MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex
Zane Cohen Centre for Digestive Diseases

NETWORK
Ontario Pancreas Cancer Study
Spring 2015

Ontario Pancreas Cancer Study (OPCS)

The OPCS is conducted to identify and characterize causes of pancreas cancer, including genetic, environmental, and lifestyle factors, as well as what treatments are available to patients with this disease. The results from this study will help us better understand risk factors, patterns of inheritance, and discover possible genetic and biochemical markers of pancreas cancer. In addition, we are interested in evaluating pancreas cancer screening techniques with the hope that, in the future, this disease may be detected at an early stage.

The first stage of the study involves obtaining information about family history, treatment, and personal history/ lifestyle from a questionnaire package that is mailed to participants. The second stage of the study involves collecting blood (or saliva), medical records, and any available tissue samples from previous biopsies or surgeries (if applicable). These samples are 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 provide information and make referrals for further genetic assessment and possibly genetic testing when appropriate.

We are now in our 12th year and are fortunate to have an outstanding team of researchers, genetic counsellors and clinicians, and together, we are collaborating on multiple national and international research projects. **The Ontario Pancreas Cancer Study team greatly 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 at 1-877-586-1559 and leave a message. We will be happy to hear from you and answer your questions.

Ayelet Borgida, MSc
Research Coordinator, Ontario Pancreas Cancer Study
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The Ontario Institute for Cancer Research (OICR)

Dr. Steven Gallinger, Principal Investigator of the OPCS, has recently been appointed as head of the Translational Research Initiative in pancreas cancer, termed PanCuRx, at the OICR. The OICR is an innovative cancer research and development institute dedicated to prevention, early detection, diagnosis and treatment of cancer. The Institute is an independent, not-for-profit corporation, supported by the Government of Ontario. The OPCS is now integrated with the International Cancer Genome Consortium (www.icgc.org) at the OICR. The ICGC was set up to help researchers around the world study genetic changes in 50 different types of cancer so that they can learn about the causes of cancer. This will lead to new ways to prevent, detect and treat cancer. The OICR is leading the study on pancreas cancer.

OICR recently formed a partnership with researchers from the Institute for Medical Research Israel-Canada (IMRIC) at the Hebrew University of Jerusalem and Sheba Medical Center in Tel-Aviv, Israel. This project is called the Alex U. Soyka Pancreatic Cancer Research Project and is made possible through a multi-year commitment by Sylvia Soyka, director, and the Board of Trustees of the SMGS Family Foundation to the Canadian Friends of the Hebrew University (CFHU). For more information about these and other collaborations, please visit www.oicr.on.ca.

BRCA Mutations in Pancreatic Cancer

Spring Holter, MS (C)CGC, Genetic Counsellor, Familial Gastrointestinal Cancer Registry

A study by our group was recently published in the Journal of Clinical Oncology (JCO) that looked at the rate of BRCA1 and BRCA2 mutations in individuals with newly diagnosed pancreas cancer. The BRCA genes are most commonly associated with an increased risk of developing female breast and ovarian cancer. However, it has long been known that individuals who carry changes (mutations) in these genes also have a higher risk of developing other types of cancers including pancreas cancer.

Although many studies have been published on BRCA mutations and pancreas cancer, no group had determined the actual mutation rate in consecutive, newly diagnosed patients. This is important to help physicians and genetic counsellors better understand which patients and family members may benefit from being referred to a genetics clinic.

All newly diagnosed pancreas cancer patients at the University Health Network were asked to participate in this study. Participants provided a blood sample for BRCA genetic testing. Over a two-year period, 306 participants were recruited into the study. BRCA mutations were found in 14 individuals for an overall rate of 4.6% (14/306). Certain factors were more common in the individuals with BRCA mutations, such as a family history of breast and/or ovarian cancer and being of Ashkenazi Jewish descent. However, one of the most interesting findings of the study is that the majority of individuals we identified with a BRCA mutation do not have a strong family history of breast or ovarian cancer.

Using this information, we are now recommending that **all patients with pancreas cancer who are of Ashkenazi Jewish descent be offered testing for the common Jewish BRCA mutations** regardless of family history. For patients with pancreas cancer who are not Ashkenazi Jewish, we still need to rely on family history to offer BRCA genetic testing. We hope that this study data may be used to change the current Ontario Ministry of Health BRCA genetic testing criteria to allow broader genetic testing for patients with pancreas cancer.

