

## NEWS FROM THE DIRECTOR

Over the past year, we have had tremendous growth in our research efforts, including our programs for the early detection of pancreatic cancer. However, the continuing expansion of the NFPTR to over 2,500 families is a humbling reminder of how much work we still need to do to fight pancreatic cancer. This work is not possible without your continued involvement in the NFPTR.

Our early detection study Cancer of the Pancreas Screening Study 3 (CAPS3) is well underway and we have just received funding to continue this work in CAPS4. We hope these studies will demonstrate the utility of early detection screening for pancreatic cancer and ultimately save many lives! For more on these studies, as well as the personal story of a participant in this study, see page 2.

In addition to our screening study, we have also developed a clinical risk prediction tool for pancreatic cancer and have made this tool available to all health-care providers free of charge. While similar tools are commonly used for other hereditary cancer syndromes (breast and colon cancer), this is the first such tool for pancreatic cancer. We hope that this tool will help clinicians and patients (who obtain the results of this tool from their clinician) to understand the patient's personal risk of pancreatic cancer.

This past year we have also witnessed the opening of the Multi-Disciplinary Pancreatic Cancer Clinic here at Hopkins. This clinic offers "one-stop shopping" to newly diagnosed patients, allowing them to be evaluated by surgery, medical oncology, and radiation oncology as well as other specialties, in a single visit to Johns Hopkins Hospital. For more about this clinic, see page 3.

Our work to identify the genetic basis of pancreatic cancer continues. With all of the advances over the past 5 years in our understanding of the human genome, we are able to do studies that we never dreamed were possible a few years ago. We can now study over a half-million genetic markers in each individual whereas just a few years ago, studies of 400 markers were considered large! While generating and examining all this information is a time-consuming and costly process, we hope that this new technology will enable us to identify the genetic basis of pancreatic cancer in the coming years.

Again, I want to thank you and your family for your continuing involvement in the NFPTR. Please remember to return your update card. All of here us here at the NFPTR wish you a wonderful holiday season.

-Dr. Alison Klein

## FROM THE COORDINATOR

As coordinator of the NFPTR, it is my continued honor to work with each and every one of the courageous, generous families who have participated in the NFPTR. The NFPTR continues to grow rapidly and has now reached another significant milestone of over 2,500 families! Our families are instrumental to the success of our research and we are deeply appreciative of your participation. As always, if you have any questions for me, or would just like to say hello, feel free to contact me at 410-955-3502, or by email at [epalmis1@jhmi.edu](mailto:epalmis1@jhmi.edu).

-Emily Palmisano



**NFPTR TEAM (left to right): Emily Palmisano (NFPTR Coordinator), Dr. Alison Klein (NFPTR Director), Marian Raben (Research Coordinator)**

**PLEASE REMEMBER TO RETURN YOUR UPDATE CARD ENCLOSED WITH THIS NEWSLETTER.** Even if there have been no changes in your family, this information is very important to our research. Thank you!

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## EXCITING STRIDES BEING MADE IN PANCREAS SCREENING PROGRAM

The Cancer of the Pancreas Screening (CAPS 3) screening study lead by Dr. Marcia Canto at Johns Hopkins is successfully underway. The goal of CAPS3 is to demonstrate that screening for early asymptomatic pancreas tumors is possible! The CAPS 3 study is evaluating three screening techniques: endoscopic ultrasound (EUS), state-of-the-art CT scans, and MRI in order to show which test(s) is best at detecting pre-cancerous changes in the pancreas. While Johns Hopkins is leading the study, three other centers are also participating: UCLA, MD Anderson Cancer Center, and Mayo Clinic.

This study has grabbed national attention. In August 2007, *The New York Times* wrote a story about NFPTR member Nancy Platt which highlighted Nancy's family history of pancreas cancer in her mother and daughter. As a result of Nancy's strong family history, she

underwent pancreas screening, and abnormalities were detected for which she underwent a total pancreatectomy at Johns Hopkins with Dr. Richard Schulick. (For more on Dr. Schulick, see page 3). To read more about Nancy's story, please see the bottom of this page.

In other exciting news, Dr. Michael Goggins and Dr. Canto have received a grant from the V Foundation to expand our screening program. This new study is called CAPS 4. At time of publication, the CAPS 4 study had not yet begun enrolling patients. However, we hope to begin accrual as soon as possible.

To learn more about these studies, you can contact the NFPTR coordinator, Emily Palmisano at 410-955-3502, or by email at [epalmis1@jhmi.edu](mailto:epalmis1@jhmi.edu), or the CAPS 3 study coordinator Hilary Cosby, R.N. at 410-502-2893 or by e-mail at [hcosby1@jhmi.edu](mailto:hcosby1@jhmi.edu) or Dr. Canto at 410-614-5388, or by email at [mcanto1@jhmi.edu](mailto:mcanto1@jhmi.edu).



