



OPINION One Family's Fight against SMA

There is perhaps no greater fear than that of the unknown. In the face of extreme uncertainty, the vast majority of us will choose the easier route: to simply run away or bury our heads in the ground like the proverbial ostrich. And then there are those rare, intrepid souls who boldly launch themselves into the darkness, thereby illuminating the path for all those who come behind.

Kate Mathany and husband Mark Storm of West Sacramento definitely fall in this second category. They are true trailblazers, teaching the rest of us what it means to forge ahead in the face of adversity, and to fight hard even against the most daunting of opponents.

When confronted with the news that their beautiful blue-eyed 4-month-old daughter Getty carried within her delicate, angelic frame a terrifying condition called spinal muscular atrophy, or SMA, not only did they refuse to succumb to fear and despair and self-pity. They took the exact opposite route, hurling themselves headlong into the complex and often confusing world of SMA research, educating themselves on every facet of the disease in the hope of helping their daughter and shining a spotlight on all those brave little souls with SMA for whom every day is both a blessing and a tremendous challenge.

They have started an organization called the Getty Owl Foundation, dedicated to spreading SMA awareness and hope for an eventual cure. They have organized jog-a-thons through the streets of Sacramento to raise money for the cause. They have held craft fairs and scavenger hunts and anything possible to shed light on this devastating disease. In short, they have stared into the abyss of SMA, and have not blinked or hesitated one moment. It is SMA that has much to fear of these two ferociously loving parents of Getty Storm.

SMA is the most common genetic cause of infant death; one in 40 people are carriers. Every time two carriers have a child there is a 25% chance that the child will have SMA. It's not uncommon for a carrier to have two or three healthy children before giving birth to a child with SMA. The disease manifests in various degrees of severity, resulting in general muscle wasting and mobility



impairment. Babies diagnosed with SMA type-I generally don't live past two years of age, with death occurring as early as within weeks of birth in the most severe cases. SMA doesn't discriminate based on race, gender or ethnic background.

Kate and Mark started the Getty Owl Foundation in part to spread

word that SMA is a very real condition and can affect anyone. The disease remains highly undiagnosed: standard prenatal testing does not include SMA. "My entire pregnancy was flawless and we thought we were having a healthy baby girl. Never in my life did I think I'd pass along a gene that stripped my daughter of all her muscle capacity," explains Kate. "I am an athlete, I run, I am active. How on earth could this have happened? But that's the nature of DNA—you never know what's hidden in your genetic code."

"The bottom line," she continues, "is that it's incredibly easy to get genetic testing for over 300 different diseases and disorders that aren't standard to prenatal testing. It can be as easy as a blood test or a swab of the mouth. There are three companies that can administer. The highest cost to the consumer is \$300, or \$99 if your insurance covers it."

Fortunately, the efforts of people like Kate and Mark are paying off: "Getty has an incredible life. She's thriving with a disorder that wants to take her life at every corner, and we're doing all we can to give her quality days that might turn into quantity. She is learning math at the age of two and a half. SMA does not inhibit the mind, so we have a little brain over here. There are all kinds of technology to enhance her world. And pre-school is right around the corner. We obviously have a new normal, and while it can feel isolating, it is also beautiful in the same breath."

Get more information about SMA at: www.gettyowl.org. **H&F**