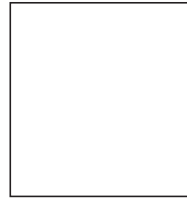




The  
**National Pancreas**  
Foundation

P.O. Box 15333  
Boston, MA 02215



Mark your calendar:

**An Evening at Via Matta**

**6:30 p.m.**

**Sunday, November 13**

**Via Matta, Boston**

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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.*



The  
**National Pancreas**  
Foundation

*In Massachusetts:  
P.O. Box 15333  
Boston, MA 02215*

*In Pennsylvania:  
P.O. Box 935  
Wexford, PA 15090-0935*

*Toll-Free 1-866-726-2737  
www.pancreasfoundation.org*

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FALL 2005

# PERSPECTIVES

The Newsletter of the National Pancreas Foundation

**Pancreatitis in Childhood:** An Excerpt from a recent paper by

Mark E. Lowe, MD, PhD  
Division of Pediatric Gastroenterology  
Children's Hospital of Pittsburgh and the University of Pittsburgh Medical Center

To read the complete paper, including tables and footnotes, as well as further reading, please visit our website at [www.pancreasfoundation.org](http://www.pancreasfoundation.org).

Knowledge about the pathophysiology of pancreatitis and the development of effective therapy has lagged behind the progress made in many other important diseases. Over the years, many factors have contributed to this disparity including the inaccessible location of the pancreas, reluctance to employ invasive diagnostic methods, and a paucity of human studies utilizing modern molecular methods. In recent years, the application of advances in cell biology and genetics and in imaging techniques in studies of pancreatitis has provided critical information about the pathophysiology, genetics and anatomy of pancreatitis. Additionally, several new single and multicenter studies have improved our understanding of the etiology and clinical course of pancreatitis in childhood. Taken together within the context of pancreatic physiology, these advances provide the basis for future diagnostic methods, treatment and prevention of pancreatic inflammatory disease.

**Overview of Pancreatitis**

Inflammatory disorders of the pancreas fall into two classifications, acute pancreatitis and chronic pancreatitis. Acute pancreatitis is defined clinically as the sudden onset of abdominal pain associated with a rise of pancreatic digestive enzymes in the serum or urine with or without radiographic changes in the pancreas. It is a reversible process with no lasting effects on pancreatic histology or function. In contrast, chronic pancreatitis is the sequelae (negative after-effect) of long-standing destructive, inflammatory injury to the pancreas resulting in fibrosis, loss of normal pancreatic cells, and chronic inflammatory infiltrates. Clinical diagnosis depends on identifying the typical histological and

*Continued on page 3*

**Kid2Kid!**

In July of 1998, Lauren Sampson, daughter of our Board member, Sally Sampson, had another pancreatitis attack and was hospitalized. She was just six years old. It was at that time that she had the idea of establishing a program to collect and deliver toys to other hospitalized children. She called that program Kid2Kid.

The toys were delivered by children who have chronic diseases, like pancreatitis, and who therefore understood what it is like to be hospitalized. The children who collected and delivered the toys were able to relate to other young patients, but also experienced great satisfaction from their deed because they were helping others. Over the years, the program has grown so that toys are collected at, and distributed from, a number of National Pancreas Foundation events.



Dee and Kathy Birsic collect toys at Golf Outing.

This fall, we are pleased to announce that The National Pancreas Foundation has established the Kid2Kid Fund, the purpose of which is to reach out to children with pediatric pancreatitis with research funding and support. In addition, the Fund will continue to collect donations of toys that will be delivered to children in hospitals across the country.

**By Kids and For Kids**

If you are a kid with pancreatitis, life can be tough. It can be good to know that someone else out there knows what you are going through. The National Pancreas Foundation is making a firm commitment to help children with pancreatitis through the following programs:

*Continued on page 3*

## Presidents' Letter

Dear Friends of NPF,

With the days getting shorter and the return to school for children across our land, the National Pancreas Foundation's emphasis in this issue is children suffering with pancreatitis—ranging from Dr. Mark Lowe's excellent article on the diagnosis and treatment of pediatric pancreatitis to recipes that are kid-friendly and easy to make on their own. As we have shared in previous issues, the suffering of a child with pancreatitis, and the frustration and pain that their parents and other loved ones experience is very personal for one of our NPF Board members, Sally Sampson, and her daughter, Lauren. Lauren Sampson started the Kid2Kid Fund, bringing toys to children like Lauren, who spend too much time in hospitals instead of playing outside and going to school. In the past 6 months, NPF has, with Lauren's approval, incorporated Kid2Kid into the Foundation and has begun to collect toys and games for distribution at hospitals across the country. At the annual NPF Golf event in Pittsburgh in late June, the golfers brought not only their clubs but hundreds of games and toys that have been donated to Children's Hospital in Pittsburgh.

