



# Ontario Pancreas Cancer Study Newsletter

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## Is Pancreatic Cancer Inherited?

*by Dr. Steven Gallinger*

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Recent cancer research discoveries are now showing that many forms of cancer are indeed caused by genetic factors, meaning that abnormalities in DNA are important in increasing a person's risk of developing cancer. If we construct a cancer family history for patients with newly diagnosed pancreas cancer, we find that up to one-third of these people have a fairly strong family history of both pancreas cancer and other cancers in their relatives.

The same observation is true for many other common cancers such as bowel cancer and breast cancer, where specific gene mutations are known to have a critical role in causing these diseases. In the case of pancreas cancer, we are making slow but steady progress in understanding the genetic factors

which may explain why some people and their relatives develop this condition. For example, individuals who have strong family histories of pancreas cancer, breast cancer, ovarian cancer, and melanoma (a type of skin cancer), may have genetic abnormalities that markedly increase their risk of pancreas cancer.

Unfortunately, studies of the genetics of pancreas cancer have lagged behind those of other common cancer conditions although our research group and others are now devoting our resources to make progress in understanding pancreas cancer genetics. Some families have many cases of pancreas cancer without other obvious cancers in relatives. It is highly likely that an unknown gene(s) is causing the disease in these individuals and we are pooling

our efforts in an international cooperative study to identify these genes.

In fact, the Ontario Pancreas Cancer Study is one of six sites in North America which is contributing data, blood and tumor samples from our registrants to accelerate scientific discoveries in understanding this disease. Although many people who develop pancreas cancer do not have a strong family history of pancreas or other cancers, it is our firm belief that identifying new genetic factors in those with strong family histories will have a major impact on understanding all cases of this disease. This type of research is vital in developing new forms of screening, prevention and treatment strategies.

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## Clinical Trials – To Enter Or Not To Enter

*by Nisha Mistry*

Many new cancer drugs are developed each year. The new treatments are first tested in a lab to see if they work. They must then be put through clinical trials before they are made available to all patients as part of standard treatment. Clinical trials are research studies where the new treatment is given to patients to see how well it works. However, without enough patients participating in clinical trials, it takes an extremely long time to get new drugs approved. With fewer than 5 out of every 100 patients participating in trials, this has become a major problem.

The issue of few patients entering into clinical tri-

als has led researchers to examine the reasons why more patients are not participating in this process. Researchers have found that many patients do not understand the concept of a clinical trial very well and are hesitant to enter into one. Patients often feel uncertain about the treatments and the entire trial process. However, the treatments tested are believed to be as effective or more effective than the standard treatment to date, and trials are always carefully carried out. Physicians themselves sometimes do not want to suggest the option of a clinical trial since it involves more work for them and their patients. This ad-

ditional work includes extra paperwork and more frequent patient visits to the treatment center.

However, there are many good reasons that make clinical trials worthwhile despite the extra work. First, patients themselves may benefit from the treatment. Second, the patients will be contributing to developing new treatments that may help many people in the future.

The fact remains that there are a number of new cancer drugs awaiting approval from Health Canada. With low patient participa-

tion in cancer clinical trials, a speedy approval of any of these drugs does not seem likely. In order to make new drugs available more quickly, we need to find ways to get more cancer patients involved in clinical trials. One way to do this is to increase awareness among patients and their families of the importance of having as many patients as possible participating in a clinical trial.

For more information on clinical trials or to find a particular trial, please go to the following website: [www.ocrn.on.ca](http://www.ocrn.on.ca).

### Additional Internet Resources

- Canadian Cancer Society (CCS)  
<http://www.cancer.ca>
- National Cancer Institute of Canada (NCIC)  
<http://www.ncic.cancer.ca>
- Health Canada  
<http://www.hc-sc.gc.ca/pphb-dgsp/dsol-smed/>  
(select cancer button)
- Pancreatic Cancer Action Network  
<http://www.pancan.org/>
- Johns Hopkins University  
<http://www.path.jhu.edu/pancreas/>
- Canadian Strategy for Cancer Control  
<http://www.cancercontrol.org>
- Canadian Association of Provincial Cancer Agencies (CAPCA)  
<http://www.capca.ca>



## Abdominal Ultrasound and MRI Screening for Individuals at Increased Risk for Pancreatic Cancer

by Heidi Rothenmund

This is a new research study that began in early 2003. The study is coordinated through the Familial GI Cancer Registry (FGICR) at Mount Sinai Hospital and the Medical Imaging Department at the University Health Network. So far we have enrolled about 80 individuals whose families have been participating in our Pancreas Cancer Registry.

