



# Clinical Center of Excellence (CCE) Application

For more info - [www.pheopara.org/clinicians/coe](http://www.pheopara.org/clinicians/coe)

Instructions: Open in Acrobat PDF & save. Navigate through the fields using 'tab' or with mouse.

Institution Name

Address

City State/Province Zip Country

### Person Completing Application

Name Title  
Email Phone

### Director/Co-Director Information

Name Title  
Email Phone

Briefly describe the Director/Co-Director's PPGL experience.

### Co-Director Information (if applicable)

Name Title  
Email Phone

Briefly describe the Director/Co-Director's PPGL experience.

### Patient Care Coordinator Information

Name Title  
Email Phone

### Patient Ambassador (optional)

Name Email  
Phone

Has this person agreed to participate as Patient Ambassador?

### **CASELOAD**

Approximately how many new cases of PPGL, including mutation carriers, have been seen at your center in the past year?

Approximately how many patients, including mutation carriers, have been seen for follow-up at your center in the past year?

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Approximately, how many PPGL surgical procedures have been done at your center in the past year?

Of these, how many are head/neck paraganglioma surgeries?

Approximately, how many pheochromocytoma surgeries have been done at your center in the past year?

### **DIAGNOSTICS & SURVEILLANCE**

All of these diagnostics are required on-site for a CCE designation: plasma metanephrines or 24-hour urinary metanephrines, genetic testing, MRI and/or CT, FDG-PET, 123I-MIBG and/or 68Ga-DOTATATE/DOTATATOC and/or 64-Cu DOTATATE. Check the box if the applicant center has all of the aforementioned?

### **Therapeutic Modalities**

All of the following therapeutic modalities are required on-site for a Clinical Center of Excellence designation:

- open adrenalectomy
- minimally-invasive adrenalectomy
- partial laparoscopic (cortical sparing) adrenalectomy
- resection of abdominal/pelvic paraganglioma
- resection of head/neck paraganglioma
- chemotherapy
- targeted therapy
- external beam radiation
- stereotactic radiosurgery
- referral to other institution for treatments not available at applicant institution and referral to clinical trials
- PRRT

Check the box if the applicant center has all of the aforementioned?

Do you have F-DOPA at your center? (not required)

Which of the following are offered at your center?

radiofrequency ablation

I-131 MIBG

re-operative partial adrenalectomy

off-label and emerging treatments

### **CLINICAL TRIALS**

Are patients actively recruited for participation in the following which can be off-site:

collaborative diagnostic trials

therapeutic clinical trials

patient registries

translational studies



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List PPGL and/or related trials patients are actively recruited for?

List PPGL and/or related publications over the past three years.

Provide detail regarding participation in PPGL and related research meetings.

### **WELLNESS**

Do patients receive educational information about the illness and information regarding upcoming seminars/conferences?

Are patients informed about wellness services by social worker or case manager?

Provide detail regarding wellness services offered, which may include education, nutrition, financial resources, etc.

### **MULTI-DISCIPLINARY REVIEW BOARD**

How often are MDRB meetings held?

Are these meetings regularly attended by: Endocrinologist, Endocrine and other Surgeons, Radiologist & Nuclear Medicine Physician?

Which of the following specialists attend as needed?

Pathologist

Psychiatrist/Psychologist

Geneticist

Obstetrician

Anesthesiologist

Oncologist

Vascular Surgeon

other/add



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### **METASTATIC DISEASE**

Are patients with metastatic disease treated on-site?

If patients are not treated on-site and they are referred to a collaborating center, please provide detail regarding the name of the collaborating center, the specialists that are involved (also include them on the specialist list document), how communication is organized and if/how the center takes part in MDRB meetings.

### **PEDIATRICS**

Are pediatric patients treated on-site?

If pediatric patients are not treated on-site and they are referred to a collaborating pediatric center, please provide detail regarding the name of the collaborating center, the specialists that are involved (also include them on the specialist list document), how communication is organized and if/how the center takes part in MDRB meetings.

### **CENTER COORDINATION & ADMINISTRATION**

To ensure the best patient experience, the following are requirements of the program:

- Patient Coordinator is available and responsible for coordinating the patient pathway.
- Central scheduling and appointment coordination.
- Protocol available describing the flow, timing and responsibilities for efficient and patient-friendly patient routing through different departments.
- Timely communication with healthcare provider.

Please confirm your center provides the following?

### **PPGL CLINICAL TEAM**

Please answer the questions below and download the On-Site Specialists Excel file found here (<https://pheopara.org/clinicians/coe>) to your computer. List any specialists with PPGL and related experience as instructed on the Excel file, save your file, and email your completed file to: [stephanie@pheopara.org](mailto:stephanie@pheopara.org).

Who is responsible for pre-surgical preparation? Add contact info to the On-Site Specialists document.

How many surgeons are available for adrenal surgery? Add contact info to the On-Site Specialists document.



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Who is responsible for extra-adrenal surgery of PGL? Add contact info to the On-Site Specialists document.

How many head/neck surgeons are available? Add contact info to the On-Site Specialists document.

### **STANDARD OPERATING PROCEDURES (SOPs)**

SOPs addressing diagnosis (biochemical testing, imaging and genetics), presurgical preparation and short-term/long-term follow-up and surveillance must be available for all health care workers in the center, and must include the names of specialists and/or Patient Coordinator primarily responsible.

Email [stephanie@pheopara.org](mailto:stephanie@pheopara.org) the SOPs for diagnosis (biochemical testing, imaging & genetics), presurgical preparation and short-term/long-term follow-up and surveillance.

### **PATIENT FEEDBACK**

Patient Feedback will be solicited after the initial application review by the MAB and virtual site visit meeting. Feedback will be gathered for at least two weeks online via Pheo Para Alliance social media outlets, mass email and website. Your center is welcome to share the anonymous survey, but it is not required. In order to collect sufficient feedback, it may be necessary to extend the two week patient feedback period. All de-identified patient feedback will be shared with your center.

Do you agree to allow Pheo Para Alliance to solicit patient feedback from patients seen at your center in the past year?

### **CERTIFICATION**

As an applicant to the Pheo Para Alliance Clinical Center of Excellence Program, I verify that the information submitted in this application is true and correct to the best of my knowledge and that all appropriate application institution personnel are aware of, and in support of, this application and will be made aware of the subsequent designation, if approved.

Signature:

Name

**Please make sure to email requested SOPs and On-Site Specialist sheet found at [www.pheopara.org/clinicians/coe](http://www.pheopara.org/clinicians/coe) to [stephanie@pheopara.org](mailto:stephanie@pheopara.org).**