RARE AWARENESS RADIO ENCORES

August 2025

Opsoclonus Myoclonus Ataxia Syndrome

RARE AWARENESS RADIO ENCORES

Welcome

to Rare Awareness Radio Encores, a publication committed to spotlighting individuals confronting and striving to overcome health disparities. Each issue features editorial summaries drawn from interviews with patients, caregivers, researchers, clinicians, and advocates whose work and lived experiences shed light rare disorders.

Our Host

Richard Juknavorian is an advocate for health equity and women's empowerment. In addition to hosting Rare Awareness Radio, he also hosts the podcast “Meeting You Where You're At”, highlighting the stories of inspiring women entrepreneurs.

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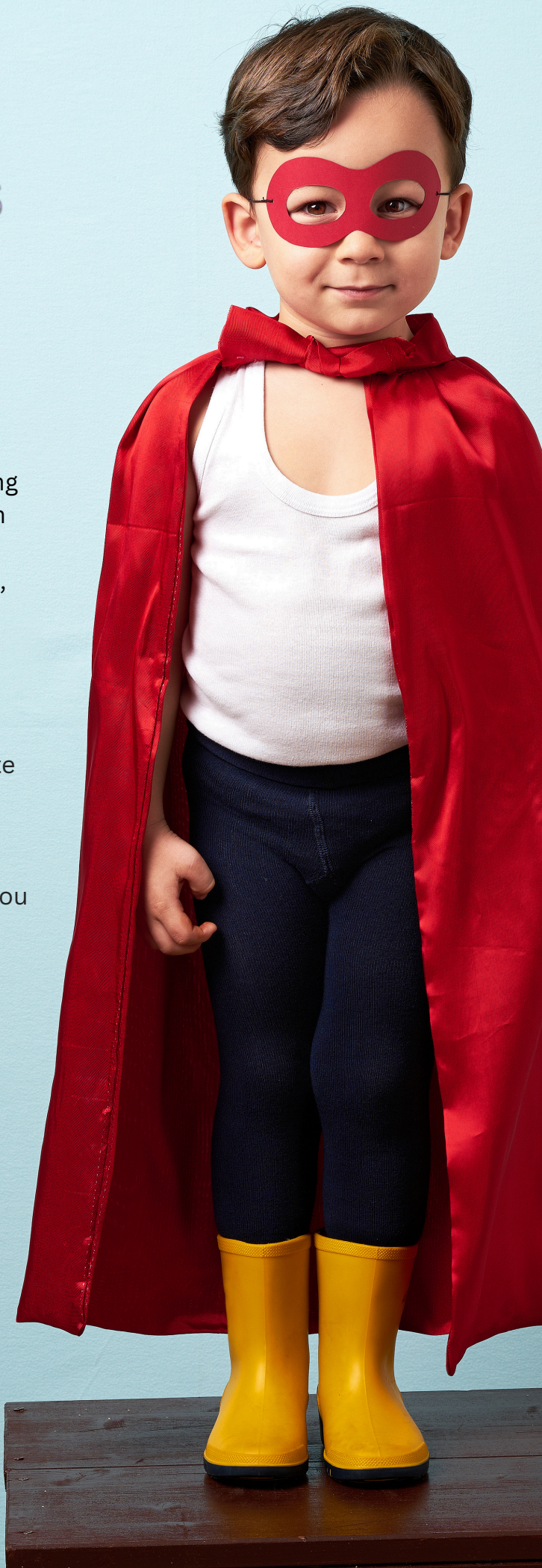

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THE PRICE OF A CUP OF

Coffee

CAN MAKE A **DIFFERENCE**

TAKE THE OMSLIFE COFFEE CHALLENGE

A brief Introduction

Opsoclonus Myoclonus Ataxia Syndrome

In this edition of Encores, you'll find personal stories from the OMAS community – their journeys and triumphs – and a shared mission of working towards a healthier tomorrow for everyone touched by this condition.

What is OMAS?

An ultra-rare, likely autoimmune-mediated neurological disorder that primarily affects young children. Affecting an estimated 1 in 5 million children worldwide annually, OMAS can lead to lifelong physical, behavioral, and cognitive impairments. Because of this, rapid diagnosis and early, aggressive treatment are crucial to minimize the disease's impact.

Diagnosing OMAS can be complex due to the varied presentation and onset of its symptoms. A diagnosis is typically made when a patient meets three out of four specific clinical criteria:

- Opsoclonus: Rapid, involuntary, multidirectional eye movements.
- Myoclonus or Ataxia: Sudden muscle jerks (myoclonus) or problems with coordination and balance (ataxia).
- Behavioral changes or sleep disturbances.
- Neuroblastoma (pediatric) or specific antineuronal antibodies (adult).

Treatment and Ongoing Care

Initial treatment for OMAS aims to halt the damage caused by the syndrome, primarily through immunosuppressive therapies. If a child with OMAS also has neuroblastoma, which occurs in over half of pediatric OMAS patients, the primary focus is on treating the tumor first. Interestingly, these chemotherapy treatments can also act as immune suppressants.

Even after initial treatment, more than half of individuals with OMAS will likely need ongoing care to help restore or manage their affected motor, cognitive, and behavioral functions. This often presents a challenge in coordinating care, as it typically involves multiple medical specialties.

Research and Community Efforts

Research is actively underway to deepen our understanding of OMAS, from its genetic and molecular mechanisms to its natural history, with the ultimate goal of determining optimal treatment approaches. Patient registries are pivotal to these efforts. They not only serve as a vital tool for collecting critical research data but also foster an engaged community dedicated to advancing treatment and improving outcomes for those affected by OMAS.

OMAS is also known as...

- Dancing Eye Syndrome
- Dancing Eyes-Dancing Feet Syndrome
- Kinsbourne Syndrome
- Opsoclonus Myoclonus Syndrome
- Opsoclonus Myoclonus Ataxia
- Paraneoplastic OMS (POMS)
- Paraneoplastic OMA (POMA)
- Neuroblastoma-Associated OMS
- Myoclonic Encephalopathy of Infants
- Infantile Polymyoclonia
- Postinfectious OMS

Disease Severity is assigned according to Mitchell-Pike Scale, which assigns values of 0 (normal) to 3 (severe) for each of the following functional domains: stance, gait, arm/hand function, opsoclonus, mood/behavior, and speech. Higher domain and aggregate values indicate greater clinical impact.

VIEWS & REVIEWS OPEN ACCESS

Diagnosis and Management of Opsoclonus-Myoclonus-Ataxia Syndrome in Children

An International Perspective

Thomas Rossor, PhD, E. Ann Yeh, MD, Yasmin Khakoo, MD, Paola Angelini, MD, Cheryl Hemingway, PhD, Sarosh R. Irani, MD, DPhil, Gudrun Schleiermacher, PhD, Paramala Santosh, PhD, Tim Lotze, MD, Russell C. Dale, PhD, Kumaran Deiva, PhD, Barbara Hero, PhD, Andrea Klein, PhD, Pedro de Alarcon, PhD, Mark P. Gorman, PhD, Wendy G. Mitchell, PhD, and Ming Lim, MD, PhD, on behalf of the OMS Study Group

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Abstract

Background and Objectives

Opsoclonus-myoclonus-ataxia syndrome (OMAS) is a rare disorder of the nervous system that classically presents with a combination of characteristic eye movement disorder and myoclonus, in addition to ataxia, irritability, and sleep disturbance. There is good evidence that OMAS is an immune-mediated condition that may be paraneoplastic in the context of neuroblastoma. This syndrome may be associated with long-term cognitive impairment, yet it remains unclear how this is influenced by disease course and treatment. Treatment is largely predicated on immune suppression, but there is limited evidence to indicate an optimal regimen.

Methods

Following an international multiprofessional workshop in 2004, a body of clinicians and scientists comprising the International OMS Study group continued to meet biennially in a joint professionals and family workshop focusing on pediatric OMAS. Seventeen years after publication of the first report, a writing group was convened to provide a clinical update on the definitions and clinical presentation of OMAS, biomarkers and the role of investigations in a child presenting with OMAS, treatment and management strategies including identification and support of long-term sequelae.

Results

The clinical criteria for diagnosis were reviewed, with a proposed approach to laboratory and radiologic investigation of a child presenting with possible OMAS. The evidence for an upfront vs escalating treatment regimen was reviewed, and a treatment algorithm proposed to recognize both these approaches. Importantly, recommendations on monitoring of immunotherapy response and longer-term follow-up based on an expert consensus are provided.