We have created a section on our website, [www.pancreasfoundation.org](http://www.pancreasfoundation.org), dedicated just to kids and an online support group recently was started for kids to exchange ideas, experiences and frustrations. Our goals are two-fold: to educate the medical and public areas about the diagnosis and effective treatment of pediatric pancreatitis; and to empower kids with information and support by participating in our support group and participation in the Kid2Kid organization.

It is an exciting time for the Foundation, gaining momentum in expanding our national presence through the ever-increasing number of fundraisers and events benefiting NPF. On the eve on the semi-annual Board of Directors' meeting, it has been a record fundraising period, highlighted by the anonymous donation of almost \$145,000, which will be directed to expanding the NPF network, enhancing our business plan to include the recently announced Million Dollar Campaign, which will target significant corporate donors. Please read in this issue about several successful fundraising events that were held recently. Don't forget to go to our new website and order the new "Courage" purple NPF bracelet! More than 7,000 bracelets have been mailed to almost all 50 states and England!

We are working closely with the American Pancreatic Association (APA) on the first collaborative APA/NPF Symposium 2005 on inflammation and pain in pancreatic disorders, which will be held in Chicago November 4-5. Discussions with pharmaceutical and diagnostic equipment companies are ongoing, to develop additional educational and information symposiums in a collaborative effort.

Finally, we cannot thank all of you enough for your incredible support, both with your time and your checkbook. We believe that the next 12 months will bring incredible growth to the Foundation, in supporting critical research in the diagnosis, treatment, and cure of diseases of the pancreas, and in expanding the information and support to empower sufferers and their families. Special thanks to our corporate donors—Altus, Axcan Pharma, Boston Scientific, Federated Investors, Solvay and the William E. Simon Foundation.

Sincerely,

Patter Birsic

Jane Holt

### Raising Golf Clubs, Raising Funds For Research More than \$100,000 raised!

Pittsburgh, PA --- June 27th



Dawn Lawson and her guests: Rick Catalogna, Vince Acri,

It was a gorgeous but hot day at Sewickley Heights Golf Club, the setting for the Fourth Annual NPF Golf Tournament, with a record 144 golfers attending this year's event. The day started early for the enthusiastic volunteers who arrived at the club at 8:30 to get ready for the arrival of the golfers for a delicious buffet lunch and a noon shotgun. Chaired by Susan Payne and Patter Birsic, the volunteers manned the registration desk, sold mulligans and raffle tickets, and displayed more than 70 silent auction items in the club's ballroom.

Federated Investors and Kirkpatrick & Lockhart Nicholson Graham LLP were the event sponsors and were well represented by a total of five foursomes on the course. Platinum sponsors were Grenen & Birsic, P.C., Shenango Incorporated and Snow Capital Management, L.P., with a total of 27 corporate sponsors supporting the event this year. Sewickley Heights Golf Club is one of the premiere golf clubs in southwestern Pennsylvania, challenging the most veteran golfers and a great venue for entertaining customers.

New this year was the request for golfers to pack a toy in their car, as well as their clubs, to donate to NPF's Kid2Kid program. The response was overwhelming and the toys will be distributed at Children's Hospital of Pittsburgh. On that same theme, Dr. Mark Lowe, chief of the gastroenterology division at Children's Hospital of Pittsburgh, spoke briefly during the 19th hole about the difficulties in diagnosing and treating pediatric pancreatitis.

Approximately 200 people attended the 19th hole festivities, sponsored by Wexford Post Office Deli & Catering, which included delicious food and drink. The silent auction items included a ski trip to Vail, a fur jacket and a fur vest, jewelry, a fabulous weekend trip to New York City, and many other unique items.

