

PEARL

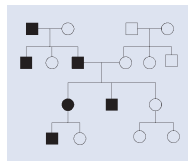


The Pancreas Education and Research Letter

Hereditary Pancreatitis Clinic Opening at UPMC

The Pancreatic Studies Office of the Division of Gastroenterology, Hepatology, and Nutrition at the University of Pittsburgh is excited to announce the opening of a Hereditary Pancreatitis (HP) Clinic. The HP clinic will take place once a week in the Digestive Disorders Center (DDC) of the University of Pittsburgh Medical Center, Presbyterian site.

The purpose of the clinic is to offer a detailed, one-time assessment of entire families who have known or suspected HP. Currently, the clinic will include a pediatrician with training in gastroenterology, pancreatology and, in particular, hereditary pancreatitis. This physician will perform a thorough medical history and physical examination of all family members wishing



to be assessed, discuss management issues, and answer any questions. A genetic counselor will collect family history information to create (or update) a

family tree, discuss how HP runs in families, explain the inheritance risks for family members, and talk about available testing options, if appropriate. There will also be an opportunity to be evaluated by experts in pancreatic disease, such as Dr. Adam Slivka or Dr. David Whitcomb. The length of the visit (between 1 to 4 hours) depends on the number of family members present and the extent of medical concerns that need to be addressed for each family member.

Since the clinic will only provide a one-time consultation, the family's primary care physicians and/or pediatricians will receive a detailed letter

summarizing the clinic visit, findings, and any management suggestions. The goal of this clinic assessment is to help families with HP better understand their condition and medical management options as well as learn about recent research findings at the University of Pittsburgh and elsewhere. Family members may also be given the opportunity to participate in ongoing research studies.

If you are interested in the Hereditary Pancreatitis Clinic, you may contact our Pancreatic Studies Office for more details: **1-888-PITT-DNA**, or directly contact our booking office to schedule a visit: **1-412-648-7893**.

We look forward to seeing you in Pittsburgh! ○

Welcome to the second issue of the Pancreas Education and Research Letter (PEARL)!

The first edition of the Pancreas Education and Research Letter (PEARL) was met with great enthusiasm by many involved in our pancreatic research studies. As a team of physicians, scientists, nurses, counselors, and technicians, it is important to us that all interested persons be kept up to date with advances in medical knowledge and patient care. Space has been reserved in future editions of PEARL for your questions and comments (please see our section "Ask Dr. Whitcomb" on the back page). Please feel free to e-mail us at askpearl@pitt.edu. We look forward to hearing from you soon. ○

Important Pancreatitis Research Opportunity

Have you tested positive for a mutation (genetic change) in the cationic trypsinogen (PRSS1) gene – the gene responsible for causing Hereditary Pancreatitis (HP)? Do you live near the Pittsburgh area? Would you be interested in participating in a study to evaluate if a medication decreases the inflammation (swelling) in your pancreas?

All the data we have gathered over the past decade are leading us to better understand how pancreatitis develops. We are now testing a medication (given by mouth) that may stop or decrease the inflammation and pain experienced by people with HP. Due to the way the medication works, this study is limited to only those with HP and a known PRSS1 mutation.

The study is open to all males and females ages 6 years and older. If you are interested in participating in our pilot study to be conducted in Pittsburgh, please contact our **Pancreatic Studies Office at 1-888-PITT-DNA** to obtain more details. ○

Volume One
Number Two

PEARL is a
publication of the

Pancreatic Studies Office in the
Division of Gastroenterology,
Hepatology and Nutrition
at the University of Pittsburgh

Editors

David C. Whitcomb, MD, PhD
Christina M. Chimera, MS

On the Internet:
www.pancreas.org

Toll-Free Phone:
1-888-PITT-DNA
(1-888-748-8362)

Hereditary Pancreatitis Study: Moving Forward

As research on Hereditary Pancreatitis has advanced, we have improved the questionnaire for the Hereditary Pancreatitis Study. We would like to have as many individuals as possible fill out the new questionnaire. This will ensure that the research team has the best information possible in order to search for a treatment or cure for this disease. If you and/or a family member have already enrolled in our study (or want to participate) and would be willing to complete our new, updated questionnaire, please call our toll free number at **1-888-PITT-DNA** and speak with one of our coordinators. We would also like to thank everyone who has already returned our new questionnaire. ○