The Wallace McCain Centre for Pancreatic Cancer

Pancreas cancer is an aggressive disease where many people are diagnosed at an advanced stage. It can be difficult to detect as symptoms are often vague and can continue for months before people visit their doctor. As part of the GI (gastrointestinal) cancer group at Princess Margaret Cancer Centre, there is a team of dedicated professionals focused on providing excellent care to individuals with pancreas cancer. In March of 2011, Wallace and Margaret McCain generously donated five million dollars with the focus of ensuring all patients with pancreas cancer coming to Princess Margaret receive the highest quality care with timely diagnosis and treatment plans. Wallace McCain battled pancreas cancer for 14 months.

The McCain Centre for Pancreatic Cancer is co-chaired by Dr. Malcolm Moore, Head of Medical Oncology and Director of the Bras Family New Drug Development Program and Dr. Steven Gallinger, Head of the Hepatobiliary/ Pancreas Surgical Oncology Program. They both provide direct care to individuals with pancreas cancer and are committed to research and academic developments to improve the management and long term survival for those fighting this disease. The McCain Centre for Pancreatic Cancer has an ongoing mission to continue to advance the quality of care provided for these patients and will develop new and innovative ways to improve the outcomes for those with pancreas cancer.

Research Opportunities at The Wallace McCain Centre

Anna Dodd, Clinical Research Coordinator, McCain Centre for Pancreatic Cancer

The McCain Centre for Pancreatic Cancer at the Princess Margaret Cancer Centre has an internationally recognized research program. There are currently more than fifteen research projects underway with many more close to start-up. Some of the goals of these projects include looking at how patients respond to and tolerate chemotherapy, exploring genetic factors that may play a role in the development of pancreas cancer, and testing new drug therapies through clinical trials.

Every patient seen at the McCain Centre is offered an opportunity to participate in research. This may include taking part in the OPCS, donating blood for genetic studies or being asked to have an extra CT or MRI (body scan) performed. Patients can be assured that their doctor will discuss any new therapies or clinical trials that are available to them at the Princess Margaret Cancer Centre. Participating in research will never take priority over a patient's treatment plan and medical care.

We greatly appreciate the participation of all patients, families and caregivers in our various research projects. If you are interested in more information about clinical trials or other research initiatives at the McCain Centre at Princess Margaret Cancer Centre, please contact Anna Dodd, Clinical Research Coordinator at 416-946-4501 ext. 3176 or by email (anna.dodd@uhn.ca).

LOCATION

The Wallace McCain Centre for Pancreatic Cancer clinic
is located on the 4th floor of the Princess Margaret Cancer Centre in the GI Clinic.

HOURS & CONTACT INFORMATION

Monday – Friday, 8:00 AM – 4:00 PM
Phone: 416-946-2184

The Wallace McCain Centre for Pancreatic Cancer is committed to contacting all people referred to them within 48 hours. They will contact everyone to inform them that their referral is being processed and will ask about anything they can assist with before the first appointment.

FOR MORE INFORMATION, PLEASE VISIT:

www.theprincessmargaret.ca

Relationship between Family History of Cancer and Medical History and Pancreatic Cancer Risk

Gord Fehringer, Ph.D. Epidemiology, The Lunenfeld-Tanenbaum Research Institute

A study by our group was published in the journal Pancreas in July 2014 that looked at both a person's family history of cancer and personal medical history to see if these factors influenced the chance of developing pancreas cancer. Information from participants with pancreas cancer, who participated in the Ontario Pancreas Cancer Study from 2003-2009, was compared with information from healthy people who were recruited through the Family Medicine Centre at the Lunenfeld-Tanenbaum Research Institute at Mount Sinai Hospital.

We looked at the family history of several cancers such as pancreas, prostate, breast and colon. We found that people with a family history of pancreas cancer are almost twice as likely to develop pancreas cancer than those who do not have a family history of pancreas cancer. This has also been found in previous studies. We also found that having a family history of prostate cancer doubles the risk of developing pancreas cancer, but only among non-smokers. One interpretation of this finding is that some genetic factors that affect prostate cancer may also affect pancreas cancer, but in non-smokers only. The relationship between family history of prostate cancer and pancreas cancer has been seen in some studies but not others. Additional studies are needed in order to provide support for this relationship, particularly in non-smokers.

