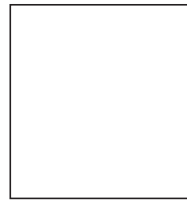




The
National Pancreas
Foundation

P.O. Box 15333
Boston, MA 02215



“Cooking Light” continued from page 7...

medium-high heat until browned, stirring to crumble. Drain well, and return meat to pan. Add sauce; bring to a boil. Reduce heat, and simmer 5 minutes. Combine cottage and Parmesan cheeses in a bowl; set aside.

Spread 1/2 cup meat mixture in bottom of a 13 x 9-inch baking dish coated with cooking spray. Arrange 4 noodles over meat mixture; top with half of cottage cheese mixture, 1 cup meat mixture, and 1/3 cup cheddar cheese. Repeat layers, ending with noodles. Spread remaining meat mixture over noodles. Cover and bake at 350° for 30 minutes. Uncover; sprinkle with 1/3 cup cheddar cheese, and bake 5 more minutes or until cheese melts. Let stand 10 minutes before serving. Garnish with parsley, if desired.

Yield: 9 servings

NUTRITION PER SERVING
CALORIES 275(20% from fat); FAT 6.2g(sat 2.8g,mono 2.1g,poly 0.4g); PROTEIN 28.1g; CHOLESTEROL 43mg; CALCIUM 181mg; SODIUM 584mg; FIBER 1.9g; IRON 2.8mg; CARBOHYDRATE 26.1g

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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.



SPRING 2005

PERSPECTIVES

The Newsletter of the National Pancreas Foundation



The
National Pancreas
Foundation

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Faith and Hope: Surviving Cancer

Mark Rush, Kirkpatrick & Lockhart Nicholson Graham LLP

It's the first day of spring, 2005. I picked up the phone to call my dad, and as the phone was ringing, I reflected. 99 days ago, my dad was diagnosed with pancreatic cancer. 98 days ago I began an immersion, an erudition, into the literature surrounding this disease. I learned the mortality and morbidity rates. I learned of the Whipple procedure and its complications. I learned terms, such as vascular inclusion and occlusion, helical CT, periampullary cancer, duodenum, clear margins, etc. I learned that that next fishing trip might never happen.

“Hello” my dad answered. “Dad, it's Mark. I'm just checking in.” He said, “You just caught me, I'm on my way to the gym.” I replied, “I won't keep you. What are you working out?” He said, “Chest and shoulders. I think the doctor took those with everything else he took out of me during the surgery.” I laughed and the call ended.

My dad is 78 years old. On December 9, 2004 he was diagnosed with pancreatic cancer. Eight days later he underwent the Whipple procedure at Allegheny General Hospital, Pittsburgh. His surgeon, his life saver, was Dr. Donald Atkinson. His guardian angel, the tenacious woman who insisted on immediate testing, immediate test results, first-rate care, not only of the patient, but for his family who just received devastating news; the pedagogue who ensured that my studies were focused, current, and well supported, was Dr. Ewa Hozakowska, a Polish political exile granted asylum in this country. Her specialty, in my view, is in the area of saving lives with dignity and a resolute purpose – she is an internal medicine practitioner.

The surgery was long and grueling for the surgeon and the patient. It was virtually unbearable for the family in the waiting room. As the surgery commenced, a laparoscopy was done

Continued on next page



Clarence and Susan Rush

Concept and Implications of Chronic Pancreatitis as a Small Duct Disease

Phillip P. Toskes, MD, Board of Directors, Grant Review Council, NPF
University of Florida, College of Medicine

Epidemiological studies have consistently underestimated the true incidence and prevalence of chronic pancreatitis since such studies focus mainly on big duct chronic pancreatitis. No doubt big duct chronic pancreatitis usually from alcohol induced disease is the most common form of chronic pancreatitis, but in some centers up to 30% of the patients presenting with a clinical picture compatible with chronic pancreatitis may have small duct chronic pancreatitis. Clinicians have tended to manage all patients with chronic pancreatitis in a similar manner and that has not been successful. It is becoming increasingly apparent that chronic pancreatitis is not one disease but there are subsets of afflicted patients that may have to be approached differently in respect to diagnosis and management. The table (see page 3) points out a distinction between big duct and small duct chronic pancreatitis.

