



Consideration for PHTS Clinical Centers of Excellence Application

The PTEN Hamartoma Tumor Syndrome (PHTS) Foundation (www.ptenfoundation.org) is dedicated to supporting our community as we work to find treatments or therapies for PTEN-related syndromes by funding research, providing education, and raising awareness. We believe that providing the best multidisciplinary care for our patient community will improve outcomes and quality. We value your support and interest in the PHTS Clinical Centers of Excellence Program; your support will improve quality of life for PHTS patients.

PHTS has two categories of care centers: Comprehensive Clinical Center of Excellence (CCCOE) and Clinical Center of Excellence (CCOE). Each center is further designated as Adult, Pediatric, or All Ages. This application is for the Comprehensive Clinical Center of Excellence and the Clinical Center of Excellence. All applications are reviewed by our Scientific and Medical Advisory Board (www.ptenfoundation.org/scientificsdivisoryboard). Acceptance into the program is not automatic, and patient feedback is always carefully considered. It is not a requirement to have every specialist working at the same medical center, but it is useful. Required specialties for all centers (CCOE and CCCOE) are marked with one asterisk "*". Additional specialties required for CCCOEs are denoted by "***". If you plan to use the services of another physician at a nearby institution, please note that. Institutions will be designated as CCOEs for a three-year term based on 1) information submitted on this form and 2) patient feedback, solicited by the PHTS Foundation, on center performance. In order to evaluate patient feedback, no new center will be approved as Comprehensive (CCCOE) until the center has functioned as a PHTS Clinical Center of Excellence (CCOE) for a minimum of 1 year.

The PHTS Foundation encourages all Clinical Centers of Excellence to provide educational opportunities for physicians and staff on the current clinical practices for all patients with a PTEN-related condition. Such training opportunities would include attendance at the annual PHTS Foundation-sponsored patient education meeting and the biennial International PHTS Medical Symposium, or on-site or web-based lectures or presentations by experts in the care of PHTS patients. In addition, each specialist included in an approved application will be added to the closed PHTS CCOE clinician listserv and will have the opportunity to participate in clinical care discussions with their colleagues.

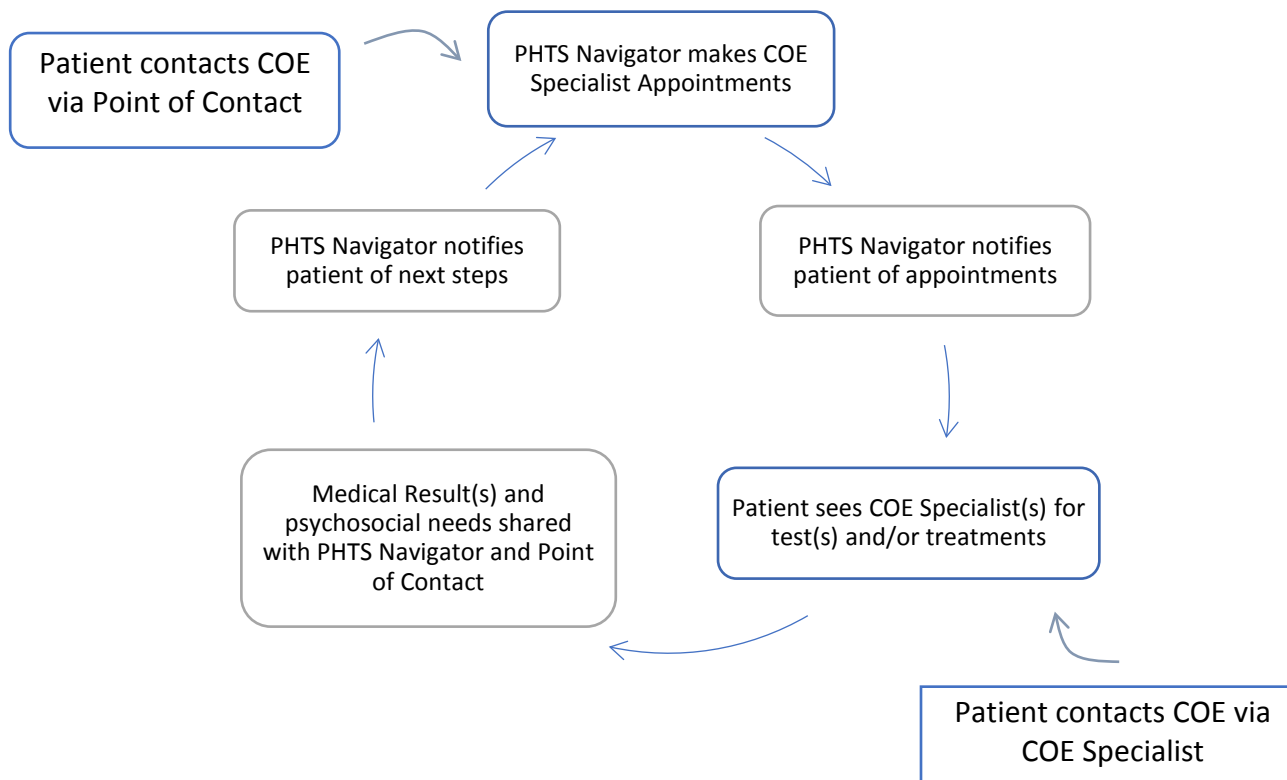
When applying to be a Clinical Center of Excellence, please provide as much of the following as possible and return as a Word file saved as *Institution Name– CCOE Application, Submission_mmYYYY* (e.g., *University of Michigan – CCOE Application, Nov 2018*).