Once again, the golf event was a huge success and next year's 5th Annual NPF Golf Tournament will be Monday, June 26, 2006. Mark Your Calendars Now! If you would like to get involved, please email Patter Birsic @ [pbirsic@pancreasfoundation.org](mailto:pbirsic@pancreasfoundation.org). The 2006 Golf Committee will begin planning in September.

### An Evening at XM Satellite Radio...

Washington, DC was the location for "An evening at XM Satellite Radio" on Thursday, October 20th, with more than 50 supporters enjoying a tour of the incredible radio station, listening to the beautiful music of renowned pianist, Ernest Barretta, and being educated by Dr. Paul Lin about pancreatic disease. Patter Birsic, Co-Founder of NPF, was

demonstrated by Joe Titlebaum and Lisa Ghezzi to make this happen." Joe, Executive Director and General Counsel for XM Satellite, lost his father to pancreatic cancer and his mother, Libby, had a five month bout of acute pancreatitis. Lisa Marie Ghezzi of the Dealy Strategy Group and advisor to XM Satellite, who has suffered with



Marc Martin, Keith Ghezzi, and Marc Sommers at the XM event.

fortunate enough to attend the evening and said "It is amazing how many people have been affected by pancreas disease who attended and the incredible support

chronic pancreatitis, coordinated the event from invitations to speakers. Thank you so much!



(left to right): John Cozzi, John Vinter, Patter Steve Leonard and Karen Leonard at XM.

## Board Member Profile



Sally Sampson

Sally Nirenberg Sampson has been a member of NPF's Board of Directors since its founding in 1998. Sampson was instrumental in designing our annual dinner in Boston, to be held this year at Via Matta. She is currently involved in helping NPF put together a cookbook for those with pancreatic disease. Her daughter, Lauren, now age 13 and profiled in the Spring 2001 issue of Perspectives, has chronic pancreatitis. Lauren is the founder of our Kid2Kid program (see related story on page 1)

Sampson is the author of *Souped Up!* (Simon and Schuster, 2003), *Party Nuts!* and *Party Dips* (Harvard Common Press, 2002 and 2004), *Bakesale* (Simon and Schuster, 2000), *The James Beard Award Nominated Fifty Dollar Dinner Party* (Simon and Schuster, 1998), *Recipes from the Night Kitchen: a Practical Guide to Spectacular Soups, Stews and Chilies* (Simon and Schuster, 1990). She is the co-author, with Cooper Gillespie (a very handsome Welsh Springer Spaniel) of *Throw Me a Bone: 50 Healthy, Canine Taste-Tested Recipes for Snacks, Meals and Treats* (Simon and Schuster, 2003) and the co-author of *The Diet Workshop's Recipes for Healthy Living (Doubleday, 1995)* and *Chic Simple Cooking (Knopf, 1995)*. She is the co-author, with Todd English, of *The Olives Dessert Cart* (Simon and Schuster, 2000), *The Figs Table* (Simon and Schuster, 1998), and *The Olives Table* (Simon and Schuster, 1997). She is also the co-author, with Stan Frankenthaler, of *The Occidental Tourist* (Simon and Schuster, 2001).

Ms. Sampson has contributed to *Self*, *Bon Appetit*, *Food and Wine*, *The Boston Globe*, *Boston Magazine*, *Mode*, *Fine Cooking*, *The Tab* and to Microsoft's online magazine, *Boston Sidewalk*. She was the editor-in-chief of *Balducci.com* and a senior writer for *Cooks Illustrated Magazine*. She also owns *Sampsons Nuts*. She lives in Boston with her two children, Lauren, 13 and Ben, 11.

## Kids' Recipes from 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.

### G.I. Joes

Sloppy Joes are not easy to eat--that's half the fun for kids of all ages. Adults who like spicy food can add hot sauce at the table.

1 cup boiling water  
1/2 cup sun-dried tomatoes, packed without oil  
1 tablespoon olive oil  
1 1/2 cups chopped onion  
1 cup chopped red bell pepper  
2 garlic cloves, minced  
1 tablespoon low-sodium soy sauce  
1 tablespoon balsamic vinegar  
1 teaspoon sugar  
1 teaspoon chili powder  
1 teaspoon dried oregano  
1/2 teaspoon ground cumin  
1/2 teaspoon black pepper  
1/8 teaspoon salt  
1 (28-ounce) can crushed tomatoes, undrained  
1 (12-ounce) bag frozen soy crumbles, thawed (such as Morningstar Farms)  
6 (2-ounce) Kaiser rolls or hamburger buns

Combine boiling water and sun-dried tomatoes in a bowl, and let stand 5 minutes or until tomatoes are soft. Drain and chop tomatoes.

