OMS life Foundation

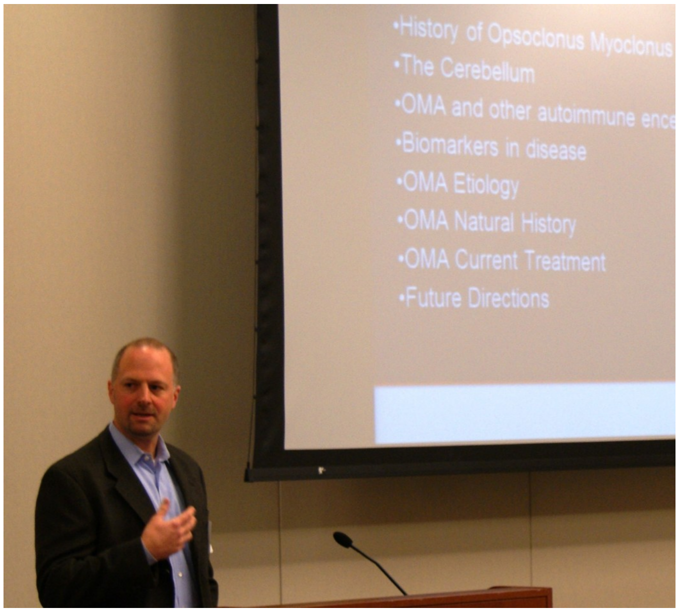
Volume 3 November 2014

OMSLIFE REGIONAL CAREGIVER CONFERENCES BEGIN

The OMSLife Foundation took a major step forward in 2014 as we began hosting regional caregiver conferences. This has been one of our foundational elements that we have strived to implement for the primary caregivers as well as other friends and family members.

In May, we introduced the concept with a caregiver conference hosted by Dr. Wendy Mitchell at Children's Hospital Los Angeles. The four hour event, attended by approximately 50 OMS caregivers and friends, met with Dr. Mitchell, Dr. Susan Terkel, and Dr. Megan Langille to discuss a variety of OMS topics including behavior, relapses, school adjustments, treatment protocols, and therapies.

In November, Dr. Tim Lotze and Texas Children's Hospital in Houston hosted a regional event. This event included presentations from Dr. Jason Shohet, Dr. Karen Evankovish, Dr. Desi Roge, and Diane Murrell. The topics ranged from the history of OMS, to oncology and psychology, to rehabilitation and social services. Approximately 40 attendees participated in conference. The conference was followed with an evening event which allowed the entire family to continue to network, while the OMS warriors and their siblings were able to play together. In some cases, it was the first time an OMS warrior had ever met another OMS warrior.



- History of Opsoclonus Myoclonus
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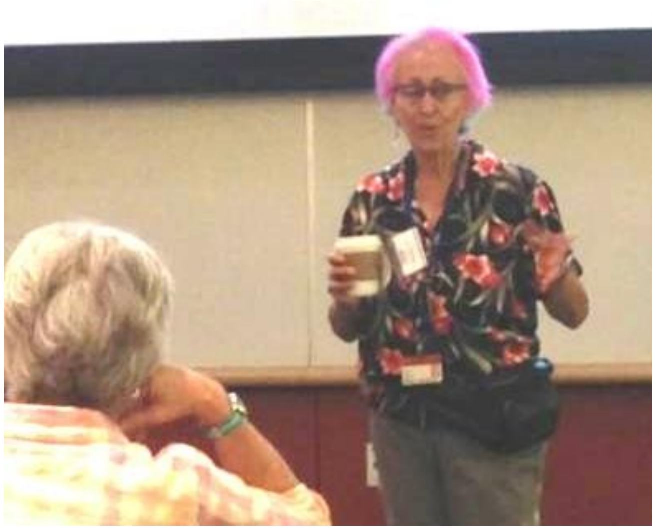
- OMA Natural History
- OMA Current Treatment
- Future Directions



Thank you to Dr. Wendy Mitchell and Dr. Tim Lotze for hosting our first two OMSLife caregiver events.