From the Children's Neurosciences (T.R., M.L.), Evelina London Children's Hospital at Guy's and St Thomas' NHS Foundation Trust, King's Health Partners Academic Health Science Centre; Department Women and Children's Health (T.R., M.L.), School of Life Course Sciences (SoLCS), King's College London, UK; Division of Neurology (E.A.Y.), Department of Pediatrics, Neurosciences and Mental Health (RI), The Hospital for Sick Children; Faculty of Medicine (E.A.Y.), The University of Toronto, Ontario, Canada; Department of Pediatrics (Y.K.) and Department of Neurology (Y.K.), Memorial Sloan Kettering Cancer Center, New York, NY; Department of Pediatrics (Y.K.), Weill Medical College of Cornell University, New York; Children and Young People's Unit (Paola Angelini), The Royal Marsden, Downs Road, Sutton, Surrey; UCL Great Ormond Street Institute of Child Health (C.H.), Department of Neurology, Great Ormond Street Hospital for Children, London; Oxford Autoimmune Neurology Group (S.R.I.), Nuffield Department of Clinical Neurosciences, University of Oxford; Department of Neurology (S.R.I.), Oxford University Hospitals NHS Foundation Trust, UK; SIRIC RTOP (G.S.), Translational Research Department, PSL Research University, Institut Curie Research Center; INSERM U830 (G.S.), PSL Research University, Institut Curie Research Center; SIREDO Center: Care (G.S.), Innovation and Research for Children, Adolescents and Young Adults with Cancer, Institut Curie, Paris, France; Department of Child and Adolescent Psychiatry (P.S.), King's College London; Centre for Interventional Paediatric Psychopharmacology and Rare Diseases (CIPPRD) Research Team (P.S.), South London and Maudsley NHS Foundation Trust, London, UK; Baylor College of Medicine (T.L.), Texas Children's Hospital, Houston; Kids Neuroscience Centre (R.C.D.), The Children's Hospital at Westmead, Westmead, NSW, Australia; TY Nelson Department of Neurology and Neurosurgery (R.C.D.), The Children's Hospital at Westmead; The Children's Hospital at Westmead Clinical School (R.C.D.), Faculty of Medicine, University of Sydney, NSW, Australia; Pediatric Neurology Department (K.D.), Assistance Publique-Hôpitaux de Paris, Hôpitaux Universitaires Paris Saclay, Bicêtre Hospital; National Referral Center for Rare Inflammatory and Auto-Immune Brain and Spinal Diseases (K.D.); Inserm UMR 1184 (K.D.), Immunology of Viral Infections and Autoimmune Diseases, CEA, IDMIT, Le Kremlin Bicêtre, France; Department of Pediatric Hematology and Oncology (B.H.), University Children's Hospital, Koln; Division of Child Neurology (A.K.), University Children's Hospital Bern Inselspital, University of Bern; Department of Pediatric Neurology (A.K.), University Children's Hospital Basel, Switzerland; Department of Pediatrics (Pedro de Alarcon), University of Illinois College of Medicine at Peoria, Peoria IL; Department of Neurology (M.P.G.), Boston Children's Hospital, Harvard Medical School, MA; Division of Neurology (W.G.M.), Department of Pediatrics, Children's Hospital Los Angeles; and Department of Neurology (W.G.M.), Keck School of Medicine at the University of Southern California, Los Angeles.

Go to Neurology.org/NN for full disclosures. Funding information is provided at the end of the article.

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OMS Study Group coinvestigators are listed in the appendix at the end of the article.

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A Few Historical Milestones

1913 *- Neurologist Kazimier Orzechowski describes chaotic eye movements in neurologic disorders as opsoclonus.*

1962 *- Marcel Kinsbourne, an Oxford-trained pediatric neurologist, publishes a description of 6 cases of Myoclonic Encephalopathy of Infants, latter to be known as OMAS. This pivotal study established OMAS as a distinct neurological disorder.*

2004 *- Significant advancements were made at a workshop on Dancing Eyes Syndrome during the Advances in Neuroblastoma Meeting in Genoa, Italy, where the OMAS diagnosis criteria and disease-severity scale were established. These standardized definitions enabled physicians across different institutions to use the same criteria, greatly enhancing cross-institute collaborations and accelerating our understanding of OMAS.*

2016 *- The OMSLife Foundation and the National Organization of Rare Disorders (NORD) establish the first patient & caregiver-based OMAS Natural History Study.*

2017 *- OMAS specialist Michael Pranzatelli and coauthors publish their findings on nearly 400 affected individuals, cementing the need for early diagnosis and initiation of treatment and shedding light on neuroblastoma prevalence & immunological features. DOI: 10.3389/fneur.2017.00468*

2018 *- International Research Network of 8 clinical sites enroll first patient into the pediatric-onset opsoclonus-myoclonus ataxia syndrome (POOMAS) registry.*

2022 *- International OMAS experts publish guidance on OMAS clinical presentation, potential biomarkers, treatment, and management.*

2025 *- The 11th International Workshop on OMAS highlights ongoing research of OMAS relapses, cerebellar atrophy, eye tracking, biomarker assessments, whole genome sequencing, patient outcomes, and care patterns.*

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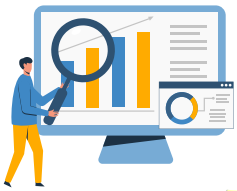
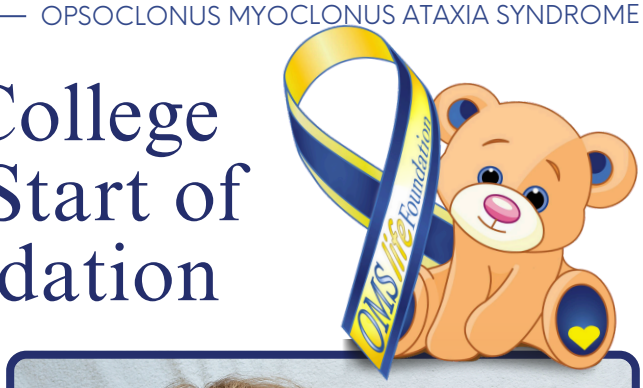


The OMSLife Foundation

Our mission is to raise awareness of Opsoclonus Myoclonus Ataxia Syndrome, maintain a support network for caregivers, and fund research for a cure.

A Grandfather, a College Roommate, & the Start of 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 ataxia syndrome (OMAS). This pivotal moment sparked the creation of the OMSLife foundation.

For thirty days following the sudden loss of Alexa's motor functions, the Michaelis family shared their story with anyone who would listen, hoping to find someone who might have an answer. Those efforts paid off when Mike's brother-in-law contacted a former college roommate, Dr. Gilbert, a pediatric neurologist at Cincinnati Children's Hospital. The neurologist suggested it might be an ultra-rare disease called OMAS. "Not only did he help diagnose it," Mike shared, "but he said, 'I've already contacted a colleague at Texas Children's Hospital, they will be waiting for you.'"

OMAS is an ultra-rare, likely immune-mediated, neurological disorder that primarily affects young children, with a median onset around 20 months.

A little over 24 hours after this connection, Dr. Wilfong, a pediatric neurologist at Texas Children's, confirmed the OMAS diagnosis. While the diagnosis brought relief, it also came with anxiety and a determination to do more. "The first thing my daughter said was we need to pray for this baby," recalled Mike. "The second thing she said was, we need to do something about this so that other families don't [have to go through the same pain]."

From Television to Teddy Bears

Six months after Alexa's OMAS diagnosis, the family was contacted by a publicist in New York representing the television show "Mystery Diagnosis." The producers were interested in featuring Alexa's story to raise awareness about the rare condition, which proved to be prophetic. After the show, the family received outreach from people across the country affected by or seeking information about OMAS. In response, the Michaelis Family created an online community via Facebook, which was followed less than a year later by formalizing OMSLife as a 501(c)(3) non-profit.

A key initiative for OMSLife has been educating frontline medical staff about OMAS, which started as part of their teddy bear drives to comfort pediatric patients. Held across the country, OMSLife-coordinated volunteers visit local hospitals and hand out teddy bears to children and connect with medical staff. "We'd hand out teddy bears on the various floors," Mike shared, "but I'd also give pins, notepads, wristbands, and bling to the nurses and doctors, saying, 'Do you know what OMAS is? Do you know how to

diagnose it?'"