There are particular characteristics of small duct chronic pancreatitis that distinguish it from big duct chronic pancreatitis and this impacts upon diagnosis and management. In respect to diagnosis, almost any test of pancreatic function or structure will be abnormal in big duct pancreatitis. In contrast, in small duct chronic pancreatitis most tests are normal except for the hormone stimulation test such as the secretin or CCK test. ERCP in patients with big duct chronic pancreatitis is markedly abnormal and minimally abnormal to normal in patients with small duct chronic pancreatitis. EUS is often markedly abnormal in big duct chronic pancreatitis but the role of EUS in detecting small duct chronic pancreatitis is under study in a number of centers. A recent study from our medical center describes 74 patients who were referred to us because of suspected chronic pancreatitis but these patients had normal CT scans and equivocal changes on ERCP. The patients were evaluated by the secretin stimulation test as well as EUS. When compared against the secretin test, EUS had a sensitivity

Continued on page 3

Presidents' Letter

Dear Friends,

As always, the spring is an extremely busy time for the Foundation with the annual Board of Directors' meeting that was held April 28th in Boston, attendance at several medical conferences and the coordination of the ever-increasing number of fundraisers nationwide.

Our first workshop on pancreatitis was held the evening of April 27th, with 14 of the leading pancreas doctors in the field participating. Chaired by NPF Board Member, Dr. Steve Freedman, the intent of the workshop was to collaborate with doctors from different perspectives on the diagnosis, pain management and treatment of pancreatitis. A "white paper" outlining the results of the evening will be used to move forward and develop a strategy for setting medical standards for treatment of pancreatitis. We would like to thank Axcan Pharma for sponsoring this critical first workshop.

The following morning, the NPF Grant Review Council members reviewed and graded the grant applications, providing recommendations to the NPF Board Members at the meeting which followed. We are pleased to announce that a record \$205,000 in research dollars was approved by the Board, and that the GRC noted a marked improvement in the quality of the grant applications. The details of the approved grants are outlined in this issue. At the NPF annual Board meeting, the members also discussed the success of several fundraisers, including the annual Armani dinner in Boston, the annual NPF Golf Tournament in Pittsburgh and a first for NPF – five runners in the Boston Marathon. Through our website, www.pancreasfoundation.org, increasing numbers of folks are making inquiries on hosting golf outings, bowl-a-thons and other types of fundraisers. If you are interested, please obtain our turnkey fundraising kit at our website or contact us at (866)726-2737.

NPF has increased our corporate partnerships with major pharmaceutical and healthcare companies over the past few months, including Altus Pharmaceuticals, Axcan Pharma, Boston Scientific, Solvay Pharmaceuticals and Therion Biologics. We will be meeting with representatives from these companies and several more during the Digestive Disease Week conference in Chicago May 14-19.

All of this activity is to raise funds to discover new treatments and new answers for the painful, and often, fatal effects of pancreatic disease. NPF is really about the people and their families who are impacted by physical and emotional suffering, and our goal is to enrich and lengthen their lives. We continue to expand the website to provide as current and comprehensive information as is possible, and to increase the number of support groups. Our online support group has been extremely successful with over 300 members sharing ideas and concerns. Please enjoy the wonderful article written by one of our Pittsburgh committee members, Mark Rush, about his dad's successful recovery from a diagnosis of pancreatic cancer.

We are blessed with a remarkable group of dedicated board members, leading doctors and volunteers that are the impetus for NPF's continuing growth. Thank you!

Sincerely,
Patter Birsic & Jane Holt

"Faith and Hope" continued from page 1...

to confirm the results of the helical CT that the cancer has not spread. Once that was confirmed, the surgeons began a process of opening my dad's abdomen. A visual inspection, as well as a physical inspection, is done of the relevant lymph nodes and surrounding organs again, looking for evidence of cancer spread. At either point, if such evidence is found, corrective surgery of the bile duct would have been done, but nothing else. We learned from the OR that Dr. Atkinson was proceeding with the Whipple procedure. Now it was a matter of waiting. Approximately every hour to an hour and a half, the circulating nurse would call to the waiting room to give us an update on the surgery. That type of information is a godsend. The day drags on. The surgery lasted ten hours.

It is funny, in a way, one's perception of time during this period is really mixed. The minutes seem like hours and, in another sense, the apprehension or dread of bad news makes the minutes fly by. Ultimately, you find yourself sitting in a waiting room with other families and then the tired surgeon enters the room to recount the surgery and discuss what is next. The most vivid memory for me is my brother and I walking toward the recovery room feeling let down – we expected a more positive message. There was no prognosis, there was no prediction. There was simply -- this is what we did; these were the complications; this is where he is; we expect pathology back in three days. Sure, the surgeons told us that the margins were clear, but that positive sign was actually delivered as one fact no more dispositive than another as to what the future would hold. Dr. Hozakowska chose to be with us during this time to answer follow up questions and to explain the demur attitude of the surgeon – it came down to – this is pancreatic cancer and the Whipple procedure.

