Thank You . . .

In this Research Update, we are pleased to share new findings from our Pancreatic Cancer Research Team. We also are opening new studies for which you may be eligible. Our overall goal is to help pancreatic cancer patients and their families by better understanding risks and using information from our research for prevention and early detection strategies.

We are grateful for your interest and participation in Mayo Clinic’s research.

Gloria M. Petersen, Ph.D., Principal Investigator

New Research Shows that Genetic Tests Can Inform About Risk of Pancreatic and Other Cancers

We know that there is an increased risk of pancreatic cancer for those with alterations (mutations) in certain inherited genes. The current medical practice is to offer genetic testing to patients who meet criteria for familial pancreatic cancer (FPC), which is defined as a family in which at least two first-degree relatives have had pancreatic cancer (e.g., your first-degree relatives are your parents, brothers, sisters, and children).

In two recent studies, we looked for mutations in over two dozen cancer genes in the DNA of hundreds of our study participants who had a personal and family history of pancreatic cancer. These genes were thought to increase risk of pancreatic cancer. We found that the pancreatic cancer in a larger percent of FPC families can be explained by genetic causes, but that many FPC families do not have a testable genetic factor involved. We also found that families without a strong family history can be explained by a testable genetic factor. These genes can increase risk of other cancers such as breast cancer, colon cancer, and melanoma. Our results suggest that there may be an advantage to being tested for multiple cancer genes. Genetic testing improves risk assessment for pancreatic and other cancers.

You can find more information about cancer genetic testing at the National Cancer Institute and American Cancer Society websites.

References:
New Genetic Research Studies Update

Mayo Clinic is a Member of the Stand Up 2 Cancer (SU2C) Dream Team to Intercept Pancreatic Cancer

The Stand Up 2 Cancer (SU2C) and Lustgarten Foundation Pancreatic Cancer Interception Dream Team is a multidisciplinary team that has the goal to reduce the number of patients with pancreatic cancer who are diagnosed at a late stage. This means detecting cancer earlier which provides more treatment options. The SU2C Dream Team will perform genetic testing on family members of pancreatic cancer patients who carry genetic mutations. An educational and genetic counseling intervention will be evaluated as family members consider being tested. Cancer-free relatives who carry a mutation could then be tested with advanced imaging techniques to see if smaller cancers missed by the human eye can be detected. A smaller group of high-risk individuals who have pre-cancerous lesions in the pancreas will be given a vaccine with the hopes that the body’s own immune system will attack the cancer. Lastly, the hope would be for the team to develop a blood test for early detection of pancreatic cancer that can be offered to people at high-risk. This is a study that will begin enrolling soon.

Participating sites include Mayo Clinic (Rochester, MN), Harvard University/Dana Farber Cancer Institute (Boston), Johns Hopkins University (Baltimore), MD Anderson Cancer Center (Houston), Massachusetts Institute of Technology (Boston), and University of California, San Diego.

We are proud to let you know that pancreatic advocates for the SU2C project include our own RAPPORT advocate, Mr. Scott Nelson, along with Mrs. Barbara Kenner of New York.

You can learn more about other current studies at the National Cancer Institute and American Cancer Society websites.

New Research Opportunity

New Pancreatic Cancer and Melanoma Study: Two Cancers, One Gene (TCOG)

Two Cancers, One Gene (TCOG) is one of our new studies in which we are looking at genetic and non-genetic factors to examine why some people in families develop pancreatic cancer, while others develop melanoma, why some develop both, and yet others never develop cancer. There is a gene (CDKN2A) which has been previously studied, but the relationship to cancer risk remains unclear. This study is funded by the National Cancer Institute. The Principal Investigator is Dr. Gloria Petersen.

Those who are interested must meet the following eligibility criteria:
✔ Have one or more first-degree or second-degree blood relatives (e.g., first -degree relatives are your parents, brothers, sisters, and children. Second-degree relatives are your grandparents, grandchildren, and aunt/uncle) with pancreas cancer or melanoma
or
Have a personal history of pancreas cancer or melanoma
✔ Over 18 years of age

Involvement in the study includes:
✔ Completion of a survey on your health and family history
✔ A one-time blood collection
✔ Completion of an authorization form that gives permission to review medical records and/or request a sample of leftover tissue to be used for future research
✔ Possibly asking you to provide names and addresses of relatives who may be interested in participating

There are no costs to be in this study, and your participation is completely voluntary.

Enrollment is now open. This study (NCT03174574) is described at clinicaltrials.gov. For more information about TCOG at Mayo Clinic, please contact the Pancreas Research team.