Face-to-Face Connections

As the OMAS community grew, so did the interest in doing more for patients and caregivers. In 2014, OMSLife began caregiver conferences, providing a rare opportunity for families affected by OMAS to come together, share experiences, and learn from leading specialists. These conferences have been instrumental in building a sense of community and support for caregivers, who often feel isolated due to the rarity of the condition. "It's not only about the presentation of the materials," said Mike, "but it's actually about the connection of the patients and the caregivers. One of the caregivers came up to me after the conference and said, 'This is the first time in 10 years I had physically met another person that could relate to what we were going through.'"

> **"One year at a drive at a regional hospital, I asked a nurse if she knew what OMAS was, and she said, 'Not only do I know what it is, but I also helped diagnosis a case last week. You guys did the teddy bear drive last year and you stopped to explain OMAS to me."**

Seeking Knowledge

Continuing in the quest to educate others about OMAS 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 OMAS, from the initial symptoms to the obstacles encountered as patients age and their care needs change. OMSLife has also been central to connecting researchers and physicians, through co-sponsorship of the biennial Workshop on OMAS with Dancing Eyes Syndrome Support Trust (DESST) 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 OMAS, with the goal of providing more consistent and accessible care for all those affected.

Mike Michaelis, a retired IT executive from a Fortune 500 company and entrepreneur, is founder and president of The OMSLife Foundation, a registered 501(c)(3) organization.

Established to provide a global support system for those affected by OMAS, the OMSLife Foundation works to increase public awareness and raise crucial funds for research. To learn more, please visit https://omslifefoundation.org/.

OMS life Foundation

The recorded interview is available on Soundcloud, Apple, Spotify, Audible, Amazon, iHeartRadio and YouTube, with links to each provided at https://rareawarenessradio.org/ and https://www.principledresources.com/.

ABOUT THE OMS *life* Foundation LOGO

A TEDDY BEAR HOLDING A BLUE & YELLOW RIBBON

In 2009, the founder's granddaughter was admitted to Texas Children's Hospital in Houston for diagnosis and treatment of OMAS. While there, a little girl in the room next door was hospitalized due to an abusive situation. CPS did not allow any visitors and the child was crying out for her Mom. The founder went to the hospital gift shop and bought two stuffed animals; one for his granddaughter and one for the child next door. The teddy bear helped the child to feel less alone. The founder decided to begin an annual teddy bear drive for patients in childrens' hospitals. Over the years, volunteers throughout the US delivered thousands of toys and teddy bears to hospitalized kids. In 2010 as they began development of OMSLife, they decided that the teddy bear holding the blue (for neurology) and gold (for cancer) ribbon represented their call to help the young OMAS warriors.

OMAS NATURAL HISTORY REGISTRY

JOIN THE REGISTRY

OMS.IAMRARE.ORG

WHAT IS A NATURAL HISTORY REGISTRY?

A natural history registry captures real-world experiences from patients, caregivers, & sometimes clinicians. Unlike clinical trials, it observes the disease, treatments, and patient outcomes as they unfold in normal care, providing insight into opportunities and successes not possible otherwise.

In 2017, The OMSLife Foundation and NORD (The National Organization of Rare Disorders) launched the OMAS Natural History Registry. As of 2025, 470 patients or caregivers had registered.

UPDATING THE REGISTRY:

In 2024, The OMSLife Foundation began the process of updating the registry to NORD's new platform with Version 2.0. The new platform is mobile friendly and allows for easier completion of surveys. The foundation also made significant updates to the surveys available, in order to reduce participant fatigue by eliminating duplicate questions and those that are irrelevant to the patient population.

ORIGINAL SURVEYS

Participant Profile/Demographics
Onset and Diagnosis
Therapy
Treatment and Review of Systems
Medical and Diagnostic Data
Family history
Relapse
Quality of Life
Treatment of OMS
Education

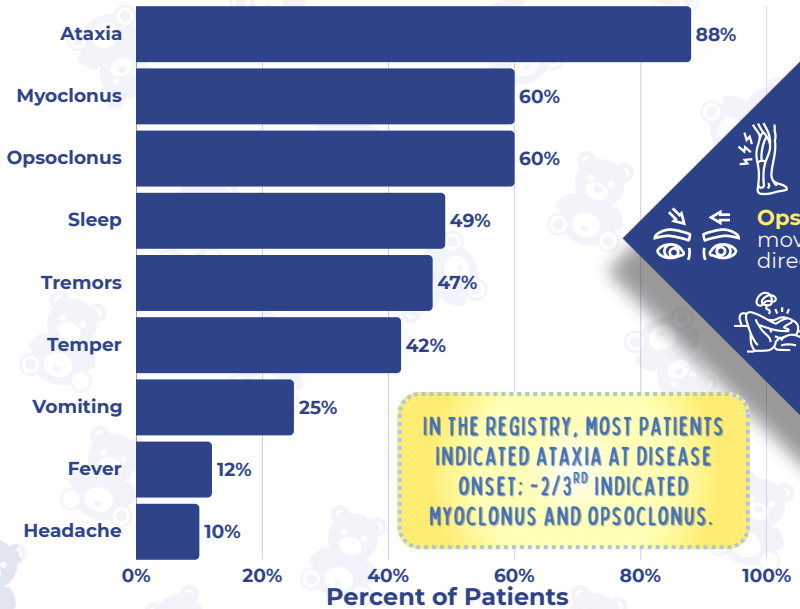
*Surveys with slightly different names that appear on both lists have since been edited and updated but still cover the same topics.

UPDATE TO VERSION 2.0

Demographics
Onset and Diagnosis
OMAS Adult
OMAS Triggers
Therapies for OMAS
Treatment + Review of Systems
Medical + Diagnostic Data
Family Medical History Survey
Vaccinations Survey
Sleep Habits
Neuroblastoma + Precocious Puberty
Teenager + Young Adult
Relapse Survey

THE NAMESAKE SYMPTOMS OF OPSOCLONUS, MYOCLONUS, AND ATAXIA VARY IN TIMING AND SEVERITY FOR DIFFERENT INDIVIDUALS, WHICH CAN LEAD TO MISDIAGNOSIS OF OMAS AS OTHER MORE COMMON DISORDERS.

SIGNS & SYMPTOMS AT ONSET



IN THE REGISTRY, MOST PATIENTS INDICATED ATAXIA AT DISEASE ONSET: ~2/3RD INDICATED MYOCLONUS AND OPSOCLONUS.

SIGNS & SYMPTOMS

Ataxia: unsteady gait or loss of ability to stand and walk (ataxia)

Myoclonus: brief, repeated, shock-like spasms of several muscles within the arms and legs or tremor interfering with hand use.

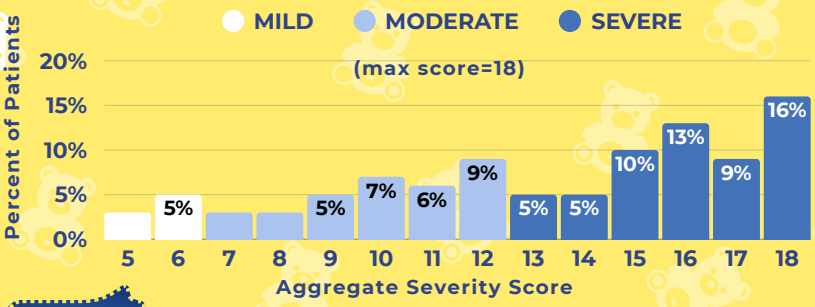
Opsoclonus: Repeated, random and rapid eye movements in both horizontal, vertical and diagonal directions

Behavioral and sleep disturbances: including extreme irritability, inconsolable crying, reduced and fragmented sleep (insomnia) and rage attacks are common.

Dysarthria: Difficulty articulating speech sometimes with complete loss of speech and language may occur.

Additional symptoms such as decreased muscle tone (hypotonia) and vomiting, and fever are common.

PATIENTS BY AGGREGATE OMAS SEVERITY SCORE



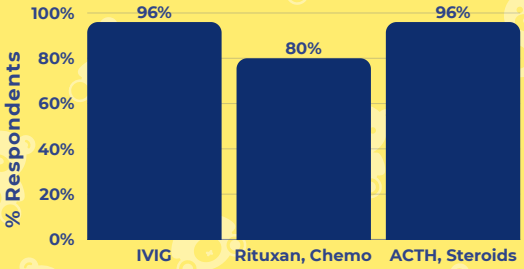
AT DIAGNOSIS, MOST OF THE INDIVIDUALS WERE INDICATED AS HAVING SEVERE DISEASE.

