New Florida-funded program includes genetic screening for babies to detect rare diseases

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Palm Harbor state Rep. Adam Anderson's son, Andrew, died at age 4 from a rare disease. He was a sponsor of the Sunshine Genetics Act.

The Sunshine Genetics Act creates a pilot program led by the Florida Institute for Pediatric Rare Diseases at FSU to offer

A key lawmaker and Florida State University leaders Wednesday touted a new law that includes offering free genetic screening for newborns and bolstering research on rare pediatric diseases.

Gov. Ron DeSantis last month signed the law (HB 907), which was unanimously passed by the Legislature in April and is dubbed the Sunshine Genetics Act.

The law creates a pilot program led by the Florida Institute for Pediatric Rare Diseases at Florida State University, with families able to choose to have their babies' full genetic codes sequenced.

The goal is to identify potentially serious but treatable conditions early, so that doctors can begin care before symptoms appear.

The bill was sponsored by Rep. Adam Anderson, a Palm Harbor Republican whose son Andrew died of a rare disease at age 4.

“People are often terrified to learn that it takes on average four to five years, plus seven or more trips to specialists and overnight stays in a (neonatal intensive care unit), to diagnose a child with a rare disease,” Anderson said during an event at the Florida State University College of Medicine. “Sadly, many of these children pass away before they receive any meaningful treatment at all.”

Rare diseases are considered to affect fewer than 200,000 people in the U.S.

“With the Sunshine Genetics program, we take a major step forward, bringing cutting-edge genomic medicine to newborns across Florida, starting from the very first days of life,” said Alma Littles, dean of the FSU College of Medicine.

The law includes establishing a consortium to create a network of people such as geneticists and physicians at state universities and children's hospitals to work on research and treatment.

“With just a few drops of blood, serious health risks before the symptoms appear can be detected,” FSU president Richard McCullough said. “That provides information for treatment that can save lives.”

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