My mom, who is 77 years old, took all of this in stride. She is a woman of faith. Faith and God brought her peace. She was hopeful, and that hope was rewarded. My dad's pathology report came back identifying a tumor less than three millimeters in size, located near the ampulla, which made him symptomatic with jaundice very quickly. He was node negative and, as indicated, had clear surgical margins. The pathology of all the lymph nodes harvested was negative. Dr. Atkinson shared with us that he had rarely seen a more positive pathology report for a pancreatic cancer patient. The demur professional surgeon was almost gleeful.

Of course, my dad was not out of the woods. A week after the surgery he battled sepsis, which put him back again into Intensive Care. He had three drainage tubes that were installed during the surgery that continued to leak for a period of weeks. He had a feeding tube. His time spent in bed

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:

Melanie's Garden-Tomato Soup

2 teaspoons olive oil
3/4 cup chopped onion
1 tablespoon chopped fresh oregano or basil
1 teaspoon chopped fresh or 1/4 teaspoon dried thyme
2 garlic cloves, chopped
5 cups diced tomato (about 2 pounds)
1-1/2 cups water
2-1/2 tablespoons tomato paste
2 teaspoons sugar
1/4 teaspoon salt
1/4 teaspoon black pepper
Thinly sliced fresh basil (optional)

1. Heat olive oil in a large saucepan over medium heat. Add the onion, oregano, thyme, and garlic; cook 4 minutes, stirring frequently. Stir in tomato and next 5 ingredients (tomato through pepper). Bring to a boil. Reduce heat; simmer 15 minutes. Place half of soup in a blender or food processor; process until smooth, and pour into a bowl. Repeat procedure with the remaining soup. Serve warm or chilled. Sprinkle with fresh basil, if desired.

Yield: 5 servings (serving size: 1 cup).

NUTRITIONAL INFORMATION:

CALORIES 81 (29% from fat); FAT 2.6g (sat 0.4g, mono 1.4g, poly 0.5g); PROTEIN 2.3g; CARB 14.6g; FIBER 2.9g; CHOL 0mg; IRON 1.3mg; SODIUM 140mg; CALC 29mg

Pasta Primavera With Shrimp

3 cups uncooked cavatappi (spiral tube-shaped pasta) or other short tube-shaped pasta
2 cups sugar snap peas, trimmed
1 tablespoon olive oil
1 pound medium shrimp, peeled and deveined
1 tablespoon chopped fresh oregano
1/4 teaspoon salt
1/4 teaspoon black pepper
2 garlic cloves, minced
4 cups torn spinach
1 1/2 cups cherry tomatoes, halved
1 cup (4 ounces) crumbled feta cheese

1. Cook pasta in boiling water 6 minutes, omitting salt and fat. Add peas, and cook 2 minutes; drain. Heat oil in a medium nonstick skillet over medium-high heat. Add shrimp, oregano, salt, pepper, and garlic; sauté 3 minutes or until shrimp are done. Combine pasta mixture, shrimp mixture,

and remaining ingredients in a large bowl; toss well.

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

CALORIES 329 (23% from fat); FAT 8.5g (sat 3.5g, mono 2.8g, poly 1.2g); PROTEIN 25.6g; CARB 36.9g; FIBER 4.1g; CHOL 131mg; IRON 5.7mg; SODIUM 458mg; CALC 204mg

Southwestern Omelet

2 tablespoons chopped fresh cilantro
1/4 teaspoon salt
4 large egg whites
1 large egg
1/2 cup canned black beans, rinsed and drained
1/4 cup chopped green onions
1/4 cup (1 ounce) reduced-fat shredded cheddar cheese
1/4 cup bottled salsa
Cooking spray

Combine first 4 ingredients in a medium bowl, stirring with a whisk. Combine beans, onions, cheese, and salsa in a medium bowl. Heat a medium nonstick skillet coated with cooking spray over medium heat. Pour egg mixture into pan; let egg mixture set slightly. Tilt pan and carefully lift edges of omelet with a spatula; allow uncooked portion to flow underneath cooked portion. Cook 3 minutes; flip omelet. Spoon bean mixture onto half of omelet. Carefully loosen omelet with a spatula; fold in half. Cook 1 minute or until cheese melts. Slide omelet onto a plate; cut in half.

