

NFPTR NEWS

December 2005

Important Contact

Information for NFPTR

Personnel

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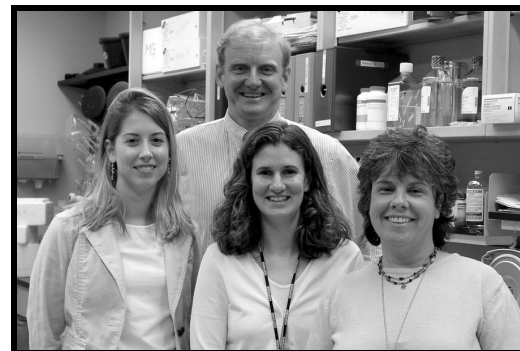
GREETINGS FROM THE NFPTR TEAM!

This year has been an outstanding year for the NFPTR marked by exciting new research and additions to the NFPTR team. The registry continues to grow and has now reached close to 1500 families. Our families are the key to the success of our research and we are touched by your eagerness to help us fight the war against pancreatic cancer. Thank you, as always, for your assistance.

There are several new additions to the NFPTR team and we would like to take a moment to introduce these people to you.

As noted in the December 2004 Newsletter, Dr. Alison Klein joined the faculty at Johns Hopkins in October of 2004. She has since taken over as Director of the registry. While Dr. Hruban continues to remain very active with the registry and remains an integral part of the NFPTR, Dr. Klein will oversee the day to day operations of the registry and handle any questions or concerns that you may have. You may recall from previous newsletters that Dr. Klein was the leading investigator on a number of important studies including an analysis demonstrating that there is evidence for a major gene influencing the development of pancreatic cancer and a study quantifying the risk of relatives of pancreatic cancer patients developing pancreatic cancer themselves. We know that Dr. Klein will provide outstanding leadership to the registry. If you have any questions regarding the registry, please do not hesitate to contact Dr. Klein either by phone at 410-955-3511 or by email at aklein1@jhmi.edu

As you may know, Miriam Tillery left the registry in May 2005 to accept another position within Johns Hopkins. Emily Palmisano was hired as the coordinator of the NFPTR. Ms. Palmisano is a recent graduate of St.



NFPTR TEAM (left to right): Emily Palmisano, Dr. Ralph Hruban, Dr. Alison Klein, and Marian Raben

Mary's College in Maryland where she obtained a Bachelors of Arts in Biology. Ms. Palmisano began working with the registry in July 2005 and has proven to be an excellent fit for the registry. We are quite excited to have Emily as part of the team and would encourage you to contact her if you have any questions or would just like a brief update on the pancreatic cancer research at Johns Hopkins. Her phone number is 410-955-3502 and her email address is epalmis1@jhmi.edu

In addition, Marian Raben, P.A. joined the NFPTR team in August of 2005. Ms. Raben trained as a Physician Assistant at St. Louis University and received her Masters of Health Sciences from Towson University. Ms. Raben will work closely with the surgical nurses and the oncology clinic at Johns Hopkins to educate patients on the research studies that are being conducted at Johns Hopkins in the field of pancreatic cancer.

We are certain that each new addition to the NFPTR Team will bring with them new ideas and enthusiasm to the pancreatic research team at Johns Hopkins.

Finally, please remember to complete the update card included in this mailing. Your continued participation in our research is sincerely appreciated.

NEW LEADERSHIP FOR THE PANCREAS SURGERY TEAM

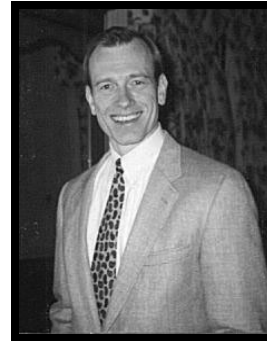
The NFPTR is excited to announce that Dr. Kurtis Campbell has been selected to be the new leader of the surgical efforts against pancreatic cancer at The Johns Hopkins Hospital. Dr. Campbell will take over for Dr. Yeo who left Hopkins to assume the position of Chairman of the Department of Surgery at Thomas Jefferson University in Philadelphia, Pennsylvania.

