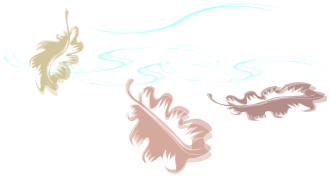
Memorial Sloan-Kettering Cancer Center

The MSKCC Pancreatic Tumor Registry

Fall 2011 Newsletter

Happy Autumn from the Pancreatic Tumor Registry Staff!



For our second newsletter, we bring you some updates on our study, including upcoming eligibility changes. Our study includes a group of patients with a special type of pancreatic cysts called IPMNs. To gain a better understanding of these types of cysts, we will introduce you to one of our study investigators, Dr. Peter Allen, and his work on IPMNs.

CHANGES IN ELIGIBILITY AND INCLUSION

Now that we have been working on the family registry for several years, we are able to better define the families and family members best suited for our registry. So we have made some changes in eligibility requirements.

- ➔ We hope to expand our study to include people who have a family history of pancreatic cancer and who are also diagnosed with certain genetic syndromes. We want to do this in order to learn more about the genetic factors that can increase the risk of getting pancreatic cancer.
- ➔ We are making some changes to the eligibility guidelines for relatives. After these changes are approved:
  - Only people who can confirm at least two close relatives with pancreatic cancer – like a parent, a sibling, or a child – will be included in our study.
  - Participants must be at least 45 years old to take part in the optional screening program. We will continue to see participants who began screening before the eligibility changes. Participants who are 35 years old and were enrolled before the eligibility changes can still join the screening portion at any time.

Have questions about the new eligibility guidelines? Want to refer someone to our study? Please contact Amethyst Saldia, Research Study Assistant, at 646-735-8194.

MORE GREAT NEWS!

Our study is expanding to other hospitals! In the next year we plan to enroll patients from the SUNY Downstate Medical Center in Brooklyn, New York.

Dr. Frank Gress, Chief of the Gastroenterology/Hepatology Division at SUNY Downstate, will take the lead on recruiting pancreatic cancer patients and their relatives. We hope to start recruitment some time in 2012.

Frank G. Gress, MD

INVESTIGATOR SPOTLIGHT: PETER ALLEN, MD

Peter J. Allen, MD, FACS

Dr. Peter J. Allen is an associate professor of surgery at Memorial Sloan-Kettering Cancer Center. He earned his undergraduate degree at Harvard University and his medical degree from Dartmouth College. Since 2003, Dr. Allen has led the surgical efforts in the treatment of diseases of the pancreas. Dr. Allen's work focuses on the development of new approaches and treatments to pancreatic cancer and cystic lesions of the pancreas, including Intraductal Papillary Mucinous Neoplasms (IPMNs). IPMN patients are included as a special group of patients in the **MSKCC Pancreatic Tumor Registry**.

Dr. Allen took time to answer some questions about IPMNs and how these cystic lesions can teach us more about pancreatic cancer.

What are intraductal papillary mucinous neoplasms?

Intraductal Papillary Mucinous Neoplasms (IPMNs) are cystic tumors of the pancreas that were first defined by the World Health Organization in 1996. IPMNs were identified before 1996, but at that time we did not understand them very well. IPMNs are lesions that are created from the discharge of a thick fluid called **mucin** from abnormal cells lining the ductal system of the pancreas. The cells continue to make the fluid, which builds up in the pancreas and creates cysts that we can see on a CT scan.

Though people with IPMNs are at greater risk of developing pancreatic cancer, we assume that not all of them will develop pancreas cancer. We know that these lesions have the ability to turn into cancer, and in some patients these lesions do turn into a cancer. The main problem is that we currently do not know how quickly that process can occur, or in how many patients it will occur.

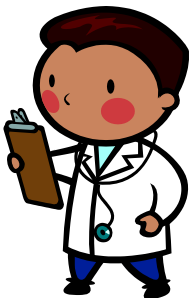
How do you diagnose an IPMN? What tests are used to find and confirm IPMNs?

Many IPMNs are found when patients have a CT scan for other problems and the results from the scan show a cyst in the pancreas. That cyst could have been created by a variety of things, including entities that pose no danger to the patient. There are many benign processes that occur in the pancreas that can create a cyst. However, some of those cysts could be precancerous like an IPMN. Based on the CT or MRI scan, we often have difficulty figuring out whether the lesion is an IPMN or a completely benign cyst. In some of those cases,

we will do an endoscopy with an **endoscopic ultrasound (EUS)** to sample the fluid that is in the cyst and test it. The best test for an IPMN is to look at the **cyst fluid CEA level**. If the CEA level is greater than 200, then it is very likely that the patient has an IPMN.