Yield: 2 servings

NUTRITION PER SERVING

CALORIES 181 (27% from fat); FAT 5.5g (sat 2.3g, mono 1g, poly 0.8g); PROTEIN 20.2g; CARB 13.8g; FIBER 6g; CHOL 116mg; IRON 2.1mg; SODIUM 822mg; CALC 184mg

Lazy Lasagna

Lasagna typically takes longer to put together than it does to cook. Precooked noodles and prepackaged convenience products, however, make this a zip to prepare.

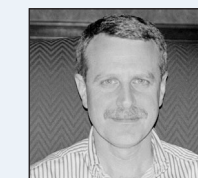
1 pound ground round
1 (26-ounce) jar low-fat spaghetti sauce
1 (16-ounce) carton fat-free cottage cheese
2 tablespoons grated Parmesan cheese
Cooking spray
1 (8-ounce) package precooked lasagna noodles
1 cup (4 ounces) preshredded reduced-fat mild cheddar cheese
Chopped fresh parsley (optional)

Preheat oven to 350°.

Cook meat in a large nonstick skillet over

Continued on next page

Board Member Profile



Dr. Steven Freedman

Being the chair of NPF's Grant Review Council is only one of the many commitments of time and energy that Dr. Freedman devotes to NPF, in spite of an incredible schedule. Dr. Freedman joined the NPF Board of Directors in 2000 and immediately advocated the organization's mission by giving public credit to NPF when presenting abstracts at the annual American Pancreatic Association and DDW meetings. Steve has also been instrumental in obtaining financial support from healthcare and pharmaceutical companies to sponsor NPF seminars and workshops.

Steve Freedman was born February 6, 1955 in Chelsea, Massachusetts. He received his BA from Boston University, his PhD from Yale University School of Medicine in the section of Cell Biology, and his MD from University of Connecticut School of Medicine. Dr. Freedman did his internship, residency and fellowship in gastroenterology at Beth Israel Deaconess Hospital and a postdoctoral fellow at Yale University School of Medicine. From 1993 to 1995, he was a part of the Clinical Investigator Training Program at Harvard Medical School. Dr. Freedman has been a Physician at BI Deaconess Medical Center in Boston since 1991 and the Director of the Pancreas Center since 1998. In 2002, Dr. Freedman was named Trustee at Harvard Medical School, Harvard Clinical Research Institute, and also became Chief of the Division of Translational Research at BI Deaconess Medical Center in Boston.

Dr. Freedman keeps himself busy seeing patients at the Pancreas Center and at the same time working on several different research projects related to pancreatic disease. His research focuses on understanding the pathogenesis of chronic pancreatitis. His recent data indicate that more than 60% of patients with idiopathic chronic or recurrent acute pancreatitis have mutations in the cystic fibrosis (CF) gene. He is also studying the cortical mechanisms of pain in pancreatitis with NIH funding following a pilot study that was funded by the NPF.

Dr. Freedman lives in Chestnut Hill with his wife, Ann, and is becoming an expert in playing the conga drums.

National Pancreas Foundation Announces 2005 Grant Recipients

The National Pancreas Foundation Grant Review Council, which is composed of nine world renowned pancreatic physicians and researchers, met on April 28th to review and grade the many grant applications that were received. Months earlier, each grant request was assigned a primary and secondary reviewer and was ranked based on the National Institute of Health evaluation guidelines. As a result of the GRC's recommendation, the NPF Board of Directors unanimously approved the funding for the following grants at the 2005 Annual Board of Directors' meeting:

* Dr. Michael Bouvet, San Diego VA Health Care System, University of California, San Diego

Title: Tumor-stroma interactions in pancreatic cancer: the contribution of type 1 collagen to growth progression and metastasis

* Dr. William R. Brugge, Massachusetts General Hospital

Title: Detection of Malignancy in Cystic and Intraductal Tumors of the Pancreas: A Long Term Study of the Natural History

* Dr. Joseph J. Cullen, University of Iowa

Title: Treatment of Pancreatic Cancer with 2-Deoxy-D-glucose (2DG)

* Dr. Marina Pasca Di Magliano, University of California, San Francisco

Title: The role of the Hedgehog signaling pathway in pancreatic cancer

* Dr. Christina Hrycyna, Purdue University

Title: Ras Carboxylmethyltransferase as a target for pancreatic cancer drug discovery

* Dr. Gail Matters, Penn State College of Medicine

Title: Impeding Pancreatic Cancer Growth and Metastasis by targeted down-regulation of Gastrin and Cholecystokinin