Heat the olive oil in a large nonstick skillet over medium-high heat. Add chopped onion, red bell pepper, and garlic; sauté 3 minutes or until vegetables are tender. Stir in the sun-dried tomatoes, soy sauce, and the next 8 ingredients (soy sauce through crushed tomatoes). Bring mixture to a boil; reduce heat, and simmer 20 minutes or until slightly thick, stirring the mixture occasionally. Stir in soy crumbles; cook 2 minutes or until thoroughly heated, stirring frequently. Spoon about 2/3 cup crumbles mixture onto bottom half of each roll; top with top halves of rolls. Yield: 6 servings

CALORIES 393(27% from fat); FAT 11.7g (sat 2.4g,mono 4.7g,poly 3.8g); PROTEIN 20.9g; CHOLESTEROL 0.0mg; CALCIUM 164mg; SODIUM 999mg; FIBER 8.3g; IRON 7.7mg; CARBOHYDRATE 51.7g

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### Oven "Fried" Chicken Fingers with Honey-Mustard Dipping Sauce

Sauce:  
1/4 cup honey  
1/4 cup spicy brown mustard

Chicken:  
1 1/2 pounds chicken breast tenders (about 16 pieces)  
1/2 cup low-fat buttermilk  
1/2 cup coarsely crushed cornflakes  
1/4 cup seasoned breadcrumbs  
1 tablespoon instant minced onion  
1 teaspoon paprika  
1/4 teaspoon dried thyme  
1/4 teaspoon black pepper  
1 tablespoon vegetable oil

To prepare sauce, combine honey and mustard in a small bowl; cover and chill.

Preheat oven to 400°.

To prepare chicken, combine chicken and buttermilk in a shallow dish; cover and chill 15 minutes. Drain chicken, discarding liquid.

Combine cornflakes and next 5 ingredients (cornflakes through pepper) in a large zip-top plastic bag; add 4 chicken pieces to bag. Seal and shake to coat. Repeat procedure with remaining chicken. Spread oil evenly in a jelly-roll pan, and arrange chicken in a single layer in pan. Bake at 400° for 4 minutes on each side or until done. Serve with sauce.

Yield: 8 servings (serving size: 2 chicken tenders and 1 tablespoon sauce)

CALORIES 185(18% from fat); FAT 3.7g (sat 0.8g,mono 1.2g,poly 1.2g); PROTEIN 21.6g; CHOLESTEROL 49mg; CALCIUM 46mg; SODIUM 306mg; FIBER 0.3g; IRON 1.3mg; CARBOHYDRATE 16g

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### Broccoli, Cheese, and Rice Casserole

1 cup uncooked instant rice  
1/2 cup chopped onion  
1/4 cup fat-free milk  
4 ounces light processed cheese, cubed (such as Velveeta Light)  
2 tablespoons butter or stick margarine, softened  
2 (10-ounce) packages frozen chopped broccoli, thawed and drained  
1 (10 3/4-ounce) can condensed reduced-fat, reduced-sodium cream of mushroom soup, undiluted

Preheat oven to 350°.

Combine all ingredients in a large bowl, and spoon into a 2-quart casserole. Bake at 350° for 45 minutes.

Yield: 8 servings (serving size: 1/2 cup)

CALORIES 137(29% from fat); FAT 4.4g (sat 1.7g,mono 1.4g,poly 0.9g); PROTEIN 6.6g; CHOLESTEROL 8mg; CALCIUM 160mg; SODIUM 410mg; FIBER 2.2g; IRON 1.1mg; CARBOHYDRATE 19.2g

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### "Kid2Kid" continued from page 1...