Kids' Corner

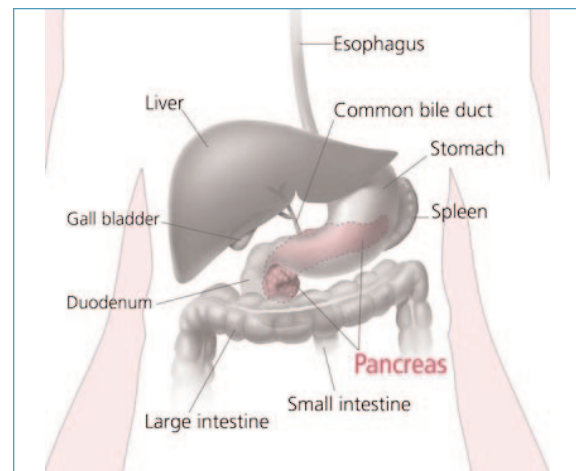
What is the Pancreas? What does it do?

The pancreas is a "gland" (a part of the body that makes special proteins and liquid) that sits deep in the middle of the "abdomen" (belly). It is close to the stomach and to the "small intestine" (gut). Some people describe the pancreas as having the shape of a flat pear. In an adult, the pancreas is about 6 inches long. In a child, it is smaller, and grows as you do. Normally, you can't feel your pancreas when you touch your belly. This makes it more difficult for doctors to check out how it is doing.

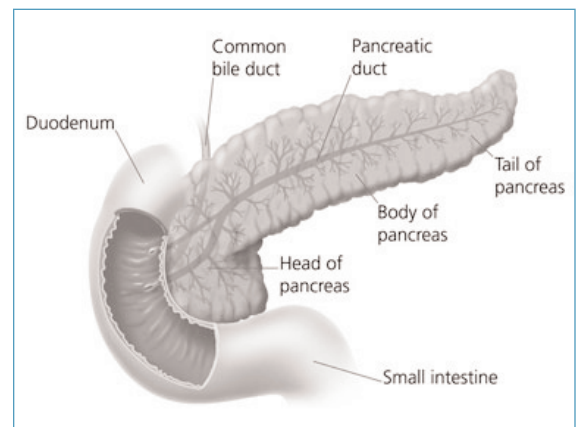
The pancreas has two main jobs. First, it has special areas called "Islets of Langerhans" that make insulin and other hormones (special proteins) that help keep blood sugar normal. Your doctor may have called this the "endocrine function" of the pancreas. Second, it has other areas called "acini" that make special proteins called "enzymes" that are needed to digest food normally. There is a special set of tubes or pipes called "ducts" that connect the acini to the small intestine. The biggest pipe is called the "pancreatic duct". The proteins made in the acini are sent down the ducts along with a mix of water and salts to empty into the small intestine. After being in the stomach, the food you eat goes into the duodenum. In the duodenum, the enzymes made by the pancreas mix with this food and break it down so that proteins, sugars, and fats can be absorbed by the body. The role in digestion is the "exocrine function" of the pancreas.

Suggestion: ask an adult to go through the diagrams with you to make sure you understand them. It's important for you to know your body! ○

Figures from the National Cancer Institute (NCI) website with permission.



The food we eat goes from the mouth to the esophagus (long tube) to the stomach and then into the small intestine (the first part of the small intestine is called the duodenum). The pancreas lies behind the stomach and the small intestine.



A cut view of the human pancreas. The pancreas is divided into 3 areas: the head, body, and tail. The pancreatic duct goes along the whole length of the pancreas and empties into the duodenum.

Pancreas Experts in South Carolina

Fortunately, there are a number of medical centers in the United States that specialize in pancreatic diseases. Pancreas centers are often part of a larger digestive disease center. The Digestive Disease Center (DDC) was founded in 1994 at the Medical University of South Carolina (Charleston) as a collaborative venture between the Hospital and the Departments of Medicine, Surgery and Radiology. The mission is to enhance patient care through inter-disciplinary collaboration, and also to support the research and education needed to improve it.

Pancreatic and biliary diseases are a special focus of the DDC, based on the expertise of gastroenterologists Peter Cotton, Rob Hawes, Mark Payne, Joe Romagnuolo and Chris Lawrence, working closely with specialist surgeons David Adams, David Cole, Nestor Esnaola and Katherine Morgan. Patients are referred from all over the southeastern United States. More than 1000 ERCPs (endoscopic retrograde cholangiography), 1000 EUS (endoscopic ultrasound) exams, and more than 619 pancreatic surgeries are performed annually.

