Thank You...

Your participation in our research is so important to many who will benefit from our discoveries. Our goal is to improve the outlook for people who are diagnosed with pancreatic cancer and those who are at risk for developing it. So much more attention is now being given to this cancer than just a few years ago. Together, we can help to make a difference to improve the way we identify those who are at risk for pancreatic cancer, and to treat it.

PACGENE Consortium

The Pancreatic Cancer Genetic Epidemiology (PACGENE) Consortium includes seven medical centers in the U.S. and Canada that are gathering information and blood samples from families with a history of pancreatic cancer. Doctors and scientists are studying why pancreatic cancer seems to run in some families. They are looking for new genes that increase the risk of developing this disease.

People who wish to join the family registry must be 18 years of age or over and meet one of the following criteria:

- At least two family members who ever had pancreatic cancer, or
- At least one family member who ever had pancreatic cancer and at least one family member who ever had melanoma.

If you or someone you know might be interested in participating, please contact the Pancreas Research Team at 1-800-914-7962.

PACGENE Grant Update

We are pleased to report that the National Cancer Institute has awarded an additional five years of funding to the PACGENE Consortium, starting in 2008. Some of the funds will be used to enroll people with a history of pancreatic cancer. Their donated biosamples and data will help us to discover and to understand the genetic basis of this cancer. To date, more than 1,800 patients and nearly 4,000 of their family members are enrolled.

Other funds will be used to perform laboratory and computer-based studies using DNA and survey data from the families. The PACGENE team has been enriched by the addition of experts using state-of-the-art technology in molecular genetics and bioinformatics. We have learned that mutations in some genes that are already known to be related to cancer, such as BRCA2 and p16, may place some people at increased risk for pancreatic cancer. We have also learned that other previously unknown genes increase the risk for pancreatic cancer, and we know how they “map” in the human genome.
New Understanding of Diabetes and Pancreatic Cancer

It is well known among clinicians that persons with long-standing (20 years or more) Type II diabetes mellitus (DM) are at twice the risk of the general population for developing pancreatic cancer. Doctors also have observed that the majority of pancreatic cancer patients have diabetes or impaired fasting blood glucose (FBG), a measure used to diagnose DM, at the time of the cancer diagnosis (see figure). Many do not have long-standing diabetes, but in fact have had diabetes diagnosed only within several years before the pancreatic cancer was found.

A Mayo Clinic research team, led by Suresh Chari, M.D., has shown that for some pancreatic cancer patients, the recent-onset diabetes may be caused by the undiagnosed pancreatic tumor. He calls this type of diabetes, “pancreatic cancer induced diabetes mellitus,” or PaCDM. The Mayo Clinic team found that 1 in 125 new-onset diabetics aged 55 and older may have PaCDM. They have also shown that levels of FBG may trend upwards in the three years prior to the diagnosis of pancreatic cancer.

However, the challenge is that at present, among people with newly elevated FBG, we cannot tell the difference between those persons who have PaCDM from those with conventional Type II DM. Dr. Chari and his team at Mayo Clinic are dedicated to finding ways such as clinical signs and more importantly, blood tests, that may help doctors to diagnose pancreatic cancer at an earlier stage. Ongoing research has been funded this year through a grant from the National Cancer Institute to the Mayo Clinic Specialized Program of Research Excellence in Pancreatic Cancer.

What is the Relationship between Pancreatic Cancer and Melanoma?

Around 10% of malignant melanoma appears to run in families. In up to 40% of hereditary forms of melanoma, a gene that appears to contribute to melanoma risk is known as CDKN2A, or p16. It has been found that mutations in CDKN2A/p16 are associated with increased risks for both melanoma and pancreatic cancer. By age 80, individuals in families with melanoma due to a CDKN2A/p16 mutation have a 58% to 91% risk of developing melanoma, depending upon where they live in the world. It has also been found that there is an association between a CDKN2A/p16 mutation and pancreatic cancer risk. Over one-fourth of families known to carry a CDKN2A/p16 mutation also have one or more members with pancreatic cancer in the family.

The rate of CDKN2A/p16 mutation detection among pancreatic cancer cases without considering family history has been found to be up to 4%. Much more research needs to be done to understand how this gene can predispose to pancreatic cancer in some people and to melanoma in others. We have an ongoing research project on this question at Mayo Clinic.

