



PEARL



The Pancreas Education and Research Letter

New Focus on Children with Pancreatitis

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It is hard to believe how little is known about pancreatitis in the littlest of patients - children. Most of what is taught in our medical education applies to adult pancreatitis with little attention to children. The reason: limited research on pancreatitis in children has been published. Pancreatitis in children was considered to be extremely rare and so no expert groups were formed to provide clear advice on how to manage this terrible disease. We now know that many of the features of pancreatitis in children are different than in adults.

Acute pancreatitis, which is recognized by the sudden onset of severe abdominal pain with elevation of amylase and lipase in the blood stream, usually is a self-limited illness in children that lasts 3-7 days in most. Children can have prolonged hospital stays, even a month or more, and can have some of the same complications that are seen in adults, although death is unusual in children. Chronic pancreatitis also occurs in children but the causes and outcomes are not well understood. The exception is cystic fibrosis in which the pancreas is the first organ to fail. In cystic fibrosis, the focus is usually on replacing lost pancreatic function by giving the child pancreatic enzyme supplements to help with the digestion and absorption of food. Otherwise, the child will not grow and will struggle fighting infections. Children with cystic fibrosis are different than kids with other forms of chronic pancreatitis because they usually do not have the same type of pain and do not have prolonged hospitalizations from pancreatitis attacks.

The research work done on hereditary pancreatitis has revolutionized the understanding of acute and chronic pancreatitis in children. Genetic testing can identify the underlying problem in many cases, allowing physicians to begin treating children with pancreatic inflammation based on the *cause* rather than the *symptoms*. This is important so that the doctor can give the right therapy to the right child in the right dose at the right time.

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Two important recent events that bring hope to kids with pancreatitis are highlighted here. The first one is the development of the *International Study Group of Pediatric Pancreatitis in Search of a Cure (INSPPIRE)*, which is a new organization led by a group of pediatric gastroenterologists dedicated to the study and cure of pancreatitis in kids. This group, which has been highlighted at the annual *PancreasFest* meetings in Pittsburgh and at other meetings now, has a very strong core group of dedicated pediatricians who are organizing the types of resources that are necessary to understand pancreatitis in children. This includes a database where important findings from each child can be organized

and studied (with the identity of the child hidden) so that everyone can work together to help find a cure. In addition, through the work of members of INSPPIRE, pancreatitis was just highlighted at the *North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN)* annual meeting in Orlando, Florida (October 2011). Through workshops and state-of-the-art lectures the entire pediatric community became aware of this group's important effort, their key leaders, and the need to dedicate time and effort to help children with pancreatic diseases.

The importance of pancreatitis in children has also been highlighted at the University of Pittsburgh. The adult-focused Digestive Disorders Center in UPMC Presbyterian Hospital, is now working in concert with the Pediatric Gastroenterology Clinic at the Children's Hospital of Pittsburgh of UPMC to provide comprehensive care for patients and families with complex pancreatic diseases. All patients are invited to join in multiple registries and studies that are designed to provide the information needed to educate doctors everywhere about how to treat pancreatitis in children, as well as ongoing advances in the treatment of adults.

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Teenagers: Coping with Genetic Risk

It's not easy being a teen these days. Pressure comes from all angles: parents, friends, school, as well as one's own pressure to succeed and be happy. But for some teens, like the ones you're about to meet, there is another added pressure in their lives. It is how they handle it with grace, fearlessness and proactivity that is ever so impressive. Here is their story:



Cammie, age 15 and her sister Delaney, age 18 are just like any other teenagers. They have plenty of friends and activities keeping them busy and focusing on their futures each

day. But it's something from the past, their family tree, to be specific, that adds to the list of life stresses.

"We never got to meet our grandmother," says Cammie. "My dad was 10 years old when his mom died of melanoma."

The story doesn't end here. Grandmother's brother and sister both died of pancreatic cancer. Years later, Cammie and Delaney's father was diagnosed with melanoma as were his two brothers. The strong family history of pancreatic cancer and melanoma suggested the Familial Atypical Multiple-Mole Melanoma syndrome, an inherited cancer predisposition syndrome caused by mutations (genetic changes) in the *p16* gene. When she was six, Cammie was found to carry the familial *p16* gene mutation, along with her dad, uncles and some of her cousins. Carrying a *p16* mutation places a person at a 75% lifetime risk for melanoma and nearly a 17% chance for developing pancreatic cancer. She says that while it is scary that a mole may contain cancer, "I'm taking all the precautions to be protected from the sun, to eat healthy and get screenings every six months since I was little by a dermatologist."

Surveillance for pancreatic cancer, which includes an endoscopic ultrasound of the pancreas, usually begins in

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Fall Recipe: Lentil Chili

Legumes such as lentils are a great source of dietary fiber and plant-based compounds that may play a role in reducing the growth of pre-cancerous lesions, thereby decreasing the risk of cancer. This recipe's phytochemicals are protective against many types of cancer, such as colon and pancreas cancer.

