

The Memorial Sloan-Kettering Cancer Center Pancreatic Tumor Registry Newsletter

Reaching the 10-Year Mark

A letter from Dr. Kurtz

Once again, I would like to extend my deepest gratitude for your participation in our MSKCC Pancreatic Tumor Registry. Our study has been active for over 10 years now, and we could not have made it this far without your help. We have accomplished a lot during this time. We have collaborated in national and international studies that have helped define both environmental and genetic risk factors for pancreatic cancer.

Our eligibility criteria for the program have changed as well. We now only recruit individuals with multiple first-degree relatives with pancreatic cancer, or a family history of pancreatic cancer and certain syndromes, such as heritable breast and ovarian cancer syndrome. Also, we now recommend that all participants with BRCA1 or BRCA2 deleterious mutations and a family history of pancreatic cancer undergo an endoscopic ultrasound (EUS) every year, in addition to magnetic resonance cholangiopancreatogram (MRCP).



We thought it would be useful to ask the experts who perform EUS to share more about this procedure. Therefore, in this issue, our endoscopy team answers frequently asked questions about EUS, including how it is performed and how it can find areas in the pancreas that need additional evaluation. We hope you find this information helpful.

I wish you all the best this year. Whether you joined our study 10 years ago, or just recently became a participant, the Pancreatic Tumor Registry research team thanks you!

Sincerely, Robert C. Kurtz, MD Principal Investigator

Other Study Announcements:

- Our research study assistants are contacting relatives by phone and mail to complete the 2-year-plus follow-up survey. The purpose of this survey is to update your health and family history information. The survey will only take 10 to 15 minutes of your time.
- Since our last newsletter, many of you have contacted us about genetic counseling and testing. Feel free to reach out to the MSKCC Clinical Genetics team for more information at 646-888-4050.



Here are definitions to help you with some of the terms mentioned in this issue.

GI stands for gastrointestinal, and refers to the parts of the body that make up the digestive system, including the esophagus, stomach, pancreas, and intestines. Gastroenterology is a term that refers to the study of the same area.

Endoscopy is a procedure that allows a doctor to look inside the body. In upper GI endoscopy, a small flexible instrument with a tiny camera at the tip is inserted in the patient's mouth and down through the digestive tract (esophagus, stomach, and first part of the small intestine).

Endoscopy can be diagnostic (looking for disease) or therapeutic (carrying out a treatment, such as treating bleeding). Therapeutic endoscopy is also called **endoscopic intervention**.

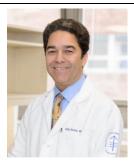
Colonoscopy is a type of endoscopy that looks for growths in the lower GI tract, also called the colon.

ERCP stands for endoscopic retrograde cholangiopancreatography. This is a procedure that combines endoscopy with x-rays. After the endoscope is inserted, dye is injected to help the doctor see areas that may be abnormal.

MRCP stands for magnetic resonance cholangiopancreatography. This is a special type of MRI (magnetic resonance imaging) that is focused on the area that includes the pancreas.

Endoscopic ultrasound, or EUS, is described in more detail on the following page.

Meet the Investigators: The MSKCC Endoscopy Group



Hans Gerdes, MD

Dr. Gerdes is an attending physician on the Gastroenterology and Nutrition Service and director of the GI Endoscopy unit at Memorial Hospital. He has a special interest in Barrett's esophagus, endoscopic methods of screening for and early detection of cancer, and endoscopic approaches to alleviating symptoms of advanced cancer. Dr. Gerdes' research interests include the use of EUS to stage GI cancers and pancreatic cancer, evaluate pancreatic lesions, and screen patients at high risk for pancreatic cancer.

Arnold J. Markowitz, MD

Dr. Markowitz is a board-certified gastroenterologist and Director of the Gastroenterology Fellowship Training Program at MSKCC. He has particular interest and expertise in performing therapeutic endoscopy, including EUS, for the detection, management and palliation of GI cancers. His clinical and research interests include the care of patients with hereditary GI cancer syndromes, including Lynch syndrome and familial adenomatous polyposis (FAP).





Mark A. Schattner, MD, FACP, CNSP

Dr. Schattner is a board-certified gastroenterologist and the co-director of the hepatobiliary (liver and bile ducts) and pancreas disease management team. He has a special interest and expertise in using therapeutic endoscopy to diagnose, treat, and palliate cancers involving the gastrointestinal tract, liver, bile ducts, and pancreas. Dr. Schattner's research involves developing and testing advanced endoscopic techniques. He has lectured both nationally and internationally on the use of advanced endoscopy to treat cancer.