In our study, people with diabetes and pancreatitis (inflammation of the pancreas) had a higher risk of developing pancreas cancer. People who had diabetes for a long time (10 or more years) were more likely to develop pancreas cancer than those who did not have diabetes. Many researchers think that diabetes might lead to pancreas cancer, so these types of results are important as it provides more information to support a relationship between long-term diabetes and pancreas cancer risk. In the future, this knowledge may help to predict which people are more likely to develop pancreas cancer. This in turn may help to prevent the disease or detect it earlier so it can be more effectively treated.

Familial Pancreas Cancer Genetic Study

Our Registry is collaborating with several other pancreas cancer registries in North America on a genetic study called PACGENE (Pancreatic Cancer Genetic Epidemiology). The goal of this study is to learn about the causes of pancreas cancer — both genetic and environmental. So far, our centre has enrolled approximately 600 families across Canada for this research and study recruitment continues. Funding for the PACGENE Consortium has been received through a grant from the National Cancer Institute.

Which families are eligible to participate?

Any family with two or more biologically-related individuals with pancreas adenocarcinoma is welcome to contact our registry. We recruit families where the cases of pancreas cancer are living and/or deceased.

What does participation involve?

We ask details about the family history of cancer. We obtain the medical records (where possible) for each diagnosis of cancer in the family. We are interested in enrolling people with cancer as well as their healthy relatives.

Participants are asked to complete a questionnaire asking about lifestyle and various environmental risk factors. We also ask participants to provide a blood or saliva sample and/or a tissue sample (from previous surgical procedures) for genetic studies. **The most helpful samples are from relatives with pancreas cancer**. All participants have an opportunity to speak with a genetic counsellor about their family history and the details of the research. Participation in this study does not require a trip to Toronto.

Who do I contact to participate?

Please e-mail fgicr@mtsinai.on.ca or call toll free at 1-877-586-1559 and leave us a message.

Pancreas Cancer Screening Study

As with other types of cancers, early detection is associated with better prognosis. Unfortunately, the majority of pancreas cancer cases are diagnosed at advanced stages. This is mainly because of the lack of early symptoms. A number of American and European research groups have been studying various screening techniques for detecting early stage pancreas cancer, but there currently are no proven effective clinical screening recommendations.

The pancreas cancer screening study at Mount Sinai Hospital and the University Health Network began in 2003. Our initial goal was to determine the effectiveness of annual MRI (magnetic resonance imaging) and abdominal ultrasound for early detection of pancreas cancer. In 2011, we analyzed the data collected from the first eight years of the study and found that although pancreas cancer was found in some high-risk individuals, it wasn't found at an early stage. This prompted us to change the study. The current protocol being followed is using contrast-MRI every six months instead of every year. We are still collecting data, but our hope is that this new protocol will prove to be more effective at detecting early pancreas cancer than our previous methods.

At this time, the study is **closed to new enrollment.** However, the study is taking names for a wait list. If new study slots are available, those on the wait list may be contacted for participation. For more information about who is eligible for the screening study, please see the study website: www.zanecohencentre.ca/gi-cancers/opcs or you can email fgicr@mtsinai.on.ca or call toll free at 1-877-586-1559 and leave a message.

A generous donation was made by Pancreatic Cancer Canada to the Princess Margaret Hospital Foundation to support our continued research in the early detection of pancreas cancer. For more information about the Pancreatic Cancer Canada foundation, please visit their website: www.pancreaticcancercanada.ca.

MOUNT SINAI HOSPITAL
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The Best Research for the Best Treatment and Care

We Invite You To Partner With Us …

… so we can quickly bring new and evolving knowledge into clinical practice

There are many ways to support us. To find out how please contact:

Patricia Tolkin Eppel PhD
Advancement Director
Mount Sinai Hospital Foundation
416-586-4800 x 2956
ptolkineppel@mtsinai.on.ca

To donate online
www.zanecohencentre.ca/donate

Stay In Touch...

Please keep us informed of any changes in your family history of cancer or other conditions. We are interested in this information for all blood relatives in the family. If you are participating on behalf of someone with pancreas cancer, please update us with changes to his/her family history. It is helpful to track this information for research purposes, but it is also important in our assessment of the family history and can help guide clinical recommendations for family members. Please also notify us with changes to your contact information.

If there are any changes, please take a moment to leave us a phone message at 1-877-586-1559 or email us at fgicr@mtsinai.on.ca.

Contact Information

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