

Profile on John Keegan

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My Life With Scleroderma After an Organ Transplant

John Keegan, of Ficklerville, N.J., first noticed something was amiss in the early 1990s. The former union pipe fitter worked outside in the harsh Philadelphia winters and would sometimes experience strange sensations, with his hands turning white or blue in response to the cold temperatures. Not knowing what it was, John visited his family practitioner for help. At that time, the doctor resolved that his symptoms were caused by the extreme temperatures at work.

Later in 2003, John experienced problems breathing while he was going up a flight of stairs. He attributed those symptoms to his weight; he weighed nearly 300 pounds at the time. A short time later, he visited again with his doctor who sent him to a local pulmonologist. In 2005, John landed at Thomas Jefferson University Hospital. "My CAT scans had the doctors puzzled," he recalled in a phone interview. "My lungs looked almost like glass to them."

John's doctors wanted to follow up with an echocardiogram on his heart. They finally found a diagnosis. "They told me I had scleroderma. At the time, I had no idea what that was," he said. The echocardiogram results indicated that he had pulmonary arterial hypertension. He was referred to a specialist at the University of Pennsylvania. "I went on Tracleer and oxygen at that time," he said. "I needed a lot of oxygen. I was also on the Tracleer for about 18 months. My pressure didn't get worse, but it didn't get better," he remembered.

A Good Candidate

Then, in February 2008, he went for a checkup. "There was a young doctor from Penn's transplant team there. He examined me and said I would be a good candidate for a lung transplant." John discussed the possibility of a lung transplant with his family. "The doctors had said I had maybe four years to live. So, I called them back and said, 'Let's do it.'"

However, before he could undergo a transplant, John needed to lose some weight. He went on a diet, and in just a few months, he lost 65 pounds, which brought his weight down to about 244 pounds. Yet, the transplant team at the University of Pennsylvania wanted him around 235 pounds. During this time, John also experienced severe esophageal motility – he had issues swallowing because his esophagus had narrowed significantly due to the scleroderma. Soon, John received a call from the Penn team. "Suddenly, they rejected me because I was too old and because of the severe esophagus problems," he said. "They just said to me, 'good luck.'"

The Waiting Game



John and his wife Charlotte in August 2009 before his double lung transplant.

Despite the rejection from the transplant team at Penn, John started researching other transplant centers online. In January 2009, John and his wife, Charlotte, went to the University of Pittsburgh for a week of tests. The team there examined him and confirmed that his esophagus was as bad he had previously been told. "They told me I was a good candidate. But, they said I needed the transplant now, or I was going to die," he said.

John lived five-to-six hours away from the hospital facilities at Pittsburgh. He immediately retired from work and took an apartment near the hospital so he could be close – just in case that important phone call came saying, they had a new pair of lungs for him.

At the end of July 2009, John ended up in the hospital. Doctors feared his heart would give out soon. Shortly after, he was notified that there was a donor. Charlotte flew to Pittsburgh to be with him. They waited nine hours, but the doctor returned with bad news – the lungs were too big for John's chest.

John and his family waited some more. Again, he was notified that a donor had been found. He waited eight or nine hours, completed lab tests, and even made it as far as the pre-op room before being told the bad news. This time, the donor's lungs had pneumonia.

He went home again. Waiting...

On Sept. 24, 2009, John received this third phone call. He recalled, "The only thing the doctor's told me was that the donor was coming from Chicago." Charlotte arrived at the hospital early in the morning. The team prepped John for surgery. At 5 a.m., they finally received the go-ahead. The lungs were good. At 3 p.m. that afternoon, John underwent a double lung transplant.



John five days after his lung transplant.



John two weeks after transplant.



John six weeks after transplant.

Following the surgery, the blood pressure in his heart was down. He was in and out of consciousness all night. He stayed in the intensive care unit for four days and was discharged from the hospital after a total of 24 days.

Living Life to the Fullest

Today, John, now 62, is back to playing golf and even going to the gym. His weight is down to 220 pounds. "My weight has been a battle for me my whole life," he said. "If I gain the weight back, it's harder on my lungs. So, I still manage my weight."

For the past two years, John also has led the Scleroderma Foundation's Camden/Burlington (New Jersey) Support Group for the Delaware Valley Chapter. "I got a second chance at life," he said. "Why not help people survive this very rare disease and help raise money to help with the research." In addition, John visits high school students of driving age through a program called

"Gift of Life." He shares with them the importance of organ donation.

Each week, John receives phone calls from people looking for support as they live with scleroderma. "I want to give back and help the community because if it wasn't for the transplant, I wouldn't be here," he said. "I try to tell people, 'never give up.' It all depends on the mental attitude that you go in with. My mental attitude is, 'I'm not ready to die yet.'"



John on a trip to the Jamaica in Oct. 2010