

# PEARL



The Pancreas Education and Research Letter

## Report from PancreasFest 2008

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Editors

David C. Whitcomb, MD, PhD

Sally M. Hollister, MS

**P**ancreasFest describes a series of highly coordinated, pancreas disease-related events for physicians and scientists each year in Pittsburgh, Pennsylvania. This year, over 50 physicians and scientists from 17 states and 24 institutions in the U.S. and Mexico attended the three-day event, July 24–26, 2008.

PancreasFest was divided into two main sections: an educational program for physicians and health care workers, and discussions related to current and future pancreatic disease research. The series of events included an Advisory Board meeting for a group of cancer research projects, a consensus conference on the best way to detect pancreatic cancer, a lecture series on managing all of the information from large studies that are simultaneously being done at multiple medical centers, technical updates on new research data, and organizational meetings for a new clinical research group.

Professor Keith D. Lillemoe, MD, Chairman of the Department of Surgery at Indiana University School of Medicine in Indianapolis, IN and world-recognized expert in pancreatic cancer surgery noted that the whole educational program was an "outstanding clinical summary of the state-of-the-art of pancreatic cancer (diagnosis and treatment)." Other prominent speakers included Peter Allen, MD, from Memorial Sloan-Kettering Cancer

Center in New York, NY; James Farrell, MD, from UCLA in Los Angeles, CA; Alison Klein, PhD, from Johns Hopkins University in Baltimore, MD; Attila Nakeeb, MD, from Indiana University; Ramesh Ramanathan, MD, from the University of Arizona in Phoenix; Raul Urrutia, MD, from the Mayo Clinic in Rochester, MN, and Paul Wagner, PhD, Program Director of Cancer Biomarker Research Group, National Cancer Institutes in Bethesda, MD. Physicians from the University of Pittsburgh held a special session on the improved care for pancreatic cancer patients in a multidisciplinary clinic that included Randall Brand, MD (high-risk families); Nathan Bahary, MD, PhD (chemotherapy); Andres Gelrud, MD (endoscopic treatment of complications);

Kevin McGrath, MD (endoscopic ultrasound for diagnosis); A. James Moser, MD (co-director and surgeon); Michael K. Sanders, MD (ERCP) and Herbert J. Zeh III, MD (co-director and surgeon).

The most important part of PancreasFest is its dedication to bring passionate physicians and scientists together. The opportunity to have detailed,

face-to-face discussions among researchers who normally work on pancreatic diseases in isolated laboratories and clinics is the key to bringing more rapid progress to the area of pancreatic disease treatment. ○



Research discussions continue over dinner at the Penn Brewery in Pittsburgh. L-R: Stephen O'Keefe, MD; Santhi Swaroop Vege, MD; Glen Lehman, MD.

On the Internet:  
[www.pancreas.org](http://www.pancreas.org)

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

### My Family Health Portrait

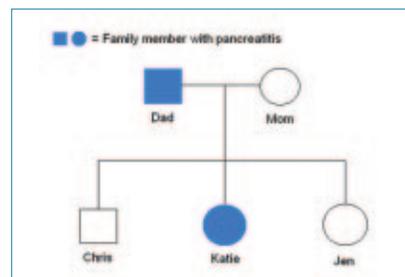
(From the U.S. Surgeon General's Family History Initiative website)

We share many things with our families: the house we live in, our neighborhood, favorite foods, and lots more! Sometimes we also share the same health problems with our parents, grandparents and brothers and sisters, including common things like diabetes and heart disease and less common things like cystic fibrosis and hereditary pancreatitis.

Knowing the specific kinds of health problems that run in your family can help your doctor predict the health problems you might have in the future, and can help in finding out the best way to keep you and your family healthy. For example, if many people in your family have had heart disease, you can make sure to eat a healthy diet and get lots of exercise (this is good to do even if no one in your family has had heart problems!)