For Kids

- We offer a weekly online support group where you can ask questions, tell your story and offer support.
- Our website also offers a host of information

By Kids

- Support other hospitalized kids through Kid2Kid
- Design a fundraiser. You can get ideas by visiting the Volunteer section of our website at: [www.pancreasfoundation.org/help/volunteer.htm](http://www.pancreasfoundation.org/help/volunteer.htm)

- Collect and distribute toys
- Contribute to Kid2Kid; You can donate funds directly to Kid2Kid on our website at [www.pancreasfoundation.org](http://www.pancreasfoundation.org)

This issue of Perspectives has been designed to tell the story of kids with pancreatic disease. We hope that you will enjoy the articles and get back to us with your ideas of how to help those children who suffer from pancreatitis and other illnesses. Please contact us at [info@pancreasfoundation.org](mailto:info@pancreasfoundation.org) with your ideas and suggestions.

### "Pancreatitis in Childhood" continued from page 1...

morphological changes in the pancreas and, eventually, loss of pancreatic function. Thus, acute pancreatitis is an event and chronic pancreatitis is a process.

#### Triggering Events or Etiology of Acute Pancreatitis

A number of factors can trigger an attack of acute pancreatitis. Acute pancreatitis is often found in association with systemic illnesses and after organ transplant. The mechanism for pancreatitis in these illnesses is unknown and likely multifactorial. Obstructive causes, which are common in adults, account for a portion of episodes in children. Gallstones may be more prevalent in children than previously thought. In previous studies gallstones were frequently lumped with other obstructive causes and the incidence is impossible to discern. One recent report from Korea found gallstones in 29% of cases. Structural abnormalities, such as pancreas divisum, choledochal cysts, and gastric or duodenal duplication cysts, and periampullary lesions, such as Crohn disease or duodenal ulcer, can also obstruct pancreatic flow and cause acute pancreatitis in children. Trauma remains an important etiology of acute pancreatitis in childhood especially in younger children. A variety of medications have been associated with acute pancreatitis. The anticonvulsant valproic acid is the most common medication reported in most series, but other anticonvulsants and chemotherapeutic agents have also been associated with acute pancreatitis. The mechanism for drug-induced pancreatitis is speculative and most theories center on disruption of cellular metabolism by the drugs or their metabolites.

#### Treatment of Acute Pancreatitis

Treatment of pancreatitis has not changed significantly over the years. The mainstay of treatment in children remains analgesia, intravenous fluids, pancreatic rest and monitoring for complications. Volume expansion early in the course of acute pancreatitis is important to maintain cardiovascular stability and to prevent the development of pancreatic necrosis. Nutrition should be implemented early if a severe or prolonged course is anticipated. Until recently, parenteral nutrition was considered the only option, but several studies show that adult patients with acute pancreatitis tolerate jejunal feedings with fewer complications than those given parenteral nutrition. Antibiotics are usually unnecessary except for the most severe cases.

#### Outcome of Acute Pancreatitis

Acute pancreatitis is usually divided into mild and severe forms. Because the clinical course and outcome differ significantly

between mild and severe cases, the physician must make a rapid assessment of the patient's condition and predict the risk of a mild or severe clinical course. Several scoring systems have been developed to assist the physician in this decision. Until recently, none of these systems had been validated in children. One group analyzed the criteria of the Ranson and Glasgow scores plus additional criteria and developed a scoring system for children that was validated in three centers. Of note, young age and low weight are major risk factors. Although acute pancreatitis can be life threatening, death does not occur in pediatric patients as frequently as in adults. Early causes of death are shock and respiratory failure. Late life-threatening complications of pancreatitis are generally associated with infected pancreatic necrosis and multi-system organ failure. Fortunately, pancreatic necrosis appears to be uncommon in children and only 1 case in 380 (0.3%) was found in patients from 7 centers.

#### Prevalence of Chronic Pancreatitis

The prevalence of chronic pancreatitis in childhood is certainly less than that of acute pancreatitis and the incidence may be increasing, but there are no reliable estimates of the true prevalence. Pathophysiology of Chronic Pancreatitis Early in the course, chronic pancreatitis may be difficult to distinguish from acute pancreatitis on clinical grounds. In chronic pancreatitis continued inflammation produces irreversible morphological changes in the gland such as fibrosis, acinar cell loss, islet cell loss and infiltration by inflammatory cells. Because the diagnosis depends on identifying decreased function and chronic changes, both of which occur late in the course, studies of natural history and of potential therapies have been hindered. Consequently, many theories to explain the pathophysiology of chronic pancreatitis have been proposed. In the last half of the twentieth century, the dominant view held that recurrent acute pancreatitis progressed to chronic pancreatitis although some authors developed theories that did not include acute pancreatitis as part of the pathway to chronic pancreatitis. Current research suggests that chronic pancreatitis is a progression that begins with acute pancreatitis and continues with chronic and recurrent inflammation to produce end stage fibrosis. In the last decade, it has become clear that susceptibility to chronic pancreatitis is influenced by both genetic and environmental factors. In children, chronic pancreatitis generally associates with abnormal genetic alleles or is idiopathic.

