



Specialized Clinical Center/Center of Excellence Program Overview & Requirements

Thank you for your interest in the program. The Pheo Para Alliance mission is to empower patients with pheochromocytoma or paraganglioma, their families and medical professionals through advocacy, education and a global community of support, while helping to advance research that accelerates treatments and cures.

The Pheo Para Specialized Clinical Center/Center of Excellence program provides an environment where patients receive the best possible pheochromocytoma and paraganglioma (pheo para) care through a geographically diverse network of clinical centers. In addition to clinical and wellness services, the centers provide professional and lay education in the areas they serve, work with the Pheo Para Alliance in its efforts to continually improve the lives of those affected by the illness, and support clinical research efforts.

The program offers two levels of designation. The Clinical Center designation recognizes emerging centers that provide quality, multi-disciplinary patient care and facilitate pheo para research. The Center of Excellence designation recognizes centers that provide cutting-edge, high-quality, multi-disciplinary care and actively participate in pheo para research. Pediatric centers can receive a pediatric designation as a Clinical Center or Center of Excellence. Centers seeking a Center of Excellence designation must provide adult and pediatric expertise. Pediatric expertise can be referred to a nearby pediatric center.

Upon reviewing this document, the application can be found [here](#).

Program Objectives

1. Increase access to multi-disciplinary, coordinated clinical care for diagnosis and treatment of pheochromocytoma and paraganglioma patients and their families
2. Educate professionals and newly diagnosed patients and their families
3. Facilitate pheochromocytoma and paraganglioma research



Partnership Benefits

The Pheo Para Alliance is the premier organization dedicated to supporting those affected by pheochromocytoma and paraganglioma. We strive to serve as a beacon of light to those who are searching for answers and the proper treatment they deserve. Overwhelmingly, patients and caregivers want to know where they can be seen by experts in their area. This program connects patients with institutions providing top-notch care.

Approved applicants will be recognized in the following ways:

- ✓ Name recognition and contact information on pheopara.org under Clinical Center/Center of Excellence directory.
- ✓ Joint press release announcing approval of Clinical Center/Center of Excellence designation.
- ✓ In-person announcement ceremony with Pheo Para Alliance Board Members, staff and/or local patient representatives (dependent on CDC recommendations pertaining to COVID-19 and budgetary restrictions).
- ✓ Mass email and social media post on Twitter, Facebook and Instagram to announce Clinical Center/Center of Excellence designation sent to 500+ healthcare providers and 2,000+ patient and caregiver constituents.
- ✓ Use of Pheo Para Alliance Clinical Center/Center of Excellence designation seal on website and social media.

Program Requirements

Clinical Centers and Centers of Excellence are required to:

- Designate a Director/Co-Director & Patient Care Coordinator
- Adhere to the [Endocrine Society Guidelines](#) as much as possible
- Attend/Participate in Pheo Para Alliance patient education activities/conferences, as requested
- Provide patients with Pheo Para Alliance educational material and peer support resources
- Provide an annual tour of center/lab to members of the Board of Directors and other Pheo Para Alliance constituents, as requested
- Provide annual self-reporting



The following outlines standards for the Clinical Center and Center of Excellence designations. Scoring, detailed below, provides allowance for variations among institutions.