THE MITCHELL-PIKE SEVERITY SCALE

The Mitchell-Pike OMAS Severity Scale classifies OMAS cases as mild (0-6), moderate (7-12), or severe (13-18). The aggregate score is based on 6 individual assessments, with a score of 0 (normal) to 3 (severe impairment or state) assigned individually for:

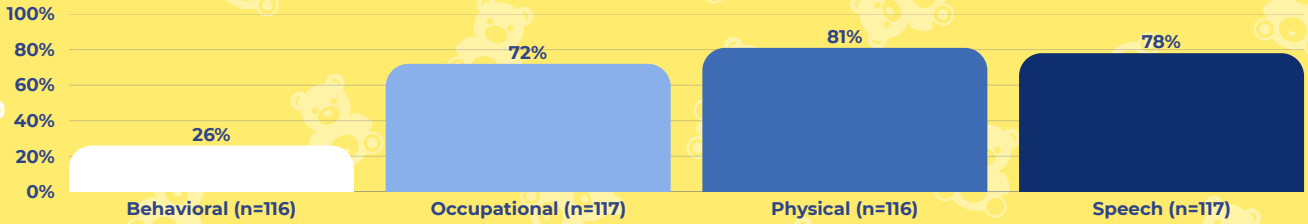
- stance
- gait
- speech
- opsoclonus
- mood/behavior
- arm/hand function

RESPONDENTS INDICATED BROAD USE OF IMMUNOSUPPRESSIVE THERAPIES – INTRAVENOUS IMMUNOGLOBULIN (IVIG), STEROIDS, ADRENOCORTICOTROPIC HORMONE (ACTH), RITUXIMAB, AND CHEMOTHERAPIES – FOR THE TREATMENT OF OMAS.



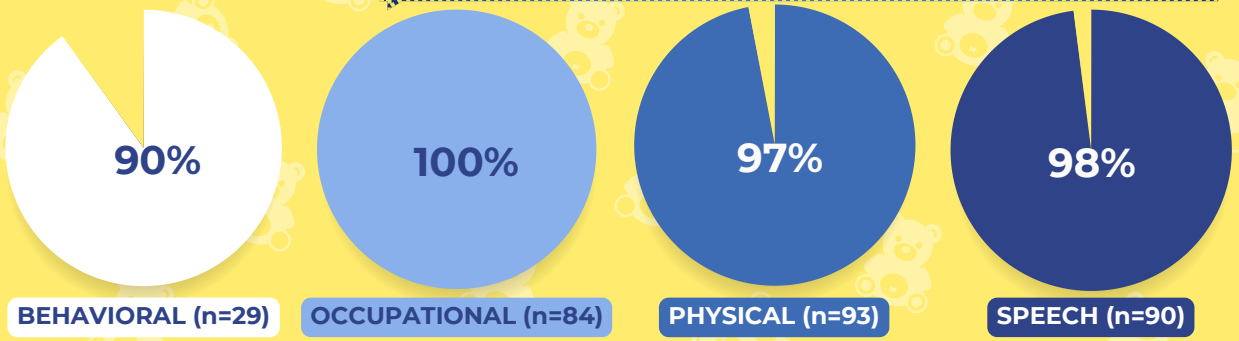
BEYOND PHARMACOLOGIC AGENTS, MOST PATIENTS ALSO REQUIRED YEARS OF PHYSICAL, OCCUPATIONAL, SPEECH, AND/OR BEHAVIORAL THERAPIES.

PERCENT OF PATIENTS RECEIVING EACH THERAPY TYPE

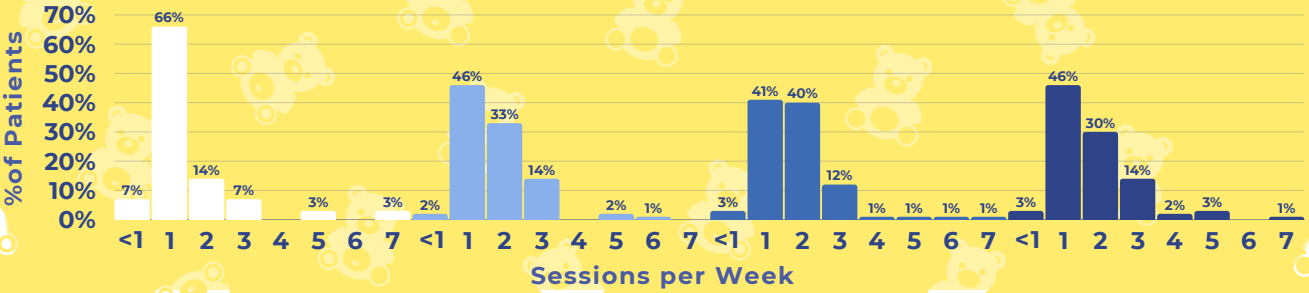


PERCENT OF PATIENTS WHO FOUND THERAPY TO BE BENEFICIAL BY TYPE OF THERAPY

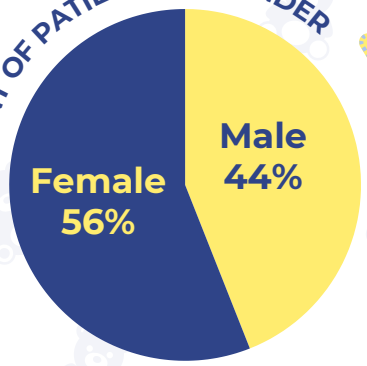
THESE NON-PHARMACOLOGIC TREATMENTS WERE OVERWHELMINGLY VIEWED AS BENEFICIAL.



FREQUENCY OF THERAPY BY TYPE



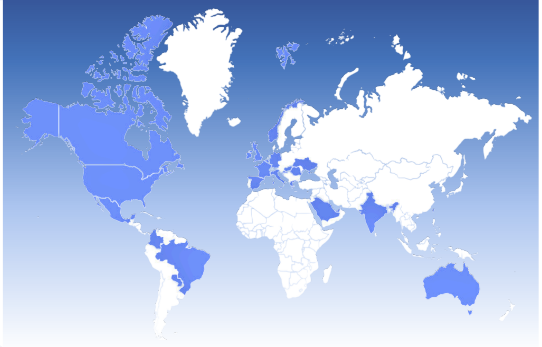
PERCENT OF PATIENTS BY GENDER



OMAS TENDS TO IMPACT FEMALES MORE THAN MALES.

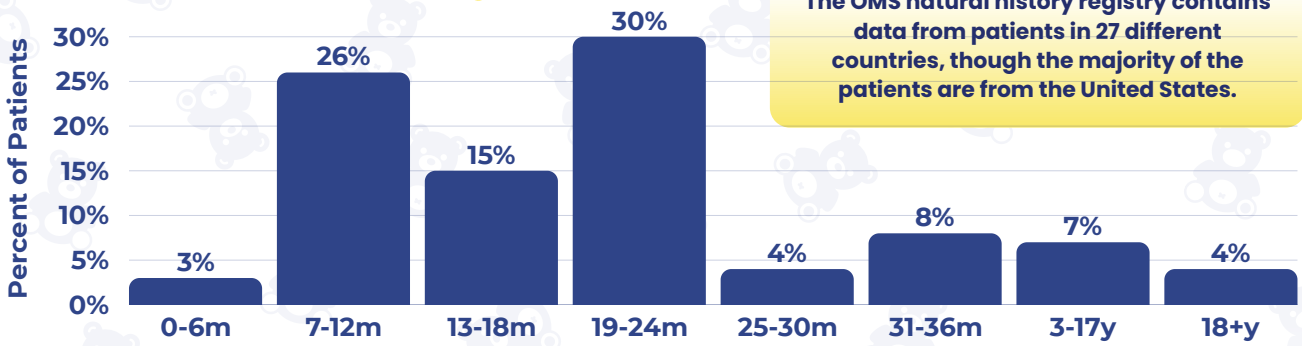
WHILE OMAS IS PRIMARILY A PEDIATRIC DISEASE, 4× INDICATED DIAGNOSIS AS ADULTS.