Our plans call for an additional two to five conferences in 2015 including the East coast, the Midwest, and possibly returning to the south and west coast again. You can follow details on our past conferences and future events at

www.omslifefoundation.org

Meet One of our Sponsors

Fairfield Women's Club

The HEART of Fairfield

One of our early sponsors of The OMSLife Foundation was the Fairfield Women's Club in Cypress, Texas. For the past four years, they have sponsored a triathlon with OMSLife being one of the four charities receiving the proceeds.

This year, the event was bigger than ever with a triathlon, a duathlon, and a kids triathlon. In total, 826 athletes participated in the event. Thank you to the Fairfield Women's Club for your continued support of The OMSLife Foundation.

Follow us at

https://www.facebook.com/OMSLifeTeddyBearDrive

Please help us provide grants for OMS research. You can send checks to:

The OMSLife Foundation
P.O. BOX 2899
Cypress, TX 77410

Or give an online donation at

www.omslifefoundation.org

The OMSLife Foundation is a 501(c)3 non-profit organization and donations are tax deductible.

CampWest

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HELP US BEAT OMS!!!! I want to help raise awareness of OMS and help in research funding! Enclosed is my donation.

$50 ☐

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Check the box if you like to receive our e-newsletter? ☐

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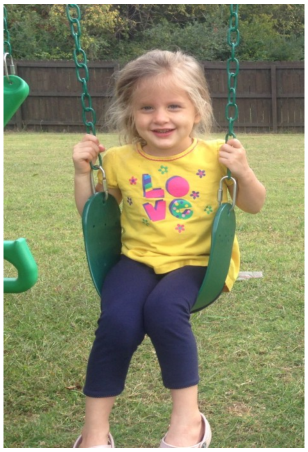
The OMSLife Foundation is a 501(c)(3) nonprofit organization founded in 2012 dedicated to educate people around the world about Opsoclonus Myoclonus Syndrome and raise funds for the research and cure of this disease.

MEET A FEW OF OUR OMS WARRIORS

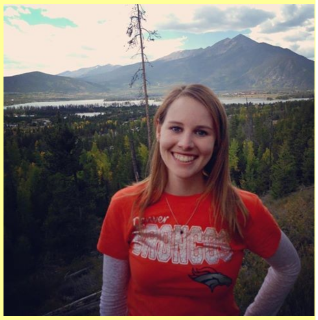
Bailey was diagnosed October 1, 2012 at almost 16 months old with Neuroblastoma and Opsoclonus Myoclonus Syndrome (OMS). Her symptoms began 2 weeks after receiving her HIB and Pneumococcal vaccines. In the month between onset and finding a correct diagnoses, she went from a vibrant, active child who could walk and run, to one who couldn't walk or even crawl and had constant opsoclonus.

The day after diagnosis, her tumor was removed and after a 3 day hospital stay, she was sent home to "wait and see" if the OMS would go away on its own after the tumor was taken out of the picture. After finding Dr. Michael Pranzatelli, Bailey and her family traveled to Illinois just 4 days after being released from the hospital. He and her local doctors, a team of 2 oncologists and a pediatric neurologist, implemented a treatment plan that included IVIG, ACTH and Rituximab. She had great success on these treatments and began walking again on October 30, 2 weeks after treatment began.

In the course of her treatment, Bailey has relapsed twice, usually starting with drool and slight opsoclonus. To curb her relapses, she's been through a round of Cyclophosphamide, and most recently, Methotrexate. She had a year of Occupational Therapy through the Early Intervention program, and saw great improvements in her abilities and confidence within that time. This past summer, Bailey added a functional medicine doctor and also a chiropractor to her team of experts and is now gluten free. She has seen great strides in her healing, is no longer on Methotrexate or Trazodone and should be off of ACTH within a couple of months.



Bailey is currently 3 1/2 and already plans on leaving her mark on the world by becoming a doctor. She is doing great, and actually just got over a cold without symptoms returning. She has the most empathic soul, is totally fearless and has never met a stranger. She loves playing outside with her sister, Hannah, and helping in the family garden.



Michelle was diagnosed with Adult Onset OMS in June of 2012, after 2 years of searching for an official diagnosis (her symptoms started in late 2010). She had always been healthy and extremely athletic, growing up downhill ski racing in the mountains of Colorado.

