

Piper's Kidney Beans Funds Specialized Genetic Testing for Kidney Disease at Nemours

Family foundation reaches goal of bringing affordable tests to the region's families

Wilmington, DE -- Piper Lee, of Garnet Valley, PA was born with a rare form of kidney disease called Denys-Drash syndrome. Special genetic testing done in England, arranged by her Nemours doctors, proved essential in guiding Piper's treatment. At 18 months, she underwent a kidney transplant. Piper's father, Chris, was the donor, the surgery was successful, and Piper is now a happy, healthy 6-year-old.

Soon after Piper's recovery, the Lee family started a foundation, Piper's Kidney Beans, to bring the specialized testing that was done overseas to Nemours. Their goal was to make it available and affordable to families in the U.S., especially in Delaware and the surrounding area. The foundation has raised more than \$115,000 to help support the development of genetic testing that enables next generation sequencing (NGS) for nephrotic syndrome and other forms of kidney disease. The Lees worked closely with Nemours physicians and scientists every step of the way. The testing, which looks at each patient's genetic makeup to help guide the course of treatment, can now be performed right here in Nemours' Wilmington [CLIA](#)-certified labs. (CLIA regulates clinical laboratories.)

The NGS test for renal disease is available at only a handful of locations in the U.S. – Nemours and a few commercial labs. Working with Piper's Kidney Beans Foundation, Nemours offer this test at a price lower than commercial laboratories to make it affordable and available to those who need it. One young man who had been waiting for an affordable test is 14-year-old Patrick Heist of Greenwood, DE. Patrick's test results gave the family good news about his chronic renal condition and its treatment going for.

"The fact that the Lee family has been focused on bringing better information and better health care to our patients is so inspiring," said Vicky Funanage, PhD, Nemours Operational VP for Research. "Our staff matched their enthusiasm and rigor and we are delighted to begin offering the test."

With the genetic testing now in place, Piper's Kidney Beans will continue to fundraise to 1) help families in need pay for the test, 2) continue to refine the test to keep up with new genetic insights about nephrotic syndrome, and 3) support gene therapy research to treat genetic kidney disease. To further promote their work, Chris and Erin Lee have accompanied Nemours officials on visits to Capitol Hill to present the family's perspective on the importance of including pediatrics in precision medicine funding.

Erin Lee said: "We partnered with Nemours because we all wanted the absolute best test and we are thrilled and proud of the lab and the hospital for making our dream a reality. The information we got from the test allowed us to make a critical decision at a critical time and that is what we wish for the many families who can now benefit from it. We are excited to keep moving forward to help more children and we are grateful to this community for their tremendous support."

About Nemours Children's Health System

[Nemours](#) is an internationally recognized children's health system that owns and operates the two free-standing children's hospitals: Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in five states, delivering pediatric primary, specialty and urgent care. Nemours also powers the world's most-visited website for information on the health of children and teens, [KidsHealth.org](#), and offers on-demand, online video patient visits through Nemours [CareConnect](#). [Nemours ReadingBrightstart.org](#) is a program dedicated to preventing reading failure in young children, grounded in Nemours' understanding that child health and learning are inextricably linked, and that reading level is a strong predictor of adult health. Established as [The Nemours Foundation](#) through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy and prevention programs to families in the communities it serves.

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