WORLD REPRESENTATION



The OMS natural history registry contains data from patients in 27 different countries, though the majority of the patients are from the United States.

PATIENT AGE AT DIAGNOSIS



SEE MORE FROM THE REGISTRY:

INAUGURAL PATIENT-REPORTED REGISTRY OF PEDIATRIC OPSOCLONUS-MYOCLONUS-ATAXIA SYNDROME: PRESENTATION, DIAGNOSIS, AND TREATMENT OF 194 PATIENTS

HTTPS://DOI.ORG/10.1016/J.PEDIATRNEUROL.2024.06.007

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A CALL TO ACTION

Bhavna Sivanand Dias' connection to Opsoclonus Myoclonus Ataxia Syndrome (OMAS) began when her daughter, Amara, just shy of 18 months old, began exhibiting a tremor in her leg. What followed was an emotionally draining journey through emergency rooms and neurology departments.

Initial tests came back negative, and despite Amara's rapid deterioration – the tremor spreading, her ability to walk vanishing, and her sleep becoming a nightmare – the catch-all diagnosis of acute cerebellar ataxia offered no real answers, just a directive to "wait and see."

A week of EEGs, blood draws, MRIs and numerous other tests as an in-patient at the hospital failed to provide insight. A day after release, Amara developed a new troublesome symptom of erratic eye movements. Convinced this was an indicator of a more serious condition, Bhavna immediately called the hospital only to be told that these symptoms did not change the diagnosis.

Undeterred, Bhavna and her husband relentlessly pursued answers online, finally stumbling upon another family's story of a child with similar symptoms, including opsoclonus, the hallmark random eye movement of OMAS.

The possibility of OMAS brought a new concern, as this rare autoimmune disorder is often associated with a tumor. With this new information, and an informed neurologist, the official diagnosis of OMAS was made. The search for a tumor began, albeit unsuccessfully with no indication of a mass via ultrasound and MRI. A subsequent test involving a radioactive tracer detected a tumor behind her liver. An odd and brief sense of relief washed over Bhavna and her husband, "We've identified the cause… now we [are] parents of a child with cancer."

Upon tumor detection, preparations for surgery began immediately, as the tumor's location required a complex procedure involving a liver transplant specialist. By the time surgery day arrived, Amara's condition had deteriorated to a critical state—she was unable to communicate or even lift her head.

After the successful surgery, the journey shifted to recovery with ongoing treatment for OMAS – a regimen of immune suppression including donor antibodies,

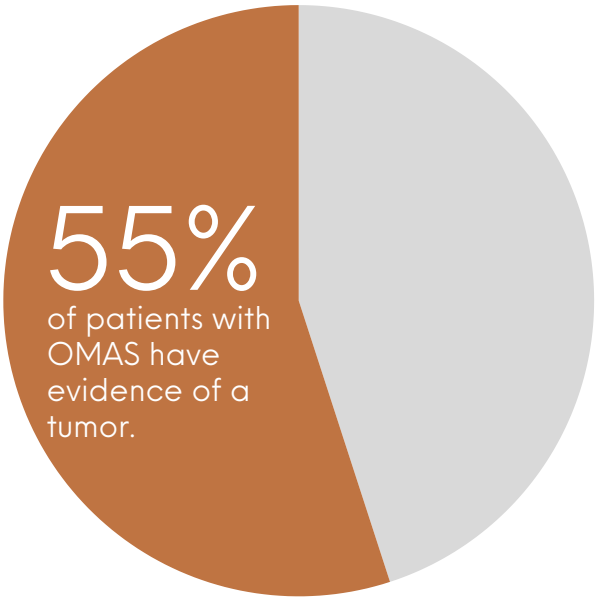
steroids, and rituximab. For 20 long months, Bhavna and her husband dedicated themselves to Amara's care. It wasn't until her second birthday that Amara began to walk again, followed by the arduous process of relearning everything - crawling, climbing, talking.

Finding Community

During this most challenging period of Amara's illness, Bhavna discovered the OMAS community on Facebook and connected with other parents who truly understood her journey. These initial connections provided crucial emotional support during a time when she felt isolated and overwhelmed.

> ***When we were in the trenches with Amara... we had a great network of friends that showed up for us, but we also felt completely isolated because we didn't have anybody that understood what we were going [through].***

Bhavna's background in public health also proved invaluable, as she meticulously researched treatment options and advocated for her daughter's care.



Pediatr Neurol. 2024 Sep;158:128-134. doi: 10.1016/j.pediatrneurol.2024.06.007.

Now in remission, Amara's resilience and recovery have inspired Bhavna to become a passionate advocate for the OMAS community. Witnessing the delays, the lack of awareness, and the sheer rarity of OMAS ignited a desire to help others navigate this challenging terrain.

"We feel like we are one of the lucky ones," she explains, acknowledging that many families face even longer and more difficult treatment journeys.

Heeding the Call

Bhavna and her husband are unwavering in their commitment to supporting families affected by OMAS. As an integral member of the OMSLife Foundation's International Steering Committee, Bhavna collaborates closely with founder Mike Michaelis to advance research initiatives and create resources tailored for OMAS families. She actively stays informed on the latest developments in OMAS treatment by attending specialist conferences in England and plays a pivotal role in organizing caregiver conferences in Los Angeles.

Drawing on her extensive background in public health, rooted in evidence-informed decision-making and policy work, she assisted in successfully advocating for the establishment of California's Rare Disease Advisory Council (RDAC), a vital step toward amplifying the voices of the rare disease community at the state level.

Beyond this achievement, Bhavna is spearheading efforts to develop comprehensive resources for families, including a curated list of OMAS-experienced providers and advocacy for increased research funding. Bhavna deeply understands the challenges OMAS families endure, such as the ever-present fear of relapse and the intricate maze of navigating healthcare systems for ultra-rare conditions. She often highlights how parents are forced to become custodians of crucial, nuanced information, as standardized protocols frequently fall short. By sharing Amara's journey, Bhavna hopes to inspire other parents to join her in transforming personal struggles into a powerful collective voice, driving meaningful change for OMAS families worldwide.

> ***You never really know why things happen the way they do, but after she got better, we realized it's because we need to help, we need to stay involved... we have the capacity to help others.***

Bhavna Sivanand Dias is the Executive Director of the UCLA Center for Social Impact, rare disease advocate, and mother to a child with OMAS. In a recent interview with Rare Awareness Radio, Bhavna shared her family's personal journey and her efforts to use her public health and policy expertise to advocate for others navigating the complexities of rare diseases.

The recorded interview is available on Soundcloud, Apple, Spotify, Audible, Amazon, iHeartRadio and YouTube, with links to each provided at https://rareawarenessradio.org/ and https://www.principledresources.com/.

OMSLIFE CAREGIVER'S CONFERENCE

Saturday, Oct 18, 2025 – Sunday Oct 19, 2025
Los Angeles Marriott Burbank Airport
2500 North Hollywood Way Burbank, CA 91505

GET YOUR TICKETS NOW!

To register for the conference, go to

www.eventbrite.com/e/2025-omslife-caregiver-conference-los-angeles-tickets-1059699231929?aff=oddtdtcreator

Hotel information at

www.marriott.com/event-reservations/reservation-link.mi?id=1729891604317&key=GRP&guestreslink2=true

or visit our website at omslifefoundation.org
Early Registration ends April 30, 2025

*You must **register** to attend.*
Attendees must be high school age or older.

INSTILLED VALUES:
A Family's OMAS Journey

Diagnosed with OMAS at 36 months old, Zeke Zaragoza faced an arduous four-year stretch of intensive therapies, painful treatments, and persistent rehabilitation. By age seven, he had not only entered remission but reclaimed the motor functions suddenly lost in toddlerhood. With the steady support of his family and care team, he began participating in sports once thought out of reach. Now 24, Zeke and his mother Chanin channel their journey into advocacy, uplifting others navigating the uncertainty of rare disease.

What began as a seemingly normal childhood for Zeke Zaragoza quickly descended into a nightmare of dizziness, uncontrolled movements, and a debilitating loss of motor skills. The first signs of trouble emerged when Zeke was barely 3 years old. "He just started having some strange symptoms where he was dizzy and would walk sideways and hit the wall," recalls his mother, Chanin. "He would complain that the wind was moving him as if he was outside, or ask 'Why is the room moving?'"

