The EHE Foundation and NORD® Launch Natural History Study of Epithelioid Hemangioendothelioma (EHE)

This research study is open to participants worldwide to advance understanding and treatments for epithelioid hemangioendothelioma (EHE), an ultra-rare vascular sarcoma.

Hobart, Wisconsin. June 13, 2023 — The EHE Foundation and the National Organization for Rare Disorders (NORD®) have launched a global patient registry study to research epithelioid hemangioendothelioma (EHE), an ultra-rare vascular sarcoma for which there are no well-established standards of care or approved treatments. It is estimated that less than 1 per million people are living with EHE. EHE can occur anywhere in the body and has a very unpredictable clinical course. Overall survival varies widely depending on tumor location and disease progression.

This new study, The EHE Global Patient Registry, creates a platform for patients around the world to share information about EHE. Its purpose is to build an international resource to be used by scientists in future research. This registry is a natural history study that consists of electronic surveys to collect information from people diagnosed with EHE about their experiences and EHE progression. Patients, or their caregivers or guardians, can enter information from anywhere in the world. The data is confidential and stored securely in the IAMRARE® online portal. The EHE Foundation may share the data with individuals or institutions conducting research or clinical trials, as approved by the study's governing board that includes scientists, doctors and patient advocates.

"Today, there are no large studies or datasets describing patients' experiences with EHE. Patients, doctors, and researchers struggle to understand the various presentations of EHE and courses of disease progression. Because EHE is so rare, the road to find treatments and a cure relies on patients joining together and this registry truly empowers patients to improve our understanding of this ultra-rare disease. I am living with EHE, and I want my voice heard in the research community. By raising our collective voices, we can envision a future where EHE is more easily diagnosed and treatable", said Jenni Kovach, President of The EHE Foundation.

The EHE Foundation is launching the study in collaboration with NORD, an independent nonprofit that built its natural history study platform as part of its mission to help identify and treat all 7,000 rare diseases. The EHE Foundation is a member of NORD, and the two organizations work together to eliminate the challenges that rare disease patients face.

"NORD's motto is 'Alone, we are rare. Together, we are strong.' The launch of this new registry is a perfect embodiment of our motto and the collaboration and community engagement needed to drive forward rare disease research and outcomes for the rare community. We look forward to furthering our partnership with The EHE Foundation to best support research and innovation for epithelioid hemangioendothelioma (EHE)," said Aliza Fink, Director of Research Programs, NORD.

For more information about the EHE Global Patient Registry, visit fightehe.org/registry.

About The EHE Foundation

The EHE Foundation is a nonprofit 501c3 organization dedicated to pursuing effective treatment and a cure for epithelioid hemangioendothelioma (EHE). The EHE Foundation was founded in 2015 by patients and families living with EHE who realized there was little information and no treatments for the disease. Since then, the organization has mobilized to raise over $1.5 million to support impactful research and serves as an educational and supportive resource for patients and families newly diagnosed and living with EHE. Today, the Foundation supports patients in over 80 countries working toward its mission to find treatments and a cure for EHE by advancing research and driving collaboration between patients, researchers, and clinicians. To learn more about The EHE Foundation visit fightehe.org.

About National Organization for Rare Disorders, Inc. (NORD®)

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 300 disease-specific member organizations, more than 15,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases. Visit rarediseases.org.

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