PAGES: Clinical study for families with multiple cases of pancreatic cancer

The PAncreatic Cancer GEnes Study (PAGES) is an ongoing study at Dana-Farber created to advance pancreatic cancer research. Researchers on this project are particularly interested in identifying susceptibility genes for pancreatic cancer and to learn whether these genes manifest through exposure to cigarette smoking.

The result of this study will be the identification of the gene(s) that predispose to pancreatic cancer, which will lead to better screening and prevention methods in the future.

As part of this study, we are comparing genetic characteristics from blood and tissue samples collected from individuals who have been diagnosed with pancreatic cancer and the blood and tissue of their family members. Secondly, we will also study responses to a survey questionnaire about family history and lifestyle.

Dana-Farber is part of a consortium of sites across the U.S. and Canada collectively known as the Pancreatic Cancer Genetic Epidemiology (PACGENE) consortium. In addition to Dana-Farber, members of this consortium include the Mayo Clinic, John Hopkins University, M.D. Anderson, Creighton University, Karmanos Cancer Institute, and University of Toronto/Mount Sinai Hospital. Work on this project is funded by the National Cancer Institute.

Who is eligible?

To be eligible for this study, participants must be:

- Individuals with or without pancreatic cancer, from families with one or more blood relatives with pancreatic cancer
- Spouses or relatives of deceased patients who had pancreatic cancer
- At least 18 years old.

What does participation in PAGES involve?

- A signed consent form
- Completing a questionnaire about your pancreatic cancer risk factors and family history of pancreatic cancer
- Permission for us to obtain relevant medical records to confirm your diagnosis
- A donation of blood (about four tablespoons) that can be drawn outside of Dana-Farber

We may also ask for:

- Permission to contact family members who may be of interest to the study
- Relevant medical records of deceased individuals
- Your permission to use excess tissue samples collected from previous procedures or biopsies

Why study pancreatic cancer in families?
Individuals with first-degree blood relatives who have had pancreatic cancer are at a significantly higher risk of getting the disease than someone with no family history of pancreatic cancer. This risk is even higher when there have been multiple cases of pancreatic cancer within a family. There is evidence of a genetic basis to pancreatic cancer. By knowing this hereditary factor we will be able to increase our understanding of the disease, screening and prevention methods.

Confidentiality

Patient confidentiality is of the utmost importance at Dana-Farber. All information we have about each participant, including the blood sample, will be kept entirely confidential. This information will be provided to others only with the individual's written permission. Being part of, or choosing not to be part of a study, will in no way affect health care or treatment at Dana-Farber or appear on health insurance records. Participation is entirely voluntary and participants may request to be taken out of the study at any point.

Related links

- Pancreatic Cancer Action Network
- The Lustgarten Foundation (for pancreatic cancer research)
- Johns Hopkins University Pancreas Web site

Study contacts

If you wish to participate or learn more about the study, please contact either:

Sapna Syngal MD, MPH  
Principal Investigator  
Phone: 617-632-5022  
Fax: 617-632-4088

Chinedu Ukaegbu, MBBS, MPH  
Project Manager  
Phone: 617-632-6355  
Fax: 617-632-3161