The DDC has a strong research team led by Paulette MacDougall, RN, BSN, CCRC, with 5 clinical research coordinators, grants management and IT support. More than 60 IRB-approved studies are currently underway. These include active recruitment for the NAPS II study, an NIH-funded study of Sphincter of Oddi dysfunction, numerous evaluations of the role of EUS in pancreatic diseases, randomized trials of different stents, and prospective follow-up studies of patients with pancreatitis, pancreas divisum, and pancreatic and ampullary tumors.

There is a strong emphasis on postgraduate teaching, with multiple workshops, live demonstrations, and a stream of "advanced trainees" from the USA and many different countries.

More details of this organization and activities can be found at www.ddc.musc.edu ○



Standing, l-r: Christine Davis, Robert Hawes, MD, Peter Cotton, MD, Tammy Glenn, RN, FNP. Seated, l-r: Joseph Romagnuolo, MD, Elaine Rawls, RN, Nancy Billings, PA-C, and Christopher Lawrence, MD.

> > > > Goodbyes & Welcomes < < < <

Christina Chimera, MS, left the Pancreatic Studies Office on March 31, 2005, and has joined the clinical Cancer Genetics Program at the University of Pittsburgh Medical Center. We certainly appreciate all the hard work Christina put into the Hereditary Pancreatitis and PAGER Studies and wish her well in her new position.

We are fortunate to be welcoming **Erin Fink**, who recently completed a Master of Science in Genetics through the Genetic Counseling Training Program at Case Western Reserve University, Cleveland, OH. Erin joined the Pancreatic Studies Office team on June 20, 2005, and will be involved with the Hereditary Pancreatitis and PAGER Studies. She will also be providing genetic counseling to families coming for assessment in our upcoming Hereditary Pancreatitis Clinic.

The Pancreatic Studies Office also welcomes **Julia Greer, MD, MPH**. Dr. Greer is a physician with a Master's degree in Public Health whose prior interests included ovarian cancer epidemiology. Beginning in June 2005, she will work with Dr. Whitcomb's team for two years. Her initial focus will be on the PAGER study.

Of course, we must not forget the hard work of the people who currently work in our recruitment office. **Beth Elinoff, RN, MPH** has continued to manage the Pancreatic Studies Office and all of Dr. Whitcomb's studies. **Véronique Morinville, MD** will be with us until the end of the year and will soon be starting up the Hereditary Pancreatitis Clinic.

We are confident our new and current team members will continue to make progress in pancreatic research and patient support! ○



Ask Dr. Whitcomb

Dear Dr. Whitcomb,

How do we get gallstones in our pancreas? I recently had my gallbladder removed and the next day I started to run a high fever. The physician went back in and I had an enlarged pancreas with multiple stones in it. My question is: do stones form in the gallbladder and go to the pancreas, or do they form in both the gallbladder and the pancreas?

Answer: Stones are mineral deposits that form in body fluids under a variety of different conditions. Stones most often form in the gallbladder, kidney, pancreas, and occasionally other organs such as the salivary gland. The pancreas may be affected by

stones that form in the gallbladder or that form in the pancreas. Stones from the gallbladder can cause acute pancreatitis (also called gallstone pancreatitis) when they roll down the bile duct and become stuck at the sphincter (muscle that opens and closes) that guards both the bile duct and pancreatic duct from the intestinal juices. Pancreatic stones usually form when the pancreas has been damaged and the pancreatic juice cannot drain properly. They are usually associated with pain rather than acute pancreatitis. If pain and fever develop the day after the gall bladder surgery, then it is more likely that the pancreatitis was caused by the gallstones that rolled down into the bile duct.

If you have questions for Dr. Whitcomb about the pancreas or management of pancreatic diseases, please e-mail the newsletter at askpearl@pitt.edu. We want to share answers to your questions each PEARL publication in order to help educate everyone about pancreatic disease. ○

*This publication has been made possible through a generous gift
by Tom Lutz in memory of his sister.*

ADDRESS SERVICE REQUESTED

David Whitcomb, MD, PhD
Pancreatic Studies Office
Hillman Cancer Center LB2.35
5117 Centre Avenue
Pittsburgh, PA 15213

University of Pittsburgh



Nonprofit Org.
U.S. Postage
PAID
Pittsburgh, PA
Permit No. 511