

{ noteworthy }

Getty Owl Foundation



by Melissa Abramovitz



Four-month-old Getty Storm's diagnosis of type 1 spinal muscular atrophy (SMA1) on July 30, 2010, shattered her parents' world. Babies with this genetic degenerative disease, which causes progressive muscular atrophy, rarely live until age 2. Bi-pap breathing machines, pulse oximeters, feeding tubes, and intermittent hospitalizations become part of everyday life.

Amidst their devastation, Getty's parents (Kate Mathany and Mark Storm) saw hope. They learned to advocate for Getty's needs and chose aggressive treatment to prevent complications. They also sought support online—at the time, there were no formal support groups in the Sacramento area.

With a goal to "to initiate local support and hope for affected families, enhance awareness of SMA, and play an active role in promoting SMA research," Kate explains, she and Mark launched

the nonprofit Getty Owl Foundation in March 2011. So-named, she says, because "when Getty was born, we noticed she had wisdom, and was an old soul from the moment she came to us. So, we started calling her our little owl."

Since then, the support, donations and business sponsorships for Getty Owl have been overwhelming. The organization has held a Sacramento craft fair and a Hoot the Grid Art Auction and Awareness Walk. The Team Getty Runners have participated in awareness-raising runs, and are running in the California International Marathon (on December 4).

They'll also lead the pack at the first annual Getty Owl Walk/Run in downtown Sacramento (on February 26, 2012), a family event that encourages healthy living and an end to SMA. "We want our events to celebrate life and families," explains Kate.

Nationwide, families are already benefiting from the foundation. When their daughter, Alli, became ill, Ron and Nicole Williams of Seattle sought support—and they found Getty Owl. "The foundation has been such a big help, giving us advice on how to get proper care and even sending a special breathing mask for Alli," Nicole says.

First Annual Getty Owl Run/Walk
Sunday, February 26, 2012 at Crocker Park in downtown Sacramento

Sign the family up for the ¼ mile kids' run or 5K/10K run/walk that loops around the Crocker Art Museum. Enjoy a post-race family festival with kids' activities, booths, healthy living guides and SMA awareness. The goal is to raise at least \$5,000 to go directly to SMA Gene Therapy Research's "200 For SMA" fundraising campaign.

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◀ Photographer: Morgan Saunders



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Getty Owl's efforts also center on informing the public about risks. Over 8 million Americans are symptomless carriers who can unknowingly pass SMA to their offspring, because testing for SMA is not routinely performed in prenatal genetic tests. Kate and Mark had no idea they were carriers. "In the future, we plan to get a dialogue going with city and state governments about making SMA a standard genetic test," Kate says. "Proper diagnosis of SMA is important for informed decisions, because SMA is often misdiagnosed, and people don't know why their child died. We want to change that."

Stacey Ball, Kate's longtime friend, helps plan Getty Owl events and serves on the Board of Directors. When asked why she believes Getty Owl is noteworthy, Stacey explains, "This is a family that is dealing with a huge obstacle in their life. Yet, instead of burying their heads in the sand, they have made it a mission to help others."

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