

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.

Genetic Counselor: Katie Lewis: 301-594-3063; katie.lewis2@nih.gov

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

Some genetic testing results are shared with a person whether or not they are related to the original reason a person had testing. Most of these have to do with increased risks for cancer, tumors or heart problems. The person is told about these so that they can get healthcare and screening related to the genetic result. Our project, the Genomic Services Research Program (GSRP) is studying people who get unexpected result like this. We want to know what people do with these results and whether they and their family members develop health problems. People in the study will be asked to take a survey and do a phone interview. We may also ask them to share medical records with us or offer genetic testing to their family members. We plan for the study to continue for at least five years.

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

Yes, the program has received clearance by the National Institutes of Health IRB on 01/19/2020.

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

We receive funding from the Intramural Research Program of the National Human Genome Research Institute. There is currently no end date for this funding.

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)?

Participants will be asked to complete a survey and a phone interview in order that we may learn both about their unexpected result and their and their family's health history. Participants may also be asked to send their medical records. Some people may be invited to come to the NIH Clinical Research Center to have additional tests run and their family members may be offered genetic testing as well. All additional testing will be free of charge.

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

No

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

We have a variety of recruitment materials that can be tailored depending on what is recommended by the PPA. This includes patient-facing letters, brief descriptions suitable for social media posts, and brochures.

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

This project may inform our understanding of the health risks associated with these genetic variants, as well as potential ways to improve healthcare for patients who receive them. Individual participants may learn basic information about their result that is useful to them and/or their healthcare providers.

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

Participants will receive basic information about their genetic result that may be useful to them or their provider(s). Moreover if a participant comes to the NIHCC we will share results of all testing an individual undergoes. We intend to develop plans for periodic communication of study findings to participants (e.g., newsletters).

Please send this form to info@pheopara.org, attn: Linda Rose Krasnor, Research Request Coordinator.