out there -- it'll be in October 1999 -- and we'll all finish together."

Wynne Brown can be reached at 523-3131, ext. 212, or [brownw@knews.com](mailto:brownw@knews.com).



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