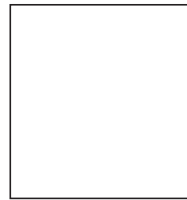




The
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The National Pancreas Foundation

Mission

To support the research of diseases of the pancreas and to provide information and humanitarian services to those people who are suffering from such illnesses.



WINTER 2005

PERSPECTIVES

The Newsletter of the National Pancreas Foundation



The
National Pancreas
Foundation

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A Portrait of Childhood Pancreatitis

Henry Graves does not remember the pain of his first pancreatitis attack, when he was two years old. The first attack he can recall occurred when he was five: "It happened out of the blue," he recounts. "The pain was really bad."

Now, Henry is thirteen and in eighth grade. He plays trombone in the school band. He also loves the outdoors and sports – baseball is his favorite. On Fridays, Henry has sleepovers with his friends, and they play Texas Hold 'Em and Capture the Flag. He and his eleven-year-old brother, Doug, practice musical instruments together and play whiffle ball.

Few limitations indicate that Henry is any different than his peers. "I'm not allowed to do football, which makes me disappointed," he says. "I also can't eat as many things as other kids – no 2% milk or high fat stuff." Also, his friends and family often provide special companionship or care: "When I'm in the hospital, my mom buys me Legos, a new book, or video games," he explains. Friends visit and send him stuffed animals when he is sick. His brother knows the signs of an attack: "If I am in too much pain to get my parents, Doug tells them."

Henry's pancreatitis makes him part of a little-understood group. According to Dr. Mark Lowe, Professor of Pediatrics and Director of Pediatric Gastroenterology at Children's Hospital of Pittsburgh, no figures exist to indicate how many children have chronic and acute pancreatitis. Doctors and researchers know little about the causes or risk factors for childhood pancreatitis.

Continued on next page

NPF Third Annual Golf Tournament, Pittsburgh, June 28, 2004

Highland Country Club in Pittsburgh, Pennsylvania was once again the site of the annual National Pancreas Foundation Golf Tournament, hosting 128 golfers on what started out to be a dreary June morning with a sky loaded with thunderstorms. However, all the volunteers reported for duty at 8:30 a.m. to help set up the silent auction tables and the golfers' registration desk, in hopeful anticipation of a full turnout. Just before the luncheon buffet began, the rain stopped for almost 18 holes. A few golfers got wet playing their final hole, but dried off with food and drink in hand, while bidding on the extensive silent auction items.

The silent auction committee chaired by Melanie Martin, did a fantastic job bringing in record donations. Silent auction items included trip packages to Deer Valley, Utah, Hilton Head and New York City; the Mercedes-Benz Driving School for two, a five course/wine-paired dinner for 12 at a fine Pittsburgh restaurant and several beautiful pieces of jewelry.

Jamie Dixon, the head coach for the University of Pittsburgh Men's Basketball team, spoke about his struggle with acute pancreatitis and

the excellent medical care he received at University of Pittsburgh Medical Center's Pancreas Center. Other local celebrities included former Pitt basketball star, Curtis Aiken and current Pitt star, Julius Paige. Gary Love, a radio celebrity, was gracious enough to act as the Master of Ceremonies for the 19th Hole.

The members of the golf committee, who met at least twice a month for seven months, did a tremendous job. The event raised \$70,000--\$30,000 more than in 2003! Particular thanks to our event sponsors—Federated Investors, Kirkpatrick & Lockhart, LLP, and the William E. Simon Foundation.

Continued on page 3



Pennsylvania State Representative Melissa Hart took time out of her busy schedule to participate in the 3rd Annual NPF Golf Tournament in Pittsburgh. Co-chairs Susan Payne & Patter Birsic thanked Hart for her ongoing support.

Presidents' Letter

Dear Friends of NPF,

Looking back at this time last year, the NPF strategic planning committee was developing a 5-year plan for the Foundation and an implementation timeline, assessing the strengths, areas of improvement, and priorities.