The CAPS 4 research group (from left to right):  
 Richard Schulick, M.D.  
 Ihab Kamel, M.D.  
 Marcia Canto, M.D., MHS  
 Michael Goggins, M.D.  
 Elliot Fishman, M.D.  
 Jennifer Axilbund, MS  
 Steve Goodman, M.D., Ph.D.  
 Alison Klein, Ph.D., MHS  
 Ralph Hruban, M.D.  
 Emily Palmisano, BA

## AN INTERVIEW WITH NFPTR MEMBER NANCY PLATT

**Nancy, what was the greatest impact that the total pancreatectomy had on your health and lifestyle?**

**Nancy:** The major impact on my life following the surgery is the diabetes. I am making progress in controlling my sugar levels, but that has been more of a challenge than I expected. However, I feel certain this will straighten out and my endocrinologist is pleased with my progress. Otherwise, once I started feeling better from the surgery itself, I began to see a positive progression weekly. I ride my bike 10 miles now, just about every day, and have no problems with eating as long as I take the enzyme pills regularly. Some foods don't taste quite the same, but most do taste the same as before.

**How did you feel about your experience at Johns Hopkins?**

**Nancy:** I was extremely pleased with the care I had with Dr. Schulick and his team of residents. They were all very interested in how I was doing each day and called for tests immediately if they saw a need for them. Dr.

Schulick was very patient and answered all my questions fully, explaining just what to expect from the surgery and afterwards. He came to see me daily while I was in the hospital. I think he is the best! I was also pleased with Dr. Canto's care and professionalism. If it hadn't been for her research and presentations at conferences, I don't know if my gastroenterologist would have been as aware and quick to get me to come to Johns Hopkins when he saw changes in my pancreas. Dr. Canto was and still is very ready to answer any questions I have and that is a wonderful situation. I would highly recommend them to anyone who is in my situation or has concerns about the possibility of this horrible disease.

**What are you most looking forward to in the coming year?**

**Nancy:** In addition to the trip we have planned this fall to Europe, I am most looking forward to many healthy years ahead to be able to spend with my husband and our children and grandchildren.



Joseph Herman, MD, M.Sc and JoAnn Coleman RN, MS, ACNP

## MULTI-DISCIPLINARY CLINIC BEGINS AT JHH

November 22, 2007 marked the first anniversary of the multidisciplinary pancreas cancer clinic (PMDC) for the evaluation of patients suspected of having a pancreas problem. The clinic was developed by Dr. Joseph Herman, a radiation oncologist at Johns Hopkins, and is coordinated by JoAnn Coleman, RN, MS, ACNP. In one day, a patient is offered a comprehensive evaluation encompassing all the resources available at Johns Hopkins for the education, diagnosis, treatment and research of pancreatic cancer. Patients undergo a clinical evaluation in the morning which includes a CT scan and blood tests, and then have the opportunity to speak with a dietician, social worker, pain specialist and clinical researchers. A panel made up of medical/radiation oncologists, surgical oncologists, pathologists, diagnostic radiologists, gastroenterologists and geneticists meet to discuss each case. Once a treatment plan has been determined, the patient is seen individually by members of this group and recommendations are given.

Most patients find the one day multidisciplinary clinic to be comprehensive, educational and beneficial. We hope this clinic enables the rapid diagnosis and treatment of new pancreatic cancers, allowing us to achieve our goal for the highest quality long-term care for our patients. For more information about this clinic, or to refer a patient, please see their website:

<http://pathology.jhu.edu/pancreas/MDC/index.html>

## SPOTLIGHT ON: Richard Schulick, M.D.

Dr. Schulick, Associate Professor of Surgery, Oncology, and Obstetrics and Gynecology, chief of the Cameron Surgical Oncology Division and surgical director for the Pancreas Cancer Program is one of our most experienced pancreas and liver surgeons and is aggressively studying this disease and exploring new ways of treating it.

In addition to his busy surgical practice, he runs a laboratory focused on

immunotherapeutic techniques and their translation into patients. His group has three main focuses:

**Eradicating liver metastases with genetically engineered *Listeria monocytogenes*.** Dr. Schulick's group has helped to develop a genetically attenuated bacteria (bacteria without the harmful genes) *Listeria monocytogenes* strain that when given to mice will eradicate colorectal cancer metastases within the liver. This work led to an experimental clinical trial at Johns Hopkins (with Dr. Laheru) in which patients with inoperable liver metastases who have finished standard chemotherapy are treated with this bacteria.

**Treating liver metastases with cytokine (GM-CSF) secreting vaccines.** Building on the seminal work of other members of the Pancreas Cancer Team (Drs. Laheru and Jaffee), his group has performed mouse experiments where the efficacy of GM-CSF secreting cancer cell vaccines has been increased by other immunologic manipulations.

**Identification of molecules on cancer cells that allow them to more effectively form liver metastases.** Dr. Schulick and his team have identified in a mouse model where cells that have increased expression of a certain cell surface molecule (Integrin-alpha2) have increased propensity to form liver metastases. Blocking these molecules reduce the formation of liver metastases. He is now working on how to apply this novel finding to the treatment of cancer patients.