### What is the research about?

As with other types of cancer, the key to improving the survival of pancreatic cancer is to detect it at the earliest possible stage. Unfortunately, there is no accepted clinical test available for individuals who may be at higher risk for this disease. Our group is very interested in studying the effectiveness of ultrasound and

magnetic resonance imaging (MRI) in detecting early stage pancreatic cancer. Hopefully, the results from this study will lead to developments in screening tests and blood tests that will facilitate the early detection of pancreatic cancer in families at higher risk for this disease.

### Who is eligible to participate in this research?

We are enrolling individuals whose family history of cancer increases their chance of developing pancreatic cancer. This may include families where there has been 2 or more members diagnosed with pancreatic cancer (on the same side of the family). We are also including families who have known hereditary forms of cancer that predispose them to

pancreatic cancer. This includes some families with hereditary breast and ovarian cancer as well as families with hereditary forms of melanoma.

### What will taking part involve?

Participants will be asked to attend an appointment once a year for 5 years. Each appointment will involve an abdominal ultrasound, an MRI and a blood sample. Each participant will meet with a genetic counsellor to discuss their family history of cancer and the details of the study.

### How to contact us:

If you would like more information about this study, or if you think your family may be eligible to participate, please contact us at 416-586-4800 x 6394.

## Understanding the Causes of Pancreatic Cancer

by Dr. Michelle Cotterchio, Cancer Care Ontario

Approximately 5 out of every 100,000 people develop pancreatic cancer each year. Over 80% of cases develop in persons greater than 60 years of age, and this cancer is slightly more common among men than women. The pancreas, a gland located deep in the abdomen, is an important part of the digestive system. Pancreas fluids enter the digestive system to aid in the digestion of proteins and carbohydrates. Pancreatic cancer has a poor survival rate because the disease is usually silent for a long time and the cancer has often spread before it is detected.

Changes in the genetic makeup (DNA) may result in pancreatic cancer; these changes can be inherited (run in families) or acquired during life. The acquired genetic changes may be due to exposure to agents that damage DNA (e.g., cigarette smoke) or may just be the result of bad luck. Scientific research has shown that certain factors may increase the risk of developing pancreatic cancer. These factors include: increasing age, cigarette smoking, and chronic inflammation of the pancreas (pancreatitis). Much more research is needed to fully understand the causes of pancreatic cancer, with prevention being the ultimate goal.



# The Ontario Pancreas Cancer Study

*By Ayelet Eppel*

The incidence of pancreas cancer is increasing in the Western world and is currently ranked fourth among the important cancers. Pancreas cancer is not as common as other cancers, therefore, very little is known about the causes of this disease. 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.

## About The Study

We are recruiting newly diagnosed patients with pancreas cancer. Patients are currently being recruited through the Ontario Cancer Registry. Patients with a recent diagnosis of pancreas cancer and who were diagnosed in Ontario are eligible to participate in the study.

The first stage of the study involves obtaining information about family history, treatment and personal history data from patients through a package that includes consent forms and questionnaires. The second stage of the study involves collecting blood and tumour blocks. These samples will be used to investigate potential sources of genetic risk for pancreas cancer.

## Study Team

There are many components of this study and therefore we have a large and diverse study team. Dr. Steven Gallinger is the Principal Investigator of the study and Hepatobiliary/Pancreatic Surgical Oncologist at Mount Sinai Hospital and the Toronto General Hospital, and is affiliated with the University of Toronto; Dr. Michelle Cotterchio is a Co-Investigator and the Senior Epidemiologist affiliated with Cancer Care Ontario and the University of Toronto; Dr. Malcolm Moore is a Co-Investigator and Medical Oncologist at Princess Margaret Hospital and is affiliated with the University of Toronto; Ms. Heidi Rothenmund and Ms. Kara Smith are Genetic Counsellors; Ms. Bev Schmocker is the Research Nurse; Ms. Ayelet Eppel is the Research Coordinator; Ms. Claudia Quammie and Ms. Saumea Thayalan are our Research Assistants. We also have a third year medical student, Ms. Nisha Mistry, who is helping with the study.

## Study Update

We are now in the process of recruiting patients for the study. The Ontario Pancreas Cancer Study team greatly acknowledges and appreciates the participation of everyone involved. Please feel free to contact the Research Coordinator at 416-586-4800 x 2424 for additional information or if you have any questions.