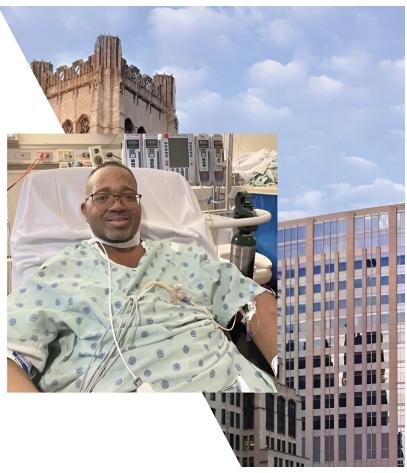


'Walking miracles': Born with lungs reversed, they suffered until getting doubleorgan transplants

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Dennis Deer woke from surgery in utter disbelief that he was breathing normally.

He'd been on <u>supplemental oxygen</u> for two years, and "I didn't know what it was like not to have something on my face," said Deer, 51, a Chicago-area politician and psychologist.

"I immediately said, 'Where is my oxygen?' And my wife said to me, 'Well, you don't need the oxygen anymore,'" Deer recalled.

Deer wasn't buying his wife's reassurance. "I said, 'Give me my oximeter.' So I put the oximeter on my finger. It was 99%. And I was like, 'Wow.'"

Deer, a Cook County commissioner, is one of two patients who recently received a rare double-<u>lung transplant</u> at Northwestern Medicine in Chicago.

Deer and the other patient, Yahaira Vega, both have a <u>rare genetic</u> <u>condition</u> where the organs in the chest and abdomen develop in a reversed, or mirrored image, from their normal position.

This was the first time these sort of transplant surgeries had been performed at Northwestern Memorial Hospital, doctors said.

"It's an important milestone for us because it's rare enough to do one <u>lung</u> transplant for this condition, forget about doing two in the span of one month within the same health system," said <u>Dr. Ankit Bharat</u>, chief of thoracic surgery at Northwestern Medicine.

Mirror images

The condition, situs inversus, made both patients' lung transplants an



"interesting dilemma," Bharat said during a media briefing on Monday, which also happened to be a shared birthday for Deer and Bharat.

"The inside of the body is essentially a mirror image of itself, so the right lung is where the left one should be and the left lung is on the right side and the heart is flipped," Bharat said. "So when we take the old lungs out of an individual, we have to tailor the new normal lungs to fit into this chest cavity, which is essentially a mirror image of itself."

Surgeons had to perform on-the-fly modifications to place and attach the donor organs for Deer and Vega, Bharat said.

Situs inversus affects about 1 in 10,000 people, but it doesn't always lead to <u>health problems</u>. Although the organs are reversed, they still function.

"In fact, many of the patients with this condition don't even realize they have this until they seek medical attention for something unrelated," Bharat said.

But Deer developed an autoimmune disorder that causes inflammation and scarring of the lungs, requiring a transplant.

Deer has needed a transplant for some time now, but doctors told Deer that he needed to lose 100 pounds before he could get on the waiting list.

"It took me a year and some change, but that's when I came back to see them and that's when my process actually started," he said.

'Bird in a cage'

In December, Deer was sworn in as a county commissioner from a hospital room as he struggled with shortness of breath.



Deer got on the donor list for new lungs at the end of March, and spent the next several months on supportive oxygen at Northwestern Memorial. He underwent a successful transplant on May 22.

Vega, 27, of Elgin, Ill., needed a lung transplant because she also was born with another rare disorder that frequently accompanies situs inversus, called <u>primary ciliary dyskinesia</u> (PCD).

PCD prevents the tiny, hairlike structures in a person's airway from removing germs and pollutants, causing excess mucus to build up.

In a single day, Vega could fill an entire 32-ounce cup with mucus, said <u>Dr. Catherine Myers</u>, a pulmonologist with the Northwestern Medicine Canning Thoracic Institute.

"Over time, she started getting progressively sicker with more infections and worsening of this mucus," Myers said during the media briefing.

Vega said her condition made her feel like a "bird in a cage."

"It really gives you an identity crisis, having an invisible disability, because growing up, you know, kids can be brutal. Growing up looking perfectly fine but internally I'm a mess, it was difficult," Vega said.

"I felt like I since I looked like everybody else, I tried to act everybody else and be like everybody else, but I wasn't like everybody else," Vega continued.

Getting back to laughter

Vega also faced the opposite problem as Deer—she needed to gain weight to be considered for transplant.



"I was falling underweight pretty rapidly and was about 76 pounds, and in order to be qualified for the surgery, I had to be at least 82 pounds, so that was a struggle," Vega said.

Vega was listed for a double-lung <u>transplant</u> in April. She spent nine days on a waiting list before receiving her new lungs on April 28.

Vega said she's most looking forward to using her new lungs to laugh.

"I have always believed that laughter is the best medicine, and maybe I'm biased because I think I'm hilarious," Vega said.

Unfortunately, her lung ailment stifled her laughter.

"When I was sick, I could never really laugh, like those ugly snorty kind of like piggy laughs, because I would always be choking on my mucus or coughing, and then it would cause frustration and then it would cause other negative emotions," Vega said.

Vega is still not strong enough to laugh. When she is, "I just know I'm going to have the ugliest laugh ever," she said.

Deer, who serves as chair of health and hospitals for Cook County, plans to make <u>organ donation</u> and equitable access to transplants one of his platform topics.

"We're both walking miracles," Deer said of himself and Vega. "Now I can breathe. Now I've got new lungs on the inside. And I'd be remiss if I did not say a huge thanks to the donor family. Somebody thought well enough to be willing to donate their lungs, or be an organ donor.

"I am going to become an ambassador" for organ donation, Deer added.
"Somebody out there saved my life. Helped me continue to be a father to



my young daughter, continue to be a husband to my wife. For that, I'm grateful."

The doctors noted that 10% to 25% of patients who need lung transplants die while on the waiting list.

"Only around 2,000 to 3,000 lung transplants are done in that in North America every year, and we see at least 150,000 patients die from COPD alone," Myers said. "That's one lung disease, and obviously it is not the only lung disease. Our need for this therapy vastly outpaces the supply, and it also limits our ability to do some of these riskier procedures just because we do have a limitation in organs."

More information: The U.S. Health Resources and Services Administration has more about <u>organ donation</u>.

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