* Dr. Veronique D. Morinville, University of Pittsburgh Medical Center

Title: Hereditary Pancreatitis Amlodipine Trial (H-PAT)

* Dr. Anna-Liisa Nieminen, Case Western Reserve University

Title: Redox Regulation of Hypoxic Apoptosis in Pancreatic Cancer

* Dr. Norihiro Sato, Johns Hopkins University School of Medicine

Title: Functional Effects of RELN

Inactivation on Pancreatic Cancer Progression We congratulate the awardees who will be presented with their funds at an Awards Ceremony at the Digestive Disease Week (DDW) on Monday May 16th at noon. The DDW annual conference is being held in Chicago, IL from May 14th-19th.

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 partner has acute pancreatitis. He now has developed a large pseudocyst. Can you tell me if recreational drugs could be making things worse?

ANSWER:

Some drugs are definitely related to pancreatitis. In general, we strongly discourage the use of any "recreational drug" because of the unknown direct and / or indirect effects on the pancreas.

QUESTION:

My son has chronic pancreatitis. A recent CT scan shows atrophy of the pancreas. He has constant pain and also has had a cyst removed. What does the atrophy of his pancreas tell us about the progression of his disease?

ANSWER:

Pancreatic atrophy is not indicative of disease progression unless your son had a previous CT scan that revealed a normal size pancreas. Depending on his age, reason why he developed chronic pancreatitis, number and type of pancreatic surgeries, an "atrophic" pancreas in imaging study, may have different clinical implications.

QUESTION:

My wife had an ERCP mid-Oct 2004. Three days later she was on life support because of complications from infection. She spent 9 weeks in ICU and is now home. My question: She can't eat. Everything comes right back up and she has abdominal pain. We are down to 93 lbs body weight. Should this nausea and vomiting pass or continue till she withers away?

ANSWER:

Abdominal pain, weight loss, nausea and

vomiting are symptom of possible complications from the recent episode of acute pancreatitis. She needs to be re-assessed by her treating physician to evaluate why she has the above symptoms. An abdominal CT scan with intravenous contrast is a good starting test to look at the pancreas and rule out the development of local complications.

QUESTION:

One of my family members found out that she has pancreas cancer. Today they went in and put a feeding tube in her. But as for the cancer they said there was nothing that they could do for her. Why? Is there any hope or faith? She is only 34 years old. She has 3 small children. Is there anything that can be done for her? She doesn't smoke, drink or anything like that. Cancer doesn't run in her family or on that side. Please help me!!!!!!!

ANSWER:

It is important to determine the type of cancer and extent of the growth in order to decide treatment options. Even if she has the aggressive type (very uncommon in her age group), there are clinical research studies that she could participate. You must ask her treating physician regarding ongoing research studies or visit our website at www.pancreasfoundation.org for clinical trial information.

QUESTION:

I have a cousin who was shot in the stomach and the doctors say they will have to do surgery to see if they can save the pancreas. If this is done and the pancreas is not saved what would the consequences be?

ANSWER:

The pancreas makes multiple different types of hormones and enzymes. The two main functions are ENDOCRINE (hormones are made in the pancreas and released directly into the blood stream). The most important being insulin production (regulates the amount of sugar in your system). The EXOCRINE pancreas (enzymes are made in the pancreas and released into the small bowel) makes the necessary enzymes that make digestion of food possible. If the surgeon is unable to "save" the pancreas and most or all is surgically extracted, she will develop diabetes (high blood sugar) requiring insulin injections and food malabsorption, requiring pancreatic enzymes (capsules) for the rest of her life.

Diabetes can be difficult to control and some institutions offer pancreatic resection with injection of the cells that produce insulin, during the same surgery, in order to prevent the development of diabetes.

recovering from the invasive surgery and the devastating sepsis increased to about 30 days. As a result of that bedtime, the muscles on this thick, former Marine and retired police commander atrophied, and the mere act of walking winded him. This proud man could not shave or comb his hair, but he insisted that it be done every day. He never gave up. He fought through rehab and forced himself to walk laps around the hospital ward. Eventually, he was discharged from the hospital to a skilled nursing facility and then, ultimately, to his home, where he now resides with his bride of 53 years, my mom, the woman of faith and hope. He's driving again. He's laughing again. He's talking of tomorrows. He's back at the gym again. He complains of abdominal discomfort at times, tenderness; but he seems to be healing and working through that pain. He is planning a return trip to Aruba, and his hazel eyes sparkle with the thought of little league baseball with his grandson this summer.