Application Process, Standards of Care, and Classification of PHTS Comprehensive Clinical Center of Excellence and Clinical Center of Excellence

Each Clinical Care Center application (both new centers and renewals) should do the following:

- Submit institutional surveillance protocol to be approved by the PHTS Foundation Scientific and Medical Advisory Board.
- Provide a list of site's participating team members who must be Board-certified in specified area (if Board certification exists), including their contact information and referral standards to help the site PHTS Navigator in the patient referral process.
- Identify and implement system to assess psychosocial needs of each patient.
- Agree to communicate medical updates, including psychosocial needs, with patient's primary care clinician.
- Agree to turn in complete, updated applications every other year to keep contacts current.
- Encourage patients to participate in the PHTS patient registry supported by the PHTS Foundation.

COE Process Matrix





PHTS CCOE Team Members

CCOE Sponsoring Physician

Physician who specializes in PHTS patient care and ensures organization and coordination at the CCOE.

- Designates Point of Contact and PHTS Navigator, ensuring sufficient FTE devoted to these roles, and creates team of PHTS Specialists.
- Shares PHTS Surveillance Guidelines with team.
- Introduces team members and facilitates team communication, including communication within electronic medical records (EMR) system.
- Educates team on the importance of patient participation in the PHTS Patient Registry.
- Encourages specialists to educate their department about PHTS.
- Promotes inclusion of PHTS patients in patient meetings (e.g.: cancer support groups), when appropriate.
- Arranges / participates in medical education meetings to teach physicians outside of CCOE team about PHTS.
- Meets with PHTS Foundation CCOE representative at least once per year.

Point of Contact

PHTS team member at the site who works closely with the Sponsoring Physician and multi-disciplinary team; could be a Genetic Counselor, Patient Navigator, Nurse, Nurse Practitioner, Physician, or Administrative position.

- Serves as initial contact for patients, families, and physicians.
- Allows contact information to be listed on PHTS Foundation website and medical institution website.
- Has PHTS Surveillance Guidelines, knows CCOE Specialists, and works closely with the PHTS Navigator and Sponsoring Physician.
- Ensures each CCOE Specialist has PHTS registry physician information sheets and patient brochures.
- Frequently encourages patients to participate longitudinally in PHTS Registry.
- Meets with PHTS Foundation CCOE representative at least once per year.

PHTS Patient Navigator

Helps patient to navigate the health care site; could be a PHTS Genetic Counselor, Navigator, Nurse, Nurse Practitioner, Physician, or Administrative position.

- Welcomes each PHTS CCOE patient and introduces them to the concept of comprehensive, coordinated care within the CCOE team.
- Makes note in patient's electronic medical record (EMR) to designate as PHTS patient, or follows similar process per site standards, and is able to review patient's EMR to follow care by PHTS CCOE team.
- Works at the patient and institutional level to help each PHTS CCOE patient to adhere to site PHTS surveillance guidelines and to receive all recommended tests and treatments.
- Works with appointment scheduling to expedite and coordinate PHTS appointments.
- Shares surveillance results with patient; ensures the patient's PCP receives a report after each CCOE visit.
- Reminds / encourages patients after every appointment / procedure to participate in PHTS Registry.
- Determines if patients are facing insurance / financial barriers; utilizes the hospital's Patient Financial Services Department to assist patients in overcoming these barriers.
- Meets with PHTS Foundation CCOE representative at least once per year.

