

Mike Michaelis & The OMSLife Foundation

When Mike Michaelis' 14-month-old granddaughter, Alexa, suddenly lost the ability to walk and sit up, her parents rushed her to the emergency room multiple times, only to be met with uncertainty from medical professionals.

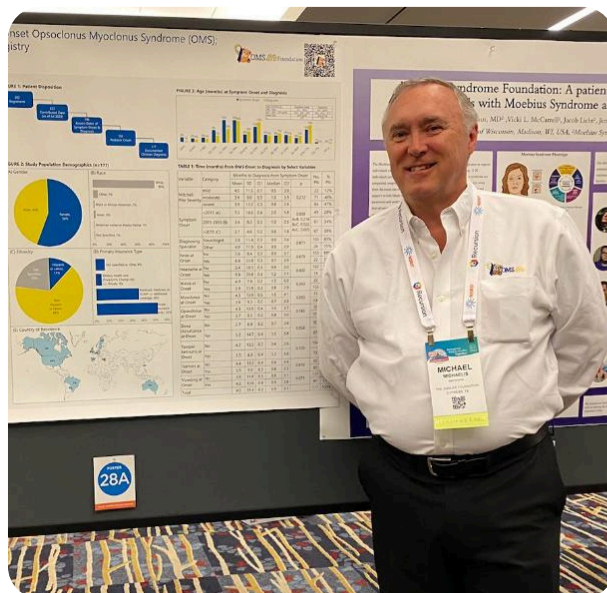
It wasn't until a serendipitous connection led the family to Texas Children's Hospital that Alexa was finally diagnosed with the rare neurological disorder, opsoclonus-myoclonus syndrome (OMS).

This pivotal moment sparked the creation of the OMSLife foundation.

Driven by Alexa's parents' desire to ensure no other family would have to endure the same harrowing experience, the Michaelis family set out to raise awareness, provide resources, and advocate for the OMS community.

Initially, OMSLife started as a simple Facebook page, but as more families reached out seeking support, the organization quickly evolved into a formal 501(c)(3) non-profit. A key focus of OMSLife has been educating frontline medical staff and the public about OMS, a disease that typically affects young children between 6 months and 3 years old, with a slightly higher incidence in girls.

Continuing in the quest to educate others about OMS and recognizing the importance of data collection for research, OMSLife collaborated with the National Organization for Rare Disorders (NORD) to establish a patient registry. This database aims to shed light on the multifaceted challenges of OMS, from the initial symptoms to the obstacles encountered as patients age and their care needs change.



Participation in the registry has largely been driven by the community created by OMSLife. Since 2014, OMSLife has organized annual caregiver conferences, providing a vital platform for families affected by OMS to connect, share experiences, and learn from leading specialists. These conferences have lessened the isolation felt by caregivers due to the rarity of the condition.

OMSLife has also been central to connecting researchers and physicians, through co-sponsorship of the Abingdon Conference with Dancing Eyes Syndrome Support Trust (DESS) in the United Kingdom. Beyond this conference, OMSLife has provided research grants to fund in whole or part 12 different projects conducted at leading academic institutions.

As OMSLife looks to the future, the foundation is exploring technologic avenues including artificial intelligence to aid in the diagnosis and treatment of OMS, with the goal of providing more consistent and accessible care for all those affected.

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