



PEARL



The Pancreas Education and Research Letter

Digestive Disease Week (DDW) Highlights

Each year physicians and scientists representing all areas of digestive disease research and care meet for an international meeting. One of the areas of focus is pancreatic disease. Prior to DDW, the PancreasClub meets (<http://www.pancreasclub.org>), with a major focus on surgical treatments and pancreatic cancer care. During DDW 2012 there were dozens of scientific



speeches and presentations on this topic. Several of the presentations that came from the North American Pancreatitis Study 2 (NAPS2) study are listed below.

undergoing endoscopic therapy, but having a pancreatic duct stone removed was the most effective. Congratulations to this research team including Drs. Lisa M. Glass, Dhiraj Yadav, Elizabeth Kennard, Joseph Romagnuolo, Michelle A. Anderson, David C. Whitcomb, Timothy B. Gardner, among others.

• *Prevalence and Validation of Alcoholism Diagnosis in*

Chronic Pancreatitis (CP) Patients. In this study, the researchers determined how frequently a patient with chronic pancreatitis also has alcoholism. Alcoholism is a risk factor for chronic pancreatitis. In the dataset, alcohol was the primary or contributing factor to the cause of the pancreatitis in over two-thirds of the study population. Further, medical record review underestimated alcohol's contribution to pancreatitis, meaning that more education about this relationship and documenting it may be needed. Kudos to Drs. Yutaka Tomizawa, Michael R. O'Connell, Melissa I. Saul, Adam Slivka, David C. Whitcomb, Dhiraj Yadav for this interesting work.

Each of these presentations came from analyzing answers provided by study participants, along with evaluation of laboratory and other tests. We thank you! ○

• *Enhanced Diagnosis of Early Pancreatic Disease: Would It Alter Management,* by David C. Whitcomb.

• *Utilization and Long-Term Effectiveness of Endoscopic Therapy for Recurrent Acute Pancreatitis (RAP),* by Bridger W. Clarke, Adam Slivka, Michael R. O'Connell, David C. Whitcomb, Dhiraj Yadav.

• *Spectrum of Use and Perceived Effectiveness of Endoscopic and Surgical Therapies for Chronic Pancreatitis in the United States.* This study evaluated the reasons for or against performing endoscopic therapies in pancreatitis and how the effectiveness was perceived by the treating physicians. Over 500 patients with chronic pancreatitis were studied. Presence of abdominal pain indicated

advanced training and education, clinical and basic research, and new program development. In the future it is envisioned that many clinical and academic centers will embrace new cCOE idea and that the best possible outcomes will be available throughout the country.

BREAKING NEWS . . .

Pancreatic Centers of Excellence.

The National Pancreas Foundation (NPF) has been leading an effort to develop certified Centers of Excellence (cCOE). An NPF cCOE would need to meet predetermined standards of excellence in several areas of specialized patient care, with proven outstanding outcomes and high patient satisfaction. To maintain status as an NPF cCOE the local site would be evaluated on a regular basis. Two general types of programs could be developed. A Clinical cCOE would provide outstanding patient care, while a Comprehensive cCOE would provide outstanding patient care, highly specialized treatments,

designed to use NGS DNA Data and use it to minimize pancreatic disease suffering and progression. The reasoning and methods have just been published online in May, 2012 in *Nature Reviews Gastroenterology & Hepatology*. This practice is called personalized medicine and is considered to be a landmark breakthrough in the treatment and prevention of many health problems. Armed with their patient's exact genetic information, doctors will be able to provide effective treatments while reducing side effects or complications. This new approach could provide an effective pattern to be followed for other complex chronic disorders. ○

Next Generation Sequencing (NGS).

Many people have heard that their entire DNA sequence (3 billion code letters) can be read for about \$1000. While this may soon be possible, it has been more challenging to figure out what the code actually means of individual patients. The *Pancreas Center of Excellence* at the University of Pittsburgh has initiated a revolutionary new program that is

On the Internet:
www.pancreas.org

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

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How You Can Help Pancreas Disease Research

Hey kids! The American Cancer Society recently announced a decline in deaths from many major cancers in the US over the last 5 years! This is great news for many patients with cancer. But the bad news is that pancreatic cancer was not on this list. This fact stresses the importance for pancreatic



cancer research so we can add pancreatic cancer to the list of fewer cancer deaths someday soon. But research takes time and it takes money. And just because you're a kid doesn't mean you can't be part of the answer. You or

someone you love has probably struggled with pancreas disease. Make it your goal to help!