The primary objectives of the final plan have been defined as 1) to expand NPF's national presence and fundraising within the private and medical sectors; 2) to provide substantive and accurate medical information and resources to individuals and physicians, 3) to increase financial incentives and educational programs, encouraging young investigators to pursue the field of pancreas disease and 4) to develop partnerships with corporations and private foundations enabling NPF to achieve all of its goals through financial growth.

In May 2004, our first two objectives successfully progressed with the Phase I implementation of our redesigned website, www.pancreasfoundation.org. We want to thank Mark Bishop, the director of the redesign project, the members of the NPF Technology Committee and dedicated staff of Hill-Holliday for their hours of research, creative brainstorming, writing and editing. It is a great start with Phase II enhancements currently underway.

The NPF Career Development Scholarship Program has been implemented to encourage young investigators to pursue pancreas disease—research, diagnosis and treatment. At the NPF annual Board of Directors Meeting, one scholarship application was approved as well as the renewal of the NPF Abstract Award at the annual American Pancreatic Association meeting in Chicago. Chaired by Dr. Phillip Toskes, the committee is developing state of the science educational seminars with new pancreas initiatives. The first workshop's theme will focus on ERCP--the diagnosis and therapy of pancreas disease.

Voicing our support of increased federal funding of pancreas disease research continues to be accomplished through lobbying on Capitol Hill with the Digestive Disease National Coalition (DDNC) of which Jane Holt is a board member, and the American Gastroenterologists' Association (AGA). In July, we met with Dr. Serrano and Dr. James of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to explore initiatives for increasing quality research grants and the development of career scholarship programs.

As always, our dedicated volunteers and board members continue to travel across this great country to participate in medical conferences in Boston, Chicago, New Orleans, Orlando, Pittsburgh, and Washington, D.C.

We hope you find our most recent issue informative. Included are articles on recent fundraising events, the upcoming cookbook, the annual United Way national campaign and information on our new on-line support group.

Please email us at info@pancreasfoundation.org with any ideas or information you would like to see in our next issue of Perspectives.

Sincerely,
Patter Birsic & Jane Holt

"Childhood Pancreatitis" continued from page 1...

Kate, Henry's mother, has experienced this lack of knowledge firsthand. "We've been lucky with the time and interest his doctors have shown, though we were never able to find a reason for Henry's pancreatitis." Recently Henry has had fewer attacks, and no one can explain that, either. "It's unclear if he's cured, or grown out of it in some way or if we are doing something to stave off the attacks. The worry is that we unknowingly stop doing something that is helping," she says. Henry says that he used to have attacks every two months and missed at least a month of school each year. He had a sphincterotomy, which stretched the time between attacks to approximately every six months for about 3 years. Recently, the episodes have occurred even further apart, which may or may not have something to do with the antioxidants Henry has been taking for the last year or so. Henry, though, doesn't seem bothered by the unexplained improvement: "I don't know why it's gotten better," he states. "I think the doctors did something."

Henry also accepts the attacks themselves. "Now they're part of my routine," he says. "It usually happens during the middle of the night. I wake up and the pain is really bad." When he begins to feel pain, he takes Mylanta – he also has acid reflux. If the pain persists, Henry and his parents head to the hospital. There, they wait in the emergency room, usually from 10 p.m. until two or three o'clock in the morning. Nurses draw blood to differentiate a pancreas attack from a bad reflux attack. While in the hospital, Henry watches TV and reads.

But the waiting begins in earnest when he returns home. Henry estimates that he is confined to the house for three to seven days each time he has an attack. He finds this part of the experience especially challenging: although he tries to keep busy, he can't always escape tediousness. "TV, computer, even reading can get boring – I need something to do. When that happens, I sit there until my mom comes home, or I sleep." Henry also can't eat or drink while he's sick, so his parents have learned the procedure to hook up an IV to nourish him.

Henry does not know anyone else his age with pancreatitis, a fact that he says does not bother him. "I just think of myself as a normal kid," he says. He knows how to weather attacks and how to take care of himself. For other children in his position, Henry advises that they pay attention to their bodies. "As soon as I feel slight pain, I tell my parents. Also, I don't eat if I think it's pancreatitis". He also tries to remember to take his medication on a daily basis. When in the midst of an attack, Henry says that the most important thing is to stay occupied. He especially likes reading, and says that The Phantom Tollbooth was the last good book

Continued on page 3

Yield: 4 servings (serving size: 2 cups salad, 3 ounces chicken, and 1 tablespoon feta cheese).

