Dr. Ming Lim, OMAS, & The Power of Community

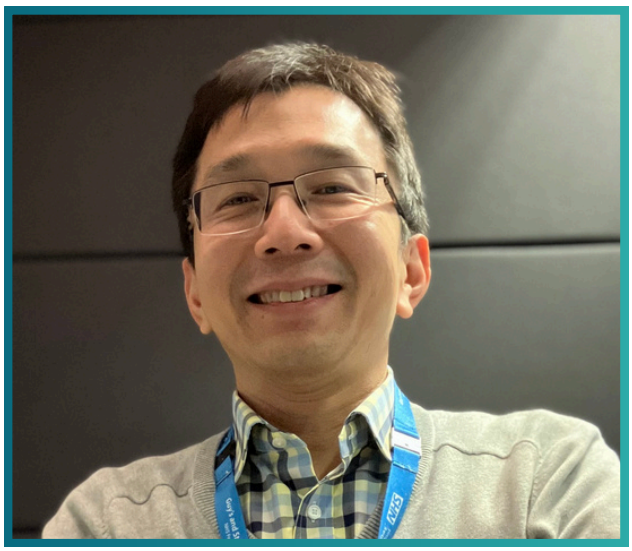
In a recent episode of Rare Awareness Radio, Dr. Ming Lim shared how researchers, clinicians, advocates, patients, and caregivers are coming together to improve care for those affected by Opsoclonus Myoclonus Ataxia Syndrome (OMAS)—a rare, likely immune-mediated neurological disorder that typically emerges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

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.



Speaking the Same Language

Diagnostic criteria for OMAS were first standardized at a scientific workshop in Genoa, Italy, in 2004, but formal consensus on treatment wasn't published until 2022. While international experts reiterated the diagnosis criteria and outlined general treatment strategies, a single adopted approach is lacking.

One strategy takes an upfront approach, initiating all available treatments—including steroids, IVIG, and stronger maintenance therapies—immediately. In contrast, a European clinical trial advocates a stepwise approach, beginning with less aggressive treatment and escalating 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—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 momentum, as more researchers across diverse disciplines turn their focus toward OMAS. A multidisciplinary approach ensures that patients receive coordinated care—addressing 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.

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 respond to treatment and others do not
  - Investigating what constitutes "immuno-unresponsivity"
  - Exploring genetic predispositions to chronic inflammation
  - Learning from immunobiology of other conditions like multiple sclerosis
- Treatment Access and Healthcare Equity
  - Improving global access to treatments
  - Addressing disparities in medical resources between high and low-income countries

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.

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

The OMSLife Foundation (omslifefoundation.org)

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.

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