Thank You . . .

In this new Research Update, we are pleased to share recent findings about genetics from our Pancreatic Cancer Research Group. The ongoing EXPAND research study is open for persons recently diagnosed with diabetes with the goal of improving earlier detection of pancreatic cancer. Read more about this study later in this newsletter. We are grateful for your interest in Mayo Clinic’s research.

Gloria M. Petersen, Ph.D.
Principal Investigator

New Genetic Findings About Pancreatic Cancer Patients with Family History

Familial pancreatic cancer (FPC) is defined as a family with at least two affected first-degree relatives (FDR). FDR include parents, siblings, and children. We can now better inform patients and families about their chances of having inherited mutations in four of the genes (BRCA1, BRCA2, PALB2, and CDKN2A) which research has shown are responsible in part for increased risk of FPC. Researchers in Canada have also found that hereditary colorectal cancer genes (MLH1, MSH2, and MSH6) have mutations that increase risk of pancreatic cancer.

Both studies conclude that:
• The genetic basis of FPC is varied.
• A given FPC family may have a mutation in one gene, but not usually in multiple genes (i.e., one family may have a BRCA2 mutation, while another may have a PALB2 mutation, etc.).
• Genetic testing may help inform patients about genetic risk when there is a positive family history, especially in families with at least two affected FDR.

References:
• Zhen DB et al. BRCA1, BRCA2, PALB2, and CDKN2A Mutations in Familial Pancreatic Cancer (FPC): A PACGENE Study. Genetics in Medicine. 20 November 2014.

Probability (%) that patients affected with pancreatic cancer (PC) will test positive for a disease-causing mutation in BRCA1, BRCA2, PALB2, or CDKN2A, if from a family with cancer history. Number of PC includes patient. Sizes of sample subsets from which probabilities were estimated are shown in parentheses.
Among bioethics researchers, there is a lot of debate surrounding if research findings should be offered to families after a participant’s death. There is law and policy that protects individuals’ privacy, choice, and control, giving the right not to learn the results of genetic tests. However, results could be helpful to those families wanting to know if they have a risk of developing cancer. Mayo Clinic researchers sent surveys to over 6,300 individuals in the pancreas registry asking about their attitudes and preferences on: “the right not to know” vs. offering results; the wishes of individuals vs. family benefit; and participant vs. researcher responsibility for learning results. The researchers received 3,645 completed surveys. 13% agreed with protecting “the right not to know” with the majority choosing to “offer genetic results to all participants, even if it risked upsetting those who may not want to know results.” Among those who wished to return genetic research results, 57% agreed that the “blood relatives would benefit.” 77% agreed that it is the researcher’s responsibility to offer results. Overall, there seems to be general support for offering genetic results to family members in spite of existing privacy protections.

References:

Who should make decisions about return of genetic information to family if a research participant dies without stating their wishes?
- Spouse/partner, 39%
- Blood relative, 36%
- PCP, 8%
- PR, 7%
- Researcher, 7%
- Other, 3%

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Who’s Doing Pancreatic Cancer Clinical Trials?

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.
Now Open: Research Opportunity

EXPAND – A New Pancreatic Cancer Screening Study

The Examination of the Pancreas in New-onset Diabetes (EXPAND) study is led by Dr. Suresh Chari, a gastroenterologist at Mayo Clinic Rochester. The study aims to find the best way to screen for pancreatic cancer in people between the ages of 50 and 85 with a new diagnosis of Type 2 diabetes. The study has two parts.

• Part 1 of this study will collect blood and other bodily samples from those with either a confirmed new diagnosis of diabetes or recent lab tests that showed elevated sugar levels. If the participant completes Part 1, he/she will be given a gift card. If the participant completes Part 1 and qualifies for Part 2, we will extend an invitation and he/she will be able to decide whether or not he/she wants to further take part.

• Part 2 will image the pancreas in order to pick out the rare person with pancreatic cancer among the many with Type 2 diabetes. Most participants will not have pancreatic cancer. Imaging includes a computed tomography (CT) scan and endoscopic ultrasound (EUS). If the participant is eligible and completes Part 2, he/she will be given a gift card.

