



## OMS PATIENT REGISTRY

We are pleased to announce the launch of the OMS Patient Registry, a collaborative effort between The OMSLife Foundation and the National Organization for Rare Disorders (NORD) to study Opsoclonus Myoclonus Syndrome (OMS). The OMSLife Foundation was selected by NORD to create the OMS Patient Registry as part of a cooperative project between NORD and the U.S. Food and Drug Administration (FDA) that supports research on rare diseases and how they progress over time - natural history studies.

## OVERVIEW OF RESEARCH STUDY

The OMS Patient Registry is more than a versatile online system that securely collects and stores data for medical research; it is a dynamic participant-driven resource that can empower and unite OMS community through shared knowledge. Registry participants not only can complete surveys about their own disease experiences, but also can learn about other participants' experiences by viewing aggregated survey data. As the registry sponsor, The OMSLife Foundation will ensure that data privacy and confidentiality are strictly maintained. Participation in the OMS Patient Registry is free and voluntary, and participants may withdraw at any time.

## COMMUNITY INVOLVEMENT

The OMS Patient Registry is a powerful opportunity for individuals with OMS and their family members to contribute directly to research that will enhance our understanding of Opsoclonus Myoclonus Syndrome, thus facilitating the development of new diagnostic and treatment options. Registry data will also enable researchers to present publications and use cases on trends in treatment, therapies, and overall quality of life for the patient over an extended period of time. This will be particularly beneficial for clinicians with little or no experience with this disease in treating OMS patients with the latest and best treatment regimen. Participation is especially vital given the rarity of OMS - every patient experience is a unique and invaluable part of the natural history of OMS.

For further information or to join, please contact:

[Mike Michaelis – [Mike@OMSLife.org](mailto:Mike@OMSLife.org) or visit our web site at [www.omslifefoundation.org](http://www.omslifefoundation.org)

OMS Patient Registry [oms.iamrare.org](http://oms.iamrare.org)

### About The OMSLife Foundation

*OMSLife is a non-profit organization which advocates for the highest quality of care for patients with Opsoclonus Myoclonus Syndrome, a rare auto-immune disease. This disease, left untreated, impacts the quality of life of the patient by attacking the physical and cognitive abilities of the patient.*

*The mission of OMSLife is to raise awareness of Opsoclonus Myoclonus Syndrome (OMS), maintain a support network for the patients and caregivers, and fund research for a cure.*

### About NORD

*NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 250 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.*

