

PEARL



The Pancreas Education and Research Letter

Pittsburgh Hosts Pancreasfest 2005

The city of Pittsburgh was the center of the pancreas world in July as national leaders in pancreatic diseases from around the United States gathered for *Pancreasfest 2005*. The theme of Pancreasfest was "Enhancing Multi-Center Clinical Studies in Pancreatic Diseases."

Pancreasfest 2005 included an educational program and investigator meetings. The educational program focused on acute pancreatitis, pancreatic cancer, and the use of endoscopic ultrasound (EUS) in diagnosing pancreatic diseases.

To demonstrate the increase in study strength and other opportunities gained by pooling resources, two investigator meetings were held related to major, ongoing multi-center pancreatic studies. The *North American Pancreatitis Study 2 (NAPS2)* is a 5-year, 20 center study of recurrent acute and chronic pancreatitis lead by David C. Whitcomb, MD, PhD from the University of Pittsburgh. NAPS2 aims to determine the genetic and environmental factors that combine to cause pancreatitis. The NAPS2 meeting included a report of recruitment goals, challenges with participant enrollment, and interim results. The study was felt to be on target to reach recruitment goals of 1,000 patients with pancreatitis and 1,000 controls (those without pancreatitis) by the end of the study. Initial analysis of the data promises a number of major findings that will help define susceptibility and progression of chronic pancreatitis as well as factors

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

As we finish our last PEARL newsletter of 2005, we would like to thank all of the participants in our studies. Without your participation we would not be able to make advances in understanding pancreatic diseases. We would also like to get some feedback on features we should include in future editions of PEARL and suggestions on how to improve our communication with interested persons. If you have any ideas about what has worked and what has not, please email us at askpearl@pitt.edu. We look forward to hearing from you!

that determine disease severity and quality of life. It was also stressed that these accomplishments required a large number of patients and that outside of a multi-center setting, the accomplishments could not be made. The second investigators meeting was for PANDA (PANcreatic cyst DNA Analysis), a molecular diagnosis study targeting malignant pancreatic cysts using endoscopic ultrasound (EUS) led by Asif Khalid, MD from the University of Pittsburgh. The study is in the initial stages but recruitment is running ahead of schedule at several major centers. Both of these

continued on page 2



NAPS2 Study Group. Front row: Beth Elinoff, RN, MPH (Univ. Pittsburgh), Michelle Anderson, MD (Univ. Michigan), Michele Bishop, MD (Mayo Clinic, Jacksonville), Randall Brand, MD (Evanston Northwestern), Andres Gelrud, MD (Univ. Cincinnati). Back row: Timothy Gardner, MD (Dartmouth-Hitchcock), Hans Fromm, MD (Dartmouth-Hitchcock), Adam Slivka, MD, PhD (Univ. Pittsburgh), David Whitcomb, MD, PhD (Univ. Pittsburgh), John Baillie, MD (Duke Univ.), Peter Banks (Harvard Univ.), Stephen Amann, MD (Tupelo, MS), Christopher Lawrence, MD (Medical Univ. S. Carolina)

Volume One
Number Three
Fall 2005



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
Erin N. Fink, MS

On the Internet:
www.pancreas.org

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

Pancreasfest 2005 *(continued from page 1)*

studies served as an example to Pancreasfest participants of successful models of multi-center studies.

Pancreasfest also included programs designed to help investigators interested in pancreatic diseases find opportunities for funding and deal with the current problems faced in conducting studies. Investigators also had the opportunity to meet and discuss plans for future multi-center studies.

By all accounts, Pittsburgh Pancreasfest 2005 was a great success as major leaders, experts and trainees met to share state-of-the-art updates and to facilitate the future success of multi-center clinical studies. Together, these efforts are important in order to understand and treat a variety of pancreatic conditions while creating opportunities and an environment that fosters the development of young investigators interested in pancreatic diseases. ○

K i d s ' C o r n e r

What is Acute Pancreatitis?

