MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex

Ontario Pancreas Cancer Study

Ontario Pancreas Cancer Study
Joseph and Wolf Lebovic Health Complex
60 Murray Street, Box 24
Toronto, ON, Canada, M5T 3L9

Volume 4, 2008

Dr. Zane Cohen
Digestive Diseases
Clinical Research Centre

CONTACT INFORMATION

MSH Research Website
www.mtsinai.on.ca/familialgicancer/Diseases/PC
Toll Free: 1-877-586-1559

Dr. Steven Gallinger
Principal Investigator

Ayelet Borgida
OPCS Research Coordinator
t 416-586-4800 ext. 2110
aborgida@mtsinai.on.ca

Heidi Rothenmund
Genetic Counsellor
t 416-586-4800 ext. 5119
hrothenmund@mtsinai.on.ca

Kara Semotiuk
Genetic Counsellor
t 416-586-4800 ext. 6119
ksemotiuk@mtsinai.on.ca

Spring Holter
Genetic Counsellor
t 416-586-4800 ext. 2088
sholter@mtsinai.on.ca

Inside This Issue

Update From The Coordinator

Welcome to the next volume of the OPCS Newsletter. We are currently in the fifth year of the Ontario Pancreas Cancer Study (OPCS). As of March 2008, almost 500 people have enrolled in our study.

The OPCS is being conducted to study causes of 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 risk factors for pancreas cancer in addition to genetic markers so that 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 contact these people with permission of their physician. We recruit all patients with pancreas cancer even though many 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 (or saliva), and tissue samples from previous surgeries. These samples will be used to investigate potential sources of genetic risk of pancreas cancer. Genetic counselling is available to every participant. If there is a family history of cancer, genetic counsellors can provide information and make referrals when indicated.

The OPCS team greatly acknowledges and appreciates the participation of everyone involved. If you have any questions regarding the newsletter or would like to be involved with our research, please do not hesitate to contact us. 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 Borgida
Research Coordinator

Pancreatic Cancer Screening Study (PCSS) Update

This study began in 2003. The goal is to determine the effectiveness of ultrasound and MRI (magnetic resonance imaging) for early detection of pancreatic cancer. We are looking specifically for the most common type of pancreatic cancer, called adenocarcinoma. Individuals are eligible to participate if they have a strong family history of pancreatic cancer, or a genetic condition that increases the risk for this disease. Participants are eligible at age 50, or 10 years younger than the youngest case of pancreatic cancer in the family.

So far we have enrolled about 240 participants and most of those individuals have had at least two screening appointments. Approximately 20 per cent of participants have required follow up after their scans (such as blood tests, a repeat ultrasound or MRI). The first case of pancreatic adenocarcinoma was detected last summer. A few participants are being followed closely for pancreatic findings that are difficult to interpret. Other cancer types that have been found during the study include a pancreatic neuroendocrine tumour, an ovarian cancer, a stomach tumour, and two kidney cancers.

At this time we plan to continue with the study protocol, although new enrollment is limited. If you would like more information about this study, please contact us at 416-586-4800 ext. 5119 (toll free: 1-877-586-1559) or by email at hrothenmund@mtsinai.on.ca.

Psychosocial Aspects of Cancer

by Dr. Mary Jane Esplen

A cancer diagnosis can affect someone just as much emotionally as physically. Cancer disrupts all aspects of life including family, work, relationships and finances. Many psychosocial issues can be encountered by individuals with cancer and help is available to assist you in dealing with these issues. While the types of issues encountered may vary depending on the stage of illness you are in (diagnostic, treatment, recurrence, terminal, etc.), there are many which persist throughout the course of illness and these issues can greatly diminish quality of life.

A few of the common issues of concern that may be encountered by patients include: fear, denial, shock, anger, depression, helplessness/hopelessness, anxiety, diminished body image as a result of surgery and treatment, identity issues, and relationship problems.

Where can I find help?

Trained professionals are able to offer a wide range of services, and many are located in your local hospital. By speaking with your physician or calling the hospital directory yourself, you can find out more information about these services and who to contact. Also, you can use some of the online resources (listed on the next page) to access information.

Why should I seek professional support?

Psychosocial support from trained professionals can significantly improve the quality of life of both patients and family members. Without emotional support, patients may struggle with issues of mortality, questions of quality of life, and have to deal with the burdens of coping with treatment on their own. Psychosocial support can also benefit family members. Relationship problems can often arise between family members and patients while dealing with the illness. Emotional support can better equip the family to cope with these issues.

What are some of the needs of cancer patients and how will professional support help?

While many needs may arise in patients, some of the most common are listed below and professional support is able to assist patients with these issues.

