

# NFPTR NEWS

December 2004

## Important Contact Information for NFPTR

### Personnel

#### • Our Website

<http://pathology.jhu.edu/pancreas>

#### • Miriam Tillery

NFPTR Coordinator

\*Phone: 410-955-3502

\*Email: [aklein1@jhmi.edu](mailto:aklein1@jhmi.edu)

#### • Jennifer Sollenberger Axilbund

Genetic Counselor

\*Phone: 410-614-0378

\*Email: [solleje@jhmi.edu](mailto:solleje@jhmi.edu)

#### • Dr. Hruban

NFPTR Director

\*Email: [rhruban@jhmi.edu](mailto:rhruban@jhmi.edu)

## UPDATE FROM THE DIRECTOR

This has been an exciting year for the NFPTR. Over 1,370 families have enrolled in the NFPTR allowing us to ask complex scientific questions that can only be answered by studying large numbers of families. Simply put, without your participation our research would not be possible.

We are also happy to announce that Alison Klein, Ph.D. has joined the faculty in the Department of Oncology here at Johns Hopkins and that she will dedicate her career to the study of familial pancreatic cancer (see page 4).

As you will learn in the other articles in this issue, we have made a number of exciting discoveries this year and we have begun a number of important collaborations with other groups. One feature that I think characterizes our research is that it is novel and innovative. We believe that creative research is the best way to make significant strides in the war against pancreatic cancer.

One ongoing study in particular that I want to bring to your attention is Dr. Iacobuzio-Donahue's "Gastrointestinal Cancer Rapid Medical Donation Program" (GICRMDP) (page 3). This research program has provided our scientists with a unique opportunity to study familial pancreatic cancer. We encourage participants in the NFPTR to consider Dr. Iacobuzio-Donahue's unique research program.

Many of you already know Kieran Brune, former NFPTR Coordinator, has started Medical School in Dublin, Ireland. While we miss Kieran deeply we are happy that she is going to become a doctor (we think a darn good one), and we are pleased that Miriam Tillery is on board as the new Coordinator of the NFPTR. Although Miriam has big shoes to fill, we are confident she will do a great job.

(Continued on Page 4)

## Inside This Issue

Mike on His Bike	2
Genetic Counseling	2
Certificate of Confidentiality	2
End of Life Research	3
A Patient Survey On Genetic Counseling/Testing	3
Fanconi Genes	3
Welcoming New Faculty: Dr. Alison Klein	4
	4

## FROM THE COORDINATOR

As many of you know, Kieran Brune has stepped down as coordinator of the NFPTR so that she can attend medical school in Ireland. I took over for Kieran as the new Coordinator of the NFPTR in September of 2004. After receiving a bachelor's from San Francisco State University in 1999, I came to Johns Hopkins to join a Colon Cancer Genetic Testing study as the research coordinator. I have since been involved with several cancer-genetic research projects here at Johns Hopkins over the past four years. Joining the NFPTR as the new registry coordinator is an exciting opportunity for me to work with patients and their families in their battle against pancreatic cancer. I look forward to interacting with many more NFPTR family members so please feel free to call



Miriam Tillery, the new NFPTR coordinator

me at 410-955-3502 or email me at [pancreas@jhmi.edu](mailto:pancreas@jhmi.edu) with any questions you may have or just to say hello!

## MIKE ON HIS BIKE: RIDING FOR PANCREATIC CANCER

Mike Mullendore, a senior lab technician in Dr. Anirban Maitra's pancreatic cancer research laboratory, plans to ride his bike across the country September and October of 2005 to raise awareness and donations for pancreas cancer research at Johns Hopkins University. We sat down with Mike and asked him about his remarkable adventure.

**What attracted you to Dr. Maitra's lab at Johns Hopkins?** There were two things actually. First, the high profile research that was going on at Johns Hopkins. Dr. Maitra and collaborators had just published a paper in *Nature* regarding the Hedgehog signaling pathway in pancreatic cancer, which was a novel discovery. I was excited that I would be working on the cutting edge of cancer research. Second, I always look for certain qualities in mentors such as intelligence, leadership, their approachability, and their ability to enjoy themselves while working. Dr. Maitra had all these wonderful qualities, and as I have come to discover, many more.

