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Family twice hit by disease hits back

[Roselee Papandrea / Times-News](#)

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When Deb Wells' oldest son was diagnosed with mitochondrial disease in 2001, his mother had never heard of it.

Now, she's an expert, of sorts.

Her son, Andrew, died eight years ago from the disease, and her youngest son, True, was diagnosed with the same disease in 2008. Both children are adopted, and they are not biological brothers. And while it was a strange coincidence to end up with two children with the same ailment, mitochondrial disease isn't that uncommon.

"Every 30 minutes a child is born that will develop mitochondrial disease by age 10," Wells said.

Most people haven't heard of it, but it's a disease that depletes the body of energy. All cells in the body have mitochondria, and mitochondria produce the body's essential energy. The disease primarily affects the brain, heart and muscles.

It impacts many children and adults, and it's one of the reasons that Wells wants to do whatever she can to raise awareness and money to find a cure.

This week is international mitochondrial disease awareness week, and Wells is holding a fundraiser at YoZone Frozen Yogurt at the Holly Hill Mall on Thursday from 11 a.m. to 9 p.m. The YoZone will donate 10 percent of its sales to the cause, and all proceeds will go to the Foundation for Mitochondrial Medicine, which funds cure-based research.

"No one knows what it is," Wells said. "It's important to me for True's sake that people know what it is. I want him to feel as normal and as accepted as he possibly can given what he has to deal with every day."

True is 6 years old and a first grader at Highland Elementary School. He was diagnosed with mitochondrial disease when he was 3.

Every day is different for True, who can only attend school about four hours a day. He is fed through a feeding tube and takes 26 doses of medication a day.

"You never know what any given day is going to be like," Wells said. "He uses oxygen as needed. He can't go outside when it's too hot, and he can't outside for long."

While True has a lot of limitations, he does get to play with other children, even if it's only for 20 minutes.

"We want him to be a little boy and get to experience everything little boys do, even if it's in short spurts so we let him play," Wells said. "He is very happy. He has a great smile."

Wells works to educate True's teachers about the disease and anyone who wants to know. She also wrote a children's book about it titled "Energy Makers and Mito Kids: A Little Book about Mitochondrial Disease."

“I want people to know what it is,” she said. “The one thing about it that is so key is there is such a range. One child that has it might not walk or talk. They could look like normal children.”

For more information about the children’s book go to mitokidsrock.com. For more information about the Foundation for Mitochondrial Disease go to foundmm.org.

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