

PHOTO SUBMITTED BY JOHN KILLIAN

Nick and Abbie Killian of Rockwall, along with their father John, meet with Congressman Ralph Hall in Washington, D.C. The Killians were among eight delegates from Texas who participated in the 10th annual legislative conference sponsored by Parent Project Muscular Dystrophy. Sam Killian, 8, has a form of muscular dystrophy known as Duchenne.

Teens ask Congress for support in battling brother's disease

BY DAWN REDIG
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MORE INFO

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Two Rockwall teens are asking legislators to support measures that would spur potential treatments for their younger brother who has muscular dystrophy.

Abbie Killian, a freshman at Rockwall-Heath High School, and her brother Nick, a seventh-grader at Cain Middle School, are among 100 delegates from 35 states returning from Washington, D.C., after participating in the 10th annual legislative conference sponsored by Parent Project Muscular Dystrophy.



Sam Killian

Abbie and Nick's 8-year-old brother, Sam, a second-grader at Amy Parks-Heath Elementary, has a form of muscular dystrophy called Duchenne.

"The progressive muscle disorder mainly affects boys. They usually end up in a wheelchair between the ages of 10 to 14, and lose the use of their arms and hands in their teens," said John Killian, Sam's dad. "Eventually, the mus-

cles of the heart and lungs are impacted, making Duchenne MD the most common fatal genetic disease diagnosed in childhood."

Since Sam's diagnosis in 2005, the Killians have been involved with PPMD, a national nonprofit dedicated to research and advocacy on behalf of the Duchenne community. The organization was instrumental in passing the Muscular Dystrophy Care Act in 2001 and its reauthorization in 2008.

"This year, the PPMD team has three goals — to encourage continued emphasis on neuromuscular diseases at the National Institute of Health; to obtain additional resources within an existing program that would encourage earlier diagnosis of DMD; and to gather support from Congress for a letter to be delivered to the Food and Drug Administration, encouraging an effective approval process for potential drug therapies that are on track for clinical trials over the next three to five years," John said.

The Texas delegation, which included Abbie, Nick, John and five others from the state, met with 22 of the 32 House offices and both Senate offices. They spoke directly to Congressmen Kevin Brady, Ron Paul and Ralph Hall of Rockwall.

"I will never forget the love and concern Abbie and Nick showed as we discussed a medical enemy that attacks their younger brother, Sam," Hall said. "My family and I suffered through a similar heartbreaking disease so I know how devastated the Killian family must be. I was anxious to support their seeking the need for earlier diagnosis, continued research — and prayer."

The Killians know the fight against MD will be long, but they report success in building awareness in Washington.

"It is a complex disease with no simple answers," John said. "With Abbie and Nick in his corner — and his 10-year-old brother, Ben, waiting to go to Washington next year, Sam knows that he and others with muscular dystrophy have a lot of support."

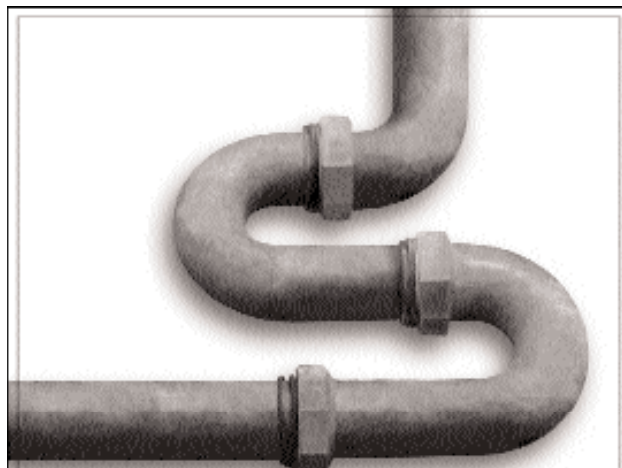
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Partners in education



SUBMITTED PHOTO BY PAULA MCLENDON

Kayleen Lavene (right), principal of Reinhardt Elementary, accepts a \$1,350 check from Wal-Mart store manager Chris Nelson and Cathy Lewis. Wal-Mart donated the money to be used "in any way that might best benefit the goals and objectives of Reinhardt Elementary."



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