Evaluation Categories	Pheo Para Clinical Center <i>Recognize emerging centers providing high-quality, multi-disciplinary patient care and facilitating pheo para research.</i>	Pheo Para Center of Excellence <i>Recognize centers providing cutting-edge, high-quality, multi-disciplinary care and participating in pheo para research.</i>
Caseload	25 patients, new and under surveillance	50 patients, new and under surveillance
Diagnosis and Surveillance Procedures	24-hour urine, plasma metanephrines, genetic testing, MRI/CT, FDG PET/CT, ¹²³ I-MIBG	All as in clinical level plus SSTR-based imaging, such as ⁶⁸ Ga- DOTATATE/DOTATOC
Treatment	<p>Surgical capability for: open adrenalectomy, laparoscopic adrenalectomy, partial laparoscopic (cortical sparing) adrenalectomy, resection of abdominal/pelvic paraganglioma, resection of head/neck paraganglioma</p> <p>Non-surgical: Chemotherapy, targeted therapy, external beam radiation, referral to institution able to provide treatments not available at applicant institution, referral to clinical trials</p>	<p>All as in clinical level plus surgical capability for: stereotactic radiosurgery, radio frequency ablation, cryoablation, re-operative partial adrenalectomy</p> <p>Non-surgical: all as in clinical center. ⁱ⁻¹³¹iobenguane and emerging off-label treatments are not required but considered in review of application.</p>
Specialists with pheo para experience (multiple specialties may be managed by one physician)	Endocrinologist, Endocrine/ENT/Urology and Vascular Surgeons, Anesthesiologist, Intensive Care Specialist, Genetic Counselor, Oncologist, Cardiologist, Nuclear Medicine Physician, Radiologist, Psychology/Psychiatry, Hypertension Specialist, Pediatrician (if pediatric designation)	All as in clinical level plus Radiation Oncologist, Nephrologist, Geneticist, Neurosurgeon, Interventional Radiologist, Pathologist, pediatric expertise, Maternal/Fetal High-Risk Obstetrics, Palliative Care, Cardiac Surgeon



Research	Active pheo para related research not required, but institution must be able to refer patients to clinical drug trials at another institution, encourage patient participation in registries and tumor tissue donation.	Maintains an active pheo para related research program with a history of publications in natural history, comparative treatment outcomes, genetics/genomics, translational research, metabolomics, immunology, experimental animal models, imaging, and/or clinical drug trials.
Wellness	Provide patients access to resources to support overall health to ensure the best possible patient outcomes. Examples may include: access to educational seminars, support groups, social worker, education on financial resources, nutritionist, survivorship program, etc.	
Center Coordination/ Administration	Examples may include: medical updates communicated to primary care physician, multi-disciplinary tumor board which meets regularly and provides formal documentation of outcomes, central scheduling and coordinated appointments.	
Patient Feedback	Overall, positive patient feedback received during two-week period via Pheo Para Alliance communication channels	

Application Scoring:

Applicants are evaluated in the aforementioned categories using the following scale:

- 3 – Fully Compliant – most, if not all, of the standards have been satisfied for the category
- 2 – Mostly Compliant – approximately 75% of the standards have been satisfied for the category
- 1 – Partially Compliant – approximately 50% of the standards have been satisfied for the category

To qualify as Pheo Para Clinical Center applicants must:

- Receive a score of 3 in the following categories: Case Load, Diagnosis and Surveillance Procedures and Treatment.
- And,
- Receive a minimum score of 2 in the other four out of five categories (one score of 1 permitted). If a score of 1 is received, a plan must be put in place to be mostly compliant within a year. Deficiencies will be evaluated in annual self-reporting.



To qualify as a Center of Excellence applicants must:

- Receive a score 3 in the following categories: Case Load, Diagnosis and Surveillance Procedures and Treatment.
- And,
- Minimum score of 2 in the other five categories.

Roles & Responsibilities

Director/Co-Director

- Serves as the sponsoring physician(s) of the program and ensures requirements of the program are met (2 Co-Directors are recommended; one must be a physician).
- Serves as the point of contact for Pheo Para Alliance staff and Medical Advisory Board
- Identifies pheochromocytoma paraganglioma team and serves as lead
- Facilitates communication with Patient Care Coordinator and Specialists to ensure best patient experience and best clinical outcome
- Attends the International Pheo Para Conference in Syracuse, NY held summer of every other year, as requested
- Encourage educational opportunities for physicians to learn about the illness. A patient representative can be requested through Pheo Para Alliance.
- Present on pheo para at physician and/or patient meetings, as requested by Pheo Para Alliance
- Ensure annual reporting is completed in a timely manner

