Get In Touch

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Thank you to our researchers and medical teams that work tirelessly to serve our PTEN Community. Also, thank you to our scientific advisory board for helping us develop PTEN Hamartoma Tumor Syndrome (PHTS) Care Guidelines.

~Kristin Anthony, President, PHTS Foundation

PTEN Foundation

Connect* Collaborate* Care

The PTEN Hamartoma Tumor Syndrome Foundation was founded to find treatments or therapies for PTEN Syndromes. Our team is developing research tools to complement existing research, including our IRB-approved patient registry and biorepository.

We fund research, provide PHTS education, and support patients. PHTS includes Cowden syndrome (CS), Bannayan-Riley-Ruvalcaba syndrome (BRRS), PTEN-related Proteus syndrome (PS), and Proteus-like syndrome.

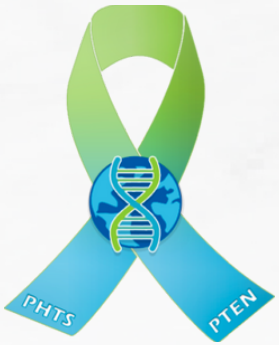
Introduction

PHTS Risks

The main health risk of PTEN hamartoma tumor syndrome (PHTS) is cancer, but being born with a PTEN mutation does not mean you will get cancer or have other health or learning problems associated with this mutation.

People can have the same type of PTEN mutation yet be affected very differently. A combination of diet, lifestyle, environment, and overall genetic makeup may be the reason for this.

Currently, routine enhanced screenings offer the best chance of finding cancer early, and preventative procedures may help to stop some cancers from



PTEN Foundation Mission

✴ Connect and support PHTS patients worldwide

✴ Work with clinicians who have expert knowledge of PHTS to develop guidelines for Clinical Centers of Excellence

✴ Work with researchers to find treatments, and offer patients opportunities to be engaged in this process

✴ Collaborate with partners who share our vision for supporting patients

PTEN Hamartoma Tumor Syndrome Foundation

Medical Team

Meet Our Advisory Board Chairperson

Charis Eng, MD, Ph.D. is the Chair and founding Director of the Genomic Medicine Institute of the Cleveland Clinic, the founding Director and attending clinical cancer geneticist of the institute's clinical component, the Center for Personalized Genetic Healthcare, and Professor and Vice Chairman of the Department of Genetics at Case Western Reserve University School of Medicine.

PHTS Screening Considerations For Women

From age 18:
▸ Breast self-exam: monthly

From age 25
▸ Breast exam by a doctor: every 6 to 12 months

From age 30-35
▸ Yearly Mammogram (consider digital breast Tomosynthesis) and Yearly breast MRI beginning at age 35 (or ten years earlier than the first relative that had breast cancer in the family)
▸ Report any abnormal bleeding and consider an endometrial biopsy every 1-2 years or discuss annual transvaginal ultrasound with your physician.

PHTS Screening Considerations For All Adults

▸Yearly physical exam, including urinalysis by cytospin for blood
▸Skin check
▸Thyroid ultrasound

From age 35:
▸Colonoscopy: every five years or more often if needed

From age 40
▸Kidney Ultrasound or CT if advised: yearly or every other year

Ask your Doctors About:
▸Common warning signs of cancer
▸Recommended: risk-reducing surgical prevention
▸The best plan for managing your health

Important Note:
If you have symptoms and/or a family history of cancer, you may be asked to start screenings earlier and have other screening tests

Additional Considerations

Under 18 years:
▸Annual physical exam
▸ Annual skin check
▸ Thyroid ultrasound: start at age 7; annual if advised.

If Advised:
▸Learning and development checks
▸Assessment for autism
▸GI screening recommended
▸Baseline Brain MRI (Annual if symptomatic and recommended by your physician)

*Please note that guidelines vary in some countries.

Join our efforts to help accelerate pten research by signing up for our IRB-approved patient registry at:

www.ptenregistry.org

This leaflet was created by patients for patients and approved by an advisor with expert knowledge of PHTS
Sources: National Comprehensive Cancer Network Guidelines for Detection, Prevention and Risk Reduction: Genetic/Familial High-Risk Assessment: Breast and Ovarian: Cowden Syndrome/PHTS: nccn.org Gene Reviews (© 1993-2018 University of Washington): PTEN Hamartoma Tumor Syndrome: ncbi.nlm.nih.gov/books/NBK1488/