



Ontario Pancreas Cancer Study Newsletter

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Important Contact Information for OPCS

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UPDATE FROM THE COORDINATOR

Welcome to the second volume of the OPCS Newsletter. We are currently in the second year of the OPCS. Initially, we restricted our study to only include people diagnosed with pancreas cancer within the Greater Toronto Area. In June 2004, we expanded our study to include all of Ontario. As of March 2005, over 130 participants have enrolled in our study.

The Ontario Pancreas Cancer Study is being conducted to study factors associated with pancreas cancer, such as genetic and lifestyle factors, as well as what treatments are available to patients with this disease. The results from this study will provide important information on the risk factors of pancreas cancer in addition to genetic markers so that pancreas cancer screening measures can be used in the future in the hopes of identifying this disease at an early stage.

We identify patients through pathology reports from the Ontario Cancer Registry and will contact these patients with the permission of their physician. Our study is not limited to patients whereby there is only one case of pancreas cancer. We recruit patients with any family history of cancer. Most patients will have no other cases of cancer in the family.

The first stage of the study involves obtaining information about family history, treatment and personal history data from a questionnaire package that is mailed to patients. The second stage of the study involves collecting blood, and tissue samples from previous surgeries. These samples will be used to investigate potential sources of genetic risk for pancreas cancer. Genetic counselling is available to every participant at this stage. If there is a family history of cancer, they can provide information and make referrals when indicated.

The Ontario Pancreas Cancer Study team greatly acknowledges and appreciates the participation of everyone involved. If you have any questions regarding the newsletter or our research, please do not hesitate to contact me. You can also call our toll free number and leave a message. I will be happy to hear from you and answer any of your questions.

Ayelet Eppel



Familial Pancreas Cancer

The majority of cases of pancreas cancer are random or sporadic in nature. However, it appears that in some families there are more cases of pancreas cancer than would be expected by chance alone. It is possible that there is a hereditary cause for the cancer in some of these families called Familial Pancreas Cancer (FPC).

Currently, there are genes that have been discovered for hereditary breast/ovarian cancer, hereditary colon cancer and some other types of cancers. At this time there are no known genes specifically for familial pancreas cancer. Our registry at Mount Sinai is collaborating on a research study called PACGENE (Pancreatic Cancer and Genetic Epidemiology) with other pancreas cancer registries in the United States, such as The Mayo Clinic and Johns Hopkins University, to work towards discovering a gene for familial pancreas cancer.

For this particular study, we are interested in families in which there are two or more cases of pancreas

cancer. Since pancreas cancer is not that common, and families with two or more cases are infrequent, it is beneficial for all of the registries to pool their interesting families in order to maximize the number of specimens used for testing, and to increase the chance of discovering a gene.

We are collecting family history information, as well as tumour and blood DNA samples whenever possible from pancreas cancer families, including both affected and healthy individuals. By comparing the genes of affected and healthy individuals within these families, researchers hope to find regions of DNA that are linked to familial pancreas cancer.

This is an ongoing study, and we hope to recruit as many interesting families as possible. If you would like to learn more about PACGENE, please contact our registry.

*Kara Smith
Genetic Counsellor*

Pancreatic Cancer Screening Study Update

We are starting the third year of the Pancreatic Cancer Screening study. The goal of the study is to determine the effectiveness of ultrasound and MRI in the early detection of pancreatic cancer. In future, we hope that there will be clinical screening recommendations available for earlier detection of this disease.

As of December 2004, there are 86 participants who have had at least one appointment. Each participant is asked to return annually for a transabdominal ultrasound and magnetic resonance imaging (MRI) of the pancreas and to provide a blood sample. Participants are also asked to complete questionnaires about environmental risk factors and psychosocial issues of interest. To date, we have obtained a blood sample for every participant for each appointment, and 80 Personal History Questionnaires and 185 psychosocial questionnaires have been completed.

We plan to enroll 200 participants in this study so our recruitment of eligible individuals continues. Eligible individuals are those who have been identified as having an increased chance of developing pancreatic cancer. This includes some individuals who have rare genetic conditions (like Peutz-Jeghers Syndrome and hereditary pancreatitis), families where genetic testing has confirmed a hereditary type of cancer (hereditary breast and ovarian cancer



and hereditary melanoma), as well as individuals who have multiple cases of pancreatic cancer in the family. Many individuals have been referred from various genetics clinics throughout Toronto and Ontario. About half of the participants live in the Toronto area – some travel from as far as Sudbury, Kapuskasing, Sault Ste. Marie, Belleville, and Windsor to participate.

Thank you to all of the study participants. We look forward to seeing you at your next appointment. We will keep you updated as the study progresses. If you would like more information about this study, or if you think your family may be eligible to participate, please contact our registry.

