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FSU NEWS

'A giant leap': Lawmaker announces FSU's new Institute for Pediatric Rare Diseases



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State Rep. Adam Anderson on Thursday announced the establishment of Florida State University's new Institute for Pediatric Rare Diseases.

The state's first-of-its-kind center is personal to the Palm Harbor Republican, who lost his four-year-old son Andrew to a rare genetic disorder called Tay-Sachs disease — a disease that causes rapid degeneration of nerve cells in the brain and in the spinal cord.

“This new institute at Florida State is not just a step in the right direction: It is a giant leap in advancing this vision forward,” said Anderson, an FSU alumnus. He has been the institute's biggest cheerleader.

The announcement was made during a press conference at the Florida Capitol during the university's annual FSU Day at the Capitol.

During an FSU Board of Trustees meeting earlier in the day, FSU President Richard McCullough said Anderson approached university leadership last year to discuss forming the institute. There are currently 7,000 known rare diseases that impact over 350 million people globally and 30 million people nationwide, Anderson said.

In other words, nearly 10% of the country's population — and more than the entire population of Florida — are affected by known rare diseases.

“Immediately, I said yes,” McCullough said. “This rare disease center will be kicking off FSU's ability to get into this area to make investments in gene therapy, DNA sequencing and artificial intelligence.”

One of the university's goals for the institute is to build up research in the FSU College of Medicine by using data to practice precision medicine. This mean high-throughput

sequencing (HTS) technologies will be purchased, machines that have the ability to sequence hundreds of millions of DNA molecules at a time to determine the most effective treatment for different individuals.

“While we call them rare, when looked at as a whole they are more frighteningly common than you think,” Anderson said, with his wife Breanne Anderson and eldest daughter Haley Anderson beside him.

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“Since our son Andrew’s diagnosis of Tay-Sachs disease in 2016, my wife Breanne and I have made it our mission to do everything in our power to ensure other families don’t have to live that same nightmare that we did, but sadly many families do,” he added.

FSU has already received \$1 million to kickstart the initiative, with Anderson behind the funding. The university hopes to receive more support this year.

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