Desperate for answers, Zeke's parents sought medical attention, only to be met with a general diagnosis of vertigo. But a mother's intuition was telling Chanin that something more serious was at play. The search for a proper diagnosis led the family on a journey that would ultimately take them to Cedars-Sinai Medical Center in Los Angeles. There, a team of 25 neurologists finally provided the answer they had been seeking: Opsoclonus Myoclonus Ataxia Syndrome (OMAS).

OMAS, a condition characterized by uncontrolled eye movements, muscle spasms, and balance issues, had robbed Zeke of his independence. "He wasn't able to walk, to sit up," Chanin recounts.

The next four years proved to be arduous for Zeke, who underwent a grueling regimen of treatment that included ACTH shots, IVIG therapy, and extensive physical and occupational therapy. "He had to do his IVIG monthly and undergo chemotherapy," Chanin explains. "He had about two and a half years of physical therapy and occupational therapy." Zeke went from living a normal life to being a child who could no longer feed himself, drink from a cup, or stack one block on top of another. Remastering these most basic tasks was a daunting challenge.

Maintaining Certainty in Uncertain Times

During this four-year period, Zeke's parents worked hard to maintain normalcy. This included allowing his next older brother to come in and play during Zeke's therapy sessions. Outside of the care setting, Chanin carved out days for each of Zeke's brothers and ensured they were able to continue in their activities. "And thankfully," Chanin said, "they have godparents who were able to help out with them, take them to school, and do things with them." As importantly, the family was determined not to treat Zeke differently or "make excuses for him" as Zeke worked towards recovery.

Throughout this time, there was a message that this struggle was an opportunity. "Probably around first grade," Zeke recalls, "more and more my mom just continued to embed, 'God gave you a story, use it', and I love that she continues to say that I have a story, and I can use this story for good."

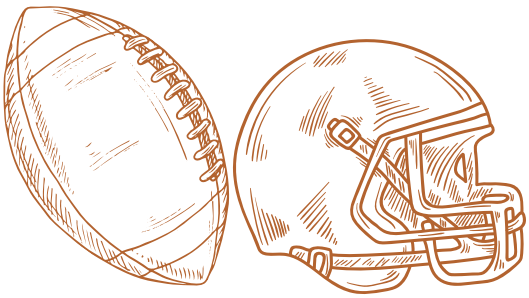
For the Greater Good

When Zeke was younger, Chanin was the one sharing his story and connecting to other families. As Zeke grew older, Chanin said she handed "him the reins and allowed this to be his story, to really embrace, and tell, and be responsible for."

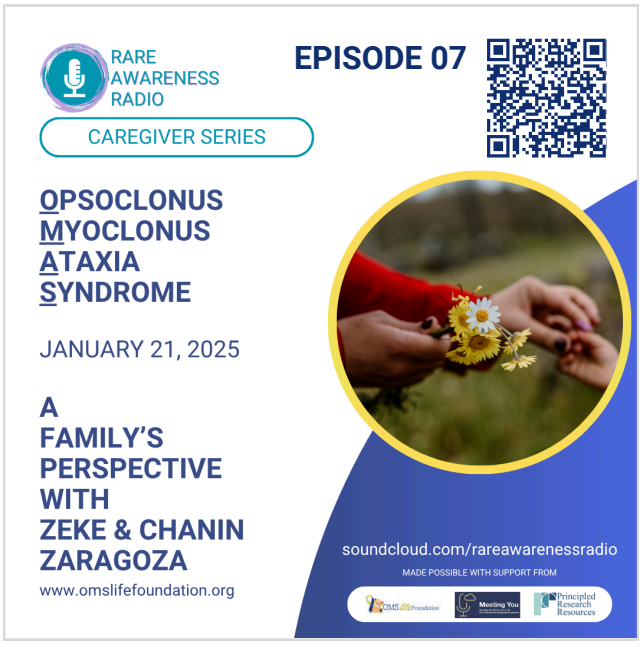
Zeke's story continued to blossom - he excelled in sports, particularly football, eventually playing at Oklahoma State University. The inspiring story of a child, once dependent upon a wheelchair, playing Division 1 sports, caught the interest of national media. Since that time Zeke has used this attention to raise awareness about OMAS and inspire others.

Zeke now leverages social media to connect with and build relationships with other families battling OMAS. In reaching out to children, he provides encouragement but also proof that a brighter future is possible. "And it's awesome because, you know, their parents say that I make their day, but really, you know, they're making mine."

The recorded interview is available on Soundcloud, Apple, Spotify, Audible, Amazon, iHeartRadio and YouTube, with links to each provided at https://rareawarenessradio.org/ and https://www.principledresources.com/.



Zeke and Chanin continue connecting with families battling OMAS and advocating for care. They are looking forward to meeting other families and researchers in person when they attend the OMSLife Caregiver's Conference in October of 2025, where they will be Keynote speakers.



Did You Know?

OMSLife is currently leading a sleep study based on the Children's Sleep Habits Questionnaire (CSHQ)

Our intent is to use this information to gain insight on whether OMAS patients face increased difficulties with sleep during active OMAS, as well as look for connections to behavioral issues.

Join Our Registry at oms.iamrare.org

"I THINK [ELLERY] HAS AN UNDERSTANDING THAT A LOT OF KIDS DON'T... PEOPLE ARE GOING THROUGH THINGS... SHE UNDERSTANDS THAT THERE'S DIFFERENT PATHS FOR PEOPLE.... BUT SHE'S HAPPY AND BUBBLY AND HAS FRIENDS AND LOVES PLAYING AND PRETENDING. AND THAT'S BEAUTIFUL."

Hindsight makes the subtle red flags seem obvious. But during the toddler years— especially when a first child—distinguishing between normal developmental setbacks and something more concerning isn't always clear. A missed milestone or a temporary regression can easily be dismissed as part of the unpredictable journey of childhood.

That uncertainty was exactly what **Maura McNamara** faced when her daughter, Ellery, began losing abilities she had already gained. Initially, the decline seemed linked to a bad fall—a possible concussion. When the pediatrician was unable to pinpoint any classic concussion symptoms, Maura's worry deepened. Ellery became clumsier, bumping into things more often, struggling with sleep.

Seeking answers, the family took Ellery to Boston Children's Hospital, where she underwent an MRI and a spinal tap. The doctors decided to monitor her over the weekend, with a diagnosis of acute cerebellar ataxia. After three days, she was discharged—no improvement, but no decline either. Maura and her husband were told that within two weeks, Ellery should begin to recover.

But improvement never came. Instead, Ellery's condition deteriorated rapidly. Ellery's hands began to tremble so severely she could no longer use them, and her speech slowed and became increasingly labored. Soon after, she began experiencing prolonged rage episodes—"toddler tantrums times a million," as Maura described them. These were not typical outbursts; they lasted for hours and were marked by intense physical aggression, obsessive-compulsive behaviors, and extreme emotional volatility. The episodes were both unpredictable and all-consuming, profoundly disrupting daily life for the entire family.

Sleep became nearly impossible—not just for Ellery, but for her parents. The only way Ellery could rest was by lying directly on top of her mother. "We'd descended into chaos at this point," Maura recalled. The family took time off work, unable to leave their apartment, trapped in uncertainty—one of the lowest moments of their parenthood journey.

Despite continued diagnoses of acute cerebellar ataxia, doctors gave them one crucial instruction: if Ellery began exhibiting uncontrolled eye movements—rapid, erratic flickering—they needed to call

immediately.

A few weeks after their stay at Boston Children's, Maura lay beside her daughter, trying to offer comfort. That's when she saw it. Ellery's eyes flickered, darting unpredictably, dancing back and forth. At first, Maura questioned whether she was imagining it. She turned to her husband, Brad, asking him to confirm what she was seeing. They captured a video and sent it to the on-call neurologist. The response was immediate: Get to the ER right away. The next morning, they had an answer—Opsoclonus Myoclonus Ataxia Syndrome (OMAS).

THE START OF TREATMENT

Once Dr. Mark Gorman, a specialist at Boston Children's Hospital, confirmed Ellery's OMAS diagnosis, an intensive treatment protocol began, involving steroids and immunoglobulin therapy. The family's life became structured around four-week treatment cycles, with Maura and Brad becoming expert caregivers. The COVID-19 pandemic added another layer of complexity, forcing them to be even more isolated and cautious due to Ellery's compromised immune system.