Contact: [rschulick@jhmi.edu](mailto:rschulick@jhmi.edu)



## CERTIFICATE OF CONFIDENTIALITY

We want to remind the participants that the NFPTR continues to be protected by a Certificate of Confidentiality (NCI-01-062) from the National Institutes of Health, Department of Health and Human Services.

This certificate further helps us protect the confidential information that you have provided by giving us legal protection from having to involuntarily release any

information about you. With this certificate, we cannot be forced by court order to disclose any information for criminal, administrative, legislative, or other proceedings.

If you have any questions regarding this certificate or would like a copy, please contact Emily Palmisano at 410-955-3502 or Dr. Klein at 410-955-3511.

## HOW YOU CAN HELP:

Please return your update card!

**Spouses** are eligible to donate a blood sample as a "control" (a person without pancreatic cancer to serve as a comparison).

**Family members** with *at least one first degree relative* with pancreas cancer (sibling, parent, or child) *as well as one other family member with pancreas cancer* are also eligible to donate a blood sample to aid our research.

For more information on contributing in the ways mentioned above, please contact us at [pancreas@jhmi.edu](mailto:pancreas@jhmi.edu).



Johns Hopkins pancreas cancer research group members Sandy Markowitz, Anna Howard, Marian Raben, Emily Palmisano, Kim Walter and Andrea Cox (not pictured) helped to raise awareness for pancreatic cancer by participating in the PanCAN's TeamHOPE Maryland two mile walk on October 7, 2007.

Follow our research progress throughout the year and keep up to date on exciting news by checking the "What's New" section of the Johns Hopkins Pancreatic Cancer Web: <http://pathology.jhu.edu/pancreas/>

### MEDICAL DONATION PROGRAM

Dr. Iacobuzio-Donahue's Gastrointestinal Cancer Rapid Medical Donation Program (GICRMDP) continues to gather crucial information about metastatic gastrointestinal cancer by participants who volunteer prior to their death to undergo a rapid, research autopsy. If this research study is something you or a family member would like to learn more about, feel free to contact Dr. Iacobuzio-Donahue at [ciacobu@jhmi.edu](mailto:ciacobu@jhmi.edu) or call Marian Raben, Clinical Coordinator at (410) 955-3512.

## SELECTED NFPTR BIBLIOGRAPHY-2007

Although we would like to be able to write about every study conducted by the NFPTR investigators, we simply do not have the space to do that. We have put together a short bibliography of recently published research conducted by investigators working with the NFPTR. If you have any questions about any of the studies discussed in this newsletter or listed here, please do not hesitate to contact the NFPTR at 410-955-3502 or [pancreas@jhmi.edu](mailto:pancreas@jhmi.edu) and we will do our best to answer your questions.

Couch FJ, Johnson MR, Rabe KG, Brune K, de Andrade M, Goggins M, Rothenmund H, Gallinger S, Klein A, Petersen GM, Hruban RH. [The prevalence of BRCA2 mutations in familial pancreatic cancer.](#) Cancer Epidemiol Biomarkers Prev. 2007 Feb;16(2):342-6.

Infante JR, Matsubayashi H, Sato N, Tonascia J, Klein AP, Riall TA, Yeo C, Iacobuzio-Donahue C, Goggins M. [Peritumoral fibroblast SPARC expression and patient outcome with resectable pancreatic adenocarcinoma.](#) J Clin Oncol. 2007 Jan 20;25(3):319-25.

Klein AP, de Andrade M, Hruban RH, Bondy M, Schwartz AG, Gallinger S, Lynch HT, Syngal S, Rabe KG, Goggins MG, Petersen GM. [Linkage analysis of chromosome 4 in families with familial pancreatic cancer.](#) Cancer Biol Ther. 2007 Mar;6(3):320-3. Epub 2007 Mar 15.

Lucito R, Suresh S, Walter K, Pandey A, Lakshmi B, Krasnitz A, Sebat J, Wigler M, Klein AP, Brune K, Palmisano E, Maitra A, Goggins M, Hruban RH. [Copy-Number Variants in Patients with a Strong Family History of Pancreatic Cancer.](#) Cancer Biology & Therapy 6:10, 1-8. 2007.

Salaria SN, Illei P, Sharma R, Walter KM, Klein AP, Eshleman JR, Maitra A, Schulick R, Winter J, Ouellette MM, Goggins M, Hruban R. [Palladin is overexpressed in the non-neoplastic stroma of infiltrating ductal adenocarcinomas of the pancreas, but is only rarely overexpressed in neoplastic cells.](#) Cancer Biol Ther. 2007 Mar;6(3):324-8.

Wang W, Chen S, Brune KA, Hruban RH, Parmigiani G, Klein AP. [PancPRO: risk assessment for individuals with a family history of pancreatic cancer.](#) J Clin Oncol. 2007 Apr 10;25(11):1417-22.

### CONTACT INFORMATION

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