Why do you think it is important to learn more about the link between IPMNs and cancer?

I feel that IPMNs currently represent our greatest ability to effectively intervene for patients who could develop pancreas cancer. Once pancreas cancer develops, it is a very difficult disease to treat. Since some IPMNs may grow into cancer, I believe these lesions represent a great opportunity for doctors to prevent pancreatic cancer. However, the biggest challenge in treating these patients is that we currently do not know who will develop cancer and how quickly that will occur. The treatment to remove an IPMN is a big operation and can be very risky. One of these operations is called a **Whipple procedure (pancreaticoduodenectomy)**. Even at centers like MSKCC where we perform the Whipple procedure with a very high success rate, the operation can still have complications.



There are other operations to remove these lesions, but when they are located in a certain part of the pancreas, the Whipple procedure is what is required. So we are faced with a dilemma: The patient has a lesion that might progress to pancreatic cancer, but the treatment to remove it could also be dangerous for the patient. This is a real decision-making challenge and requires very careful discussion with the patients.

The cells that are producing these cysts go through a series of changes that can lead to cancer. When we look at those cells under a microscope, we can see those changes, called **dysplasia**. Dysplasia is an abnormal-appearing cell. As it becomes more and more abnormal in its appearance, it is closer to becoming a true cancer that can invade other parts of the body. We group the grades of dysplasia into three categories: low-grade, moderate-grade, and **high-grade dysplasia**. Cells with high-grade dysplasia look like pancreatic cancer cells when you look at them under a microscope, but they have not yet invaded through the lining of the ductal system of the gland. If they have not invaded through that lining, they cannot spread elsewhere in your body and harm you, so they are not considered a true cancer. In other areas of the body like the breast and colon, we call this type of dysplasia *carcinoma in situ*.

What we need is the ability to determine when a patient's lesion has high-grade dysplasia. I tell patients that if we had the ability to determine the exact day when their lesion was going to turn from high-grade dysplasia to an invasive cancer, then treatment would be very easy; we would just do the operation the day before. But at this time we obviously don't have that ability. Right now what we look for are findings on the CT scan or endoscopy that suggest that the lesion has high-grade dysplasia. Unfortunately, these tests are not currently very accurate.

What research is being done at MSKCC to learn more about IPMNs?

Pancreatic Cyst Registry

Every patient we see with a cystic lesion in their pancreas is entered in our database. This includes about 250 to 300 IPMN patients. These patients' data are continually updated as we follow them over time. This will give us the ability to define the natural history of these patients in the future. As we follow IPMN patients over time, we will learn the real risk of an IMPN progressing to cancer in this group of people. That is a very valuable resource.

Pancreatic Tumor Registry

This study uses questionnaires and DNA samples to get information on genetic and lifestyle factors that increase risk for pancreatic tumors and cancer. We encourage those diagnosed with an IPMN, either through elevated CEA levels or operation, to join this registry as well. Findings from this study are going to be very useful, because they will give us an idea of what factors may be involved in the growth of IPMNs. There has been some research to suggest that there is a familial pattern to the growth of IPMNs, and this study will help us figure out if there is really a genetic factor involved.

Looking for Markers of High-Grade Dysplasia

A huge area of research that we have ongoing right now is geared toward identifying patients with high-grade dysplasia. Currently we're very limited in our ability to determine high-grade dysplasia. This project is an effort to store and bank all of the cyst fluid collected from patients we take to the operating room. We are using that fluid to look for different markers of high-grade dysplasia. We recently published on a variety of interesting and new markers, and we were the first to describe the link between markers in the fluid and high-grade dysplasia. One future outcome we hope for from this research effort is to be able to pull out some of the cystic fluid and look for a marker that tells us whether high-grade dysplasia is present. If it is absent, an operation would not be necessary.

QUESTIONS? CONTACT US!

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Participants may call Dr. Kurtz's office to schedule appointments.

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Contact Amethyst or Radhai with questions about the study and eligibility, to update contact info and participant status, and for other pancreatic cancer resources.

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FIND US ON THE WEB!

MSKCC Pancreatic Tumor Registry
www.mskcc.org/mskcc/html/75408.cfm

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