NUTRITIONAL INFORMATION:
CALORIES 231 (30% from fat); FAT 7.7g (sat 2.1g, mono 3.9g, poly 1g); PROTEIN 30.3g; CARB 10.3g; FIBER 3.4g; CHOL 72mg; IRON 2.9mg; SODIUM 613mg; CALC 110mg

Recipe Copyright © Cooking Light Magazine

Strawberry Cheesecake Frozen Yogurt

This has all the appeal of traditional cheesecake: It's rich, tangy, creamy, and fruity.

4 cups strawberry fat-free frozen yogurt
1 cup fat-free sour cream
1 (8-ounce) block 1/3-less-fat cream cheese, softened
1 cup powdered sugar
1/2 teaspoon vanilla extract

INSTRUCTIONS:

1. Place a large bowl in freezer. Let yogurt stand at room temperature 45 minutes or until softened.
2. Place sour cream and cream cheese in a bowl. Beat with a mixer at medium speed 1 minute or until well blended. Gradually add sugar, beating well. Beat in vanilla.
3. With a rubber spatula or stand mixer, combine softened yogurt and cheese mixture in chilled bowl. Cover; freeze to desired consistency.

Yield: 12 servings (serving size: 1/2 cup).

CALORIES 181 (23% from fat); FAT 4.7g (sat 3g, mono 1.3g, poly 0.1g); PROTEIN 5.6g; CARB 28.8g; FIBER 0g; CHOL 16mg; IRON 0.1mg; SODIUM 144mg; CALC 144mg

Grilled Corn and Black Bean Salad

INGREDIENTS FOR 6 SERVINGS:

3 ears shucked corn
1/2 cup fresh lime juice (about 2 limes)
1/3 cup minced red onion
1/3 cup minced fresh cilantro
3 tablespoons white vinegar
2 teaspoons sugar
2 teaspoons ground cumin
2 teaspoons chili powder
1 (15-ounce) can black beans, drained
Lime wedges (optional)

INSTRUCTIONS:

Serve this juicy salad with a slotted spoon over chips or chicken.

1. Prepare grill.

2. Place corn on a grill rack; grill 20 minutes or until corn is lightly browned, turning every 5 minutes. Cool. Cut kernels from corn; place in a bowl. Add juice and remaining ingredients; stir gently. Cover and chill for 1 hour. Garnish with lime wedges, if desired.

Yield: 6 servings (serving size: 1/2 cup).

NUTRITIONAL INFORMATION:
CALORIES 98 (8% from fat); FAT 0.8g (sat 0.1g, mono 0.2g, poly 0.3g); PROTEIN 4.7g; CARB 22.9g; FIBER 5.4g; CHOL 0mg; IRON 1.6mg; SODIUM 238mg; CALC 36mg

Recipe Copyright © Cooking Light Magazine

Baked Shrimp With Feta Cheese

INGREDIENTS FOR 4 SERVINGS:

1 teaspoon olive oil
3/4 teaspoon dried oregano
1/2 teaspoon salt
1/4 teaspoon crushed red pepper
1 pound medium shrimp, peeled and deveined
3 garlic cloves, minced
Cooking spray
1/2 cup dry white wine
3 cups diced plum tomato (about 3/4 pound)
3/4 cup (3 ounces) finely crumbled feta cheese
4 cups hot cooked linguine (about 8 ounces uncooked pasta)
1/4 cup minced fresh parsley

INSTRUCTIONS:

1. Preheat oven to 350 degrees.
2. Heat oil in a large nonstick skillet over medium-high heat. Add the oregano and the next 4 ingredients (oregano through garlic); saute for 3 minutes. Spoon the shrimp mixture into an 11 x 7-inch baking dish coated with cooking spray.
3. Add wine to skillet; cook over low heat until reduced to 1/4 cup (about 3 minutes). Stir in tomato, and pour over the shrimp mixture. Sprinkle with cheese, and bake at 350 degrees for 10 minutes. Serve mixture over pasta, and sprinkle with parsley.