Dr. Campbell is an Associate Professor of Surgery and active attending surgeon at The Johns Hopkins Hospital. He obtained his undergraduate degree at Denison University in 1982 and graduated from The Johns Hopkins University School of Medicine in 1986. He completed his residency training in General Surgery at The Johns Hopkins Hospital in 1993 after which he spent an additional year of training in pancreatic and biliary tract surgery with Dr. Cameron. Thereafter, he was recruited to the Hopkins

surgical faculty and has been an important part of the surgical efforts against pancreatic cancer since that time.

Although we will greatly miss Dr. Yeo's contribution, we wish him well in his new position and know that Dr. Campbell will continue to provide outstanding expertise and leadership to the pancreatic cancer surgical team at Hopkins.

If you would like to schedule a clinic visit with Dr. Campbell, please call him at 410-955-5800 or email him at kcampbel@jhmi.edu



Dr. Kurtis Campbell

A TOOL TO FIND DNA MUTATIONS

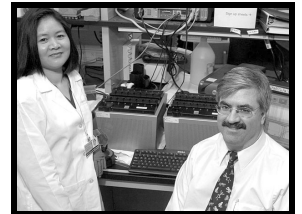
Drs. James Eshleman and Chanjuan Shi created a sensitive new molecular tool to help detect specific DNA changes or mutations in a single cell. This tool, called "LigAmp," is able to detect a mutation in a single cell that is surrounded by thousands of normal cells. Normally this task would be quite difficult, as it is similar to trying to find a single typographical error in a library of books, but LigAmp is able to filter out the background "noise" that is created by the normal cells and detect these hard to find mutations.

LigAmp works by creating a molecular probe for the DNA with the mutation. When the probe finds the mutation in the DNA, it binds to the DNA and inserts a bacterial gene. This bacterial gene produces a fluorescent color that is visible to special computer programs.

LigAmp has been tested on pancreatic juice samples

collected from patients with pancreatic cancer. It was able to detect mutations in the KRAS gene in these samples and these mutations are important in the early development of pancreatic cancer. Dr. Eshleman is now working to test this tool on more samples.

It is hoped that this sensitive tool will enable us to find early pancreatic cancers that are still small enough to be treated surgically.



Drs. Chanjuan Shi and James Eshleman

EXAMINING PRECURSOR LESIONS

In order to better understand the precursors to invasive pancreatic cancer, Kieran Brune and Dr. Hruban reviewed the available microscope slides from a series of patients with early changes in their pancreata. These individuals were identified as part of Dr. Canto's "Cancer of the Pancreas Screening Study" (CAPS), completed in 2004. In this study Dr. Canto screened 109 high-risk individuals for evidence of early changes in the pancreas that may develop into cancer. Ten individuals underwent surgery at Johns Hopkins for early pancreatic lesions.

Ms. Brune and Dr. Hruban found that the pancreas tissue of these ten individuals contained a large number of PanIN

lesions (**P**ancreatic **I**ntraepithelial **N**eoplasia) throughout the pancreas. PanINs are a type of pre-cancer change in the pancreas. In addition, four of the pancreata studied were found to have an intraductal papillary mucinous neoplasm (IPMN). Importantly, these precursors produced changes in the adjacent pancreas and the investigators believe that these changes are detectable by endoscopic ultrasound.

They concluded that some individuals with a family history of pancreatic cancer develop multiple precursor lesions of the pancreas. This discovery is important as it gives more clues about the familial pancreatic cancer gene.

*"Determine that the thing can and shall be done, and then we shall find the way."
Abraham Lincoln*

DR. DANIEL LAHERU

Dr. Daniel Laheru is an oncologist at Johns Hopkins whose primary focus is the treatment of pancreatic cancer patients. In this capacity, Dr. Laheru has been an important part of the clinical trials for the pancreatic cancer vaccine that was developed by Dr. Elizabeth Jaffee.

The vaccine was created from the pancreatic cancer cells of two patients who had surgery to remove their cancer. These cells were irradiated in the lab so they could not grow but still contained all of the proteins needed for immune system recognition. In addition, the cells were genetically altered to secrete a molecule called GM-CSF that would lure the immune cells to the vaccine injection site. Once injected into the patient, the patient's immune system mounts a response against the cancer cells in the vaccine and learns to identify that these cells are cancerous. This vaccine is not a preventative vaccine but instead is given to patients who have already been diagnosed with pancreatic cancer.

