

OMSLife Projects - 2026

ICD 10 codes – One challenge for the OMAS community is the lack of an ICD10 code. ICD10 stands for International Classification of Diseases and is the coding used to describe diseases in patients' charts and portals for hospital records and billing as well as for researchers to collect OMAS specific data. ICD10 is the standard version used in the US. Acquiring a code is an extensive collaborative effort involving physicians, patients, billing specialists, and non-profit organizations to convince the CDC that the code is justified. It usually takes years to acquire a code. OMSLife is working with the Everylife Foundation and Combined Brain foundation, as well as OMAS specialists around the world to develop the justification for an OMAS specific ICD10 code.

We hope to present our case to the CDC in 2027.

OMSLife is funding this project and serving as project lead in the effort.

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Late Detection of Tumors in OMAS patients – OMSLife is collaborating with Boston Children's Hospital in a followup study on tumor detection in OMAS patients. In our first study, we found there is about 8% of the OMAS population with tumors that have their tumors diagnosed later than three months after OMAS onset – see study at [Inaugural Patient-Reported Registry of Pediatric Opsoclonus-Myoclonus-Ataxia Syndrome: Presentation, Diagnosis, and Treatment of 194 Patients - ScienceDirect](#) . This study will take a deeper dive into the scan reports of that population to determine trends that may exist in the late detection of the tumors. The project involves a joint study of the population from the OMSLife and the POOMAS registries of OMAS patients.

The study should conclude in 2027.

OMSLife is providing a portion of the registry data obtained for this project and also serving as a consultant.

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OMAS Behaviors Study - Neuropsychological and Neuropsychiatric Care of Pediatric Patients with Opsoclonus Myoclonus Ataxia Syndrome (OMAS): A Provider Delphi Survey.

This study is a collaborative effort with Dr. Aaron Hauptman at Kennedy Krieger Institute in Baltimore, Dr. Hannah-Lisa Schofield at Children’s Hospital of Philadelphia, and the OMSLife Foundation. The project will be multi-phase. The first phase is for the project team to send a Delphi survey to other providers regarding tests performed and treatment of OMAS patients with behavior related issues. The second phase will be an in depth survey to the caregivers regarding the types of tests and treatments the patients have received.

The phase I study should conclude in early 2027. The phase II study is TBD.

OMSLife is funding this project Including IRB costs and costs for publishing to open source, and is also serving as a consultant in phase I.

OMSLife plans to fund this project, provide registry data for this project, and also serve as a consultant in phase II.

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Fertility Outcomes and the Impact of Pregnancy in Patients with OMAS – OMSLife is partnering with Dr. Prerna Kumar and Dr. Pedro DeAlarcon at University of Illinois School of Medicine Peoria to study the effects of a pregnancy on patients who had or has OMAS. Utilizing the PRAMS (Pregnancy Risk Assessment Monitoring System) we intend to study any issues with the OMAS patient or their child during pregnancy and afterwards.

The study will launch in Q4 2026 and should be completed in 2027.

OMSLife is funding this project, providing registry data for this project, and also serving as a consultant.

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Long Term Outcomes of OMAS Patients – OMSLife is participating in a comprehensive study of the quality of life (long term outcomes) of OMAS patients as they mature into adulthood. The objective is to find answers to the common question that many caregivers ask “What will life be like for my child?”.

The study team will utilize two common surveys; The EQ-5D-5L Health Questionnaire and the Neuro QOL Health Surveys. Final development of the OMAS survey is being finalized and IRB approvals acquired. The study team includes Dr. Sithara Ramdas from Oxford Children’s Hospital, Dr. Kate Scarff from Oxford Psychological Medicine Centre, Dr. Alfred Balasa from Cook Children’s Hospital in Dallas, and Mike Michaelis from The OMSLife Foundation.

The study will launch in Q4 2026 and should be completed in 2027.

OMSLife is funding this project, providing registry data for this project, and also serving as a consultant.

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Sleep Habits Study – The OMSLife Foundation is partnering with researchers to expand the initial analysis of OMAS patients’ sleep habits before, during, and after active OMAS. The study is based upon the Children’s Sleep Habits Questionnaire (CSHQ) and measures how sleep habits change for patients.

The objective of the study is to identify those sleep trends that change and provide techniques and treatments to address those issues.