Patient Care Coordinator

- Serves as the initial point of contact for patients (contact information is listed on pheopara.org and outreach materials)
- Serves as part of the lead team for the program
- Understands the basics of pheochromocytoma and paraganglioma (does not provide medical advice)
- Shares Intro to Pheo Para and Pheo Para Genetics brochures to newly diagnosed and genetic mutation carriers (provided by Pheo Para Alliance)
- Directs patients and families to Pheo Para Alliance resources, as needed
- Ensures diagnostic and specialist appointments are scheduled, and appointments are coordinated for best patient experience
- Monitors patient's psychosocial needs and assists in finding support close to home
- Ensures patient's primary care physician receives visit reports and diagnostics results
- Provides direction to wellness resources available



Patient Ambassador

- Patient/caregiver that serves as local contact for patients at your center
- Provides peer support and connects patients with other local patients, if requested
- Provides Pheo Para Alliance and relevant resources to patients, as needed
- Provides patient testimonials to educate healthcare providers at your center about pheo para
- Shares feedback received from patients with center to improve patient experience

Specialist

- Serves as department expert on pheochromocytoma and paraganglioma
- Adheres to Endocrine Society Guidelines as much as possible
- Monitors patient's psychosocial needs and communicates them to Patient Care Coordinator
- Understands and adheres to all Clinical Center of Excellence program guidelines
- Participates in multi-disciplinary tumor board meetings, as needed
- Supports the coordination of multiple appointments for best patient experience
- Encourages educational opportunities for physicians to learn about the illness. A patient representative can be requested through Pheo Para Alliance.
- Present on pheochromocytoma paraganglioma at physician and/or patient meetings, as requested by Pheo Para Alliance

If a Director leaves the institution, the outgoing Director can name an internal replacement, or the incoming staff replacement can serve as the new Director of the Center. If a Co-Director leaves the institution, the other Co-Director of the Center will appoint a new Co-Director or serve as the sole Director of the program. Co-Directors are encouraged to ensure the program provides continuity of care and consistently meets program expectations.

If a new staff member is appointed as Director/Co-Director an introductory call is required with a Pheo Para Alliance representative within 30 days of appointment as Director/Co-Director of the program. In addition, changes in Coordinator and Specialists must be communicated to Pheo Para Alliance within 30 days.

Onboarding Process

Below is a diagram of the application and onboarding process, which can take 2-4 months from the time the application is received to application approval. Applications are reviewed, and upon recommendation by the Medical Advisory Board, an online meeting is scheduled with members of the Medical Advisory Board and the Center Director/Co-Director, Care Coordinator, Patient Ambassador, and Specialists as identified by the applicant.