#### Genetics of Chronic Pancreatitis

Trypsinogen mutations associate with the majority of hereditary pancreatitis kindreds. The most common mutations include the cationic trypsinogen R122H and N29I mutations. Hereditary pancreatitis caused by these mutations usually presents as recurrent acute pancreatitis in childhood with a median age of 10 years with a range of >1year to 60 years of age. In 50% of patients, chronic pancreatitis develops about 10 years after the first bout of acute pancreatitis although some patients will present with chronic pancreatitis without a clear history of acute pancreatitis. The most important clinical clue is the presence of pancreatitis in other family members. The diagnosis is confirmed by testing of the gene encoding cationic trypsinogen.

#### Genetic Testing in Recurrent or Chronic Pancreatitis

Genetic testing for pancreatic diseases has become an important part of medical practice. The purpose of genetic testing can be divided into two general categories, diagnostic and predictive. Diagnostic testing is done when a patient has symptoms of a disease and a genetic test can determine the underlying cause. Predictive testing is genetic testing in subjects who do not have evidence of pancreatic disease, but may have relatives with pancreatic disease or a known mutation in the genes encoding CFTR or cationic trypsinogen. In general the indications for diagnostic testing validate its use, but the role of predictive testing is less clear and controversial.

#### Conclusions

Inflammatory disorders of the pancreas are seen with regularity in regional children's hospitals. Both acute and chronic pancreatitis occur in childhood and the incidence may be increasing. Important differences in the etiologies between children and adults exist for both acute and chronic pancreatitis, but the treatment is the same. The greatest progress in understanding the pathophysiology of pancreatitis has come from studies linking genetic mutations to increased risk for pancreatitis. Mutations in the gene encoding cationic trypsinogen cause hereditary pancreatitis. Mutations in genes encoding CFTR and SPINK1 act as modifiers that along with other factors, such as other genes, drugs or toxins, increase the risk of developing pancreatitis. A greater understanding of the genes involved in pancreatitis and in the biological events associated with pancreatitis will eventually lead to better diagnostic methods, new treatments and improved prevention of pancreatic inflammatory disease.

### Second Annual Boston Trunk Show raises over \$7,700 for NPF

In May, Lynne Sullivan, NPF Board Member, once again hosted NPF's Boston Accessories Trunk Show at her home in West Newton, Massachusetts. Over 100 friends of NPF turned out in support of this event. The show featured a beaded collection of necklaces and earrings by Bonnie Allen Rotenberg, Pam Kubbins Pashminas and Exotic Scarves, Julian Gifts, and Details (Marion Curtis), Hi-Monogramming by Amye Kurson, Apparent Style (evening wear, suits and one-of-a-kind handbags) represented by Linda Schulman, and beaded tunics by Impressionist, (Menisha). A selection of beaded bags, straw pocketbooks and totes, and sequined sandals were among the items available for sale. The accessories show provided a wonderful day of shopping with friends and exposure for the Foundation.

### Light Up the Night: Rhode Island Summer Fundraiser

Friends of the NPF in Rhode Island certainly did Light up the Night! Guests gathered under the stars at the Dunes Club in Narragansett, Rhode Island, to enjoy the wonderful summer weather, dance to the music of Felix Brown, and learn more about the milestones, current work, and future plans of the National Pancreas Foundation. Through the efforts of the evening's Co-Chairs, Beth and Brian Fallon and Jane and Tom Holt, the event raised over \$17,000 for NPF.

### Hawn/Hupp Golf Tournament in Washington State

In July, friends of the late Karen Hawn gathered in Grandview, Washington for a golf tournament in her memory. Karen's late husband, Ray Hawn, a Washington State Patrol officer killed in the line of duty, was also honored, as well as a friend, Shawn Hupp, who died from inflammatory breast disease. Karen's parents, Charles (Chuck) & Marilyn



Photo: Kelsey Hawn and Marilyn Trimm

Trimm, sister, Kathy Casebolt, and friend Tracy Keller raised \$6,600 for NPF along with additional funds for two other charities.

