



Research Opportunity Inquiry

The Pheo Para Alliance (PPA) welcomes research that will advance our knowledge of pheochromocytomas and paragangliomas, as well as investigations that will 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 opportunity for the pheo para community to participate in research.

The Pheo Para Alliance asks investigators who seek patient-centered feedback or who seek a platform to share volunteer research opportunities to provide the information below. This information will be used to inform our Board of Directors and patient population about the study.

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

1. Please list the names and contact information for researchers.

2. Please provide a brief “lay language” summary of the research, including the title of the study and its time frame.

3. Has the study received ethics clearance from a hospital or university IRB? Please identify the IRB(s) and date of clearance.

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

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

6. Are there any expectations for the PPA beyond distributing information about the study to potential participants? If so, please describe.

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

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

9. 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, Research Request Coordinator.