

HISTORY OF OMSLIFE...

2009 – 2015 THE EARLY YEARS

In December 2009, shortly after baby Alexa's OMS diagnosis, the Michaelis family decided to honor the wonderful staff at Texas Children's Hospital with Alexa's first OMS Teddy bear drive. In 2010, the producers of a television show on TLC called *Mystery Diagnosis* wanted to air a segment on Alexa's journey with Opsoclonus Myoclonus Syndrome. Filmed on location at Texas Children's Hospital and the Michaelis' home, *The Toddler who Stopped Walking* debuted on September 6. After the show, the family was contacted by OMS caregivers across the US. They began a Facebook group and a website.



In 2012, The OMSLife Foundation, a 501 (c) 3 non-profit organization, was formed. Our mission became: to raise awareness of OMS, to develop a support network for patients and caregivers, and to fund research for a cure.

In 2014, The OMSLife Foundation introduced our first caregiver conference in Los Angeles and Houston. Dr. Wendy Mitchell and CHLA offered to be the site for the first OMSLife Caregiver Conference in May. In November, Dr. Tim Lotze and Texas Children's Hospital Houston offered to host the second regional OMSLife conference. The OMSLife en Espanol Facebook group started up for our Spanish speaking community. That same year, the OMSLife Information Facebook page was created to offer public information for interested parties.

In 2015, we hosted our third and fourth caregiver conferences in Cincinnati and Boston; first with Dr. Don Gilbert's team and Cincinnati Children's Hospital in April, followed by a May event at Boston Children's Hospital with Dr. Mark Gorman's team.

During the early years, we hosted numerous teddy bear drives across the US and raised funding for several OMS institutions; National Pediatric Myoclonus Center (Dr. Pranzatelli), Children's Hospital Los Angeles, Boston Children's Hospital, Pablove, and the Pediatric OMS Research Fund.

By the end of 2015, OMSLife had a list of over 500 patients from 40 countries. In December, OMSLife became a member organization of the National Organization for Rare Disorders (NORD). We had no idea how impactful that membership would become...

2016-2020 THE GROWING NETWORK

In 2016, we returned to Los Angeles for our fifth OMS Caregiver Conference. Dr. Michael Pranzatelli and Liz Tate joined Dr. Wendy Mitchell in presenting at the conference. That was followed by the Houston Conference in 2017 and another conference in Boston in 2018.

Also in 2016 we were invited to co-host the 8th International OMS Medical Workshop with the UK based Dancing Eyes Syndrome Support Trust (DESST). This partnership has continued for four workshops now.



Researchers and clinicians and a few caregivers from Europe and the US met in these three-day workshops. Two outcomes of the 2018 workshop were the creation of the OMS Education letter (translated in 8 languages) and the commitment to generate a consensus statement on OMS treatment.

That same year, the National Organization for Rare Disorders (NORD) awarded OMSLife with a grant to develop a Patient Reported Registry for OMS patients. We spent the year working closely with a team at NORD on the registry development. The OMSLife Patient Reported Registry went live in 2017 with seven initial surveys. The goal of this project was to collect large sample sizes of OMS patient data to enhance research and studies on OMS. In October of 2018, OMSLife presented “Early Data” from the OMSLife Patient Reported Registry at the annual NORD Conference in Washington DC. This was the first public display of this data.

During this period of this decade, OMSLife presented Boston Children’s Hospital with a three-year grant totaling \$75,000 for Dr. Gorman to develop of their POOMAS database with nine hospitals.

At the end of this decade, COVID interrupted progress on many of our projects and all of our conferences. We used that time to reflect on our priorities at OMSLife.

The OMS caregiver community continued to expand during this time with 1,025 patients in 57 countries.

2015 OMS Caregivers Conference

The Department of Neurology at Children's Hospital of Cincinnati and the OMSLife Foundation invite caregivers to attend an educational workshop on OMS.

Saturday, April 11, 2015 | 11:00AM-3PM
Children's Hospital of Cincinnati
3636 Linn St., 3rd Floor
Cincinnati, OH 45229-3024
Tel: (513) 636-4200

Conference Agenda:

- 11:00AM Mike Michaels, OMSLife Foundation, President and Co-Chair
- 11:15AM David L. Smith, MD, PhD, Department of Neurological Sciences
- 11:30AM Dr. Akshay Kumar, MD, Neuroscience
- 12:00PM Mike Michaels, OMSLife Foundation
- 1:00PM Dr. Brian Weiss, MD, Neurology
- 2:00PM Dr. Wood Sperry, MD, Neurology
- 3:00PM OMS Campaign Fund Donations

RSVP by March 25, 2015 to:
Mike Michaels
mike@omslife.org
Tel: (513) 636-4200

RSVP by March 25, 2015 to:
Maura Scarpelli
maura@omslife.org
Tel: (513) 636-4200

Adults age 18 and older are welcome to attend free of charge. A list of topics that have already been held for you of these patients is provided.

Registration Fee:
\$100 (includes lunch)
Childcare: \$100
Tel: (513) 636-4200

To reserve your space, please be sure to include OMSLife.

You're Invited!

The Division of Neurology at Children's Hospital of Los Angeles and the OMSLife Foundation invite families and friends to attend an educational workshop on OMS.

