



FOR IMMEDIATE RELEASE

Contact: Kate Mathany
Vice President
Telephone: (916) 476-3977
Fax: (916) 916-739-0942
Cell Phone: (916) 335-0430
Email: hoot@gettyowl.org

Spinal Muscular Atrophy (SMA) is a genetic degenerative condition, without a treatment or cure, causing severe muscle weakness. It typically leads to breathing and swallowing difficulties for infants and children. It is often fatal by age 2 and is not included in standard prenatal screening. SMA is the #1 genetic killer of young children.

Getty Owl Foundation is a 501(c)(3) nonprofit organization founded in 2011 by Mark Storm and Kate Mathany to raise awareness of SMA, help families affected by SMA, and accelerate a cure for SMA.

Our daughter, Getty, was diagnosed with SMA when she was 4 months old. We had no idea we were carriers of SMA because it is not part of normal prenatal screening. 1 in 40 people and over 11 million Americans unknowingly carry the SMA gene. Getty is now 26 months old and beating the odds. As a family, we knew we could not sit back and allow SMA to define Getty or affect another family. If we can educate the community, perhaps we will be able to convince people to get a simple blood test to see if they are carriers. There is hope because SMA has been deemed the #1 disease closest to treatment of over 600 neuromuscular diseases.

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5714 Folsom Blvd #193 Sacramento, CA 95819
☎ 916.476.3977 ☎ 916.739.0942 ✉ hoot@gettyowl.org

www.gettyowl.org

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