Reference:
Message from the Study Coordinators

We have all enjoyed working with you and your families on our pancreas research. Thank you for the time and dedication you put into taking part and providing us with information and blood or tissue samples. If you learn of any relevant updates to your personal or family medical history in the future, we would be grateful if you let us know by mail or by calling us at 1-800-914-7962. These updates may include new diagnoses of cancers, pancreatic conditions, or genetic testing results.

Jodie Cogswell, Maureen Griffin, and Cindy Chan
Study Coordinators

Ongoing Research Opportunity:
Cancer of the Pancreas Screening (CAPS 3) Study

This study aims to find the best way to screen for pancreatic cancer. Five medical centers across the U.S. are working together on this study. The screening includes a genetic counseling session, blood tests, an MRI, a CT scan and an endoscopic ultrasound (EUS). The cost of these procedures will be covered by the study, but the cost of travel to one of the medical centers will not be covered.

People who are interested in taking part must meet one of the following criteria:

- At least two close family members (parent, sibling or child) who ever had pancreatic cancer, or
- Diagnosis of Peutz-Jeghers syndrome, or
- BRCA2 or FAMMM (p16/CDKN2A) gene mutation and at least one family member who ever had pancreatic cancer

For more information about the CAPS 3 study at Mayo Clinic, please contact:

Jodie Cogswell, Study Coordinator
1-800-914-7962, extension 2
caps3@mayo.edu

Frequently Asked Questions

Should I join more than one pancreas research registry?
The Pancreatic Cancer Family Registry at Mayo Clinic exists to gather information and blood or tissue samples from people with a family history of pancreatic cancer, which may be used for many studies, including PACGENE and CAPS 3. Other institutions may have similar registries. By joining more than one registry, you may learn about studies being done at one institution that are not being done at another. Also, we often work with other institutions on the same study, but we cannot share information that may allow outside researchers to identify you. These federal and institutional policies serve to protect your privacy. Therefore, we prefer that you join the registry at Mayo Clinic even if you already joined another registry.

Why are spouses of people with a family history of pancreatic cancer asked to take part in the registry?
Spouses usually do not have a history of pancreatic cancer on their side of the family and would be compared as normal study controls to people who do have a family history. Also, spouses may provide helpful medical and family information about their husband or wives’ family. Lastly, if we cannot obtain a blood or tissue sample from a deceased family member, blood samples from the spouse and children would help us to determine the genetic makeup (DNA) of the deceased.
**Importance of Family Health History**

Some diseases and health conditions can run in families, such as cancer and diabetes. Knowing your family health history can help you and your doctor to assess your risk for some diseases and to manage your health and that of your family.

To gather information about your family health history, start by talking to family members, asking questions, and taking notes. Information from death certificates and medical records also will be very helpful. The information that you gather can be used to create a family tree, or pedigree. The example below displays three family members with disease in three generations (grandmother, her son, and her daughter’s son).

![Family Tree Example](image)

The Surgeon General’s website is a great resource for managing your family health history and displaying it in a family tree using their free online tool called, “My Family Health Portrait,” which can be found at: https://familyhistory.hhs.gov. This family tree can be printed and shared with other family members, your doctor, and other health care providers.

**Genetic Information Nondiscrimination Act (GINA)**

Genetic testing can help predict your risk for developing certain diseases, but the risks of learning your genetic test results may include emotional upset, family conflicts, and discrimination. A federal law, the Genetic Information Nondiscrimination Act (GINA), was passed in May 2008, which protects people from discrimination from health insurers and employers. This law, however, does not cover members of the military or life insurance, disability insurance, and long-term care insurance.

*For more information about GINA and genetic testing, please visit the National Human Genome Research Institute website at [http://www.genome.gov](http://www.genome.gov).*

**Resources**

- **Pancreatic Cancer Action Network, Inc. (PanCAN)**
  [http://www.pancan.org](http://www.pancan.org)
  National advocacy and patient support organization for pancreatic cancer.

- **The Lustgarten Foundation for Pancreatic Cancer Research**
  [http://www.lustgarten.org](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](http://mayoresearch.mayo.edu/mayo/research/petersen_lab)
- **Study Coordinators:**  
  Cindy Chan  
  Jodie Cogswell  
  Maureen Griffin