Pari Shah, MD

Dr. Shah is a board-certified gastroenterologist with a special interest and expertise in therapeutic endoscopy. Her clinical interests include the diagnosis and treatment of pancreatic and biliary diseases and the evaluation of pancreatic cystic lesions. She performs procedures such as EUS and endoscopic retrograde cholangiopancreatography (ERCP), as well as upper endoscopy and colonoscopy. Dr. Shah's research focuses on risk factors for pancreatic cancer and outcomes of endoscopic intervention.



Frequently Asked Questions about EUS

What is an EUS?

An EUS, or endoscopic ultrasound, is a procedure that allows doctors to view parts of the digestive system and the organs that surround it. Using special equipment, areas deep inside the body, such as the pancreas, can be seen up close. Also, very small abnormalities can be identified and, in some cases, biopsied using a thin needle.

How is an EUS different from a scan such as magnetic resonance imaging (MRI)?

An EUS is different from a scan such as MRI in that it is a procedure in which anesthesia is used to ensure comfort. A special instrument with a tiny camera at the tip is inserted in the patient's mouth and down through the digestive tract, and ultrasound is used to visualize the internal organs. Ultrasound uses high-frequency sound waves that reflect off body structures, allowing for a computer program to make pictures of internal organs. An EUS provides a much clearer view of the internal organs, which enables doctors to view very small things that may not be seen with a scan.

How can an EUS be used to find cancer or conditions that can lead to cancer?

In addition to viewing lesions in greater detail, a doctor can perform a biopsy during an EUS. For example, if a cyst or tumor of the pancreas is found with an EUS, the doctor can then perform a biopsy to determine if the cyst or tumor is benign or cancerous. This is called an EUS-guided biopsy.

How effective is EUS in finding pancreatic cancer?

The effectiveness of EUS in finding pancreatic cancer is currently unknown. Past studies have shown that EUS can confirm the presence of a tumor that has already been identified by MRCP or a computed tomography (CT) scan. An EUS-guided biopsy also has been shown to be effective in diagnosing such tumors and can sometimes prevent the need for surgery. The effectiveness of EUS in screening patients for early-stage pancreatic cancer is unknown, but is currently being studied.

Who should be screened for pancreatic cancer with an EUS?

Individuals from families at high-risk for pancreatic cancer should consider having an EUS. However, there has been no research showing a clear benefit of doing so. Therefore, EUS should only be done in the setting of a research study or a special program to follow people at higher risk of pancreatic cancer. If an abnormality is found by MRCP or a CT scan, an EUS-guided biopsy should be done to determine if it is benign or cancerous.

When and how often should EUS of the pancreas be performed?

There are no established guidelines on how often individuals at high risk for pancreatic cancer should have an EUS. Currently, we advise most high-risk individuals participating in the registry to have an EUS only if an abnormality was first found by MRCP. However, we advise participants with BRCA 1 or BRCA 2 gene mutations to have MRCP and an EUS once a year.

Are there any complications associated with EUS?

EUS is generally considered to be a safe procedure. However, EUS with or without a biopsy of the pancreas is associated with a small risk of complications. About 1% of patients experience pain, bleeding, pancreatitis, perforation (a hole through the wall of the esophagus, stomach, or small intestine), or infection.

What other research is being done at MSKCC on EUS and pancreatic cancer?

Our Pancreatic Tumor Registry group has previously done research on EUS in the evaluation of cysts in the pancreas that are found incidentally, that is, in the course of a medical test for an unrelated condition. In studying the fluid removed from these cysts, we found that high levels of CEA protein in the fluid indicated that the cyst was more likely to be mucinous, but did not indicate that the cyst would grow over time.

Our group has also demonstrated that screening at-risk relatives from families with a high risk of pancreatic cancer for pancreatic lesions with MRCP and EUS had a significant diagnostic yield (that is, several possibly important conditions were found). Additionally, these findings have established our current screening recommendations for participants of the registry.

We also have ongoing research collaborations with Dr. Peter Allen, who conducts studies on pancreatic cyst fluid to identify which cysts may progress to cancer.

Contact the MSKCC Pancreatic Tumor Registry

• Robert C. Kurtz, MD, Principal Investigator

Participants may call Dr. Kurtz's office to schedule appointments at 212-639-7620.

Amethyst Saldia, Research Study Assistant

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

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You received this newsletter because you are enrolled in the MSKCC Pancreatic Tumor Registry study.