Heart-Stopping Surgery Cures Woman Of Rare Lung Disease

Susan Donaldson James

Kathleen Anderson was only 26 and a manager for a major drug chain when she first developed a blood clot in her leg, and then 11 unrelated blood clots in her lungs. She was a smoker and overweight, so doctors told her to quit and lose weight.

Anderson lost 100 pounds, but over nearly a decade her health problems got worse. She was eventually diagnosed with lupus and an unnamed clotting disorder.

"Over the years, I had symptoms – I was tired all the times and irritable and had trouble breathing," said Anderson, now 42 and living in Lake in the Hills, Ill. "My joints hurt all the time. At one point, I was diagnosed with fibromyalgia."

Anderson had suffered numerous lung clots, which had, in turn, had triggered congestive heart failure. Her condition was so disabling, she was confined to a wheelchair and couldn't work.

In 2011, she was told she had chronic thromboembolic pulmonary hypertension or CTEPH [1], a largely unrecognized disorder. Its prevalence is hard to measure because many people die before they are even diagnosed.

"I was told I wouldn't make it," she said. "They got me an advanced [breathing] machine and I was on eight liters of oxygen a day. My sister became my caregiver. I couldn't even fold the laundry. I couldn't do dishes or cook a meal."

When she arrived at the Cleveland Clinic in October 2012, her doctors didn't believe she would live beyond a month.

There, surgeons performed an intense operation, cooling down her body as they stopped her heart, so no brain damage occurs, then delicately stripping the blockages in her pulmonary arteries that were robbing her body of oxygen.

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