Saturday, March 12, 2016
10 a.m. - 4 p.m.

Date: Malibu, California Conference Room
Hosted by: Dr. S. Anderson, Pediatric Neurology
Children's Hospital Los Angeles
4650 Sunset Blvd. • Los Angeles

Keynote Speakers:

- Michael Pranzatelli, MD, Neurology, The Children's Hospital
- Wendy Mitchell, MD, Neurology, The Children's Hospital
- Michael Pranzatelli, MD, Neurology, The Children's Hospital
- Wendy Mitchell, MD, Neurology, The Children's Hospital

The workshop is hosted by:
OMSLife Foundation

RSVP to Akshay Kumar by March 1, 2016:
akumar@chla.usc.edu | (323) 261-2427

Lunch and self-parking services will be provided.

Adults 17 and older are welcome to attend. We regret that we cannot accommodate children, and do not have suitable drop-off.

Children's Hospital of Los Angeles

2014 OMS Caregivers Conference

The Department of Neurology at Texas Children's Hospital and the OMSLife Foundation invite caregivers to attend an educational workshop on OMS.

Saturday, November 8, 2014 | 11:00AM-3PM
Texas Children's Hospital, 6600 Frazier Street
Houston, Texas 77030

Conference Speakers:

- 11:00AM Dr. Thea Lema (Dept of Child Neurology), Penn. State, and Director of OMS
- 11:30AM Dr. Anne Hubler (Dept of Neurology), Penn State, USA
- 12:00PM Dr. Dick Hager (Dept of Physical Medicine and Rehabilitation), Rehabilitation Nurse of OMS
- 1:00PM Dr. Bruce Emswiler (Dept of Psychology), Neuroscience Institute
- 1:30PM Dr. Bruce Marshall (Dept of Social Work), Community and Child Support

Adults age 18 and older are welcome to attend.

2021 - TODAY

Despite COVID preventing conferences, we used the time to continue development of the OMS Patient Registry and to update documentation. OMSLife worked with Dr. Mitchell, Dr. Lotze, and Dr. Gorman to update and develop new resource materials on the NORD website. This included updated narrative on OMS as well as an animated video on OMS –

https://rarediseases.org/videos/opsoclonus-myoclonussyndrome/?_rt=M3wxfG9wc29jbG9udXN8MTc1MDQ3MDQyMQ&_rt_nonce=64b9384258



In another project, working in collaboration with NORD and Trio Health, we were one of ten rare disease registries featured in a book titled “Power of Patients”. This book contains stories of OMS warriors and shows data from the OMSLife registry.

After numerous delays due to Covid, in October 2022 the tenth International OMS Medical Workshop in Abingdon England was held. This conference featured the presentation of the OMS Consensus Statement. The most recent OMS Medical Workshop was held this past April in Oxford England. The 50+ attendees represented researchers and clinicians from 17 countries. At the workshop, presentations were given on two OMSLife sponsored initiatives: a sleep study and Toronto Eye Movement project. OMSLife and DESST once again co-hosted these workshops.

Caregiver conferences resumed in 2023 as OMSLife hosted the eighth event in Chicago. Over 110 caregivers and doctors attended.

Our registry has become a credible resource for clinicians and researchers. Boston Children’s

Hospital and OMSLife published the results of the Inaugural Data Registry project in Pediatric Neurology magazine in 2024. OMSLife presented a second registry poster at the 2023 NORD conference in Washington DC, followed by another poster session at the Atlanta ISPOR conference in 2024, and the 2025 CNS conference in Charlotte. We kicked off an OMS sleep study in the OMS Patient Registry in 2024.

We continued to fund exciting projects, including the Eye Movement Project and also providing additional funding to Boston Children’s Hospital for their POOMAS registry.

We expanded our social media presence with Instagram – moderated by Jana Hall. We again expanded our social media into LinkedIn and now partner with a new venture called Rare Awareness Radio, a podcast featuring rare diseases.

The OMS community has grown to 2,130 patients in 72 countries as of April 2025.



2025 – 2030 LOOKING AHEAD TO A BRIGHT FUTURE

The OMSLife Foundation anticipates an exciting agenda of projects and programs for the next few years. Much of the work will focus on data driven research from the OMS Patient Registry and from connections with researchers and clinicians at the Oxford Medical Workshops. Here is a short list of some of the work planned for the coming years:

- ✓ Enhancements to the OMS Patient Registry including mobile friendly surveys and translation to Spanish and other languages
- ✓ Publication and next steps on the sleep study
- ✓ Continued collaboration on the Eye Movement study with Toronto Sick Kids Hospital, Cincinnati Children's Hospital, and CHLA
- ✓ Adoption and implementation of ICD codes specific to OMAS
- ✓ Publication of findings on the late tumor detection project with Boston Children's Hospital
- ✓ Publication of an OMAS Behavior Consensus Statement with CHOP and Kennedy Krieger Institute
- ✓ Continue co-hosting the International OMAS Medical Workshops in Oxford
- ✓ Publication of findings on the long term outcomes project with Oxford and Cook Children's Hospital Dallas
- ✓ Development of a Caregiver PTSD Study

