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Lawmaker giving hope to Floridians with kids with rare diseases after losing his 4-year-old son



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PINELLAS COUNTY, Fla. (WFLA) — There are more than 7,000 known rare diseases that affect 350 million people across the globe. One local State Representative sponsored a law that is giving a glimmer of hope to Floridians.

Rep. Adam Anderson (R-Palm Harbor) said his family’s life is on a different trajectory after the loss of his son, Andrew. Andrew’s ninth birthday passed six days ago, but his memory is alive as his dad fights for other kids, just like him.

Anderson has a new purpose in the legislature.

“Position the State of Florida to be a nationwide leader in genetics and gene therapy,” Anderson said.

It’s all in honor of Anderson’s third born child, Andrew, who was born healthy but around six months, he and his wife began noticing developmental delays.



“Then we went through a period that lasted about 15 months total from birth to misdiagnosis, after another one, after another, and it wasn’t until he was about 15 months old, where we finally did genetic testing on Andrew and he was diagnosed with Tay Sachs disease,” he said.

Tay Sachs is an ultra-rare, fatal genetic disorder with no cure. It leads to the destruction of the nervous system and one of the worst side effects are seizures.

“There were times where Drew had 50, 60 or even 70 seizures in a single day before we got them under control,” Anderson said.

Anderson said he worked with researchers on the first clinical trial for Tay Sachs Disease, which has since been rolled out.

“Unfortunately, it’s too late for Drew, but it’s helping kids today,” he said. “Gene therapy is working.”

Andrew tragically died at the age of four in 2019, right before Christmas.



“The average time it takes to diagnose a rare disease for a child is more than five years,” Anderson said. “Some are seven years or more, some are never diagnosed before they die.”

Anderson said, ideally, kids need to be diagnosed before they’re affected by a rare disease and that’s where early genetic testing comes in. [He sponsored a bill](#) that has since been signed into law by Gov. Ron DeSantis, and it’s named after his son, The Andrew John Anderson Pediatric Rare Disease Grant Program.

The program’s purpose is to advance research and cures for pediatric rare diseases by awarding grants through a competitive, peer-reviewed process.

“It’s a pot of money that is designed specifically to help fund the most complex type of research, funds that are available for only for these rare diseases,” Anderson said.

The grant program is open to any university or established research institute and is managed by the [Florida’s Health Department](#). In the

Currently, \$500,000 is available, so Anderson hopes to grow funding and the program in the years to come.

“I think the most special part of it is that it was never my intention,” Anderson said. “This was a door that opened, and I ran into it and now that I’m in there, we’re going to make it big.”

As a Florida State University alum, Anderson also spearheaded a \$1 million grant to fund the College of Medicine’s [Institute for Pediatric Disease](#). The goal is to bring together educators, researchers, and clinicians to identify new rare diseases, improve treatment outcomes, and understand the root causes of different pediatric rare diseases.

The institute also offers a clinical health center, which will act as a regional hub for parents and families to go to when they can’t get any answers for their kids.

FSU is also building a master’s program for [genetic counselors](#). Anderson said the University’s College of Medicine has also identified nine rare diseases that they’re already researching cures for, and Tay Sachs is one of them.

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