For me and my brother, Tim, we still have our dad – amazing considering the disease. We make it a point to call him every day if, for no other reason, than just to hear his voice and feel his warrior spirit.

I count my blessing each day that I speak with my dad, but that is not enough. The devastating disease has left me with so many questions. My dad is a non-smoker. He worked out 4-5 times per week, both anaerobically and aerobically. He had well developed muscle mass for a man of his years, and had never had any significant medical condition before being diagnosed with pancreatic cancer. How did he get it? Why did he get it? Are there answers in his genealogy? Are there answers in his genetic code? Was it an environmental cause? Are there preventative measures that can be identified? Are my children at risk? Are there screening protocols that can be developed? How do we inspire and fund really smart people to think about these issues and the issues I'm not smart enough to identify?

Perhaps my mom's reliance on "Faith" and "Hope" is right, but I would add a twist. The "Faith" we have must be faith to all do our part. To give what we can in time and/or money. To challenge corporations, governments, churches, groups and individuals to do the same. We need to seek out the necessary funding to participate in genealogy studies, to give DNA samples to do all that is necessary for science to find a cure, a preventative treatment, a better screening protocol or a less invasive procedure to attack pancreatic cancer with the same venom and ruthlessness that pancreatic cancer attacks us.

The "Hope" we must have is that doctors and scientists will not shy away from this incurable disease, because there are

far too few happy endings. The "Hope" is that men and women of science will dedicate themselves to fully utilize their talents and their intellect to eradicate this disease.

My dad's story is a good one. One of very few. More families deserve good stories. We, collectively, can write those stories with happy endings – get involved.

"...Small Duct" continued from page 1...

of 57% and a specificity of 64%. More studies are needed to adequately define the role of EUS in diagnosis of patients with small duct chronic pancreatitis. The natural history of big duct chronic pancreatitis is to progress to steatorrhea. That progression is rare in small duct chronic pancreatitis. Patients with small duct chronic pancreatitis have as their clinical problem, persistent abdominal pain. In regard to therapy, pancreatic enzyme therapy with a proton pump inhibitor gives a good to excellent response in approximately 70% of patients with small duct chronic pancreatitis but such enzyme therapy is not very helpful in big duct chronic pancreatitis perhaps helping up to 20% of such patients. The preferred enzyme formulation for treatment of pain, particularly in those with small duct chronic pancreatitis, is a non-enteric coated enzyme preparations. The non-enteric coated enzyme preparation in contrast to enteric coated enzyme preparation release proteases into the duodenum, the site of feedback control of pancreatic secretion,

lower CCK blood levels, decrease pancreatic secretion and reduce pain. The recent finding that trypsin mediates nociception via the proteinase-activated receptor 2 provides another potential rational other than normalizing feedback control mechanisms as to why pancreatic enzymes may decrease pain, particularly in those with small duct chronic pancreatitis. Exogenously administered pancreatic enzymes will decrease luminal trypsin resulting in less activation of nociceptive neurons.

Surgical procedures such as ductal decompression have been the main stay of surgical management of big duct chronic pancreatitis but such procedures are not as successful in patients with small duct chronic pancreatitis. Another characteristic of small duct chronic pancreatitis is constant abdominal pain associated with elevated blood levels of CCK. Patients with big duct chronic pancreatitis will often have normal or decreased fasting levels of CCK and seem to have a defect in CCK homeostasis since eating does not appropriately release CCK into the blood of such patients. Recently it has been demonstrated from our laboratory that a large percentage of patients with small duct chronic pancreatitis may demonstrate delayed gastric emptying. Such delay in gastric emptying is important since treatment with pancreatic enzyme therapy depends upon appropriate emptying of the stomach of the enzymes into the proximal small bowel. A cornerstone of the importance of small duct chronic pancreatitis centers on

Continued on next page

Features of Big Duct and Small Duct Chronic Pancreatitis

FEATURE	LARGE DUCT	SMALL DUCT
Sex predominance	Male	Female
Diagnostic findings		
Secretin test	Abnormal	Abnormal
Serum trypsinogen	Often abnormal	Usually normal
Difuse pancreatic calcification on plain abdominal film	Frequent	Infrequent
ERCP	Often markedly abnormal	Minimally abnormal to normal
Natural history		
Progression to steatorrhea	Frequent	Rare
Therapy for pain		
Pancreatic enzyme	Fair to poor response	Good to excellent response
Surgical procedure	Sometimes helpful	Not usually indicated

“...Small Duct” continued from page 3...

the acceptance of a hormone stimulation test such as the secretin test as an accurate way to diagnose early impairment of pancreatic exocrine function. When compared against histology, studies have shown that the secretin test has a sensitivity of 96% and a specificity nearly of 90%. ERCP has been demonstrated to be 60% as accurate as the hormone stimulation test. The management of pain in all patients with chronic pancreatitis is unsatisfactory.