Yield: 4 servings (serving size: 1 cup shrimp mixture, 1 cup pasta, and 1 tablespoon parsley).

NUTRITIONAL INFORMATION:
CALORIES 404 (19% from fat); FAT 8.7g (sat 3.8g, mono 2.3g, poly 1.5g); PROTEIN 29g; CARB 51.8g; FIBER 3.1g; CHOL 148mg; IRON 5.5mg; SODIUM 677mg; CALC 182mg

Board Member Profile



Suzanne Fisher Bloomberg

Suzanne Bloomberg has served as a board member of the National Pancreas Foundation since it began six years ago. She met Jane Holt, a founding co-president of NPF, through the Friends of Dana Farber 15 years ago and became involved when Jane first started the organization. Suzanne brings her expertise in fundraising and her commitment to sharing the experiences of patients and families who have been touched by pancreatic cancer, pancreatitis, and other disorders of the pancreas.

Her involvement has a deeply personal side – Suzanne lost her first husband William Luntz to pancreatic cancer. Since that time, she has shown her dedication to community involvement by working not only with NPF, but also by serving on the boards of the Friends of Dana Farber, the Max Warburg Courage Curriculum, the Boston Landmark Orchestra, and the Leadership Council of the Boston Medical Center.

At NPF, Suzanne is involved mainly in fundraising activities and has chaired the Boston dinner for five years. She especially values working with this foundation, she says, because it is "an incredibly dedicated and committed group of people who are dedicated to finding a cure and to providing patient services to those who suffer from pancreatic disease." She also brings strong networking skills to NPF, which she employs to bring together people who know firsthand the effects of pancreatic disorders.

A New York native, Suzanne earned a B.S. from the School of Communication at Boston University. She also did graduate work there, at the School of Education. In what free time she has, she enjoys golf and gardening. Suzanne is married to Jeffrey Bloomberg and has two children: Ben, who works for Clear Channel Entertainment, and Heather, a sophomore at Dartmouth College.

"Childhood Pancreatitis" continued from page 2...

he read. But patience – the calmness with which Henry approaches each attack – is sometimes the only tool there is. "Be careful with the pain," he suggests. "Find something to do – it will be over soon."

"Third Annual Golf..." continued from page 1...

The event co-chairs, Patter Birsic and Susan Payne, are currently looking at other golf clubs for one reason—they had to turn away foursomes this year! "The support from the community is overwhelming and continues to grow, says Sue Payne. "It is a lot of work, but what a wonderful cause."

Mark your calendars for June 28, 2005. If you would like to become involved, please email Patter at pbirsic@pancreasfoundation.org.

Volunteer Event Raises \$5,000 for NPF

The Ed Anneken Memorial Golf Scramble was held September 2 at Twin Oaks Golf Course in Covington, Kentucky. We applaud Eva Anneken, NPF volunteer, for organizing this successful event. Sixty Six of Eva's family and friends turned out for the event. Eva reported that "the weather was perfect and everyone had a great time for a good cause."



Ed Anneken died of pancreatic cancer on February 2, 2004. He was 75. His wife of five years, Eva, said that "Ed was well-liked by everyone." A pharmacist and life-long Kentucky resident, Ed was re-introduced to golf by his wife, and loved to travel and play different golf courses.

Accessories Trunk Show raises over \$4,000 for NPF



The National Pancreas Foundation held its first accessories trunk show at the West Newton home of Lynne Sullivan, NPF member. Over 150 new and

old friends enjoyed a wonderful day of shopping and socializing and raised over \$4,000 for research in pancreatic disease.

The show featured a beaded collection of necklaces and earrings by Bonnie Allen Rotenberg, and summer hats and a fall preview of knitted fur accessories by Deborah Harper Millinery. Other featured designers were Pam Kubbins Pashminas and Exotic Scarves, handbags from Julian Gifts and from Details of Hingham MA. Jane Holt, NPF Co-President; Suzanne Bloomberg, Chair, NPF Fundraising; Ranney Lawless; Beth Martignetti; and Judy Phillips all helped Lynne Sullivan in hosting the event.

