



# Ontario Pancreas Cancer Study Newsletter

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## UPDATE FROM THE COORDINATOR

Welcome to the third volume of the OPCS Newsletter. We are currently entering the fourth year of the Ontario Pancreas Cancer Study (OPCS). As of July 2006, over 290 participants have enrolled in our study.

The OPCS 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 permission from 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, the Genetic Counsellors 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*



## A Journey To Remember

In the spring of 2000, my dad was diagnosed with pancreatic cancer. At the time, I had little understanding of the severity of the problem or the trip we were about to begin together. In the course of his treatment, my dad had a Whipple, liver resection, underwent many rounds of chemotherapy and radiation, as well as elected to take any other medications that his doctors believed may help. He managed to survive for almost 6 years, making his case one of the most extraordinary his doctors had ever seen. We worked together to support one another and ensure that every measure possible was taken to extend his life beyond what many saw as unrealistic expectations.

Although we were aware of the statistics at the time, we choose to ignore them and instead focus on my dad as an individual, not a number. Unfortunately these numbers do have meaning to thousands of Canadians across the country, and hundreds of thousands of families across the world. This is what led my dad to start the PCF (Pancreatic Cancer Foundation). The PCF is the **first foundation in the country dedicated to raising money and awareness around pancreatic cancer**. We estimate that total funding in

2005 dedicated to pancreatic cancer is close to one million dollars. This pales in comparison to many other diseases that have undergone incredible improvements in treatment, yet are still seeing dramatic increases in funding and public attention.

We are committed to working with local groups to raise awareness and funds. The PCF has received official charitable status from the CCRA. We are also having a fundraiser, the LPH memorial, on August 22, 2006. Please don't hesitate to contact us for more information. We need your help. As my dad was fond of saying, hopefully it will soon be you answering the phone calls here.

Michael Haughton  
*President PCF*

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## Pancreatic Cancer Screening Study Update

We are starting the fourth year of the Pancreatic Cancer Screening Study. The goal of the study is to determine the effectiveness of ultrasound and MRI (magnetic resonance imaging) in the early detection of pancreatic cancer. In the future, we hope that there will be clinical screening recommendations available for earlier detection of this disease. So far, we have enrolled 170 participants. We plan to enroll 200 participants in this study so our recruitment continues. Eligible individuals are those who have been identified as having an increased chance of developing pancreatic cancer based on the details of the family history of cancer.

If you would like more information about this study, or if you think your family may be eligible to participate, please contact us at 1-877-586-1559 or by email: hrothenmund@mtsinai.on.ca.

*Heidi Rothenmund*  
*Genetic Counsellor*



## Does Smoking Increase My Risk Of Pancreatic Cancer?

### *What studies have shown...*

- ◆ The only consistent and well established risk factor associated with pancreatic cancer is smoking
- ◆ Smoking accounts for approximately 25% of all cases of pancreatic cancer
- ◆ Several studies have shown that smoking doubles the risk of pancreatic cancer
- ◆ A study by Rulyak *et al.*, 2003, found that smokers developed pancreatic cancer one decade earlier compared to non-smokers
- ◆ Smoking has consistently been found to be a strong additional risk factor in families with familial pancreatic cancer
- ◆ A study in Michigan (2001) showed that smokers who have a close family member with pancreatic cancer, diagnosed under the age of 60, are at a higher risk of getting pancreatic cancer compared to non-smokers with the same family history
- ◆ A study in Sweden (2005) found that the risk of pancreatic cancer for ex-smokers approached the risk for non-smokers 5-10 years after quitting
- ◆ A computer simulation study in Europe (2002) estimated that if smoking is reduced by 20% by 2015, 29,500 fewer males and 9,500 fewer females will develop pancreatic cancer
- ◆ Further evaluation of the effects of second hand smoke is needed

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## Keep An Eye Out...

