



Specialized Clinical Center/Center of Excellence Application

Program Requirements and Overview document can be found [here](#).

Date:

1. Institution Information

Institution Name:

Phone:

Address:

City, State, Zip:

Country:

Contact Info for Person Completing Application

Name:

Title:

Email:

Phone:

Institution is applying for designation as:

Institution is applying for designation to treat:

Adult only (18+) is for Clinical Center only.

Both pediatric & adult designation is for Center of Excellence only.

2. Team Contact Information

Center Director/Co-Director

Name:

Title:

Specialty:

Link to bio:

Mailing Address:

Email:

Phone:

Pheo Para Experience:

Center Co-Director (if applicable)

Name:

Title:

Specialty:

Link to bio:

Mailing Address:

Email:

Phone:

Pheo Para Experience:



Patient Care Coordinator

Name:
Title:
Specialty:
Link to bio:
Mailing Address:
Email:
Phone:

Patient Ambassador (optional)

Name:
Email:
Phone:
Patient's current relationship with center:

How do the Applicant Center Director/Co-Director and Patient Care Coordinator work together currently?

3. Specialists

List the specialists that have PPGL and related experience. Refer to the Overview & Requirements document for information on specialties recommended for each designation and a description of the specialists role in the program. To allow for variations among centers, multiple specialties can be managed by one physician, which will be discussed during the applicant meeting. To list additional specialties, a separate document can be submitted with application.

Specialty:
Name:
Email:
Pheo Para Experience:

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4. Caseload

How many pheochromocytoma and paraganglioma patients does the applicant institution see annually?
(includes patients under surveillance)

Minimum of 25 patients are required for Clinical Center designation.

Minimum of 50 patients are required for Center of Excellence designation.

5. Diagnosis & Surveillance Procedures

Which of the following diagnosis and surveillance procedures is the institution able to perform on-site?

24-hour urine metanephrines
plasma metanephrines
Genetic testing
MRI/CT

FDG PET/CT
¹²³I-MIBG
⁶⁸Ga-DOTATATE
⁶⁸Ga-DOTATOC

Please list other relevant diagnostic and surveillance procedures performed on-site.

6. Treatment

Which of the following treatments is the institution able to perform on-site?

Non-surgical:

Chemotherapy
Targeted therapy
External beam radiation
Referral to clinical trials off-site
Referral to institution able to provide treatments not available at applicant institution
¹³¹I-iokebenguane
Emerging & off-label treatments

Surgical capability for:

Open adrenalectomy	Re-operative partial adrenalectomy
Laparoscopic adrenalectomy	Stereotactic radiosurgery
Partial laparoscopic (cortical sparing) adrenalectomy	Radiofrequency ablation
Resection of abdominal/pelvic paraganglioma	Cryoablation
Resection of head/neck paraganglioma	

Please list other relevant treatments performed on-site.

7. Research

Please indicate activities the institution engages in on-site.

Referral to clinical trial at another institution	Genetics/genomics
Encourages patient participation in patient registries	Translational research
Encourages tumor tissue donation	Metabolomics
On-site clinical drug trials	Immunology
Natural history studies	Animal models
Comparative treatment outcomes	Imaging

Please provide detail on pheochromocytoma and paraganglioma related research activities.

8. Wellness

Please describe how patients access resources to support overall health. Examples may include: access to educational seminars, support groups, social worker, education on financial resources, nutritionist, survivorship programs, etc. Please include links to institutional programs offered.



9. Center Coordination/Administration

How is the primary care physician involved in pheochromocytoma and paraganglioma patient care? Explain how visits, diagnostics, and course of treatment are communicated to primary care physician?

How are patient appointments coordinated to reduce multiple institution visits? How is appointment scheduling streamlined? Please provide detail.

What does the point of entry process look like for patients? Please provide detail.

Beyond electronic medical records, how does your institution's pheochromocytoma and paraganglioma specialist team communicate to ensure the best possible health outcomes? Please provide detail such as, frequency of meetings, who may attend, and how meeting results are implemented in patient's treatment plan.

Please provide additional detail on how your institution provides the best patient experience and provides the best patient outcomes as it relates to center coordination and administration.

Please list additional certifications, designations, accreditations or awards received by your center.

Patient Feedback

Patient feedback will be solicited after the initial application review and online meeting. Feedback will be gathered for two weeks online via Pheo Para Alliance social media outlets, mass email, and website.

Please send application to stephanie@pheopara.org
9721 Whitley Park Place, Bethesda, MD 20814 / www.pheopara.org /info@pheopara.org / [@pheopara](https://twitter.com/pheopara)



Certification

As an applicant to the Pheo Para Alliance Clinical Center/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 applicant institution personnel are aware of, and in support of, this application and will be made aware of the subsequent designation, if approved.

Signature

Date

Title