



The International PTEN collaborative is excited to introduce the first Patient-powered PTEN Hamartoma Tumor SYndrome (PHTS) Natural History Study and Registry

Overview of the Research Study

The International PHTS Natural History Study and Registry is more than a versatile online system that collects de-identified patient data for medical research; it is a patient-powered registry empowering the PHTS community to propel research forward. Registry participants can complete surveys about their personal disease experience and also learn about all registry participant's experiences with the option to view aggregate de-identified reports. As the registry sponsor, The International PTEN collaborative will work to ensure data privacy and confidentiality. Participation in the PHTS patient-powered registry is free and voluntary, and participants may withdraw at any time.

Community Involvement

The International PHTS Natural History Study and Registry is an opportunity for individuals with PHTS and their family members to contribute directly to research enhancing all PHTS families and Researchers understanding of PHTS. The PHTS International Collaborative believe that this will lead toward new diagnostic and treatment options. Participation is important given the Rare nature of PHTS. Every PHTS patient is unique and your participation in the registry will drive research forward and help improve the quality of life for all PHTS families.

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We are launched the first International PHTS Patient-Powered Registry & rebuilt our platform with a new user-friendly program. We are sharing it with you today!

Our Community will now have the opportunity to participate in driving research forward!

In collaboration with PTEN Italia we are offering our community the opportunity to participate in data sharing and we will share de-identified information with you.

Patient first!

We are building an International bridge for our PTEN patient and research community.

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