

Parents join fight against genetic disease that took their infant son

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OGDEN -- When Dylan Strebel was 2 months old, his parents took him to the doctor for a well-baby check up.

They left the office with bad news, however. Their son might have a fatal illness, the doctor said, and she sent them to Primary Children's Medical Center.

After several tests were performed, the couple's fear was confirmed. Dylan had spinal muscular atrophy and wouldn't live to celebrate his first birthday.

SMA, as it is better known, is a genetic disorder that refers to a group of diseases affecting the motor neurons of the spinal cord and brain stem. Degeneration and death of these neurons produces weakness in the muscles that allow breathing, swallowing and moving. SMA kills more babies than any other genetic disorder, according to SMA.org, and it's incurable.

"It's similar to Lou Gehrig's disease. The muscles just slowly atrophy," said Amy Strebel, Dylan's mother. "There are several types of the disease. Dylan had Type I, which is considered the most fatal. Approximately 65 percent of SMA patients have Type I and it has a 95 percent fatality rate by the age of 2."

In order to have SMA, both parents must carry the gene, Strebel said. The gene mutation that causes SMA is carried by one in every 40 people, or approximately 7.5 million Americans. Although no one on either Amy's or her husband Darren's side of the family had SMA, both were carriers.

"We had never even heard about it before," Strebel said. "We learned that when both parents carry the gene there's a 1-in-4 chance of passing it on to your child. Every day, a child receives a diagnosis of SMA, so it's more common than most people think."

Strebel said after countless hours in the intensive care unit at the hospital, Dylan was taken home, where his bedroom was turned into a mini-ICU. He slowly lost his ability to move, smile and ultimately breathe. He died in May 2006.

Strebel said the family doesn't want more people to go through the same heartache, so they have joined the fight against SMA and created a Utah chapter called FightSMA.

The family will hold a fundraiser from 7 p.m. to 11p.m. Oct. 20 at the First Pres-byterian Church, 880 28th St.

"The event will include entertainment by The Legendary Porch Pounders," Strebel said. "We'll also have catered food by Peddler's and a silent auction."

All funds will go toward research of SMA, Strebel said, as well as studies to improve the quality of life for children with the disease.

"There is also an SMA Acceleration Act in front of the House and Senate right now, which can potentially impact SMA as well as 40 other diseases if it passes," Strebel said. "In the past year, SMA was chosen as the model disease by the National Institutes of Health for its promise for therapy and treatment."

Strebel said the public is invited to attend the fundraiser and she's hoping for a big turnout.

"These diseases are out there, but a lot of people don't talk about them because losing a child is so painful, so it gets pushed under the carpet, but the fact is, SMA is the No. 1 genetic killer of children, and we need to talk about it and we need to fight for it," she said.

Tickets for the fundraiser are \$35 per person, \$65 per couple or \$250 per table. For more information or to purchase tickets, call 782-5525 or 389-4573 or visit the Web site at www.fightsma.org.