



The Familial Pancreatic Cancer Family Registry

Winter 2011 Newsletter

THANK YOU!

FROM THE FAMILIAL PANCREATIC CANCER REGISTRY STAFF

From the staff of the Familial Pancreatic Cancer (FPC) Registry at Memorial Sloan-Kettering Cancer Center, we want to extend our sincerest thanks to all of you who have taken part in our study.

Established in 2002, the FPC Registry recently succeeded in its initial goal to recruit 1,800 participants to the study.

Through this newsletter, we hope to bring you regular updates on our progress with the registry as well as other news regarding our research into the possible causes of pancreatic cancer.

Please enjoy, and thank you again for all your help!



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A MESSAGE FROM DR. ROBERT C. KURTZ

Dear Pancreatic Tumor Family Registry participants,

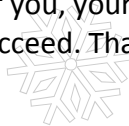
Thank you for your ongoing participation in our Memorial Sloan-Kettering Cancer Center Pancreatic Tumor Family Registry.

Pancreatic cancer still is the fifth leading cause of cancer deaths in the United States. In spite of this, relatively little is known about what causes this disease or how to diagnose it at an early and potentially curable stage. We hope through our efforts centered on our registry's screening program, and epidemiology and genetic laboratory research, we can begin to answer some of these important questions. Your participation in this program plays a central role in our ongoing efforts. We have been working to analyze the information that you provided in the study questionnaires and in our screening program. We have included some of the results found so far in this newsletter.

Moving forward, we will continue to actively enroll more at-risk family members to our study. We greatly value your efforts on behalf of this study, and for some of you, your long-term commitment. Your participation is vital in helping us succeed. Thank you very much for your support.

Sincerely,

Robert C. Kurtz, MD



Dr. Robert C. Kurtz is the Chief of Memorial Sloan-Kettering Cancer Center's Gastroenterology and Nutrition Service and Principal Investigator for the FPC Registry. Dr. Kurtz also attends to at-risk relatives participating in the surveillance portion of the study.



Recruitment Numbers*

1,873
total number of individuals recruited and enrolled

927
patients with pancreatic cancer

505
control participants

355
relatives at-risk for pancreatic cancer

* Dec 2002 through Nov 2010

MEET OUR NEW RESEARCH ASSISTANT!



Amethyst Saldia, BS
Research Study Assistant

Amethyst Saldia joined the Department of Epidemiology at the end of October 2010 to take up the work of the FPC Registry Research Study Assistant.

Amethyst holds a bachelor of science degree in brain, behavior and cognitive science from the University of Michigan.

Please feel free to contact Amethyst with any questions you may have about the study. She can be reached at **(646) 735-8194** or **saldiac@mskcc.org**.



STAFF SPOTLIGHT: ERIN SALO-MULLEN, MS, CGC

Erin is a genetic counselor certified by the American Board of Genetic Counseling who works directly with the Pancreatic Cancer Family Registry. Erin joined the Clinical Genetics Service (CGS) at MSKCC in 2009.

The genetic counseling process includes an initial consultation with Erin and one of the CGS physicians. During this meeting, Erin evaluates each patient's medical and family histories to determine if they may have a higher risk for certain cancers. If genetic testing is deemed appropriate, Erin coordinates that process. When the test results become available, Erin reviews the implications of the results with the patient. Erin also assists in making medical management and cancer screening plans with the patient and possibly their family members.

If you are interested in meeting with Erin for a genetic counseling consultation or have any questions about the process, please contact her directly at **(646) 888-4060** or e-mail her at **salomule@mskcc.org**. Erin has enjoyed her time working with the registry thus far and hopes that she can be of assistance to you and your family in the near future regarding your concerns about hereditary predispositions to cancer.



Erin Salo-Mullen, MS, CGC
Genetic Counselor



MORE GREAT NEWS!

Our previous research study assistant, Jennifer Simon, left us earlier this year for motherhood. We're all grateful for the work she has done for the MSKCC Familial Pancreatic Tumor Registry and wish her and her family the best!

SUMMARY OF RESEARCH FINDINGS



Allergies, Genes, and Risk of Pancreatic Cancer



Many studies have found that people who have allergies may be less likely to develop pancreatic cancer than people without allergies. A 2007 MSKCC study published in *Cancer Detection and Prevention* found similar results. Dr. Sara Olson, Dr. Robert Kurtz, and their team found that people with allergies were less likely to develop pancreatic cancer. This was especially true for people who reported having hay fever. People who said they were allergic to animals (such as cats, horses, and birds) were also less likely to develop pancreatic cancer. The study also looked at how two genes named IL-4 and IL4Ra might be related to allergies and pancreatic cancer. This study did not find an overall association between these two genes and risk of pancreatic cancer, but found some associations in certain groups of patients. Researchers do not know why allergies are protective against pancreatic cancer. It is thought that the immune system in individuals with allergies may somehow protect against pancreatic cancer.