The ideal patient who is apt to response to pancreatic enzyme therapy is a patient with small duct disease with a normal CT and no evidence of fat malabsorption. It is also quite relevant to know the gastric emptying of a given patient with small duct chronic pancreatitis and abdominal pain in whom you are considering enzyme therapy. This striking increase in gastroparesis in patients with small duct chronic pancreatitis may be due to the elevated CCK levels that are affecting gastric emptying. Future neurohormonal therapy for abdominal pain in patients with small duct chronic pancreatitis will include improved enzyme formulations (designer enzymes) which have greatly enhanced protease content, long acting forms of octreotide, and CCK antagonists. Studies are now appearing to demonstrate that CCK antagonists may have a major role in managing the pain of small duct chronic pancreatitis. It behooves the clinician to accurately make a diagnosis of chronic pancreatitis and to characterize the kind of chronic pancreatitis that the given patient is manifesting. Identification of subsets of patients by the methods described here or by genetic abnormalities and other characteristics may be a very important initial step in the approach to patients with chronic pancreatitis.

An Evening at Armani

On a glittering night this past December, Boston friends of the National Pancreas Foundation gathered once again at Armani Café for an incredibly successful evening of dining, shopping, and raising awareness of pancreatic disease.

Friends of NPF were treated to an evening of shopping for elegant clothes and accessories with 15% of the proceeds going towards the Foundation. A silent auction featured items including a week in Ireland, Patriots tickets, and a Jason Varitek signed baseball, as well as golf outings, restaurant gift certificates and jewelry.

Many thanks to event chairs Jane and Tom Holt, and Suzanne and Jeff Bloomberg and their committee who put together a group that loves to laugh, eat and

support a good cause! The evening, along with our Recognition and Remembrance tribute book, filled with memories and good wishes, raised almost \$110,000 for the Foundation that will fund so much of our important research this year.

Rose Hooper Benefit Bowling Tournament in Virginia

Rose Hooper is “a survivor in the truest sense of the word,” according to her son, Vincent Waterfield. Her remarkable story started on Tuesday, June 22, 2004 when she came home from bowling in her league, feeling sick. By that Friday, she was in the ICU with multiple organ failure as the pancreatic enzymes were literally eating away at her organs. This was Rose’s first experience with pancreatitis.



Soon after, Vincent began to plan a bowling tournament to raise money for NPF, in honor of his mother. On March 13, 2005 over 65 guests gathered for the event at AMF Lanes in Norfolk, Virginia. Sponsors, including Sam’s Club, Bank of America and Pizza Hut, generously provided give-aways and items for a silent auction. The event raised almost \$2,000 for NPF’s research and patient services, including hundreds of dollars personally raised by Vincent’s family and friends including Mike Tidwell. Most importantly, Rose was able to leave the hospital just before the event to join her family and friends at the tournament.

We are so grateful to volunteers like Vincent who take the initiative to increase awareness of the Foundation in their communities, as well as raise funds for much-needed research.

Running for NPF:

The Boston Marathon

April 18th marked the first date that runners from NPF participated in the Boston Marathon. This year, we received five charity applications that enabled us to obtain Boston Marathon numbers for our runners. Those runners have now raised

over \$15,000 for NPF!

We would like to thank Boston College student Nell Curran, Marten DeVlieger, our young Canadian runner who has cystic fibrosis (often associated with pancreatitis), Colleen Dougherty and Joseph Euteneuer of XM Satellite Radio, and Jason Golub of Kirkpatrick & Lockhart Nicholson Graham LLP, Boston.

All of our runners had personal reasons for running, as well as their own approaches to fundraising. Nell Curran, who lost an aunt to pancreatic cancer, hosted her own fundraiser at her home in Sudbury, Massachusetts, prior to the Boston Marathon. Marten DeVlieger approached businesses in his hometown of Taber, Alberta for sponsorship. Jason Golub entertained his colleagues with his periodic fictional accounts (by email) of his co-workers’ placing wagers on his ability to finish the race.

We are so proud of all our Boston Marathon runners for finishing the race and reaching out to the community for support!