Within a few short years of Ray's death, Karen had died of pancreatic cancer; leaving their young children, Kelsey and AJ, with no parents. Chuck and Marilyn stepped up to care for Kelsey and AJ. Today, the children are doing well and attend the annual fundraiser in their parents' memory.

### Boston: All One Family

The Four Seasons Hotel in Boston was the setting for a special preview party for Bill Brett's pictorial masterpiece: Boston: All One Family. Bill Brett has been a photographer for the Boston Globe for over 42 years; his book is a collection of portraits of prominent Bostonians. Attendees, many of whom were new friends of the Foundation, heard Bill share his many experiences photographing renowned Bostonians, met many of those photographed in the book, received complimentary signed copies of the books and heard more about NPF. We are grateful to our Co-chairs Jane and Tom Holt and Mary Joyce and Jim Morris, and our sponsors: Kirkpatrick & Lockhart, Nicholson, Graham LLP and The Four Seasons Hotel, Boston. Although designed as a cultivation event, the evening raised over \$7,000 in donations.

### Arizona Diamondbacks root for NPF



We received this picture from Vince Alcazar, Clubhouse manager for the Arizona Diamondbacks (MLB). The photo shows Vince and Luis Gonzalez, the team's left fielder. Gonzalez has been an All Star a few times and is best remembered for getting the game winning hit to beat the Yankees in the 2001 World Series. Vince ordered our "Courage" bracelets for the whole team this summer, after being stricken with pancreatitis. If you look closely, you can see our purple bands (also the team's color!!) Vince, like so many of our friends, is planning a fundraiser for NPF this fall.

### Kids' Online Support Group

This summer, NPF launched an online support group for kids with pancreatitis and their loved ones. Each week, we continue to add names, and are up to about 17 participants. As far as we know, this is the only such online support group in the country.

The support group offers a place to share stories, ideas and experiences. Past mailings have included info. on what to do when you're in the hospital, diet, recipes, photos of the Arizona Diamondbacks wearing our Courage Bracelets and two stories of children with chronic pancreatitis.

Due to safety concerns around children's groups, we cannot have members post and communicate directly with each other. For more information, or to join the group, please send an email to: [info@pancreasfoundation.org](mailto:info@pancreasfoundation.org) with the words Kids Support Group in the subject line. If you have anything you would like to share with the group, you can also email information to the same address.

### Ask the Doctor...

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 daughter is 10 years old and was recently diagnosed with chronic pancreatitis of genetic bases (etiology). Nobody else in the family has pancreatitis but my brother died of pancreatic cancer at age 41.

My questions are:

- (1) What should I do?
- (2) What is her risk of pancreatic cancer?
- (3) Should we remove her pancreas?

#### Answer:

Based on the early onset of pancreatitis and the strong family history of pancreatic cancer I agree on the genetic predisposition for your daughter's condition. You must obtain a second opinion with a pancreas expert (Gastroenterology) who will get a history and check for other causes of pancreatitis, for example, anatomic variations, metabolic disorders and gene mutations. Depending on the presence or not of a

gene mutation she would be or not at higher risk to develop pancreatic cancer in the future. Chronic pancreatitis alone does increase the risk for pancreatic cancer when compared to the general population.

Regarding the removal of the pancreas (total pancreatectomy) the first question is what are we treating, is this for pain control or to prevent cancer? Either way, we have limited data on the patients that really would benefit from such procedure, remember, once the pancreas is out the patient will develop brittle diabetes (difficult to control blood sugar levels) and exocrine pancreatic dysfunction (malabsorption of fat, proteins and some vitamins). A few academic centers in the United States are doing auto-islet cell transplantation (removing the insulin producing cells and injecting them back into the patient to prevent diabetes) with encouraging early results. To answer your last question, I would not remove her pancreas at this time.

Please note: There are criteria highly suggestive for hereditary pancreatitis, genetic testing is the gold standard. The clinical presentation of the sporadic pancreatitis and hereditary pancreatitis are indistinguishable.