As treatment continued through the pandemic, the original two-year estimate expanded to five. Physical, occupational, and behavioral therapies were added. During this time, Maura and her husband sought answers through online resources and the OMAS community. Maura remembers reading books about children undergoing medical journeys, hoping to prepare for what lay ahead. But no books were available specifically on OMAS. That realization sparked an idea: What if she could create something herself?

OMAS SYMPTOMS VARY IN ONSET AND SEVERITY, BUT ATAXIA—DIFFICULTY WITH BALANCE AND COORDINATION—IS OFTEN THE FIRST SIGN, DESPITE OPSOCLONUS (INVOLUNTARY EYE MOVEMENTS) BEING DIAGNOSTIC.

BECAUSE ATAXIA ALSO DEFINES ACUTE CEREBELLAR ATAXIA (ACA), WHICH IS 50 TIMES MORE COMMON THAN OMAS, MISDIAGNOSIS IS FREQUENT. UNLIKE TYPICALLY SELF-LIMITING ACA, OMAS REQUIRES PROMPT, INTENSIVE IMMUNOTHERAPY TO PREVENT LONG-TERM COGNITIVE AND MOTOR IMPAIRMENTS.

ELLERY THE BRAVE CELERY

Maura wanted a way to capture both the complexity and resilience of a child's journey with OMAS—something kid-friendly and meaningful for adults. What began as a personal story about Ellery evolved into a whimsical world where "Ellery the Brave Celery" navigates Veggieland, meeting vibrant characters who reflect the reality of her experience in a way children can understand. The book blends a serious medical condition with playful storytelling—helping newly diagnosed families process the experience while keeping the heart of the journey accessible.

Ellery herself played a key role in shaping the book, contributing original artwork and ensuring her little sister was included in the world she created. With the support of the OMSLife Foundation, the book will be distributed to newly diagnosed families as part of an essential resource packet—offering not just medical insight, but a story that connects, informs, and reassures.

THE NEXT CHAPTER

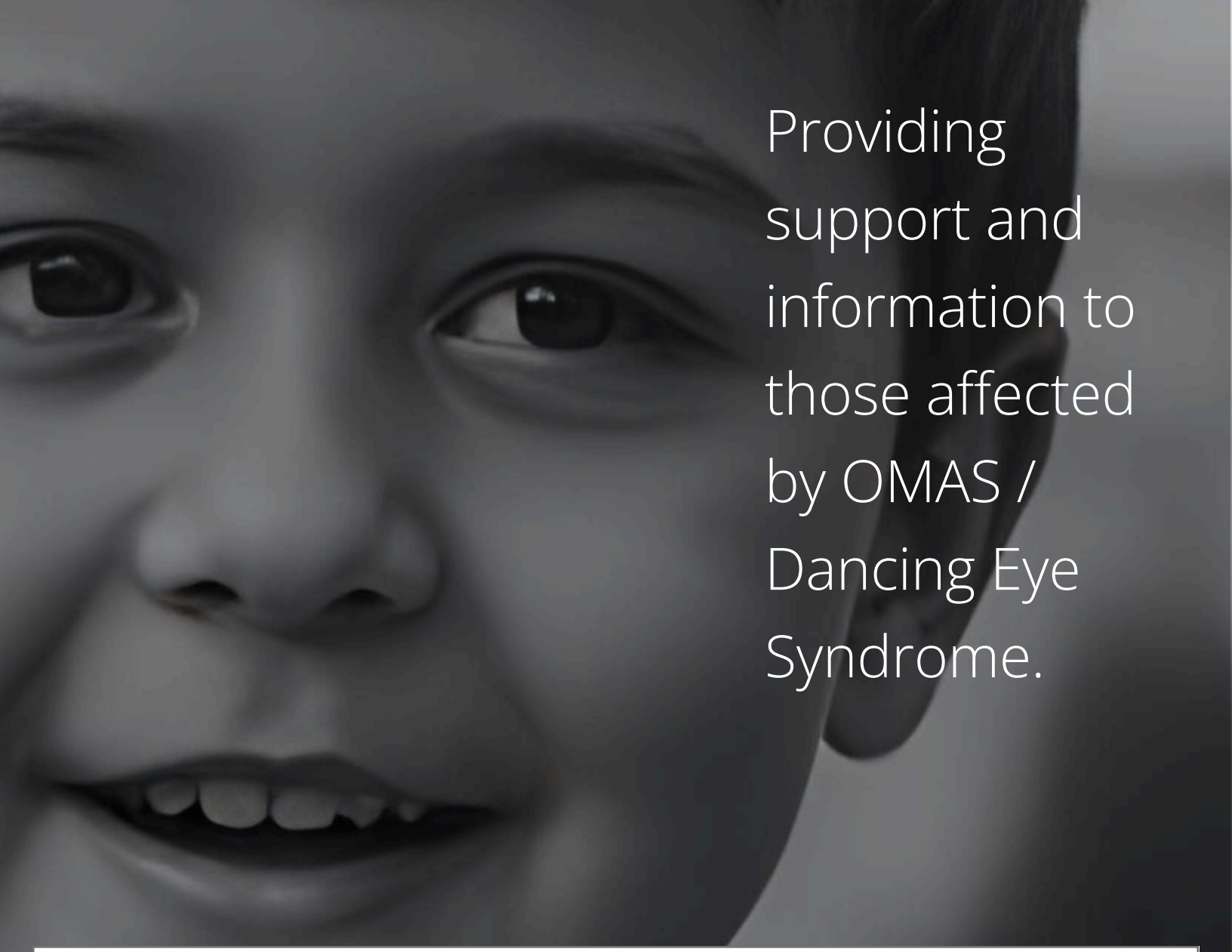
Now in third grade, Ellery has made remarkable progress. She thrives in a neurodiverse classroom with an extensive Individualized Education Plan (IEP), navigating academic challenges while building meaningful friendships. Though learning delays and the lasting effects of her diagnosis require careful planning, her family remains steadfast in ensuring she has the support to succeed.

Ellery approaches life with resilience and embraces her role as a caring big sister. When reflecting on challenges faced, Maura shared, "I think [Ellery] has an understanding that a lot of kids don't... people are going through things... she understands that there's different paths for people.... but she's happy and bubbly and has friends and loves playing and pretending. And that's beautiful."

Maura's book, Ellery the Brave Celery, is available on Amazon.

Maura McNamara is the Executive Director of the Neurodiversity Center for Excellence at Curry College, a rare disease advocate, and author. Her professional and personal passions intersect in her work, especially as a parent of a child diagnosed with Opsoclonus Myoclonus Ataxia Syndrome (OMAS).

The recorded interview is available on Soundcloud, Apple, Spotify, Audible, Amazon, iHeartRadio and YouTube, with links to each provided at https://rareawarenessradio.org/ and https://www.principledresources.com/.



Providing support and information to those affected by OMAS / Dancing Eye Syndrome.

The Dancing Eye Syndrome Support Trust ~ Established 1997

The Trust gives those affected by OMAS / Dancing Eye Syndrome in the UK an opportunity to talk to others who are in the same situation as themselves and who may have already experienced similar problems. In this way, members can provide mutual support and encouragement to those facing more recent diagnosis.

Online And In-person Support Group
The online support network is a safe space for parents, families, carers, and those with OMAS to share their experiences, tell their stories, offer medical information, and be involved in this unique rare disease community. An annual get-together, funded by the trust, allows respite to all who wish to join in.

Raising Awareness
Raising awareness of OMAS / Dancing Eye Syndrome is key; an earlier diagnosis can lead to better outcomes. Specialists, and their kind hearts, are becoming aware, therefore misdiagnosis is steadily improving, but there is still work to do.

Are you looking for a Community or just someone to talk to?
Find DESST on Facebook - https://www.facebook.com/groups/48271703613/

Workshop
The workshop was first introduced by a parent, within this trust, liaising with a specialist OMAS medical doctor, and this legacy continues to engage and welcome leading paediatric neurologists, oncologists and researchers from many countries.

Greater Access To Information
As research yields new information about this disease, the need to deliver this knowledge to help doctors, children and parents on their journey, is significant. This is what drives our dedicated volunteers.

Important Contact Information
Website: https://dancingeyes.org.uk
Telephone: 07884 053453
Email: support@dancingeyes.org.uk

The Trust remains committed to advancing a multi-disciplinary approach and continuously exploring new ways to better serve the diverse needs of our community. We recognize that care varies by provider, and we offer lived experience to raise awareness and share resources where they're most needed.