Past Newsletters...

For more information about pancreatic cancer research, please refer to our previous newsletters, they can be requested by contacting the Pancreas Research Team or viewed online at: http://mayoresearch.mayo.edu/mayo/research/petersen_lab
Disclosing Research Results to Family Members When a Research Participant is Deceased

There has been much debate on whether or not research findings should be returned to relatives of a participant after the participant is deceased. We know that there could be significant benefits to family members by being informed of such findings, especially if it may have an impact on their future health status. Our team conducted a survey that examined the attitudes and preferences of participants in the Mayo Clinic pancreatic cancer research registry. Surveys were sent to over 6,000 people who had previously been involved in research, with a return of 3,630 completed surveys. Results showed that 94.4% of participants agreed that they “would be OK with sharing genetic research results with blood relatives who wanted to know them” and 87.9% of participants reported they “would feel obligated to share their genetic research results with blood relatives”. Overall, our findings show that most participants would like to learn about their own genetic research results and would support sharing their genetic research results with their blood relatives even after their own death.

Reference:

Representing Advocacy for Pancreas Patients with Outreach and Research Teams (RAPPORT)

RAPPORT is a patient advocate group based in Minnesota that was established in October 2008 as an affiliate of the Pancreatic Cancer SPORE at Mayo Clinic. RAPPORT includes pancreatic cancer survivors, caregivers, and other participants. Their mission is to determine the critical issues facing those affected by pancreatic cancer and to serve as a resource to both the pancreatic cancer research community and conduct outreach efforts.

RAPPORT members provide a patient and caregiver perspective on current pancreatic cancer research efforts with the goal of helping to find a cure. RAPPORT members also work to assist patients and caregivers as they fight this disease.

If you are interested in helping in our battle against pancreatic cancer, please contact Bridget Rathbun at 1-800-914-7962 (option 1) or pancreas@mayo.edu.

RAPPORT Member Advocacy Story: Bonnie and Mark Rekucki

Being a part of the patient advocacy group allows Mark and me the opportunity to share a pancreatic cancer survivor's perspective with medical professionals who have taken on the challenge of researching this disease. RAPPORT has given us the privilege of seeing the continued efforts of such a remarkable group of dedicated researchers, who in turn give hope to fellow patients and their caregivers. We are grateful and proud to be included in the patient advocacy group on behalf of all those diagnosed with pancreatic cancer.

Bonnie Rekucki
Message from the Study Coordinators

We have enjoyed working with you and your families on this important cancer research. Thank you for your time and dedication during the course of the study and for providing us with important information and blood or tissue samples. Without your help, our research would not be possible. If you learn of any relevant updates to your personal or family medical history (new diagnoses of cancers, pancreatic conditions, or genetic testing results), we would be grateful if you notified us by mail, by phone (1-800-914-7962), or by email (pancreas@mayo.edu).

Genetic Testing Information

If interested in more information about cancer genetic testing or locating a genetic professional near you see the links below:

- National Cancer Institute: https://www.cancer.gov/about-cancer/causes-prevention/genetics/directory
- National Society of Genetic Counselors: https://www.nsgc.org/p/cm/ld/fid=164

New Cures, New Hope - Support Pancreatic Cancer Research at Mayo Clinic

Mayo Clinic has been known as a top-notch destination for hope and healing, and for its commitment to innovative biomedical research. As a not-for-profit organization, we rely on support from donations and grants to find the latest answers. Make your tax-deductible gift for pancreatic cancer research today by phone: call 855-852-8129 (toll-free); or email: development@mayo.edu. We are grateful for your interest in advancing our work.

Who’s Doing Pancreatic Cancer Research?

ClinicalTrials.gov
http://www.clinicaltrials.gov/
This website is a detailed and current registry of federally and privately supported clinical trials for many different diseases and conditions in the U.S. and around the world.

Clinical Trials at Mayo Clinic
http://clinicaltrials.mayo.edu/
This website provides information about research studies for many different diseases and conditions at Mayo Clinic.

How to Contact Us

Address: Pancreas Research Project
200 First St SW
Mayo Clinic
Rochester, MN 55905
Phone: 1-800-914-7962
E-mail: pancreas@mayo.edu
Website: http://mayoresearch.mayo.edu/mayo/research/petersen_lab
Study Coordinators: Sarah Amundson, Cynthia Beinhorn, Cassandra Bell, Jennifer Brooks, Christen Muenkel, Bridget Rathbun

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