In order to evaluate the effectiveness of this vaccine,

the group completed a clinical trial of sixty patients who underwent surgical resection (removal) of their cancer. They received the vaccine shortly after their surgery to help destroy any cancer cells that may have been left behind. Although some patients are still receiving treatment, the results thus far look promising.

This vaccine opens up more treatment options for patients with pancreatic cancer. We are extremely thankful for the efforts of oncologists like Dr. Laheru. If you have questions about this vaccine, please email Dr. Laheru at laherda@jhmi.edu or call him at 410-955-8974.



Dr. Daniel Laheru

A RISK PREDICTION MODEL FOR PANCREATIC CANCER

Although we are still searching for the gene or genes responsible for the large majority of familial pancreatic cancers, it would still be very useful for clinicians to be able to identify individuals who are at a high risk of developing pancreatic cancer and therefore would benefit from screening.

For this reason, Dr. Klein, Dr. Giovanni Parmigianni, and Wenyi Wang, developed a mathematical risk prediction model for pancreatic cancer called PANCPRO. This model is patterned after the breast cancer model already developed by Dr. Parmigianni and was based upon previous segregation analysis studies by Dr. Klein. The PANCPRO model was validated by comparing the predicted number of pancreatic cancers in 900 families enrolled in the NFPTR, to the actual number of pancreatic

cancers that developed in the registry. The data for this study came from the updated information the NFPTR families provide to the registry each year on their response cards!

PANCPRO will be made available to the scientific community. We hope this model will be an important tool to help identify individuals who are at a high risk of developing pancreatic cancer.



Dr. Giovanni Parmigianni
and Wenyi Wang

ADDITIONAL STUDIES BY THE NFPTR TEAM

The team of researchers at Johns Hopkins who have dedicated their efforts to understanding more about pancreatic cancer includes scientists and clinicians from a variety of fields and expertise. Briefly, we have pathologists, epidemiologists, gastroenterologists, molecular biologists, surgeons, oncologists, geneticists, and cytogeneticists who assist the NFPTR. Having a wide variety of investigators from an extensive range of fields truly enables us to look at pancreatic cancer from all angles.

We have used this newsletter to briefly detail some of the many ongoing research studies being conducted by investigators working with the NFPTR. Although we

would like to be able to write about each and every study conducted by all of the NFPTR investigators, we simply do not have the space to do so.

We have therefore put together a brief bibliography of some of the other research studies conducted by investigators working with the NFPTR. We hope that this list helps you see the wide variety of studies that we are conducting. If you have any questions about any of the studies discussed in this newsletter or listed on page 4 of the newsletter, 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.

Thank you for your incredible help with our research!

AN END OF LIFE CHOICE

One way that patients with terminal pancreatic cancer can greatly assist pancreatic cancer research is by agreeing to undergo an autopsy for research purposes. The Gastrointestinal Cancer Rapid Medical Donation Program (GICRMDP) was initiated by Dr. Christine Iacobuzio-Donahue at The Johns Hopkins Medical Institutions in 2003 to supplement ongoing research of pancreatic cancer. Dr. Iacobuzio-Donahue is committed to studying pancreatic cancers that have spread (metastasized) to organs beyond the pancreas. Information gathered from the pancreatic cancer tissues collected at autopsy will form the basis for research directed towards the creation of new drugs to specifically target late stage pancreatic cancers and will help guide our studies of familial pancreatic cancer.

There is no monetary benefit to the patient or their family for consenting to an autopsy as part of the GICRMDP, and there are no direct health benefits to the patient by joining this research study. However, we believe that any patient willing to undergo a research autopsy at the time of death will be making the single most important contribution any individual could make to help researchers better understand and treat metastatic cancer. Participation in this study is purely voluntary and it may help other patients and their families in the future. If this research study is something you would like to learn more about, please contact Dr. Iacobuzio-Donahue at ciacobu@jhmi.edu or call 410- 955-3511 Monday through Friday from 8 a.m. to 5 p.m. (EST).

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**PLEASE REMEMBER TO
RETURN YOUR UPDATE
CARD. THANK YOU!**

CERTIFICATE OF CONFIDENTIALITY

We want to remind the participants in our registry 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 to our registry and affords us legal protection from having to involuntarily release any information about you or your family. With this certificate, our

investigators cannot be forced by court order to disclose any information which may identify our participants in any federal, state, or local civil, 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.