Allergies and Survival from Pancreatic Cancer

In 2010, Dr. Sara Olson, Dr. Emmy Ludwig, Dr. Peter Allen, Dr. Robert Kurtz, and several other members of the research team published a paper in the *International Journal of Cancer* on survival and risk factors for pancreatic cancer. Known risk factors for pancreatic cancer include smoking, high body mass index (BMI), family history of pancreatic cancer, and diabetes. The study at MSKCC found that smoking, family history of pancreatic cancer, and diabetes were not associated with shorter survival among individuals with pancreatic cancer. In this study, individuals with pancreatic cancer who had allergies were more likely to live longer than individuals with pancreatic cancer who did not have allergies. Additional studies should be conducted in order to confirm these findings.



Screening for Pancreatic Tumors

In 2009, Dr. Emmy Ludwig and her research team wanted to know whether screening for pancreatic cancer in relatives of individuals with pancreatic cancer could be accomplished in an effective and safe manner. To investigate this, relatives from high-risk families initially underwent an MRCP (magnetic resonance cholangiopancreatogram), a specialized MRI of the abdomen and the pancreas that can reveal abnormalities in the pancreas. Of the 109 relatives screened at MSKCC, an abnormality was initially seen in 18 people; 15 of them agreed to undergo further evaluation with endoscopic ultrasound (EUS) as per our protocol. After EUS, suspicious lesions were confirmed in nine patients, six of whom underwent surgical resection, three of whom refused. There were no complications from either the MRCPs or the EUS examinations. The yield from screening was 8.3%, a figure comparable to that of other published screening programs. Dr. Ludwig's study supports the use of MRCP followed by EUS as an effective and safe screening method in individuals from high-risk families. You may read about Dr. Ludwig's study in an upcoming issue of the *American Journal of Gastroenterology*.



Emmy Ludwig, MD

Dr. Emmy Ludwig is a gastroenterologist at MSKCC and part of the FPC Registry research team.



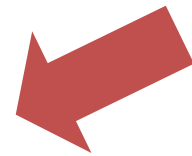
CURRENT PROJECTS

We are pursuing our interests in the association of allergies with risk of pancreatic cancer. Like some other cancers, allergies, especially hay fever and other respiratory allergies, seem to be related to reduced risk of pancreatic cancer. One project looks at the results of allergies and risk in several studies in the Pancreatic Cancer Case-Control Consortium (PANC4). By combining data from several studies, we can get a better idea of the risk and whether the reduced risk is related to the severity or timing of allergies, and whether it differs in subgroups such as men and women, or smokers and non-smokers. This analysis is funded by a grant from the National Cancer Institute.

People with allergies have high levels of an immune factor called IgE in their blood, but to date there have not been any studies to see whether the level of IgE is related to development of pancreatic cancer. We expect to receive funding from the National Cancer Institute in 2011 to study this relationship, using blood samples collected up to 15 years before people were found to have pancreatic cancer in a study conducted by the National Cancer Institute.

We participated in a large genetic study conducted by the National Cancer Institute to try to identify differences in genes that might influence why some people get pancreatic cancer and others do not. Several interesting findings came from these studies. These clues as to the cause of pancreatic cancer are being followed in laboratory studies. In keeping with our interest in allergies and risk, we are studying whether differences in genes related to allergies may be important.

Know someone who may be eligible for our study? Contact Us!



HOW TO CONTACT US

Robert C. Kurtz, MD | PRINCIPAL INVESTIGATOR
(212) 639-7620

Contact: To schedule screening appointments

Amethyst Saldia | RESEARCH ASSISTANT
(646) 735-8194

Chelsea Schneider | RESEARCH ASSISTANT
(646) 735-8164

Radhai Rastogi | RESEARCH PROJECT COORDINATOR
(646) 735-8088

Contact: For questions about the study and eligibility, to update contact info and participant status, and for other pancreatic cancer resources

E-Mail | FPCRegistry@mskcc.org

Postal Mail | Attention: Amethyst Saldia
MSKCC Dept. of Epidemiology
307 East 63rd Street, 3rd Floor
New York, NY 10065

OTHER RESOURCES

FPC Registry Website
www.mskcc.org/mskcc/html/75408.cfm

MSKCC Genetic Counseling Services
www.mskcc.org/mskcc/html/8627.cfm

Pancreatic Cancer Action Network
www.pancreaticcancer.org