Be sure to talk with your parents first and to get their permission before you start.

Here are some ways kids can get involved in fundraising for pancreas diseases:

Find Your Charity

There are many organizations and university hospitals that specialize in pancreas research. Choose your favorite and contact them with the good news that you'll join the fight! Or even call your family member's doctors to see if the hospital can designate the money to pancreas research.

Choose How to Raise the Money

- **Host a lemonade stand.** Remember: make your signs big, bold and with advertisements noting that all proceeds go to pancreatic disease research.
- **Ask your family, friends or neighbors** if they would pay you to rake leaves, pull weeds or garden for them and that the fee would be donated to pancreas disease research.
- **If you already do chores** around the house for money or have a job, consider taking a percentage from your wages and donating it.
- **Get permission from your local grocery store to collect money outside** (decorate a large jar or table with purple posters). It may help to have information about pancreatic diseases available on the table or even a brochure from the organization where you are donating the money.
- **Collect old books and toys** to sell (with your parents' permission) at a yard sale in the neighborhood.



- **Have a party!** Instead of having your guests bring gifts, ask your friends to make a donation or bring \$5 (or so) along with them.

Whatever you do, be creative and have fun. You will feel great once you make your donation and so will the research organization. You CAN BE a part of the team to help cure pancreas diseases! Way to go! ○

Watermelon Wave Smoothie

This smoothie is the perfect afternoon pick-me-up on a warm summer day.

This recipe's lycopene (watermelon) and vitamin D (yogurt) may help prevent the following cancers: pancreas and breast.

Ingredients:

- 2 cups fresh seedless watermelon chunks, cubed
- 1 cup fresh or frozen unsweetened raspberries
- 2 scoops non-fat vanilla frozen yogurt

Preparation:

Blend watermelon and raspberries about 30 seconds. Add frozen yogurt to blender and blend approximately 20 more seconds or until smooth. Makes 2 servings.

Nutritional information per serving:

- Calories: 233.5
- Fat: 1.5 g
- Saturated fat: 0 g
- Carbohydrate: 43.0 g
- Total sugars: 31.5 g
- Protein: 7.5 g
- Sodium: 48 mg
- Cholesterol: 4 mg
- Dietary fiber: 1 g



Wayne Fusaro PC Research Fund Hosts Fundraising Event

To honor the life of their father and husband, Wayne Fusaro, his family made a pact to continue the fight on his behalf. The Wayne Fusaro Pancreatic Cancer Research Fund (WFPCRF) was established after his all-too-short battle with pancreatic cancer. Their mission is to ensure that his [Wayne Fusaro's] legacy was never forgotten and that attention be brought to this disease with the hope of finding a cure. To achieve this mission, the WFPCRF hosts local fundraising events which have raised over a quarter million dollars to date.

The most popular event includes the flagship annual golf outing and silent auction for more than a decade. Held at Green Oaks Country Club outside of Pittsburgh, this year's 12th annual event teed off on July 9 and was a great day of golf and fun. Supporters at the event include many researchers and physicians working towards finding cures for pancreatic cancer, as well as backers from the community, friends and family. In May, 2012 the WFPCRF hosted a fantastic social event at the Pittsburgh Zoo and PPG Aquarium. Allegheny Valley Bank partnered with the WFPCRF to co-host the Walk4Wayne charity walk, which was a great success.

With the money raised, the WFPCRF was able to fund an innovative research project at the University of Pittsburgh linking the genetics of pancreatitis and pancreatic cancer using the newest genetic technologies. This project hopes to identify the subtle genetic changes that can give clues for the progression of these diseases.

We salute you, WFPCRF and we promise to keep up the fight right along with you in memory of Wayne Fusaro. ○



Dr. Whitcomb with members of the Fusaro family.

