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PEDIATRICS

Little Miracles

Brittney J. Miller | 8/31/2024

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Andrew Anderson was a perfectly normal newborn, his parents thought, just like his two older sisters.

It wasn't until he was 6 months old that they sensed something was wrong with their only son, who wasn't hitting his milestones. After a year of misdiagnoses and genetic testing, they uncovered the cause: Andrew had Tay-Sachs disease, a rare inherited disorder that damages nerve cells in the brain and spinal cord. It has no cure. When he was 4 years old, Andrew passed away. The end of his life marked the start of a legacy — one furthering research into rare pediatric diseases in Florida.

"It led us where we are," says state Rep. Adam Anderson, Andrew's father. "There's no way I'd be working on this stuff if I hadn't lived that experience. It's not only become a passion; it's literally my calling in life." Last year, Anderson, a Republican from Palm Harbor, successfully pushed for \$1 million in state funding to launch the Florida State University Institute for Pediatric Rare Diseases. The institute, which opened earlier this year and is the first of its kind in the state, is dedicated to researching and treating rare childhood diseases.

It's a cause that's largely underrepresented in the health care industry, says developmental neurobiologist and institute director Pradeep Bhide.

A disease is classified as "rare" if it afflicts fewer than 200,000 people. Between 7,000 and 10,000 diseases are considered rare, and 70% of them manifest in childhood. An estimated 30 million Americans — or about 10% of the country — are diagnosed with a rare disease. Less than 5% of these conditions have treatment options; none have cures.

The FSU Institute for Pediatric Rare Diseases is already researching several childhood conditions, including Tay-Sachs disease and pediatric brain tumors.

As the institute grows, Bhide plans to open a genomics facility that will use patient samples to better diagnose and research rare diseases. Eventually, he'd like to create a master's program in genetic counseling at FSU.

"The idea was really to build something that may be a little bit slow to take off, but will have a lasting impact here in North Florida and hopefully in the entire state of Florida," Bhide says.



As a state representative, Anderson helped create the Andrew John Anderson Pediatric Rare Disease Grant Program, named after and inspired by his son. Administered by the Florida Department of Health, it awards funding to researchers searching for new diagnostics, treatments and cures for pediatric rare diseases. The Legislature appropriated \$500,000 annually for the program. Anderson is hoping for more in sessions to come, considering the 30-plus grant applicants in hand so far.

“I genuinely want to see Florida as a nationwide leader,” he says. “And I know we can do it. I'm not going to quit until we are.”

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