Michelle first developed OMS symptoms just before her 24th birthday. It started with episodes of severe dizziness and nausea. As her balance and dizziness worsened, Michelle hit her head and had a concussion. After the concussion her OMS symptoms continued to get worse, however her symptoms seemed to fluctuate in severity over the weeks and months. One of the greatest challenges Michelle has experienced as an adult with OMS, is that her doctors never wanted to take action, commit to a diagnosis and start the treatment. She would see a doctor a few times, often the doctors would blame her for being stressed, making up her symptoms, or just admit they didn't know what to do. Michelle would then be referred to another new doctor.

Over almost 2 years of searching for answers Michelle had been tested for everything from multiple sclerosis to Lyme disease and vitamin deficiencies to brain tumors. Michelle saw about a dozen different doctors. At one point early on, Michelle's chiropractor (who specialized in neurology) did suspect she had OMS. Thankfully through the OMSLife support Michelle got a connection with a neurologist who had seen OMS in a few other adults. She had to travel to New York, where this doctor took about 5 minutes to confirm the diagnosis of OMS. He wrote up a plan of starting 5 days of IVIG in-patient at the hospital close to her home. Most neurologists she saw were unfamiliar with IVIG. So, Michelle and her family traveled back to NY where she finally started 5 days of IVIG.

IVIG significantly helped, but Michelle still had symptoms. So after finding an excellent local immunologist she has continued doing IVIG for the past few years. About 8 months ago Michelle started Rituxan. This has allowed her to taper IVIG a little. As long as she continues getting IVIG and Rituxan, Michelle has had few OMS symptoms and has been able to enjoy getting back to her outdoorsy lifestyle. To improve her strength and balance Michelle started doing water fitness classes and working with a personal trainer. Michelle and her husband enjoy backpacking and hiking with their dog. Michelle also has been able to once again enjoy skiing with her family.

The OMSLife Foundation
P.O. BOX 2899
Cypress, TX 77410

OMS
Opsoclonus Myoclonus Syndrome

MEET OMS WARRIOR LOGAN....

Logan's OMS battle began June 12, 2012. Two days earlier Logan was running around and swinging on the swings at Imagination Station and cheering his daddy on during a baseball game. Logan went from being able to walk, run, jump, and starting to put two words together to a child that could not walk straight, let alone run or jump, and could only say mama and agua.

Initially his pediatrician diagnosed him with an ear infection. After a few days of lethargic behavior and what we eventually came to know were rage attacks we took him to St. Clare's ER where we were told it was complications to teething. A few days later we took him to Morristown Medical Center where he was admitted and told it was cerebral ataxia, encephalitis, and then meningitis. We were there for over a week and Logan received two treatments of IVIG. We were sent home and told that he would have to relearn how to walk but he should be okay. For a few days we saw improvements but then his condition rapidly began to get worse. We tried NY Presbyterian Hospital's ER where we were told it was Sandifer Syndrome (acid reflux). When we realized that this was not a correct diagnosis we went back to Goyreb's Children's Hospital at Morristown Medical Center where we were eventually told that they thought it was OMS and recommended we fly out to see Dr. Pranzatelli in Springfield, Illinois. Here the diagnosis was confirmed and a treatment protocol was recommended. We flew back and two days later started treatment of ACTH injections, Retuximab infusions, and IVIG infusions as well as several scans where no neuroblastoma was found. He was also prescribed Zantac, Bactrim, Trazedone, Calcium, and Vitamin D drops. While on this treatment protocol, Logan was essentially on lockdown and his contact with other people was limited. He was enrolled in Early Intervention where he received Development Intervention and Speech Therapy. He also received PT for a few weeks but was discharged quickly as he relearned how to walk before all the other issues were resolved.

Logan underwent treatment from June 2012 till December 2013 when he received his last IVIG infusion. His port was removed in May 2014 and he is now in remission. He was tested by Early Intervention and our local school district when he timed out of Early Intervention and he did not qualify for services. Today, he sees his local neurologist, an immunologist, and Dr. Gorman every six months. He has made great progress and continues to amaze us daily. He loves reading and building houses with his legos. He loves trucks and can name many different types of construction vehicles with ease.