Ingredients:

- 2 tablespoons olive oil
- 1-3/4 cups onions, chopped
- 2 cups each zucchini, diced
- 2 cups carrots, finely diced
- 2 cups unpeeled eggplant, finely chopped
- 1 small jalapeño pepper, seeded and chopped
- 2 tablespoons garlic, finely chopped
- 1 tablespoon dried oregano
- 1-1/2 tablespoons ground cumin
- 1/2 teaspoon cayenne pepper
- 1 bay leaf
- 56 oz. (two 28-oz. cans) diced tomatoes with juice
- 2-1/2 cups low-sodium vegetable stock
- 1-1/2 cups red or brown lentils
- Salt and pepper to taste
- Low-fat sour cream to garnish

Preparation: Heat olive oil in a large saucepan or stock pot over medium heat. Add onions, zucchini, eggplant, carrots, jalapeño, and garlic. Sauté about 4 to 5 minutes, until almost tender. Add oregano, cumin, cayenne, bay leaf; stir a few seconds. Add tomatoes with juice, vegetable stock and lentils; bring to a low boil. Reduce heat and simmer, uncovered, until lentils and vegetables are tender, about 40 minutes. Season with salt and pepper as desired. Pour into 6 bowls or mugs and garnish each with 1 teaspoon low-fat sour cream. Makes 6 servings. ○



Nutritional information per serving:

- Calories: 335
- Fat: 6 g
- Saturated fat: 2 g
- Carbohydrate: 40 g
- Total sugars: 10 g
- Protein: 25 g
- Sodium: 500 mg

Discovery Channel Comes to Genetics Research Laboratory

On a sunny August morning in Pittsburgh, a camera crew descended on Dr. Whitcomb's Genetics Research Laboratory at the University of Pittsburgh. Complete with a director, sound specialist and makeup artist, filming began for a Discovery Channel program about personalized medicine in the age of genomics. This exciting series of health related films includes late breaking research topics on pancreas disease research at the University of Pittsburgh and other institutions around the country. Principal investigator Dr. David Whitcomb and his research team were interviewed about the impact of genetics on pancreas diseases and how prevention, diagnosis, and treatment of these diseases is improving in the era of personalized medicine. The program is geared for healthcare professionals who are interested in the topic and to obtain continuing education credits, though anyone can view the film. ○



To view the film go to: <http://discoveryhealthcme.discovery.com/>

Kids' Corner *continued from page 2*

adulthood. Cammie and Delaney did not want to wait to learn about it as adults. They wanted to learn more now. During their summer break, the sisters embarked on a journey to Pittsburgh from their hometown in Ohio to learn more about genetics, family history and what they can do to prevent pancreatic cancer. At the University of Pittsburgh Medical Center, they observed an endoscopic ultrasound procedure for a patient who was at familial high risk similar to them. Delaney remembers how interesting it was to observe the endoscopic ultrasound because "I had always heard about my dad going out of town to have 'the scope', but now I know what it really meant."

They toured the research facility of Dr. Randall Brand and had a chance to speak with researchers first-hand about the difficult and exciting work being performed about pancreatic diseases. Cammie recounted that "a lot of the [patients coming for high risk pancreatic cancer surveillance] have experiences similar to ours. It was interesting to see that there are other people like us out there."



"We flipped through pamphlets about hereditary genes and different types of genetic testing that teenagers can learn about" recalls Delaney. "That's when we decided to make a pamphlet for teens so that if they have *p16* [mutations] they can understand it better and learn what they can do. Teens may not want to listen to their parents, but they may like to read information written by other teens and would maybe take this to heart." The sisters' finished product is an elegant brochure which describes the *p16* gene, cancer risks and precautions for disease prevention all written in language especially for teens and young adults.

Back home, they took the project to the sun-drenched fields of their field hockey team practice. "We got our booster group to buy a tent for us to get out of the sun, along with a bucket filled with sunscreen lotion. Each break, the coach has us 'lotion up.' Friends encourage each other."

What would Cammie and Delaney tell other teenagers about having a genetic condition that increases cancer risk? "It can be scary knowing you have a gene like this, but if you stay close with your family and take precautions that the doctors advise, talk with people about it and stick together, you'll get through it together." And that's exactly what they've done. ○

NEWS AND EVENTS

Mark Lowe, MD, PhD, an internationally recognized expert in pancreas research and Chief of Pediatric Gastroenterology, Hepatology, and Nutrition, at Children's Hospital of Pittsburgh of UPMC, has recruited Sohail Husain, MD, a pediatric gastroenterologist and scientist from Yale University to broaden basic pediatric pancreatitis research. This important recruitment strengthens the

pancreas program at Children's Hospital of Pittsburgh of UPMC, as well as the University of Pittsburgh. Dr. Husain has already made major contributions to the weekly multidisciplinary Pittsburgh Pancreas Working Group meetings where physicians and scientists come together to discuss ways of advancing medical care of patients with pancreatitis, including those seen in children.

It's November and that means **Pancreatic Cancer Awareness Month**. Events and programs to raise awareness are happening all over the country. Check out the links below to find an event near you.

Pancreas Cancer Action Network: Multiple events and programs throughout the country.
<http://www.pancan.org/index.php>

National Pancreas Foundation: The National Pancreas Foundation announces a worldwide statement on pancreatic cancer awareness month in November and encourages you and your loved ones to share this letter with everyone you know: <http://pancreasfoundation.org/2011/10/worldwide-statement-november-is-national-pancreatic-cancer-awareness-month/>



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