*Heidi Rothenmund
Genetic Counsellor*

Translocated in Pancreatic Cancer (TPC)

By Dr. Steven Gallinger

Pancreatic cancer is an extremely difficult cancer to treat, leading to a dismal 3% five-year survival rate. A comprehensive understanding of the genetic changes associated with pancreatic cancer will help identify more effective treatment options. Our research team is interested in identifying the genetic alterations leading to pancreatic cancer. Although most pancreatic cancers occur randomly, a significant fraction of this disease concentrates in families. Thus, we have studied the genetic material from patients with either 1) a high occurrence of cancer in their families or 2) a presentation of cancer at a young age, as genetically predisposed individuals are more likely to develop cancer early in life.

From these studies, we have identified a genetic alteration in a patient who presented with pancreatic cancer at the age of 42. The genetic alteration found in this patient is a chromosomal translocation. A chromosomal translocation is a genetic change where a fragment of one chromosome is broken off and attached to another.

This can result, as in our patient, in the disruption of a gene. The gene that is disrupted in our patient is a new gene with unknown biological function and we have named it Translocated in Pancreatic Cancer (or TPC for short).

Our experiments support a role for this gene in the development and progression of pancreatic cancer as well as in other digestive tract cancers (e.g., colorectal cancer) and we have hypothesized that the TPC gene is a tumor suppressor gene. A tumor suppressor gene carries the genetic information cells need to produce a protein with an important role in preventing the development of cancer. The identification of a new tumor suppressor gene with a role in pancreatic cancer will further our understanding of this disease. These advances will aid in the development of prevention and early detection strategies as well as more effective medical approaches to treatment, and ultimately lead to a reduction in the rate, morbidity and mortality of pancreatic cancer.



Pancreatic Cancer Foundation

By Lawrence Haughton

I have lived with pancreatic cancer for nearly five years. I know what an amazing statement that is and I know how statistically rare that is. Last year I asked the obvious question----WHY ME?

Without too much thought, I came to the following conclusion. I have survived this long so that I might use the experience, skills, and contacts I have accumulated to start a foundation that would assist people and their families who have been struck with pancreatic cancer. At the same time, this foundation can raise money to help in the diagnosis and research that is sorely needed to defeat this terrible disease. During the time that passed, I required more chemo and operations and at times the foundation work was put on hold. As of today, we are incorporated provincially and will be federally incorporated soon in Canada and the U.S. Our board is made up of members from Canada and the U.S., and we have an advisory council made up of doctors that many of you will recognize by name. There is room for growth in the council and the board and there is plenty of room for growth in the foundation, its' work, and its' participants. There is still a great deal to be decided about structure and activities. These are the early days and people are invited to participate and give input. The growth has been amazing, but it is just the beginning!

Currently, we are designing a website and will eventually have formal offices. We have money in the bank due to the generosity of a few directors. We have auditors, Adams, Masin & Tilley LLP and lawyers, Legge & Legge, who have donated expertise and time. We have two functions coming this summer. The first event will be the Dick Aldridge Golf Classic being organized by Betty Aldridge in honour of her husband who died suddenly last June of pancreatic cancer. Some of you will know Dick's name from his nine years playing with the Toronto Argonauts in the 60's and 70's. Many more recognize his name from his years of teaching. The event will be held on Thursday August 18, 2005 at Caledon Woods in Bolton. More information will soon be available on the website www.dickaldridgecgc.com.

The second function will be a tournament that will run under the name of the Pancreatic Cancer Foundation. This event doesn't have a date yet but I expect it will be late August or early September. Without the extremely generous support of Clublink Corporation, neither of these tournaments would be able to get off the ground. Their support has been outstanding, but we still need sponsors, workers and participants. This foundation is the first of its type in Canada. The deadline for this newsletter causes us to give you information without enough detail, but we wanted you to know that finally something of this type is happening.

If you wish to contact me, please call me at 416-315-5399 or by email at lph@cogeco.ca but please remember that some days are not as good as others. So, if it takes a few days for me to get back to you, please be patient. One day soon, I will have help and your correspondence and calls will be answered in a more timely fashion. Who knows, maybe it will be you answering the calls we get---I couldn't be happier. Just remember.....SOMEONE HAS TO WIN!

Internet Resources

- ◆ **Johns Hopkins University**
<http://www.path.jhu.edu/pancreas/>
- ◆ **Pancreatic Cancer Action Network**
<http://www.pancan.org/>
- ◆ **Pancreatic Cancer Genetic Epidemiology**
<http://mayoresearch.mayo.edu/mayo/research/pacgene/>
- ◆ **Canadian Cancer Society (CCS)**
<http://www.cancer.ca>
- ◆ **Health Canada**
<http://www.hc-sc.gc.ca/pphb-dgspsp/dsol-smed/>
- ◆ **National Cancer Institute of Canada (NCIC)**
<http://www.ncic.cancer.ca>
- ◆ **Canadian Strategy for Cancer Control**
<http://www.cancercontrol.org>
- ◆ **Canadian Association of Provincial Cancer Agencies (CAPCA)**
<http://www.capca.ca>
- ◆ **Ontario Cancer Research Network**
<http://www.ocrn.on.ca/>