



## 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.

Kayla Hamilton (genetic counselor): [kayla\\_hamilton@dfci.harvard.edu](mailto:kayla_hamilton@dfci.harvard.edu), phone: 857-215-0766  
Junne Kamihara (MD, oncologist, PI of study): [Junne\\_Kamihara@dfci.harvard.edu](mailto:Junne_Kamihara@dfci.harvard.edu)

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

The study is titled “Psychosocial outcomes and family communication after genetic testing for a childhood-onset hereditary cancer syndrome”. Our goals are to describe the experiences and psychosocial outcomes of families who have undergone testing for a childhood-onset hereditary cancer syndrome and evaluate how genetic results impact family dynamics and communication, particularly when siblings have discordant results. We will be conducting interviews with positive adolescents, negative adolescents, and their parents. We plan to conduct interviews throughout the Winter of 2021-2022.

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

We have IRB approval through Dana-Farber Cancer Institute. The study was approved in September, 2021.

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

We anticipate interviewing participants through April 2022. We have funding through Dana-Farber Cancer Institute as well as a small grant through the National Society of Genetic Counselors.

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 are being asked to participate in a one-on-one interview with a researcher. The interviews typically take less than 1 hour.

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

There are no expectations beyond distributing the flyer to potential interested participants.

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

I have provided an IRB approved study flyer as well as an IRB approved email draft that can be sent to participants.

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

We hope that the study will improve genetic counseling, results disclosure conversations and follow up for individuals with hereditary cancer syndromes, including PGL-PCC. We hope to learn about the best ways to support families, including supporting the individuals who have the hereditary risks and their family members who do not have the genetic risks.

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

We will not be sharing results directly with participants but we do hope to publish the study and would be happy to share the final publication with anyone who is interested.

Please send this form to [info@pheopara.org](mailto:info@pheopara.org), attn: Linda Rose Krasnor, Research Request Coordinator.