For information on hosting your own event, please contact khornstein@pancreasfoundation.org.

Volunteer...

Design your own fundraiser! There are many ways to raise money for the National Pancreas Foundation. Whether you organize a sporting event, dinner, dress-down day at school or work, "skip-a-snack," trunk show, or auction, you can help those with pancreatic disease while having fun with your family and friends.

Sporting events: Plan a golf outing, walk-a-thon, or bowl-a-thon to benefit NPF. Participate in a local marathon and ask friends and family to sponsor you for the miles you run. Hold an exhibition softball, soccer, or hockey game with ticket sales to benefit NPF.

Other "Thons": Dance-a-thon, walk-a-thon, read-a-thon, good-deed-a-thon, hop-a-thon. These activities are especially fun for children.

Nickels and Dimes: Save those nickels and dimes – Bring coins to school and work. Bring the coins to your nearest Coinstar machine, where you can turn your coins into dollars. Or send a check to the NPF in exchange for the coins you count in paper rolls. Talk to local merchants about collecting change at their businesses.

Other ways of helping NPF:

Volunteer at our national headquarters: If you live in the Boston, MA or Pittsburgh, PA, area, contact our offices about volunteering to assist with special events, support groups, or patient education nights.

Be an advocate: Join us in lobbying activities in Washington, D.C. Join our

mailing list to find out about legislation supporting pancreatic disease research and awareness.

For more information: We would be happy to provide educational materials and an event planning kit for your fundraiser.

For more information, please contact khornstein@pancreasfoundation.org.

United Way Campaign – 2004

The National Pancreas Foundation is a Contributor's Choice selection in the 2004 annual United Way campaign, which officially kicked off on September 1st. Our initial United Way designation in 1999 was through the United Way of Southwestern Pennsylvania and has grown to include several states including Rhode Island, West Virginia, Connecticut, Arizona and New York.

Depending upon the part of the country you reside in, you can simply write "The National Pancreas Foundation" on the Contribution Form, which will generate an inquiry and minimal paperwork for NPF to complete.

It is a very easy and generous method of donating to NPF. Over the past 4 years, we have received more than \$100,000 through the local United Way campaigns. Please remember NPF when you are completing your forms.

NPF Research Sponsorship Program

Naming an NPF Research Grant is a wonderful way to remember or honor a loved one. It's also a great way for an individual, corporation, or foundation to be honored for its contribution to NPF.

Named Fund

With either a single gift of \$25,000, or several gifts from a group that total \$25,000, we can designate money for research in a particular area, such as pancreatic cancer. The money will be awarded to the best grant applicant in that field, as determined by our Grant Review Council. All publicity and website listings will refer to that particular grant as the specific named fund.

The Fellowship Fund

The Foundation has learned that there is a shortage of fellows interested in pursuing research in pancreatic disease. The Fellowship Fund requires a donation of \$60,000 that would go directly to pay for

the salary of a Fellow, including fringe benefits. The Fund can be directed to a fellow who is doing research in one particular area of pancreatic disease. The money will be awarded to the best applicant in that field, as determined by our Grant Review Council. All publicity and website listings will again refer to that particular fellowship as the specific named fund.

For more information, please contact our office at khornstein@pancreasfoundation.org.

Ask the Doctor: FAQ's for Winter

This segment contains a sample of questions that we receive from our website and answers provided by Dr. Andres Gelrud, co-Director of the Pancreatic Disease Center of the University of Cincinnati Medical Center, and Assistant Professor of Medicine at the University of Cincinnati.

Question:

My wife has stones in the pancreas. (This was discovered accidentally from an x-ray taken for a different purpose). A CT Scan has revealed a few more are developing. Fortunately these stones are not blocking the ducts. Therefore, the doctors have advised that there is no need to worry at this time and no medication is required. My wife is very concerned over the matter. In spite of the doctors opinion and my continuous advice she thinks this is her end!!! Please advise me whether there is any treatment available. Can these stones be removed?

Answer:

The presence of stones in the pancreas is indicative of pancreatic disease. If she has no risk factors for the development of pancreatic disease and no symptoms are present, clinical follow up is indicated. Make sure that a Gastroenterology doctor is involved in her care.