Normally, when the pancreas is working well, we don't feel it – we don't even realize it's there. But sometimes, the pancreas can get swollen, or "inflamed", and lead to symptoms (things we feel), changes in blood tests and on x-rays. We call this **Acute Pancreatitis** ("*Acute*" means sudden, or not long-lasting; "*-itis*" means swelling).

Our body tries to keep us healthy from things around us that may hurt us (cause "damage"). Some things can cause damage to the pancreas, such as some viruses, medications, and injuries (falling off a bicycle, being in a car accident). Some of us are born with different "drainage" systems for the pancreas and the gallbladder and this can also lead to blockages and pancreas swelling. And finally, some of us are born with special genetic differences (called "mutations") that make our pancreas more likely to get swollen.

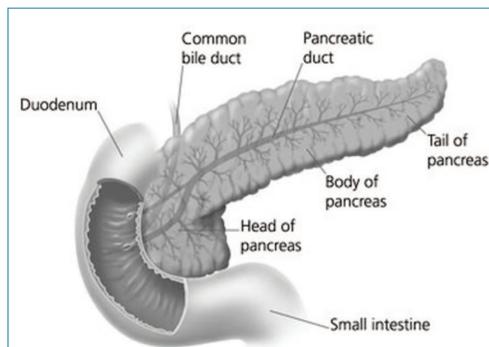
No matter what makes the pancreas swollen, if it becomes inflamed, it can make you feel very sick. You can throw up, feel like throwing up (nausea), have stomach pains (especially above the belly button), and back pain. Sometimes it's hard to tell others exactly how you feel – you just know you don't feel well.

At the hospital, if the doctors think your pancreas is swollen, they will order special blood tests such as "amylase" and "lipase", which are special proteins made by the pancreas. When a person has acute pancreatitis, the amounts of amylase and lipase in the blood are higher than normal. You might have pictures taken: an x-ray of the belly (abdomen), an ultrasound, or even a special x-ray called a CT scan (Computer Tomography). These tests may show that the pancreas looks larger than it should be (swollen) and that it has damage.

In order to make a person feel better, the doctors will usually do what is called "putting the pancreas to rest". That usually means the person cannot eat or drink; an intravenous line (IV) is put in so water, sugar, and salts can be given; and pain medications are given. The doctors and nurses continue to feel the person's belly and ask how they are feeling. Usually after a few days, and most often within a week, people begin to feel better and are able to start to drink and then eat again. (This happens as the swelling in the pancreas is going away). When they feel very well, the intravenous line (IV) is stopped and the person can go home.

For most people, the pancreas returns completely to normal after acute pancreatitis. If we can find the reason why the pancreas got swollen, we may be able to stop it from happening again. Unfortunately, for other people, especially those who have a genetic mutation, pancreas swelling can happen *many* times, and sometimes can lead to something called "**Chronic Pancreatitis**" (to be in the next Kids' Corner). ○

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



The pancreas has a "drainage" system for the digestive juices it makes, going into the pancreatic duct. When this drainage system is blocked, it can cause acute pancreatitis.

This diagram shows a normal pancreas. During acute pancreatitis, an ultrasound or CT scan may show that the pancreas looks swollen/bigger than it should be because of inflammation.

Fifth International Symposium on Inherited Diseases of the Pancreas

Graz Austria, July 9, 2005 – The beautiful city of Graz, Austria (hometown of Arnold Schwarzenegger) was the location for the Fifth International Symposium on Inherited Diseases of the Pancreas. The conference, which is held every two years and alternates between the United States and Europe, is designed to bring the world's experts together to discuss genetic factors that are linked to pancreatic diseases. The first conference was held in Pittsburgh, PA in 1997 and focused on hereditary pancreatitis and the trypsinogen gene mutations. Since then, the major topics covered have included the role of the cystic fibrosis gene (CFTR) in pancreatic diseases, the pancreatic secretory trypsin inhibitor gene (SPINK1), and others. The genetic cause of rare diseases have also been discussed including Shwachman-Diamond syndrome and Johanson-Blizzard syndrome. Shwachman-Diamond syndrome causes loss of pancreatic enzymes without inflammation, and bone marrow problems. Johanson-Blizzard syndrome causes pancreatitis in infancy, plus birth defects of the nose, face and internal organs.



