



Research Opportunity Inquiry (*for investigators*)

The Pheo Para Alliance (PPA) welcomes research that advances our knowledge of pheochromocytomas and paragangliomas, as well as investigations that help patients and their families cope with their condition.

Patient-Focused Research Program Objectives:

1. To provide feedback to investigators during all phases of a research cycle to ensure their work is patient-centered and useful, leading to greater use of research results by patients and the broader healthcare community.
2. To provide a platform for investigators to share their opportunities for the pheo para community to participate in research.

The Pheo Para Alliance asks investigators who seek patient-centered feedback or a platform to share volunteer research opportunities to provide the information below. This information will be used to inform our patient population about the study. Recruitment can be more successful when patients understand, in lay terms, their commitment, the aims of the research, and how it might help them, and when it provides answers to the pheo para population in the future.

The purpose of this program is to share information with our patient population. We do not endorse any particular study or research.

1. What is the title and time frame of the study?
2. Please share the link to the study and indicate whether we are able to share this link with our patient population directly.
3. Please list the names and contact information for researchers.
4. Has the study received ethics clearance from a hospital or university IRB? Please identify the IRB(s) and date of clearance.
5. Please list any general inclusion criteria that are required for participation, such as diagnosis, genetic status, age, or place of residence.

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6. Please provide a brief “lay language” summary of the research.

7. What is the funding source and funding duration for the research?

8. What are potential patient participants being asked to do as part of this study (e.g., receive treatment, fill in a survey, be interviewed, keep a journal)?

9. What recruitment information will you provide for distribution to potential participants?

10. How might the research benefit individual participants, PPA, and/or the medical/scientific community?

11. How will individual participants and PPA receive feedback about the results of the study?

Please send this form to info@pheopara.org, attn: Linda Rose Krasnor, Chair of the Board of Directors of the Pheo Para Alliance. Upon the Research Advisory Board's review of this form and a recommendation to the Board of Directors, the study will be posted here: <https://pheopara.org/education/clinical-trials>, which is also shared regularly on social media.

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