One tool that doctors and genetic counselors use everyday is a family history. They ask you questions about different family members and the health problems they have, and may draw out your family history showing each person in your family and how they are related. Try visiting this website (<https://familyhistory.hhs.gov>) from the Surgeon General, and get a head start in creating your own Family Health Portrait!

Ask your mom, dad, or older family member to help you fill in the information for your Family Health Portrait – don't worry if you don't know all the details, just fill in what you know. After you enter the information that you know about people in your family, you can see a picture of your family tree! ○



### Pittsburgh: NAPS2 Update

The **North American Pancreatitis Study 2** (NAPS2) is a five-year study of 1000 subjects with recurrent acute pancreatitis and chronic pancreatitis from 20 centers in the United States. The study is unmatched in depth and quality, and preliminary analysis of the new information from this study is expected to change much of our understanding of pancreatic diseases.

Initial results were presented at a scientific meeting during *Digestive Disease Week* (DDW) in San Diego, California in May, 2008. The most important initial finding was that alcohol use is not as common or as heavy as previously thought in the majority of patients with chronic pancreatitis, especially in women. The NAPS2 study also uncovered the very strong effect of tobacco smoking on the development of chronic pancreatitis, even in small amounts. The most important message from this early report is to STOP SMOKING.

#### NAPS2 – CV and Follow-up Studies

David Whitcomb, MD, PhD, was recently notified that the NAPS2-CV (continuation and validation)

study will be funded by the National Institutes Diabetes and Digestive and Kidney Diseases (NIDDK). The NAPS2-CV will be especially important to determine the genetic causes of pancreatic disease. This information will be critical for the next step in understanding who will develop pancreatic diseases and why.

#### The Follow-up Study is also VERY important.

The 1000 subjects who participated in the NAPS2 have had new experiences related to their pancreas over the past 5 years. It is important to collect updated information on everyone to be able add *prognosis* to the diagnosis. Prognosis is a term meaning "foreseeing" (the future) and is the doctor's prediction of how a disease will progress and the chances for recovery. Expert physicians want to take the guesswork out of predicting the course of pancreatic disease, and they want to be able to give the right medicine to those who need it to prevent complications. If you or someone you know was part of NAPS2 (with pancreatitis or as a control) and want to participate, please contact the Pancreas Study Center at the University of Pittsburgh at **1-888-PITT DNA** (1-888-748 8362). ○

## Welcomes & Farewells

**W**e are excited to welcome several new members to our team!

**Randall Brand, MD**, is a recent addition to the University of Pittsburgh faculty from Evanston Northwestern Healthcare, Evanston, IL. He is Director of the GI Malignancy Early Detection, Diagnosis and Prevention Program, and has worked extensively in the early detection of Pancreatic Cancer including projects funded by the Early Detection Research Network. Dr. Brand is actively studying how to apply novel optical technology to the diagnosis and risk stratification of pancreatic cancer. He is a recognized expert in familial pancreatic cancer and presently leading efforts on recruiting additional patients to the pancreatic cancer family registry at the University of Pittsburgh Medical Center.

**Andres Gelrud, MD**, joins the division of Gastroenterology, Hepatology, and Nutrition at the University of Pittsburgh from the University of Cincinnati. He brings comprehensive experience in interventional endoscopy, management of patients with recurrent and acute chronic pancreatitis, as well as medical therapy for chronic pancreatitis caused by cystic fibrosis and other genetic conditions. Dr. Gelrud has been a collaborator with Dr. Whitcomb in the past as the principal investigator on the NAPS2 study at the University of Cincinnati.

**Venkata Muddana, MD**, has been a volunteer researcher in the lab at the University of Pittsburgh for the past two years, and joins the team officially

this fall. Also joining the team is **Sally Hollister, MS**, a genetic counselor and research coordinator.

Ms. Hollister will be taking the lead in the ongoing Hereditary Pancreatitis study, and will be enrolling patients in the PAGER study at the University of Pittsburgh, investigating the genetic and environmental causes of pancreatic cancer.