### Canadian Pancreas Cancer Research Website

The OPCS is in the process of creating a Canadian Pancreas Cancer Research Website ([www.pancreascancer.ca](http://www.pancreascancer.ca)). Besides websites such as that of the Canadian Cancer Society, the availability of websites for Canadian patients and families is limited. Most of the information comes directly from American websites, which present different statistics, treatment options and resources. There is a great need to provide Canadian patients and their families with an accurate and up-to-date resource containing information that is of greatest relevance to Canadians.

The main part of the website will be dedicated to information for patients and families on issues about pancreas cancer causes, inheritability, prevention, diagnosis, treatment and palliative care. We will provide a list of open clinical trials as well as updates on pancreas cancer research, and information on our research studies and familial pancreas cancer research programs. Online email links to our Research Coordinator and Genetic Counsellors will be available. The site will also include a list of Canadian support services available to patients and their families.

### Fundraising Opportunities

Betty Aldridge lost her husband, Dick Aldridge, to pancreas cancer in 2004. As a result, she founded the Dick Aldridge Charity Golf Classic and the Dick Aldridge Pancreatic Cancer Foundation. The 2nd annual Dick Aldridge Charity Golf Classic was held this year on July 25, 2006. Please access the website ([www.dickaldridgecgc.com](http://www.dickaldridgecgc.com)) for future tournaments and fundraising opportunities.





## Pancreatic Cancer Genetic Epidemiology (PACGENE)

In 2002, the National Cancer Institute in the United States provided funding for a pancreatic cancer collaboration called PACGENE. This collaboration includes 7 centres involved with pancreatic cancer research, including our Pancreas Cancer Registry at Mount Sinai Hospital in Toronto. The goal is to understand what causes pancreatic cancer, with particular interest in identifying the gene(s) that cause hereditary pancreatic cancer. It is estimated that approximately 5-10% of patients with pancreatic cancer will have a family history of this disease. Families with 2 or more relatives diagnosed with pancreatic adenocarcinoma (this is the most common type of pancreatic cancer) are eligible for this study.

A recent publication about this collaboration (“Pancreatic Cancer Genetic Epidemiology Consortium”, Peterson, et al., *Cancer Epidemiology, Biomarkers & Prevention*, 2006) summarizes our progress to date. Eligible families are identified by screening newly diagnosed patients (e.g., The Ontario Pancreas Cancer Study), physician referrals, and self-referrals (often via the internet). Collectively, over 13,000 patients were screened for a family history of pancreatic cancer. So far, approximately 475 families with familial pancreatic cancer have been enrolled, including the participation of over 1900 relatives. These families have provided information on diet, lifestyle, family history, medical history, and many have provided blood and/or tissue samples for genetic studies.

The mean age of diagnosis of pancreatic cancer in these families was approximately 64 years (with ages ranging from 30-97). This is approximately 5 years younger than the mean age of diagnosis in the general population. However, they did not see decreasing ages of diagnosis in families where there were a higher number of relatives affected with pancreatic cancer. This was unexpected since other types of hereditary cancers (such as hereditary breast and colorectal cancer) tend to have diagnoses decades younger than the general population. Since smoking is known to be a significant risk factor for pancreatic cancer, there is also interest on the smoking status of these patients. They found that 38% of patients were “never-smokers” and 47% were either smokers or ex-smokers.

Our recruitment of new families and data collection continues and the significant task of finding the pancreatic cancer gene(s) is on-going. We have recently provided the second batch of samples for genetic analysis. A very large number of families need to be screened to identify the few families that likely have a gene causing hereditary pancreatic cancer. The barriers to this type of research include the prognosis of this disease, the accuracy of family history details, the interest of family members to participate, the availability of medical records to confirm cancer diagnoses in the family, and the availability of blood and/or tissue samples from key family members. Almost all families have limitations as to what information and samples are available, and it may be difficult for any one research site to have enough families and data to determine the causes of this disease. The PACGENE Consortium is a valuable resource that will hopefully improve our understanding of pancreatic cancer. Please contact us if you or your family is interested in participating.

### **WE’VE MOVED!!**

(Please note the new phone numbers on the sidebar on Page 1.) Our new address is:

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Joseph and Wolf Lebovic Building, Mount Sinai Hospital  
Box 24, 60 Murray Street  
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