Courage Bracelets

In April of this year, NPF rolled out the first of its Courage bracelets, developed to let patients, doctors, and researchers know that they are not alone—they are supported by an organization that is committed to finding a cure for and better treatment of pancreatic disease.

The purple bracelets which say “Courage” feature a flower designed to look like acinar cells in the pancreas. The word courage was chosen to give courage to researchers to move forward in a field that is so understudied; to give courage to doctors to treat patients with a very difficult disease; and most importantly to give courage to patients and their families to continue to move forward.

We plan to distribute our bracelets in medical facilities, as well as retail outlets across the country. Bracelets will be available for a cost of \$2 each at our retail outlets; watch our website for details. You can also order a minimum of 10 bracelets through our office at info@pancreasfoundation.org or by calling 1-866-726-2737.



NPF Supporters enjoy a night of beautiful cars

The National Pancreas Foundation Awareness Night at Bobby Rahal Motor Co.

What do the world of luxury automobiles and cutting-edge disease research have in common? Pittsburgh!!

On the evening of February 25th, Pittsburgh area friends of the National Pancreas Foundation gathered at Bobby Rahal Motorcar Co. to hear more about the Foundation’s work, savor luxury automobiles such as Aston-Martins and Jaguars, and raise over \$4,000 to further the work of NPF.

The surroundings were festive with beautiful cars, flowers, balloons and background music by the Bill Tobin Trio, but the purpose of the evening was to increase public awareness of pancreas research. Dr. Adam Slivka of the University of Pittsburgh Medical Center spoke to the crowd of more than 150, providing an update on the current state of pancreatic disease research. Dr. Slivka spoke about recent developments in research and patient care. He explained that improved diagnostic tools, including better use of ERCP, is leading to breakthroughs in the treatment of those with pancreatitis.

Dr. David Whitcomb, Division Head of UPMC’s Division of Gastroenterology, Hepatology and Nutrition, and an NPF Board Member, spoke about how increased awareness of pancreatic disease is leading to tremendous interest in research of these diseases. He praised NPF for being at the forefront of advocating cutting edge digestive disease research and promoting young researchers to pursue the field of pancreatic disease.

The Foundation would like to thank Paul Mitchell, a loyal NPF Golf Committee member and Patti Linane of Bobby Rahal Motorcar Co. for designing an entertaining event that also brought the need for continued research into the light. Patter Birsic, NPF’s Co-President was delighted when Patti and Paul approached her last fall with the concept. “We had been brainstorming about a winter event that would attract a different audience than the annual golf tournament, and this certainly did,” exclaimed Birsic. “I was thrilled with the outcome because we saw many new faces. I just wish I had won the raffle for the Dream Weekend donated by Bobby Rahal which included a Jag for the weekend!”

Welcome to our new corporate supporters!

In recent months, NPF has been the recipient of a number of new corporate gifts. Several other corporations have renewed their support of NPF with generous gifts. We are very grateful to have a growing family of support helping us to reach our new goals in the year ahead. Here are some highlights:

Altus has made a generous gift to become a Platinum Sponsor to help us grow our Grant Program this year. Altus, a manufacturer of pancreatic enzymes, including the experimental TheraCLEC is hoping to make our patient and physician base aware of their clinical trials and their outcomes.

Axcan Pharma, one of our past supporters, is this year sponsoring our Workshop to Foster Collaborative Research in Pancreatitis with a gift as a Gold Sponsor. Axcan, another manufacturer of pancreatic enzymes including Viokase, has been a great supporter since our inception, printing all of our educational materials.

Boston Scientific Endoscopy is this year providing general support to NPF with a gift as a Platinum Sponsor. A past supporter of our dinner in Boston, BSE is now reaching out to support our general program.

Solvay, manufacturer of Creon, another pancreatic enzyme, is this year providing general support as a Gold Sponsor to our organization and collaborating with us to begin sponsorship of conferences for young pancreatic disease researchers.

Therion, manufacturer of an experimental vaccine for pancreatic cancer (PAN-VAC) recently provided assistance in funding the manufacture of our “Courage” bracelets (see accompanying story). We hope to make more patients and physicians aware of their clinical trials through a link on our website.

XM Satellite, one of the largest satellite radio providers in the U.S. provided support for our annual Armani dinner in December 2004, and sponsored two runners in the Boston Marathon who ran for NPF.

For more information on corporate support and how to become part of our \$1 million Campaign for 2005-2006, please contact khornstein@pancreasfoundation.org.