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Golf tournament will help fund research for a genetic disease

By [Kim Kinzey](#)
For the Herald-Journal

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Aleena Hope Miller came into the world with big, blue eyes that sparkle in photographs of her as an infant.

But only months after Aleena's birth, her parents, Aaron, a Spartanburg native, and Stephanie began to notice a few problems.

Aleena had difficulty nursing and did not flail her arms or kick her legs like most infants.

The Millers took Aleena to a pediatrician, then to a neurologist.

At 4 months old, the couple's only child was diagnosed with spinal muscular atrophy, an incurable and life-threatening genetic disease that affects one in 6,000 children. It's a disease most people have never heard of, even though it is the leading genetic killer of children younger than 2, according to the Families of Spinal Muscular Atrophy Web site: www.fsma.org.

"People don't know about it and there are babies dying every day," said Aleena's aunt, Amanda Lawson.

SMA is a motor neuron disease that affects muscles throughout the body, including respiratory muscles. Sensation and the ability to feel

are not affected, nor is intellect, according to information provided by Families of SMA.

The Millers have dedicated themselves to caring for Aleena and to finding a cure for a disease they had never even heard of before her diagnosis.

The family moved from Atlanta to California where Aleena is receiving treatment and participating in research that could lead to a cure for SMA.

"It is just a horribly destructive disease, it's a degenerative disease," Lawson said. "As she (Aleena) has gotten older, her muscles have atrophied. Now she can barely move her fingers. She can't lift her arms or her legs."

Aleena has the most severe form of SMA, called type 1 or Werdnig-Hoffmann Disease.

Babies and toddlers with type 1 don't accomplish the normal motor skills expected early in infancy, such as the ability to sit up by themselves, according to Families of SMA.



Aleena Hope Miller, 2, daughter of Aaron and Stephanie Miller, was diagnosed with spinal muscular atrophy when she was 4 months old. The motor neuron disease is genetic and affects muscles throughout the body.



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Half don't live to celebrate their second birthday and most die from respiratory failure before age 1, the organization said.

Aleena has defied doctor's expectations. And the toddler is already living up to her middle name: Hope.

She turned 2 in February and is even learning to speak -- a feat most children with SMA Type I never accomplish.

Aleena primarily communicates with her eyes, letting her parents know her wants and needs by blinking her eyes.

As it becomes increasingly difficult for Aleena to even smile, her eyes have literally become the windows to her soul.

"Her personality shines through her eyes," Lawson said.

The Millers must care for her 24 hours a day.

They do three respiratory treatments a day with Aleena, which last about two hours each, according to Lawson.

In addition to respiratory therapy, Aleena also has regular physical therapy and some speech therapy.

Aleena is part of a research program that is working to find a cure for SMA.

Dr. Ching H. Wang, director of Lucile Packard Children's Hospital's neuromuscular disorder clinic, is testing a drug called hydroxyurea to treat children with type-1 and type-2 SMA.

Aleena is one of the children enrolled in the drug trial.

The Millers have established the Hope and Light Foundation, which is dedicated to finding a cure for SMA through research, educating the public about the disease, and putting SMA on the forefront of the medical community.

Aleena's family said SMA has been left behind in funding, and treatments have been slow to materialize.

Lawson has organized the first Hope and Light Foundation Charity Golf Tournament and Silent Auction to be held May 26 at Carolina Country Club.

Proceeds from the tournament will be used to fund research and provide "all around support" for families coping with SMA.

For more information, visit www.hopeandlight.org.

Kim Kimzey is a freelance writer who lives in Spartanburg.

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