COE Multi-Disciplinary Team Specialists

Physician specialists who treat PHTS patients, such as Gastroenterologists, Endocrinologists, Breast Specialists, Urologists, etc.

- Incorporates PHTS Surveillance Guidelines into patient’s medical care.
- Encourages patients to participate longitudinally in the PHTS Registry (in development) after each appointment / procedure.
- Serves as department expert on PHTS.
- Receives notification from departmental colleagues each time a new PHTS patient is seen. Notifies PHTS Navigator when new or existing PHTS patients are seen in their specialty departments, if PHTS Navigator did not schedule the appointment.
- Educates department on need for multiple specialists to properly manage PHTS.
- Understands CCOE structure. Knows, works with, and communicates with other team members.
- Becomes a member of closed PHTS CCOE clinician listserv. Posts questions/responses to clinicians at other CCOEs.
- Willing to give PHTS presentations at physician and/or patient meetings when requested by the Sponsoring Physician.

PLEASE REVIEW THE FOLLOWING CCOE APPLICATION SPECIALIST REQUIREMENTS:

	REQUIRED	OPTIONAL
Specialists	<ul style="list-style-type: none"> - *Genetic Counselor - *Surgical breast specialist - *Thyroid/Endocrine surgeon - *Endocrinologist - *Dermatologist - *Gastroenterologist - *Gynecologist - *Urologist - *Neurologist 	<ul style="list-style-type: none"> - **Medical Geneticist - **Neurooncologist - **Surgical Oncologist - **Neurosurgeon - **Psychologist experienced in a wide range of ages (expert in autism) - **Vascular Surgeon - Social Worker - **Psychologist with expertise in inherited cancer syndromes - Medical breast specialist <p><i>* Required Specialists for CCOEs</i> <i>**Additional Required Specialists for CCCOEs</i></p>

PHTS CCOE Application Questionnaire



PLEASE ANSWER THE FOLLOWING QUESTIONS:

1. The Institution Name, Date, Mailing Address and Main telephone number of the applicant institution:

Institution Name	Click here to enter text.
Date	Click here to enter text.
Postal Mailing Address	Click here to enter text.
Telephone Number	Click here to enter text.

2. Why do you feel this institution is a good candidate to be a Clinical Center of Excellence for PHTS?

Click here to enter text.

3. Please indicate the patient ages treated at your institution:

<input type="checkbox"/>	Adults Only (age 18 years and over)
<input type="checkbox"/>	Pediatric Only (under 18 years of age)
<input type="checkbox"/>	All ages

4. Name and contact information for the sponsoring physician for the Clinical COE program (for our office use only).

*Sponsoring Clinician	Click here to enter text.
Sponsor Specialty	Click here to enter text.
Mailing Address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

5. The name of the person to be contacted by patients seeking treatment, defined above as Point of Contact or PHTS Navigator. This should be someone who understands PHTS and will take responsibility for helping the caller find the care needed, in whatever specialty is required. The Point of Contact should be provided with the following information:

- Names and contact information of all PHTS team members
- PHTS Surveillance guidelines
- PHTS referral guidelines

The contact information provided below for the Point of Contact will be listed in the PHTS newsletter and on the internet. This e-mail address will be used for routine mailings for the program and for internet contacts, often from physicians asking for assistance with a difficult case. We do not expect the site point of contact or PHTS Navigator) to answer any medical questions that require a patient appointment.

*Point of Contact	Click here to enter text.
Specialty	Click here to enter text.
Mailing Address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

What is the professional relationship between the Point of Contact and the Sponsoring Clinician?

Answer Here:	Click here to enter text.
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- Will the Point of Contact be provided with names and contact information of all PHTS team members?
 Yes No
- Will the Point of Contact be provided surveillance guidelines?
 Yes No
- Will the Point of Contact be provided with PHTS referral guidelines?
 Yes No

6. Name and contact information of the patient navigator for the Clinical COE program (for our office use only).

* PHTS Patient Navigator	Click here to enter text.
Sponsoring MD Specialty	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

7. For the information for our Scientific and Medical Advisory Board, please supply the names of the physicians who have consented to be called upon to treat PHTS patients requiring attention in these specialties. We will add them to our e-mail mailing list to receive our PHTS newsletter, and will not release their e-mail addresses to patients, but our staff may ask incidental questions via the closed PHTS CCOE clinician listserv.