The cause of Johanson-Blizzard syndrome was just discovered and reported for the first time at the Fifth International Conference. The other major topics that were discussed included problems of complex genetic disorders, pancreatic cancer families, genetic causes of diabetes mellitus, and studies on pancreatic enzymes including various forms of trypsin. These international meetings are important in helping to organize very complicated research programs, and to figure out why there are so many different types of pancreatic diseases and different degrees of complications. ○

Dr. Herrmann Studies Coping Skills in Hereditary Pancreatitis Patients

As many of you may remember, I requested the participation of the members of the University of Pittsburgh Hereditary Pancreatitis study in fall of 2004 for a research project. Many of you agreed to participate in my study, and I would like to share some of the more important findings with you.

The purpose of my research was to study the relationship between personality traits and coping strategies and how these factors have an impact on a person's everyday life. Previous studies have focused on other chronic illnesses and chronic pain populations, but no research had been conducted on the unique experience of individuals dealing with pancreatitis. One of the most important findings was that patients with HP were much more likely to use passive coping strategies rather than active. Passive coping strategies refer to actions that do not require much effort, such as worrying or hoping. By contrast, an active strategy requires more intentional effort and focus, such as distracting oneself by watching TV or engaging in tasks or activities like exercise. Previous research has shown that active coping helps people feel more control over situations in which they otherwise do not have control, such as dealing with one's pain. Thus, a more active approach to coping with pain may help a person be better able to function in daily life. Additionally, this study has found that patients have increased chronic emotional tension. This tension may have interfered with participants' ability to use more active coping

strategies because of the overwhelming pressure of adapting to their pain while also managing everyday stresses, such as relationships with spouses and children or responsibilities at work. These stressors may combine to become too emotionally, physically, and mentally taxing to attempt an active coping strategy. I did not require participants to report if they had experience with therapy, but the findings of this study suggest that outlets such as therapy or a support group may be an important source of support for patients coping with chronic illness.

The results of this study became my dissertation, which I have successfully defended. I have since graduated with my doctorate in clinical psychology. I would like to take this opportunity to thank all of you for your participation and cooperation in this study. I would also like to acknowledge the members of the Hereditary Pancreatitis Research Team at the University of Pittsburgh, including David C. Whitcomb, MD, PhD, Christina Chimera, MS, Laura Jenkins, MS, CGC, Laura Hepp, MS, and Suzanne Applebaum Shapiro, MS. This project would not have been possible without their dedication to the advancement of pancreatitis research and assistance with data collection. ○

For additional questions, comments, or feedback please feel free to contact me.

Elizabeth A. Herrmann, PsyD
eherrmann@loyola.edu



Ask Dr. Whitcomb

Dear Dr. Whitcomb:

What are the early signs of pancreatic cancer?

Answer: This is an excellent question, especially if the risk of pancreatic cancer in a particular family is high.

Unfortunately, the symptoms of pancreatic cancer are seldom recognized until the cancer has progressed to an advanced stage and often spread to other areas of the body. The signs and symptoms of pancreatic cancer that occur in more advanced stages include, yellowing of the skin and eyes (jaundice) when the bile duct is compressed, abdominal or back pain, unexplained weight loss, loss of appetite, nausea, and fatigue. However, these are symptoms that can also be caused by other health conditions, making the diagnosis tricky. If the cancer is in the head of the

pancreas and blocks the draining ducts, it may cause jaundice (blocking the bile duct) or pancreatitis (blocking the pancreatic duct). New onset of diabetes in a person older than 40 years (who does not have chronic pancreatitis) is often seen up to 1 or 2 years before pancreatic cancer is found.

All these nonspecific symptoms make pancreatic cancer difficult to diagnose in the early stages (when it is most treatable), although it may happen. These are some of the reasons that our laboratory and others are working so hard to find new tests that can detect cancer before symptoms develop. The good news is that we have developed some promising new techniques to detect cancer and pre-cancerous changes in pancreatic cysts and strictures. Other types of testing are also under development and major advances are expected in the next few years.

If you have any 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 the 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.*

PEARL

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