

TITLE: The OHSU Pancreas Community Registry**PRINCIPAL INVESTIGATOR:** Brett C. Sheppard, MD (503) 494-8372**REGISTRY COORDINATOR:** Hope Hardaker, MPH (503) 494-8820**PURPOSE:**

You are being asked to take part in this registry because you have been identified as someone who has a personal history of pancreatic cancer, pancreatitis, or other pancreatic disease or are a relative or friend of someone who has had pancreatic cancer, pancreatitis, or other pancreatic disease. The purpose of this study is to serve as a resource for communicating with you about future pancreatic disease community outreach projects and research that may be of interest to you.

PROCEDURES:

This is a registry, a type of research data repository. Research registries include only people who choose to take part. By agreeing to be included in the OHSU Pancreas Community Registry (OHSUPancreas), you are providing consent or permission for OHSU researchers to keep your information in a confidential, privacy-protected, ethics board-approved database. You are also providing consent to be contacted periodically with additional surveys and future pancreatic disease community outreach projects.

Your name, responses to questionnaires you decide to complete, and contact information will be stored in a database of information. The information you provide could be used for future research. The OHSU Brenden-Colson Center for Pancreatic Care may contact you in the future to let you know about pancreatic disease-related events. Researchers may ask the Brenden-Colson Center for Pancreatic Care to contact you about research studies they want to do, in which case we will contact you (other researchers will not be given your contact information unless you directly provide it to them) so that you can decide if you'd like to participate in that future research. If you decide you do want to participate, you will have the information necessary to let the researchers know.

Before you agree to participate in any future research, the investigator must tell you:

1. Why the research is being done, what you will have to do, and how long it will last
2. The risks and benefits of the research
3. What other choices you have if you prefer not to join the research study and
4. How information about you will be protected.

Depending on the study, the investigator may also tell you about:

1. What will happen if you are harmed by the study
2. What happens if you decide to stop participating in the study
3. New risks that may be discovered during the study
4. The reason(s) why you may be asked to leave the study before it is completed
5. Costs, if any, you may responsible for

6. How many people will be in the study.

If you have any questions, concerns, or complaints regarding this study now or in the future, or you think you may have been injured or harmed by the study, contact study coordinator Hope Hardaker at telephone (503) 494-8820 or via email at OHSUPancreas@ohsu.edu.

RISKS:

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.

BENEFITS:

You may or may not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

CONFIDENTIALITY:

Your information will be kept in a confidential, privacy-protected, ethics board-approved database. We will take steps to keep your personal information remains secure and confidential, but we cannot guarantee total privacy.

COSTS:

There will be no cost to you or your insurance company to participate in this registry.

PARTICIPATION:

This research is being overseen by an Institutional Review Board ("IRB"). You may talk to the IRB at (503) 494-7887 or irb@ohsu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at <https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html> or by calling toll-free (877) 733-8313 (anonymous and available 24 hours a day, 7 days a week).

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.