The OMSLife Foundation Launches Natural History Study of Opsoclonus Myoclonus Syndrome (OMS)

Research study is open to participants worldwide to advance understanding and treatments for rare autoimmune disease impacting toddlers.

Cypress, Texas, February 28, 2017 — The OMSLife Foundation has launched a natural history study to research Opsoclonus Myoclonus Syndrome (OMS), a disease that causes developmental and cognitive delays. The disease primarily impacts toddlers at an average age of eighteen months. OMS currently has no cure.

"The OMS Patient Registry will provide a complete picture of each patient's experience with OMS," said Mike Michaelis, President, The OMSLife Foundation. "We are launching this initiative to help fill one of the missing links researchers and medical experts need to advance research and get to a cure."

To help drive awareness and participation, The OMSLife Foundation will kick off a pilot program shortly. The foundation plans to formally kick off the formal launch of the registry on Rare Disease Day in late February 2017.

"Our goal is to enroll as many patients, or their parents or legal guardians, as possible," said Michaelis. "The success of the registry is dependent upon community participation."

The OMS Patient Registry is a natural history study that consists of electronic surveys to collect information about the patient experience and disease progression. Phase I and II of the project will allow patients, or their caregivers or guardians, to enter information from anywhere in the United States. Future phases hope to address expansion of the registry to other countries. The data is made anonymous and stored securely in an online portal called a registry. The OMSLife Foundation may share the data but not your personal identifying information with individuals or institutions conducting research or clinical trials, as approved by the study's governing board that includes scientists, doctors and patient advocates.

The OMSLife Foundation is launching the study in collaboration with the National Organization for Rare Disorders (NORD), an independent charity that built its natural history study platform as part of its mission to help identify and treat all 7,000 rare diseases. Funding is supported by a cooperative agreement between NORD and the U.S. Food and Drug Administration (FDA). The FDA has praised NORD's program as a helpful tool "that protects the security and privacy of personal information, while making valuable information available to a researcher or drug developer interested in creating a new therapy for a rare disease."[1]

NORD President and CEO Peter L. Saltonstall said, "NORD's natural history studies platform empowers patients and families to drive research and eliminate some of the unknowns that still exist in rare diseases. We are glad to be working with our Member Organization on this project and thank the FDA for its support and ongoing commitment to help people with rare diseases."

1 Woodcock, J. "The more we know about rare diseases, the more likely we are to find safe and effective treatments." *FDAVoice* (Oct. 23, 2014)

OMS is a rare autoimmune disorder that occurs in approximately one out of every six million people. The disease typically affects toddlers between the ages of one and three years old. Since the disease impacts these young patients, it is often difficult to diagnose and is very challenging to develop a treatment protocol.

For more information on OMS Patient Registry, visit https://oms.iamrare.org/.

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About The OMSLife Foundation
An independent 501(c)(3) nonprofit organization, The OMSLife Foundation is a leading advocacy organization representing all patients and families affected by Opsoclonus Myoclonus Syndrome (OMS) across the world. The OMSLife Foundaton was established in 2012 with the mission to raise awareness of OMS, provide a resource network for caregivers, and fund research for a cure of OMS. To date, OMSLife has assisted in connecting patients with doctors and specialists around the world, developed resource materials, provided social media forums for caregivers, hosted caregiver conferences across the US, and provided thousands of dollars in research grants. OMSLife currently networks with patients in fifty-one countries. More information is available at www.omslifefoundation.org .

About National Organization for Rare Disorders (NORD)
An independent 501(c)(3) nonprofit organization, NORD is the leading advocacy organization representing all patients and families affected by rare diseases in the U.S. Established in 1983, NORD is committed to the identification, treatment and cure of the 7,000 rare diseases that affect 30 million Americans, or 1 in every 10 people, through programs of advocacy, education, research, and patient/family services. In addition to educational resources for patients, families, medical professionals and students available on its website (www.rarediseases.org), NORD represents 250 member organizations and collaborates with many others in specific causes of importance to the rare disease patient community.

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