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The PTEN Hamartoma Tumor Syndrome Foundation announces its Centers of Excellence Application

Huntsville, AL — August 21, 2018 —Today, The PTEN Hamartoma Tumor Syndrome (PHTS) Foundation Today, The PTEN Hamartoma Tumor Syndrome (PHTS) Foundation announces the immediate release of its application for Centers of Excellence designation, the first initiative to advance the care and treatment of patients affected by PTEN Hamartoma Tumor Syndrome (PHTS). PHTS, a thought to be under-diagnosed hereditary cancer syndrome puts patients at high risk of developing multiple types of cancer including breast, thyroid. Colon, kidney, and endometrial cancer, as well as melanoma. Some patients might also be affected by neurocognitive issues including Autism as well as other benign problems. The PHTS Foundation encourages improved quality of care for the PTEN patient community by detailing criteria for multidisciplinary coordinated care by knowledgeable, experienced medical specialists at designated Centers of Excellence. According to Kristin Anthony, President of the PTEN Foundation, this initiative is “a must for our patients.” “This is a huge step to set the highest standard of care for patients with PHTS,” said Anthony. “We are pleased with this progress and thankful for the opportunity to work closely with our External Scientific Advisory Board to meet a significant unmet need of our patient community. We are making it easier for our community to find a center with experienced, and knowledgeable specialists who follow appropriate screening guidelines. For centers interested in applying, the full application will be available at www.ptenfoundation.org.

Positive Patient Impact

PHTS patients often state that there is a gap in care for the PHTS community, expressing the need for a focus on care coordination. “I have dreamt of the day where our family can spend less time being full-time care managers and gain our life back,” said Lori Ortega, patient, and caregiver. “I am excited to lessen the burden of constantly managing appointments and care, thus improving our family’s overall quality of life.” Candace Allday, coming from a multi-generational PHTS family, states that “the time spent seeking care for their family is exhausting.” She believes this initiative encouraging multidisciplinary teamwork across care specialties where communication will not only improve patient care but will also advance research. Candace also states that seeking care for herself and family has “been a struggle,” and that the PTEN Foundation encouraging the highest standard of care for our community “is a step in the right direction.” Charis Eng, MD, Ph.D., Chairman of Cleveland Clinic’s Genomic Medicine Institute and Director of the Center for Personalized Genetic Healthcare, is the chair of the PTEN Foundation’s External Scientific Advisory Board and helped drive the Centers of Excellence application and designation process to completion. Dr. Eng shares that “all PHTS patients deserve coordinated care from multiple healthcare specialists under one roof who have seen and treated other patients with PHTS and are knowledgeable regarding PTEN features and screening guidelines.”

Driving Excellence

The PTEN Foundation aims to reduce the burden of multiple hours spent seeking care from different physician offices and hospitals, bringing an entire multidisciplinary care team with PHTS expertise under one roof. We believe that this Centers of Excellence program will provide hope for our community and will drive excellence for PHTS patient care and research. We want to thank our External Scientific Advisory Board and PTEN Italia for their support and input in the development of the Centers of Excellence program and application.

Founded in 2013, The PTEN Hamartoma Tumor Syndrome (PHTS) Foundation advocates for PHTS Patients. The Foundation provides patient support by connecting patients and researchers and fostering collaborations to advance PHTS research.

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The PTEN Hamartoma Tumor Syndrome (PHTS) Foundation is a 501C3 foundation founded in December 2013. EIN 46-4279769

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To learn more about PTEN Hamartoma Tumor Syndrome visit:

www.ptenfoundation.org