

Walk fuels research, support

By Layla Wilder

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Families of Spinal Muscular Atrophy (FSMA) has given the Megale family of Centreville a hope they are sharing with everyone.

More than eight years ago, Shea Megale, 11, was diagnosed with the rare genetic disease that debilitates the anmuscles.

Soon afterward, her family joined FSMA for support and now donates all the proceeds from an annual community walk in Shea's honor to FSMA because they want the organization to be able to help others, said Megan, Shea's mother.

Last Sunday, more than 400 people participated in the annual Walk for Shea and raised more than \$17,000, according to Mo Nieves, who organized the event.

Since the walk started in April 1998, the Megale family has donated more than \$1 million to the nonprofit group.

FSMA is a small organization of volunteers based in Illinois that advances SMA research and supports families with SMA patients.

For Megan Megale, being able to talk with people who understand her daughter's rare disease gives her hope, she said.

"There are very little resources for SMA patients and families because it is a very rare disease, and they were the only support group that was available to us," she said.

FSMA connected the Megales with people who could educate them about the disease and teach them how to help Shea lead a normal life.

It was through FSMA that the Megales met the Rogers family from Arlington who also have a daughter with SMA.

Philomena Rogers said knowing the Megales has meant a lot to her, too.

"I don't feel alone," she said.

The Megales also hope their donations will help advance SMA research.

Barbara Trainer, head of the local chapter of FSMA, said much of the money donated to the organization goes to research scientists looking for a cure.

Spinal muscular atrophy is caused by a malfunction in the production of proteins in the body.



A regular near the side of her father, Larry Megale, who coaches the Centreville High School boys lacrosse team, Shea Megale, 11, has spinal muscular atrophy – an incurable form of muscular dystrophy.

Researchers believe there may be a way to fix the problem through medicine, according to a report from Dr. John Kissel of Ohio State University.

Kissel said that, within the next three to five years, scientists should know whether the method will work.

"Of course, both basic scientists and clinicians will continue to look at other strategies that might be effective in treating this disease," Kissel wrote.

"When the nurses find that cure, I am not going to take it. That's why the 'Walk for Shea' is really the 'Walk for SMA,'" Shea Megale wrote in a letter her family posted on her Web site, <http://www.walkforshea.com>