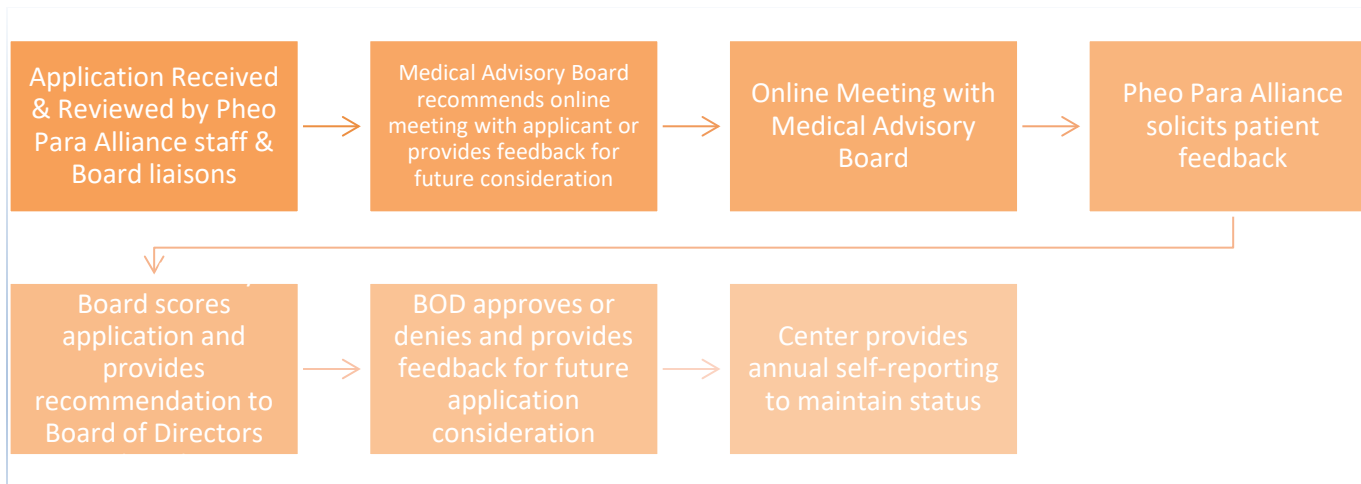


After the online meeting, Pheo Para Alliance will solicit patient and caregiver feedback via email and social media about care received at the institution. The Medical Advisory Board will then score the applicant and provide the Board of Directors with a recommendation to approve/deny the designation. In both cases, feedback will be provided to the applicant institution.

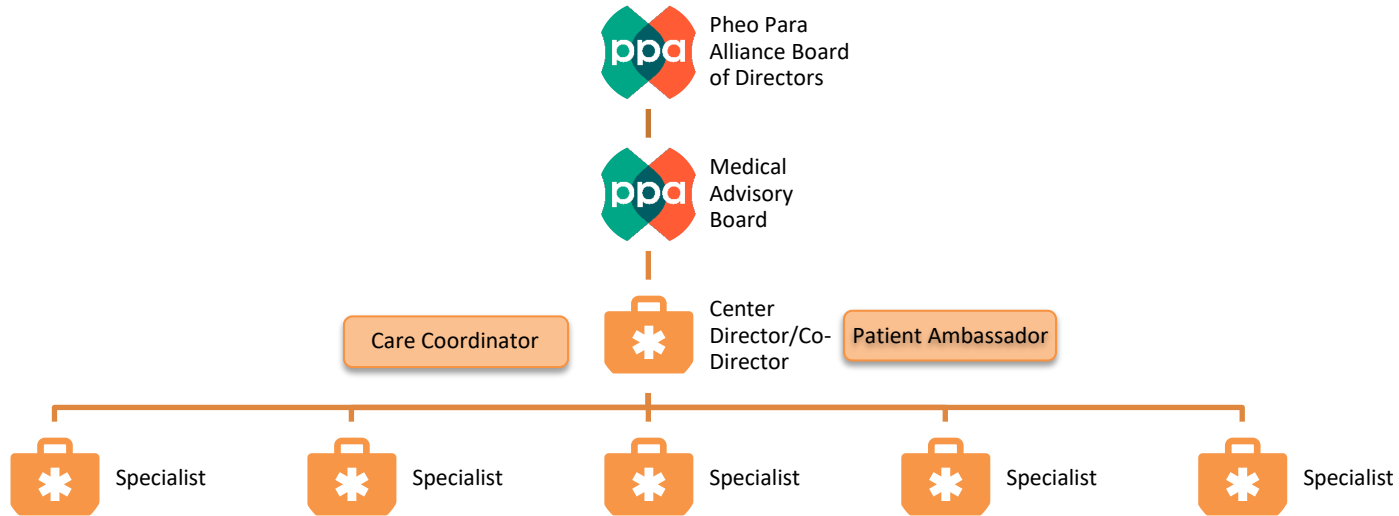
Centers must provide self-reporting annually, due on the anniversary of their approved designation. Centers must reapply for Center designation every three years.

In any year in which an unsatisfactory report is submitted, the Center fails to submit a report, or upon failure to deliver the services or adhere to the requirements of the program, Pheo Para Alliance reserves the right to suspend the Center of Excellence or Clinical Center designation until identified deficiencies are resolved. If deficiencies are not resolved within 90 days, designation will be revoked.

Application Process



Governance Chart



[Link to Application](#)