**Timothy B. Gardner, MD** is an Assistant Professor of Medicine at Dartmouth Medical School in Hanover, NH. He completed advanced training in clinical pancreatology at the Mayo Clinic in Rochester, MN in July 2008.

Dr. Gardner has started a pancreas clinic at Dartmouth-Hitchcock Medical Center. He will be recruiting patients for NAPS2-CV from New Hampshire and Vermont regions of New England.



*Andres Gelrud, MD, lectures on the topic: "Endoscopic Management of Malignant Obstructions."*

### Farewell

We will miss the hard work of **Janette Lamb, PhD**, laboratory director, as she moves on to a new position within the University. She has accomplished a significant amount of work in the past four years in Dr. Whitcomb's lab, and her presence is already missed! We look forward to continued collaboration with Dr. Lamb in the future.

**Erin Fink, MS**, genetic counselor, began working at LabCorp in Maryland this past spring. While working at the University of Pittsburgh, she helped coordinate hereditary pancreatitis and other studies, and counseled patients attending the Hereditary Pancreatitis clinic.

We wish Ms. Fink and Dr. Lamb the best of luck! ○

## What's New in the High Risk Pancreas Clinic?

**W**e are excited to introduce several new changes to the University of Pittsburgh High Risk Pancreas Clinic including new personnel, a new location, and a new clinic time. As mentioned above, our division has recruited two physicians over the past year, Randall Brand, MD and Andres Gelrud, MD and a genetic counselor, Sally Hollister, MS with expertise in hereditary pancreatic diseases.

This team, in association with Dr. Whitcomb and our existing genetic counselors at the University of Pittsburgh, is available to provide patient care and genetic counseling services tailored to patients and individuals from hereditary pancreatic cancer and pancreatitis families on Wednesday afternoons at UPMC Shadyside and the Hillman Cancer Center. If you are interested in further information or making an appointment to be seen by Dr. Brand or Dr. Gelrud in the High Risk Pancreas Clinic, please call **412-623-3105**. ○

## New Law Protecting Patients from Genetic Discrimination

The Genetic Information Nondiscrimination Act (GINA) was signed into law on May 21, 2008 by President Bush. This welcome law, cosponsored by Sen. Olympia Snowe (Maine) has been debated in Congress for 13 years. GINA protects individuals from discrimination based on genetic information by insurers and by employers. Specifically, group health insurance (including small group plans) is prohibited from "adjusting premium or contribution amounts for a group on the basis of genetic information." Health insurers are also prohibited from requiring or requesting genetic testing. Eligibility for health insurance coverage cannot be based on genetic information in individual or in group health insurance plans. Genetic information is treated as health information under GINA, which is protected by the current HIPAA legislation (Health Insurance Portability and Accountability Act of 1996).



GINA specifically addresses Medicare, in which premium rates cannot be adjusted based on genetic information and may not be used as a preexisting condition. Medicare cannot require or request an individual or family member to undergo a genetic test, and cannot request a genetic test prior to enrollment.

Discrimination based on genetic information is considered an "unlawful employment practice." This includes discrimination in hiring, compensation, terms, conditions or privileges of employment. This applies to employment agencies, labor organizations, and training/apprenticeship programs as well. An employer may not request or require an employee's genetic information except in the case of family leave certification.

GINA is a giant step forward in protecting individuals from discrimination in health insurance and employment; however, there are still some limitations. GINA does not protect people when applying for life insurance or long term care and disability insurance, and does not apply to individuals in the military. Individuals should also always use caution when considering "non-medical" or "personalized" genetic testing not offered by their physician or genetic counselor due to many issues, including a potential lack of privacy. ○

Source: National Human Genome Research Institute webpage ([www.genome.gov](http://www.genome.gov)) Washington, DC.

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ADDRESS SERVICE REQUESTED

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

University of Pittsburgh



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