Pancreatic stones are usually embedded in the pancreatic tissue. Only when the patient has symptoms due to blockage (stone obstructing the pancreatic duct) would we refer the patient for endoscopic retrograde pancreatography with stone removal. Occasionally, the patient might need surgery.

Question:

Can you live without a pancreas and if so what do you need as medication?

Answer:

Yes you can. The pancreas makes many hormones,

among them insulin, which is the main regulator for glucose control. Total pancreatectomy is a radical surgery where the entire gland is removed; the main indication is for the treatment of pain in patients with chronic pancreatitis. It is only performed in selected places in the United States and islet auto transplantation is usually performed to preserve endocrine (insulin) function.

Question:

What is it like to die from metastasized pancreatic cancer? Is it painful? What medications help the pain?

Answer:

The pancreas is surrounded by many abdominal nerves. Pancreatic cancer can be painful particularly when nerves are involved.

Different treatment options for pain control include:

1. Endoscopic ultrasound nerve block.
2. Percutaneous nerve block.
3. Medications, particularly narcotics.

Question:

I was recently in the hospital with a pancreatitis attack. Now they have told me that I have a pancreatic pseudocyst and that I need surgery. I'm rather nervous and would appreciate you getting back to me about how this procedure works and if I have other options. So, please help me understand what is going on...thank you

Answer:

Pancreatic pseudocyst, an accumulation of fluid in the pancreas, is the most commonly seen complication from pancreatitis. The treatment of pancreatic pseudocyst is only indicated when the patient has symptoms like abdominal pain, nausea or vomiting and early satiety. Treatment options include:

1. Surgical drainage (connecting the cyst to the stomach or small bowel).
2. Endoscopic drainage (connecting the cyst to the stomach or small bowel).
3. Percutaneous drainage (going through the skin into the cyst and leaving a catheter until it drains).

New online support group!

Our re-designed website includes an opportunity for individuals to join our online support group, designed for those with pancreatic disease and their loved ones. We now have nearly 200 members, and have addressed topics such as massage therapy, local support, the importance of hydration, and "seasonal pancreatitis." We hope the group will serve as a forum for members to share their ideas and

experiences. Please join us by sending an email to info@pancreasfoundation.org with "Support Group" in the subject line.

Or visit our website at www.pancreasfoundation.org/live/supportgroups.htm

Cooking Light

These recipes have been donated exclusively for the NPF by Cooking Light Magazine. All recipes are extremely low in fat content, and generally do not irritate those with pancreatic diseases. The NPF recommends that you consult with your physician in all cases before eating any of the dishes listed below

Greek Salad With Grilled Chicken

INGREDIENTS FOR 4 SERVINGS:

- 1/4 cup fat-free, less-sodium chicken broth
- 2 tablespoons red wine vinegar
- 1 teaspoon sugar
- 1 teaspoon dried oregano
- 2 teaspoons olive oil
- 1/2 teaspoon salt
- 1/2 teaspoon freshly ground black pepper
- 1 garlic clove, minced
- 4 (4-ounce) skinless, boneless chicken breast halves
- Cooking spray
- 8 cups torn romaine lettuce
- 1 cup sliced cucumber (about 1 small)
- 8 pitted kalamata olives, halved
- 4 plum tomatoes, quartered lengthwise
- 2 (1/4-inch-thick) slices red onion, separated into rings
- 1/4 cup (1 ounce) crumbled feta cheese

INSTRUCTIONS:

Total time: 35 minutes

1. Prepare grill or broiler.
2. Combine the first 8 ingredients in a small bowl. Brush the chicken with 2 tablespoons dressing; set remaining dressing aside.
3. Place chicken on grill rack or broiler pan coated with cooking spray; cook for 5 minutes on each side or until chicken is done. Cut into 1/4-inch-thick slices.
4. Combine the romaine lettuce and the next 4 ingredients (romaine lettuce through red onion slices) in a large bowl, and toss with the remaining salad dressing. Divide the salad evenly among 4 plates; top each serving with sliced chicken, and sprinkle with feta cheese.