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FEATURE

Rutgers Expands Care for Adults with Cystic Fibrosis as Survival Rates Rise

Robert Wood Johnson Medical School joins international trial that holds promise for finding a cure

By Sherrie Negrea | Thursday, April 17, 2014



Photo: Courtesy of Julia Rae Schlucter
Julia Rae Schlucter, cystic fibrosis patient and advocate

[High Res](#)

When Julia Rae Schlucter was born with cystic fibrosis in 1992, a person with the genetic lung disease could expect to live into his or her late 20s. New therapies, medications and newborn screening programs have helped edge that figure up to middle age and beyond.

Because patients with cystic fibrosis are living longer – the median predicted age of survival is in the early 40s – Schlucter, a professional singer, can envision a future working as a patient advocate for children and running the foundation she created, [Singing at the Top of My Lungs](#), to raise money for cystic fibrosis research.

"I'm a prime example of why funding for research is so important," says Schlucter, 21, a sophomore at Fordham University. "Research is the key. There's a possibility I wouldn't be here without the drugs."

For the past eight years, Schlucter has benefited from the treatment she has received at the [Cystic Fibrosis Center](#), part of the Department of Pediatrics at Rutgers Robert Wood Johnson Medical School in New Brunswick. The center, ranked among the top facilities in the country, has been at the forefront of testing drugs to treat the disease, which causes the body to produce thick, sticky mucus that can clog the lungs, pancreas and other organs.

On March 6, the center was approved to become part of an international trial to test the second phase of two drugs that work directly on the defective protein linked to the disease.

"This is the most specific medicine developed for CF," says Thomas Scanlin, a physician and the center's director. "These drugs are going right to the root cause to fix the chloride channels in the

lung. That may have the potential for creating a cure someday, but we don't have it yet."

Because cystic fibrosis patients now live well into adulthood, the Rutgers center in 2007 created a [program](#) to offer specialized treatment for people older than 21. It is led by director Sabiha Hussain, a pulmonologist. Of the 135 patients the center treats annually, 38 are part of the adult program, one of three accredited programs in New Jersey that serve adult patients. One of the adult patients being treated at the Rutgers center is now 63.

In 2012, the Rutgers center ranked first in the nation for an assessment of lung function for patients, 18-29, based on a review of raw data, according to Scanlin. Known as FEV₁, the measurement is based on the amount of air a patient can blow out in one second. The most recent assessment showed patients in this age group at the Rutgers center had a median FEV₁ of 85.7 percent, compared to the national average of about 70 percent.



Photo: John Emerson

Thomas Scanlin, director of the Cystic Fibrosis Center, Robert Wood Johnson Medical School

[High Res](#)

While the services for adults are similar to those for children, the focus for older patients is motivating them to commit to treatments that clear their lung passages twice a day. For Schlucter, that means spending up to two hours a day wearing a lung vest that loosens the mucus and using a nebulizer to inhale a mist of albuterol and hypertonic saline.

"For the most part, I feel like I lead a normal life," says Schlucter, who has an older brother with cystic fibrosis. "The breathing treatments are hard to do, but I get them done and I try not to let it run my life."

Because Schlucter is a professional singer, she does more than the required number of treatments so that she can perform. She often sings at fundraisers for the Cystic Fibrosis Foundation and performs a song she recorded, "Be That Girl," featured in the 2011 movie, *The Greening of Whitney Brown*. Despite being hospitalized three times in the last five years, Schlucter's lungs have improved to a level considered above-normal because of her dedication to the daily treatments that clear her air passages, the new drugs she takes, and the specialized interdisciplinary care she receives at the Rutgers' center.

"She's on a track to do very well for a very long time," Scanlin says. "If these medicines that we're testing will work for the mutation she has, that's all she needs."

Over the past five years, Schlucter's foundation has raised more than \$35,000, which she has

donated to the Cystic Fibrosis Foundation, the Robert Wood Johnson Cystic Fibrosis Center and the Children's Hospital of Philadelphia.

Last May, Schlucter also sang at the first Cystic Fibrosis Foundation Great Strides Walk in Middlesex County, which was led by Scanlin and raised \$30,000. [This year's walk](#) will be held May 3 at Johnson Park in Piscataway.

As she transitions into the world of work, Schlucter, like all adults with cystic fibrosis, faces the challenge of managing her treatments when she lands a job. "I worry about keeping up with the pace of a 9-to-5 job or how would I fit my breathing treatments in with that schedule," she says. "Cystic fibrosis isn't going away, but treatments and research have come a long way. And thanks to that research, we're close to finding better treatments and even a cure."

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