The study team includes Dr. Yasmin Khakoo at Memorial Sloan Kettering Cancer Center in New York, Dr. Aaron Hauptman at Kennedy Krieger Institute in Baltimore, Dr. Hannah Schofield at Children’s Hospital of Philadelphia, Dr. Thomas Rosso at Evelina Children’s Hospital in London, Kelsey Milligan of Principled Research Resources, Mike Michaelis with The OMSLife Foundation, and Bhavna Dias.

The study findings should be published in early 2027.

OMSLife is funding this project, providing registry data for this project, and also serving as a consultant.

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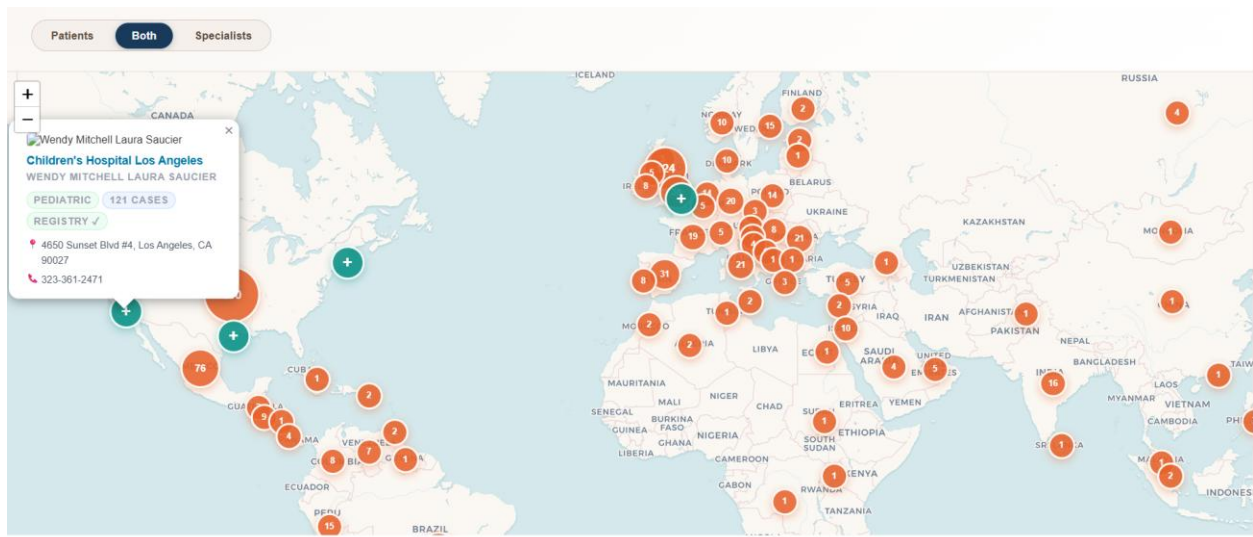
Electronic Health Records – OMSLife is beginning a pilot project with NORD to obtain Electronic Health Records (EHR) of OMAS patients from hospitals and medical facilities. The objective is that

The pilot will launch in Q4 2026 and should be completed in 2027.

OMSLife is funding this project and also serving as the primary investigator (PI).

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World Map – Dealing with OMAS is extremely difficult since it is an ultra rare disease. It can often feel as though you are the only one in the world battling this disease. We are addressing that concern in part by developing the first OMAS world map. This map shows two key aspects of the disease; patient counts around the world and where to find a specialist or clinician near you. Our goal is that whether you are in a big city in the US or a remote location anywhere in the world, you can find someone who knows about OMAS.



Eye Movement Project (Toronto Sick Kids Hospital). OMSLife has provided funding for Dr. Ann Yeh's Eye Movement project at Toronto Sick Kids Hospital. The funding has allowed Dr Yeh to expand the study to include patients at Children's Hospital Los Angeles and Cincinnati Children's Hospital. The study objectives include:

- i. To objectively assess functional and neurological outcomes of patients with OMAS
- ii. To evaluate the usability of eye tracking as an outcome measure for OMAS
- iii. To evaluate cerebellar volumes and cognitive ability in relation to oculomotor functions in pediatric OMAS

3. HYPOTHESES

- i i. Poor oculomotor performance will correlate with poor cognitive outcomes in pediatric OMAS
- ii ii. Decreased cerebellar volume will correlate with cognitive impairment related to expressive language and disease severity in OMAS

The study launch is TBD as they await final IRB approvals.

OMSLife provided a \$30,000 grant for this project to be included at CHLA and Cincinnati Children's Hospital.

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Wiki updates – OMSLife is updating the OMAS manual found in wikipedia. The content is being updated based upon recent studies. Additional resources are also being shown in the Wikipedia.

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