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FSU celebrates rare pediatric disease pilot program signed into law

EDUCATION, GOV & POLITICS, HEALTH CARE | Jul 09, 2025 | 4:26 pm ET | By Jay Waagmeester

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FSU President Richard McCullough, left, and Rep. Adam Anderson, right, unveil a check funding the Institute for Pediatric Rare Diseases during a ceremony on campus on July 9, 2025. (Photo by Jay Waagmeester/Florida Phoenix)

The Florida State University community gathered Wednesday to showcase the creation of an institute in its College of Medicine and a pilot program that will provide free genetic screening to newborns, established by HB 907, passed this spring.

The Florida Institute for Pediatric Rare Diseases was a "labor of love" for state Rep. Adam Anderson, the Palm Harbor Republican first elected to the House in 2022. It memorializes his late son Andrew, felled by Tay-Sachs disease, a deadly genetic malady.

Anderson called the project a "truly a historic milestone that's giving Florida a once-in-a generation opportunity to lead the nation in genetic and precision medicine," adding that "half-a-dozen" states have reached out to him about the idea.

The law establishes a five-year pilot program, called "Sunshine Genetics," that allows parents of newborns to screen their children for rare diseases at no cost using genomic sequencing, or reading DNA.

Anderson's son was born with Tay-Sachs, which damages nerves in a child's brain, although he and his wife weren't aware until Andrew was over a year old. He died at age 4.

The law charges the institute to research causes and treatments for rare pediatric diseases, develop faster and more accurate genetic screening tools, and educate pediatricians, genetic counselors. and others about rare diseases.

"But this is not only about diagnosis and treatment. This is about the future. This is about research," said Pradeep Bhide, director of the FSU institute, emphasizing the usefulness of the anonymized data the project will compile.

The law creates the Sunshine Genetics Consortium of researchers, geneticists, and physicians from Florida universities and children's hospitals.

The institute was established by FSU a year ago after it was allocated $5 million in the state budget.

Rep. Adam Anderson speaks during a ceremony celebrating the Sunshine Genetics program on July 9, 2025. (Photo by Jay Waagmeester/Florida Phoenix)

The 2025-26 budget allocated $3 million for the Sunshine Genetics pilot program and $4.5 million for the institute, although the originally proposed version of HB 907 called for $25 million.

FSU dedicated $2 million to the initiative, too.

"Your work today is providing hope to countless families, but it's just a matter of time before that hope is transformed into cures for rare diseases," Anderson said, thanking the people involved in the institute.

FSU President Richard McCullough said the passage of the bill was a "big deal."

"I've been in Florida for almost four years now. It's not easy to get those three signatures," McCullough said, gesturing to a enlarged copy of the bill bearing the House speaker's, Senate president's, and governor's signatures.

Pilot

Currently, the Department of Health's Florida Newborn Screening Program sweeps in before Florida babies are discharged from the hospital and tests for about 60 diseases.

Under the new, optional pilot program, FSU can screen for approximately 7,000 rare diseases, Bhide told the Phoenix. Of those, about 600 have actionable treatments.

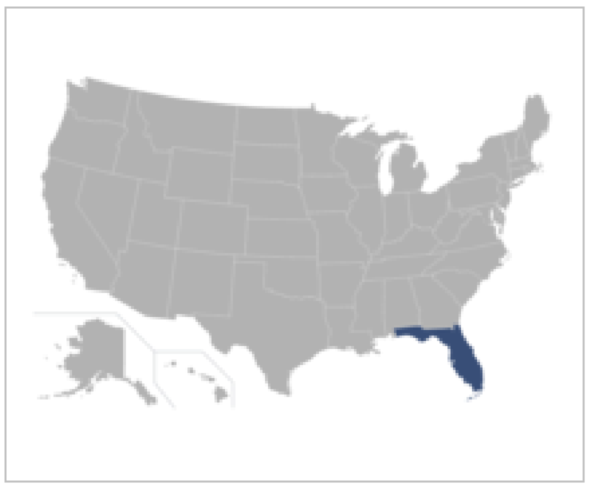
Anderson said he wasn't sure if he would've consented to his children's DNA being sequenced at the time they were born, but, "I didn't know what I know today back then," he said.

"The unique thing about genetic testing at birth is that if there is a genetic abnormality, oftentimes you wouldn't know about this for three, four, five, seven, even more years down the road. But if we're doing this sequencing at birth, then it can be detected, and that child will have an option for rapid and early treatment of that condition," Anderson said.

Anderson said his vision is for the program to operate statewide. For now, it's at select hospitals in the state.

The program can't exist solely with taxpayer dollars for the longterm, Anderson said.

"Today I'm calling on biotech firms and gene therapy firms, genetic medicine companies, and nonprofits throughout the country. Partner with us. Help us to fund this program. Help us to grow the program, join the consortium, be on the right side of medical history, and help us bring whole genome sequencing to every newborn child, statewide." Anderson said.



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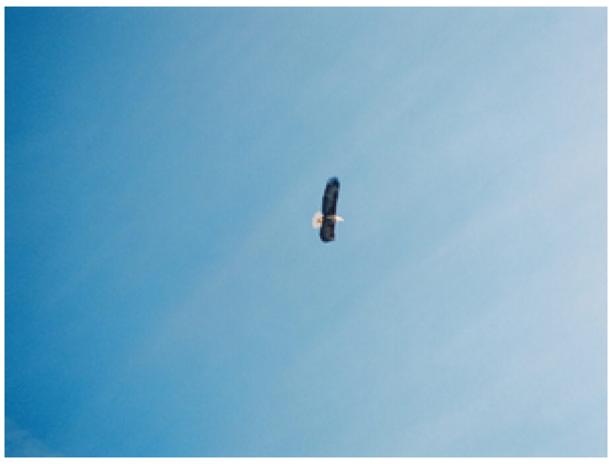

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