#### Question:

I was diagnosed with abdominal pain syndrome four years ago at age 50, since then the pain is just getting worse particularly after eating. I am now losing weight because I am afraid of eating. My doctor did two endoscopies from above and below and everything is looking good. I want my pancreas to be looked at (suggested by my friend). What should I do? I like my family doctor but I am not getting better.

#### Answer:

You should request to be seen by a gastroenterologist. There are multiple ways to look at the pancreas, the non invasive ones include abdominal CT scan, magnetic resonance imaging and abdominal ultrasound (not as good as the first two). If there are any findings, your doctor would decide what the next step should be. I would also suggest you get your blood checked for amylase, lipase (both pancreatic enzymes) and a liver function test when you are having an episode of pain.

#### Question:

I am a female aged 30 yrs. Due to unbearable abdominal pain, I was advised

to have a CT of the upper abdomen. The procedure revealed a dilated pancreatic duct with multiple punctuate calcific foci in the pancreatic head and body. CT findings show impressions of chronic pancreatitis.

My questions are:

- (1) How badly damaged is my pancreas?
- (2) Is this life threatening?
- (3) Can I conceive again as I am worried about the unbearable abdominal pain which can resurface during the time period of my pregnancy?

#### Answers:

- (1) You have established chronic pancreatitis and further testing is needed to evaluate the degree of pancreatic damage. You might need pancreatic enzyme supplementation and your blood sugar needs to be checked.
- (2) Chronic pancreatitis is not life threatening but it might have important implications in your quality of life. If you know why you developed pancreatitis and the cause may be treated, make sure you get it to prevent the disease from progressing.
- (3) Can you conceive again, yes. During pregnancy the pancreatitis may remain latent without symptoms or it may flare up. Depending on the severity of your symptoms and clinical course, your doctor will suggest for or against becoming pregnant.

#### Question:

I have chronic pancreatitis. I have two very young kids. I am concerned about leaving them before they are ready to face life as it is. How many years can I live with this disease?

#### Answer:

Your life expectancy depends on the etiology (reason why you got pancreatitis) and severity of the disease. Patients with mild chronic pancreatitis that are followed up regularly and well nourished have the same life expectancy as a healthy individual.

#### Question:

In March 2002, I was hospitalized for acute pancreatitis. I was only 19 years old, and the doctors said it was probably because of binge drinking a few days before the attack. I am not an alcoholic. I was cured. A few months later, in November 2002, I was hospitalized for acute pancreatitis again, but I had not drunk any alcohol since the first episode. The doctors called it "idiopathic." I stayed on a low-fat diet, and was careful

with everything I ate and drank. Now it is June 2005 (3 years later), and I am very healthy. I eat all foods, exercise daily, and live a normal life. Is it safe for me to drink alcohol again?

#### Answer:

Alcohol is known to trigger pancreatitis, your first episode was clearly related to alcohol ingestion and the second time not. I am assuming that a full work-up did not reveal the reason why you got pancreatitis the second time. Patients who develop pancreatitis have an underlying predisposition; minimal alcohol intake (even in moderation) can be sufficient to trigger a severe episode of pancreatitis. I tell my patients not to drink again, but I don't know if they always follow my suggestions.

### Sam's Club/Wal-Mart and AMF present Check for NPF in Virginia

On July 17, 2005, Wal-Mart/Sam's Club in Norfolk, Virginia presented a check for over \$1,800 to match AMF's Rose Hooper Benefit Bowling Tournament in March. Many thanks to Mack Jacobs of Sam's Club and Vincent Waterfield of AMF for their continued support of NPF. Dr. Tom Cholis, pediatric ICU doctor at Children's Hospital in Norfolk and son of NPF Board Member, Tom Cholis, was on hand to accept the check.

### \$1 Million Dollar Campaign Update: Anonymous Donor Makes gift of over \$140,000

We have received a major gift of more than \$140,000 from an anonymous contributor, to be used to expand our national presence. The funds will be used to expand our network of volunteers who host fundraising events, and reach out to more patients and their loved ones with education and support in the form of support groups, education nights and written materials.

We are so grateful to this individual who hoped the gift would spur on our campaign to raise one million dollars over the next two fiscal years. To make a gift to the \$1 Million Dollar Campaign for NPF, or to receive a portfolio of named gift opportunities, please write to [info@pancreasfoundation.org](mailto:info@pancreasfoundation.org).