

# TROY Eccentric

## Cueter family continues fight to cure muscular disease of children

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By Sandra Armbruster

Community Editor

By Joe Cueter "plugging away, keeping doing the things that we're doing," researchers are closer to finding a cure for spinal muscular atrophy disease.

Cueter, whose son, Joshua, was diagnosed with the disease at age 2, has served on the national board of Fight SMA. He has kept tabs on the progress of research, taken the case for more funding before Congress and helped to sponsor a benefit walk called Joshua's Buddies.

And he's done all that while watching the progress of Joshua, who will be a third-grade student at Martell Elementary in Troy this fall.

"He has a full life expectancy, since he has a mild form of the disease," Cueter said. "He's been doing really well."

Unfortunately, that's not the case for all of those diagnosed with SMA.

Spinal muscular atrophy is the No. 1 inherited killer of children under the age of 2, Cueter said. SMA destroys the nerves that control voluntary muscle movement, such as crawling, walking, head and neck control and even swallowing. The gene that causes SMA is carried by seven million people (one in every 35 persons), unknowingly.

Despite those facts, funding has not kept pace with the promise of a cure. Financial support has been slighted, Cueter said.

"Some diseases have actors and sports figures (testifying) before Congress," he said. Yet SMA has a higher incident and fatality rate than many other illnesses.

Still, researchers "have made great strides." Cueter said that the gene for SMA was discovered in the early '90s, far ahead of most other research studies. A cure is expected soon.

That promise was recognized recently by the National Institute of Health, which Cueter said has labeled SMA as a disease to be taught across medical disciplines. "(NIH) said we need to be put on a pedestal and used as a model," he said.

But more funding is needed for research, and so, for the sixth year on Saturday, a benefit run organized by Cueter, his wife, Kris, and other family members was held at St. Elizabeth Ann Seton Church in Troy.

Cueter estimates that the nearly 500 runners collected \$25,000 for the cause.

"We were really pleased because of the heat," he said. "It wasn't easy, we thought we would need

500 bottles of water, but at the last minute, we had to go out and get another 100 bottles.

"Luckily, people just keep coming out."

This year's event was presented by Detroit Flexible Metals of Troy and U.S. Manufacturing Corp. of Warren.

The walk was originally organized by his sister-in-law and Joshua's godmother, MaryLynn Ventimiglia, in West Bloomfield. It has grown ever since.

That kind of support has meant that Joshua's Buddies\_FightSMA Michigan awarded a research grant in the amount of \$32,000 to Children's Hospital of Michigan during Saturday's annual benefit walk. Details are still to be worked out, Cueter said.

Joshua's Buddies is a local chapter of FightSMA, a Virginia-based 501(c)(3) international nonprofit corporation dedicated to raising awareness and funds for spinal muscular atrophy research. The group has awarded research grants to institutions in the U.S., Canada, the United Kingdom and France.

Contact Kris and Joe Cueter by e-mail at [mi@fightsma.com](mailto:mi@fightsma.com) or for more information on how to participate, donate, or to be a volunteer - go to [www.fightsma.com](http://www.fightsma.com).

"We need more funding," he said.

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