Genetic Counselor*:

Counselor name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Medical Geneticist (Preferably formally trained in Clinical Cancer Genetics):**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Neurology*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Neurosurgery:**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Neurooncology:**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Urology*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Endocrinology*:

Physician name	Click here to enter text.
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Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Thyroidology/Endocrine Surgeon*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Gastroenterology*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Dermatology*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Surgical Oncologist:**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Gynecology*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Social Worker/Counselor:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.

E-mail	Click here to enter text.
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Psychology/Psychiatry (experience with wide age range, including autism):**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Medical Breast Specialist:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Surgical Breast Specialist*:

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Psychologist (expertise in hereditary cancer syndromes):**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

Vascular Surgeon:**

Physician name	Click here to enter text.
Postal Mailing address	Click here to enter text.
Telephone	Click here to enter text.
Fax	Click here to enter text.
E-mail	Click here to enter text.

8. Please indicate whether your facility provides the following services on site:

Surveillance and Diagnosis:

<input type="checkbox"/>	MRI Scanner	<input type="checkbox"/>	Ultrasound
<input type="checkbox"/>	CT Scanner	<input type="checkbox"/>	Genetic Testing
<input type="checkbox"/>	PET Scanner	<input type="checkbox"/>	Comprehensive Lab
<input type="checkbox"/>	PET/CT Scanner	<input type="checkbox"/>	Psychosocial Testing/Services

<input type="checkbox"/>	Kidney Screening	<input type="checkbox"/>	Colonoscopy
<input type="checkbox"/>	Skin Screening	<input type="checkbox"/>	Thyroid Exams

Treatments:

Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.

Therapy:

Click here to enter text.	Click here to enter text.
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Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.

9. How many patients with PHTS are seen annually?

Click here to enter text.

10. How many patients with BRRS are seen annually?

Click here to enter text.

11. How many patients with Cowden Syndrome are seen annually?

Click here to enter text.

12. Coordinated Care:

A. How does your organization define coordinated care?

Click here to enter text.

B. Beyond electronic medical records, how does your team implement coordinated care?

Click here to enter text.

C. Will you meet regularly as a team? If yes, what will be the frequency?

Click here to enter text.

D. How will your site update other PHTS team members about a medical status after a patient is seen at your center?

Click here to enter text.

13. How will your site assist patients in arranging appointments with needed specialists?

Click here to enter text.

14. How will your site assist patients in scheduling their annual scans?

Click here to enter text.

15. How will your site update a patient's PCP on their medical status?

Click here to enter text.

16. Coping with PHTS can be difficult for the patient and loved ones. How will your site incorporate care for emotional issues into the patient's medical care?

Click here to enter text.

17. How will your site encourage patients to participate in the PHTS Foundation patient registry?

Click here to enter text.

18. How can we better support your site in communication between your site and prospective patients? We welcome your feedback.

Click here to enter text.

19. Please add any additional comments in support of your application to become a PHTS Clinical Center of Excellence.

Click here to enter text.

Gene-guided clinical management of PTEN mutation positive patients

**PTEN
mutation +**

~25%

Cancer	General population risk (SEER)	Lifetime Risk with PTEN mutation+ CS	Screening Recommendations
Breast (female)	12%	85%	Starting at age 30, or 5-10 years before earliest known breast cancer in the family (whichever comes first): annual MRI alternating with screening mammogram with consideration of tomosynthesis*
Thyroid	1%	35%	Starting at time of PHTS diagnosis: Annual ultrasound
Endometrial	2.6%	28%	Starting at age 30: annual endometrial biopsy and/or transvaginal ultrasound
Renal cell	1.6%	34%	Starting at age 40: renal imaging every 1-2 years
Colon	5%	9%	Starting at age 35, or 5-10 years before earliest known colon cancer in the family (whichever comes first): colonoscopy, follow-up dependent on findings
Melanoma	2%	6%	Annual dermatologic examination

*The appropriateness of imaging modalities and scheduling is still under study. High-quality breast MRI limitations include having: a need for a dedicated breast coil, the ability to perform biopsy under MRI guidance by experienced radiologists in breast MRI, and regional availability. Breast MRI is preferably performed on days 7-15 of a menstrual cycle for premenopausal women.

Tan MH et al. *Clinical Cancer Research* 18:400-407 (2012)

Mester JL et al. *American Journal of Medical Genetics* 9999:1-8 (2013)

NCCN Clinical Practice Guidelines in Oncology®. Genetic/Familial High-Risk Assessment: Breast and Ovarian. V 1.2019 available at nccn.org (2018)

Thank you for your interest and support of the PHTS community.