The Power of Community:
Advancing Research and Hope for OMAS

In a recent episode of Rare Awareness Radio, Dr. Ming Lim shared how researchers, clinicians, advocates, patients, and caregivers are coming together to improve care for those affected by Opsoclonus Myoclonus Ataxia Syndrome (OMAS)—a rare, likely immune-mediated neurological disorder that typically emerges in children by or before age 3.

Recognizing the Signs

"Like all syndromic descriptions of a condition, once you have all the parts, it becomes very obvious," Dr. Lim explained. The "parts" that comprise the OMAS diagnostic puzzle—abnormal eye movements (opsoclonus), involuntary muscle jerks (myoclonus), and coordination difficulties (ataxia)—vary in severity and onset, often leading to misdiagnosis as more common neurological conditions. And with misdiagnosis comes a delay in proper treatment, which can be particularly damaging during critical stages of brain development.

"[A] key challenge in OMAS is that we don't really have a biomarker for the disease, so no antibody that I can measure to say I've got the condition."

"The young, inflamed brain does not do as well as the more mature, inflamed brain," Dr. Lim emphasized, underscoring the urgency of early diagnosis and intervention.

Shared Diagnostic Criteria, Varied Treatment Realities

Diagnostic criteria for OMAS were first standardized at a scientific workshop in Genoa, Italy, in 2004, but formal treatment recommendations were not published until 2022. While international experts reiterated the diagnosis criteria and outlined general treatment strategies, experts differed on the initial treatment protocol.

One protocol recommends initial aggressive treatment, starting all available therapies including steroids, IVIG, and stronger maintenance, immediately. A different protocol uses a stepwise approach, which starts with less aggressive treatment and escalates only if symptoms persist.

Beyond these differing philosophies, practical implementation remains a challenge. Access to effective therapies depends heavily on local resources, healthcare infrastructure, and each country's economic capacity.

Advancing Research Through Community

How do researchers determine the most effective treatment approach while also addressing the broader variables that impact patient outcomes?

One answer lies in expert collaboration, which has been facilitated by the biennial international OMAS workshop. For over 22 years, this UK-based gathering has fostered cross-institutional partnerships and knowledge exchange. "Every meeting that we have, so many important things come out of it, putting us another step forward," Dr. Lim noted.

For rare diseases, collaboration is essential. Researchers must pool limited resources, share emerging technologies like AI-assisted diagnostic tools, and accelerate progress in understanding complex neurological conditions.

However, Dr. Lim stressed that individual institutions often have limited experience due to OMAS's rarity. "For any sort of research, we ask, how many patients have you got? And we're going to say, I have 25, and then another [clinician] will say 30... But to really pull all this together—the only way we're going to make a difference—is to get all patients together."

This call to unite patients and data led to the creation of the OMSLife Natural History Registry in 2017. A collaboration between the OMSLife Foundation and the National Organization of Rare Disorders, the registry captures global caregiver- and patient-reported information, including symptoms, diagnosis, treatment, and demographic data.

Complementing this effort, in 2018 an international consortium of clinical institutions initiated the pediatric-onset OMAS (POOMAS) registry, which links natural history and clinical data, including MRIs, to broader care records. These registries ensure research keeps pace with the ever-changing healthcare landscape.

"Contemporary data is always different from historical data," Dr. Lim pointed out. "Medicine doesn't change in just one dimension—it evolves with social health provision, with better medicines."

Miles Traveled and the Path Ahead

After years of workshops and collaboration, Dr. Lim is particularly gratified to see research progress accelerating, with the international community now "speaking the same language" regarding diagnostic criteria. He is equally energized by increasing

Critical Initiatives for Improved Outcomes

- Registry and Data Collection
  - Pooling information from different sources
  - Collecting real-time clinical and scientific data
  - Understanding treatment outcomes across different patient groups
- Scientific Understanding
  - Unraveling why some patients do or do not respond to treatment
  - Investigating what constitutes "immuno-unresponsivity"
  - Exploring genetic predispositions to chronic inflammation
  - Learning from immunobiology of other conditions (multiple sclerosis)
- Treatment Access and Healthcare Equity
  - Improving global access to treatments
  - Addressing disparities in medical resources between high and low-income countries

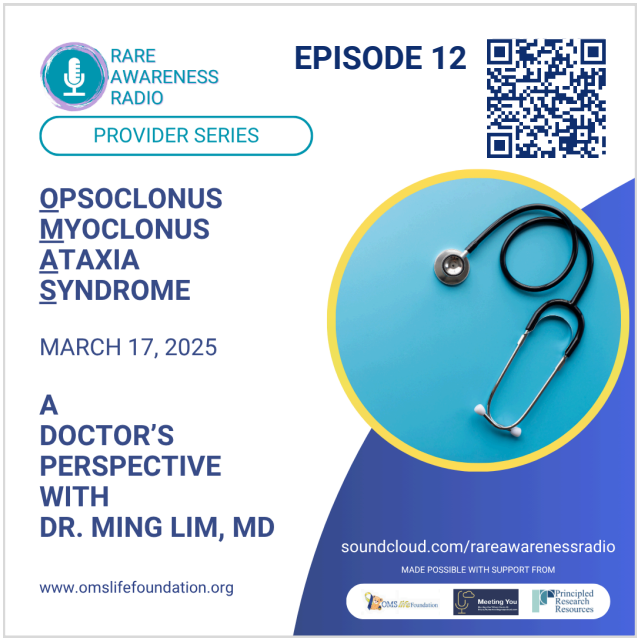
momentum, as more researchers across diverse disciplines turn their focus toward OMAS. A multidisciplinary approach ensures that patients receive coordinated care that addresses immediate medical concerns while also prioritizing long-term developmental support. Yet awareness remains a critical challenge. "It's human nature," Dr. Lim observed. "Unless you think about it, you're not going to diagnose it." Increasing recognition of OMAS among clinicians could improve early detection and patient outcomes; a goal that the medical and advocacy communities continue to push forward.

To Learn More

The Dancing Eye Syndrome Support Trust (dancingeyes.org.uk) and The OMSLife Foundation (omslifefoundation.org) websites provide a host of resources for families, researchers, clinicians, advocates, and other healthcare stakeholders.

The recorded interview is available on Soundcloud, Apple, Spotify, Audible, Amazon, iHeartRadio and YouTube, with links to each provided at rareawarenessradio.org and principledresources.com.

Dr. Ming Lim is head of children's neurosciences at the Evelina London Children's Hospital, a pediatric neurologist, and leading expert in opsoclonus myoclonus ataxia syndrome (OMAS). He is also a trustee of Dancing Eye Syndrome Support Trust (DESST), a UK-based organization that provides support and information to families affected by OMAS.



The Dancing Eye Syndrome Support Trust (dancingeyes.org.uk)

The OMSLife Foundation (omslifefoundation.org)

Rare Awareness Radio (rareawarenessradio.org)

Principled Research Resources (principledresources.com)

RESOURCES

OMSLIFEFOUNDATION.ORG
OMAS Resource documents
OMAS publications
OMAS Caregiver Conference Presentations
Registry information
Social media information

OMS.IAMRARE.ORG
Patient reported registry of OMAS data Series of surveys developed for research and clinical use.

DANCINGEYES.ORG.UK/
Providing support and information to families of children with DES/OMAS. Based in the United Kingdom.

RAREDISEASES.ORG
National Organization for Rare Disorders (NORD) site with specific details and an animated video on OMAS.

WIKIBOOKS.ORG/WIKI/OMS_MANUAL
A collection of resources including publications, government & private agencies, statistics, and other data.

NEUROLOGY.ORG/DOI/10.1212/NXI.0000000000001153
OMAS consensus statement on diagnosis and treatment of OMAS, authored by an international working group that included 18 leading OMAS specialists.

AMERICAN ACADEMY OF NEUROLOGY®

PRINCIPLEDRESOURCES.COM
A benefit organization that empowers advocacy groups to harness healthcare data to drive meaningful change for patient communities.

RAREAWARENESSRADIO.ORG
A multimedia platform that supports the rare community by sharing honest dialogues, lived experiences, and collective wisdom from patients, caregivers, clinicians, and advocates.

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It's easier than you think
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sunshine
in the life of someone with OMAS.
OMS life Foundation
Coffee Challenge
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Cafe
Take the coffee challenge.
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