There is no cost to be in the study, unless a fine needle aspiration (FNA) is required in Part 2.

The blood draw, CT, and EUS are paid for by the study. In addition, if the participant lives more than 50 miles from Mayo Clinic Rochester, he/she will be reimbursed up to $150 for travel expenses including mileage, lodging, and food.

People who are interested in taking part in the EXPAND study must meet all of the following criteria:

Part 1
✓ Age between 50 and 85 years
✓ One of the following:
  • Recent diagnosis of diabetes (within the last 6 months)
  • Fasting blood glucose ≥ 126
  • Random blood glucose ≥ 200
  • Hemoglobin A1c ≥ 6.5
✓ Not on steroids during the blood draw
✓ No personal or family history of pancreatic cancer

Part 2
✓ Confirmed diagnosis of diabetes
✓ One of the following:
  • Weight loss of 5 pounds or more in the last year
  • Elevated blood CA 19-9 levels

Enrollment for the study at Mayo Clinic is now open.

For more information about EXPAND at Mayo Clinic, please contact the EXPAND Study Coordinator at 1-800-914-7962 or pancreas@mayo.edu

Glossary

Computed tomography (CT) scan: A procedure using X-rays to produce detailed cross-sectional images of organs in the body.

Endoscopic ultrasound (EUS): A procedure using ultrasound waves to produce detailed images of organs in the body. An ultrasound probe is attached to an endoscope, which is a fiber optic tube used to look inside the intestinal tract.

Fine needle aspiration (FNA): A procedure inserting a thin needle into an area of abnormal appearing tissue or body fluid. The sample collected can help make a diagnosis or rule out conditions such as cancer.
Mayo Clinic Specialized Program of Research Excellence (SPORE) in Pancreatic Cancer

The National Cancer Institute has awarded Mayo Clinic five more years of funding to advance research in pancreatic cancer, bringing findings from the laboratory to the patient. This $11.3 million grant is funded from September 2014 to August 2019. Directed by Dr. Gloria Petersen, this grant supports four projects plus provides seed money and supports young investigators to more rapidly find ways to prevent, screen, and treat pancreatic cancer. The research cores include patient registry, clinical trials, tissue collection, and biostatistics, and support coordinated pancreatic cancer research at Mayo Clinic. More details can be found at http://www.mayo.edu/research/centers-programs/cancer-research/research-programs/gastrointestinal-cancer-program/pancreatic-cancer-spore-grant/pancreatic-cancer-spore-grant

Message from our Study Coordinators

We have enjoyed working with you and your families on this important pancreatic research. Thank you for the time and dedication you put into taking part and providing us with 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 or by calling 1-800-914-7962.

Past Newsletters...

For more information about pancreatic cancer research, please refer to previous volumes of this newsletter, which may be requested by contacting the Pancreas Research Team can be viewed online at: http://www.mayo.edu/pmts/mc1100-mc1199/mc1185-66.pdf http://www.mayo.edu/pmts/mc1100-mc1199/mc1185-0209.pdf http://www.mayo.edu/pmts/mc1100-mc1199/mc1185-1009.pdf http://mayoweb.mayo.edu/sp-forms/mc1100-mc1199/mc1185-1010.pdf

Frequently Asked Question:

Will I find out my results from the research?

When we study the samples and medical information that you have provided for our pancreas disease research registry, it often takes us many years to find results. You should typically not expect to get your results from taking part in our research. However, there is a small chance that we could discover something that might have important health implications for you. If this happens, we will contact you to see if you want to learn more. If you do not want to find out the results, you can say no. Because this is research, we would not give your results to your doctor or put them in your medical record.

Resources


The Lustgarten Foundation for Pancreatic Cancer Research http://www.lustgarten.org Non-profit organization for supporting pancreatic cancer research and education

How to Contact Us

Address: Pancreas Research Project Charlton 6, 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: Bridget Eversman Sarah Amundson