Spotlight on the VCU Medical Center

The VCU Medical Center is an urban, comprehensive academic medical center in central Virginia which provides patients with the most progressive treatments and medical technology available. VCU Medical Center's Pancreatitis Clinic is dedicated to treating patients and promoting research on pancreatitis and other pancreatic disorders. Under the leadership of Bimaljit S. Sandhu, MD, the Pancreatitis Clinic provides patients with access to the most experienced pancreatitis team in the area, the benefit of innovative therapies and access to research/clinical trials, which improve the quality of care in the community, the nation and the world.

The clinic is comprised of a team of experts from multiple specialties including gastroenterology, transplant surgery, hematology-oncology, surgical oncology, radiology, radiation oncology, interventional radiology, registered dietitians, research certified registered nurses, clinic research specialist as well as a full administrative support staff. This vast team of specialists offers cutting edge therapies including:

- Endoscopic Ultrasound (EUS) with biopsy capabilities
- Diagnostic and Therapeutic Endoscopic Retrograde Cholangiopancreatography (ERCP)
- Dietary counseling

- Magnetic Resonance Cholangiopancreatography (MRCP), a noninvasive study of the bile and pancreatic ducts to determine blockage
- Genetic screening and counseling
- Access to research and clinical trials
- Nursing care recognized by the national Magnet award since 2006

The Pancreatitis Clinic welcomes both internal and external referrals to the clinic. We can be contacted at VCU Medical Center, P.O. Box 980341, Richmond, VA 23298, (804) 828-7208 or Fax (804) 828-5348.

The dedication, compassion and expertise of our team make the care we provide second to none. The team includes: Bimaljit Sandhu, MD; Doumit Bouhaidar, MD; Ravi Vachhani, MD; Sherri Maters, NP-C; Peggy King; Jolene Schlosser, RN; Amy Newcombe; Janet Starkey, RD; Sakita Sistrun, RD; James Maher, MD; Silas Chikunguwo, MD; Brian Kaplan, MD; Lou Usry, RN; Janet Schmidt, RN; Glenda Bruce, RN; Yvonne Gotico, RN; Gloria Underdue, LPN; Joyce Pegeas; Joelle Lemmons, RN; Robin South, RN; Lisa Hall, RN; Robin Barber, RN; Ethel Doggett, RN; Donna Kessel, RN; Sherry Boyette, RN; Betty Pleasant, RN; and Sherry Bremer. ○

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RESEARCH UPDATES

Hereditary Pancreatitis (HP) Update: Why do 20% of people with the HP gene mutations such as *PRSS1* R122H never have any symptoms while others may suffer from early childhood? Why do half of patients with HP who have recurrent acute pancreatitis progress to chronic pancreatitis while other do not? Fewer than 40% of patients with years of chronic pancreatitis develop diabetes or pancreatic cancer – but which ones? We may *FINALLY* be able to start answering these questions. New and powerful DNA analysis methods are becoming available to researchers on a continuous basis. Progress is now to the point that they should be applied to HP complications.

Dr. Whitcomb is updating the HP registry and will be applying for grant funding in October. Patients and family members are urged to contact Sheila Solomon, MS, CGC by phone (**1-888-PITT-DNA**) or e-mail (askpearl@pitt.edu) to update their health status, join the study, or report serious complications that occurred in themselves or a close family member (such as insulin-dependent diabetes or pancreatic cancer).

Fighting HP is a TEAM activity, and the more who participate, the faster a win will come.

NAPS2 Study Update: The NAPS2 study focuses on recurrent acute pancreatitis and chronic pancreatitis. Physician-led teams from nearly 30 centers have been working for over a decade to enroll patients into the study. There are now over 2,000 patients with pancreatitis (subjects) and over 1,000 patients without symptoms (controls) in the study. This represents a critical number to permit advanced genetic evaluations that have never been done before. Dr. Whitcomb, who leads the NAPS2 studies, along with his research laboratory, the Epidemiology Data Center, and several research collaborators are finishing an advanced study of genetics. Early results suggest a breakthrough in understanding genetic risk for alcohol-associated pancreatitis, as well as a genetic factor that protects people from developing some types of pancreatitis. These genetic factors are common and very important in understanding how to treat pancreatic diseases. More exciting, valuable results are on the way as well. For those who contributed blood and personal information over the past decade – Thank You! Your participation has helped us help people like you. ○

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