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 NFPTTR 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 NFPTTR.

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 NFPTTR. Please remember to return your update card. All of here us here at the NFPTTR wish you a wonderful holiday season.

-Dr. Alison Klein

FROM THE COORDINATOR

As coordinator of the NFPTTR, it is my continued honor to work with each and every one of the courageous, generous families who have participated in the NFPTTR. The NFPTTR 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.

-Emily Palmisano

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!

Inside this issue:
CAPS 3 and CAPS 4 2
Interview with Nancy Platt 2
Spotlight on Dr. Schulick 3
Multi-Disciplinary Pancreas Cancer Clinic 3
How You Can Help Us! 4
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, or the CAPS 3 study coordinator Hilary Cosby, R.N. at 410-502-2893 or by email at hcosby1@jhmi.edu or Dr. Canto at 410-614-5388, or by email at mcanto1@jhmi.edu.

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 answers 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.
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

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.

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 and we will do our best to answer your questions.


CONTACT INFORMATION

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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.