1. Informational Needs

   Counsellors can help patients and families access accurate information. They can also assist in finding appropriate information and provide advice on how to use the information. The counsellors can assist with weighing the benefits and side effects of treatments before making a choice, providing information on managing side effects, and providing other types of resources to assist you and your family with coping.

2. Psychological Challenges

   Counsellors can help patients to:

   - Manage fear and its consequences
   - Manage anger
   - Express their emotions surrounding cancer
   - Deal with feelings of guilt (guilt over cause of illness, not being able to look after family members, impact on children)
   - Confront depression
   - Manage stress
   - Adjust to issues of identity and self image
   - Manage fatigue
   - Help with anxiety

3. Social Issues

   Counselling can help to deal with some difficult social aspects of cancer, such as:

   - Communication (disclosing information to family members, dealing with the reactions of others)
   - Addressing family issues
   - Dealing with changes in relationships

4. Practical and Financial Issues

   You may find yourself dealing with a change in lifestyle due to lower income or increasing expenses, and support can assist in advocating for the patient, making referrals, helping to reorganize finances, and providing information.

Links

Canadian Cancer Society Support Services www.cancer.ca/ccs/internet/standard/0,,3543_12887__langId-en,00.html

Mount Sinai Hospital Pancreatic Cancer Registry www.mtsinai.on.ca/familialgicancer/Diseases/PC/default.htm

PanCAN - National advocacy organization for pancreatic cancer community www.pancan.org

The Healing Journey – Princess Margaret Hospital www.healingjourney.ca/main.htm

Canadian Association of Psychosocial Oncology (CAPO) www.capo.ca/eng/index.asp

American Cancer Society – Resources for Patients, Family, and Friends www.cancer.org/docroot/HOME/pff/pff_0.asp

Princess Margaret Hospital – Psychosocial Oncology and Palliative Care www.uhn.on.ca/About_UHN/programs/psychosocial_oncology/index.asp

Pancreatic Cancer Genetics

Q. Is pancreatic cancer hereditary?

We suspect that pancreatic cancer is hereditary (passed on) in about five to ten per cent of patients. It is more likely to be hereditary in families where multiple relatives have had pancreatic cancer, in patients who are diagnosed at young ages, or in families where there is a strong family history of certain types of cancer.

Q. Has a gene for pancreatic cancer been identified?

There is a large pancreatic cancer family in Seattle where genetic studies narrowed down a region on chromosome 4 that was suspected to be linked to pancreatic cancer. In 2006, it was reported that this family carries a variation in a gene called palladin.

Q. Is this palladin gene variant found in other families?

Our Pancreas Cancer Registry at Mount Sinai Hospital tested samples of DNA (genetic makeup) from 84 pancreatic cancer patients to see how many individuals carried the same genetic change in the palladin gene. These patients were considered to be at higher risk for hereditary pancreatic cancer based on a young age of diagnosis, or having a family history of pancreatic cancer (familial pancreas cancer). We also tested DNA samples from 555 healthy controls. This palladin variant was identified in one pancreatic cancer case and one control. Therefore, our analysis of this palladin variant suggests that it does not explain most of the familial or young diagnoses of pancreatic cancer.

Q. How are genes identified?

This is no easy task. A new way to identify disease-causing genes is to look for large segments of DNA that are missing or duplicated. These DNA segments are called Copy Number Variants, or CNVs. Although CNVs have only been recently described, we know that a proportion of them are common and benign (not cancerous), but others are associated with various diseases. We hope to identify CNVs that are linked to pancreatic cancer by comparing a large number of DNA samples from pancreatic cancer patients and healthy controls.

Q. How can my family participate?

We continue to recruit new families for genetic studies through our registry at Mount Sinai Hospital. Participation involves completing questionnaires and donating samples. We thank all of the patients and their family members who have contributed to these studies.

All Those Questionnaires – What Have We Learned So Far?

- Being overweight or obese appears to increase the risk of developing pancreas cancer.
- Having diabetes almost triples the risk of developing pancreas cancer.
- Current smokers are four times more likely to develop pancreas cancer compared with non-smokers and previous smokers.
- In our study, we found that a history of allergies or hay fever was associated with a reduced risk of pancreas cancer by over 50 per cent. Our study on allergies is published in the International Journal of Cancer: www3.interscience.wiley.com/cgi-bin/abstract/114281139/ABSTRACT
- Although our study identified several potential risk factors of pancreas cancer, only smoking has been identified consistently in other studies. Further research is needed to confirm the link between weight, diabetes, allergies and pancreas cancer risk.
- Even though pancreas cancer is relatively rare, it is one of the deadliest forms of cancer. Therefore, it is important to always maintain a normal weight, eat a well-balanced nutritious diet, and not smoke.