**What is your most important project you are working on in the lab?** I am working on a signaling pathway called the Notch pathway which has been shown to be active in pancreas cancer. Dr. Maitra and I are studying the pathway activity on the molecular level so that we can develop new drugs to block it. We are trying to see if this pathway is a driving force in pancreatic cancer, and if blocking this pathway will cause cancer cell death. If we find it to be a valid target in cell culture, then we will take the study into mice.

**Why did you decide to ride your bike across country for pancreatic cancer?** I love working on cancer, especially pancreatic cancer because it is such a terrible disease. I know the cure is out there, we just have to look in the right place. Here at Hopkins great things are being done to better understand this disease, but in order to stay on the cutting edge and continue to move forward we need money to continue this important research. That is why I decided to ride my bike across county – to combine my love for riding with my desire to help people.



Dr. Anirban Maitra and Mike Mullendore

**What states do you plan to ride through?** I will be starting in Los Angeles, California and ending in Baltimore, Maryland at Johns Hopkins. In between I plan to ride through Nevada, Utah, Colorado, Kansas, Missouri, Illinois, Indiana, Ohio, Pennsylvania and Washington, DC.

**How can people help you achieve your goal?** Besides supporting my mission of raising awareness and donations, I would love to occasionally sleep in a bed, be able to take a hot shower or have a home-cooked meal. I also plan to restock my water supply daily and my food each week so that I am not hauling an enormous load. Simply waving at me as I ride by would help.

For more information about Mike on his Bike, please go to his web page at <http://pathology2.jhu.edu/pancreas/mikebike/>. If you are interested in helping Mike reach his goal, please contact Sandy Markowitz in Dr. Ralph Hruban's office at 410-955-2163 or email Sandy at [smarkow2@jhmi.edu](mailto:smarkow2@jhmi.edu).

## CERTIFICATE OF CONFIDENTIALITY

We want to remind the participants in our registry that the NFPTC continues to be protected by a Confidentiality Certificate (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

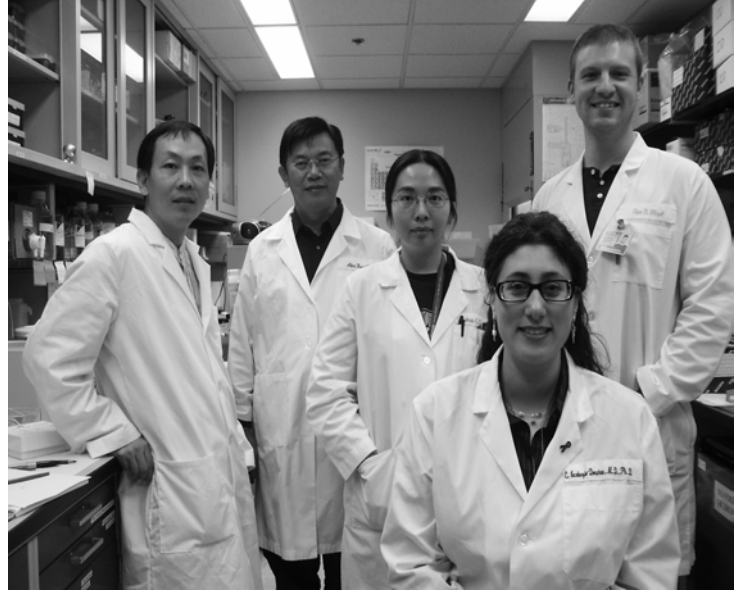
involuntarily release any information about you or your family. With this certificate, our investigators cannot be forced by court order to disclose any information which may identify our participants in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings.

If you have any questions regarding this certificate please contact Miriam Tillery at 410-955-3502.

## END OF LIFE RESEARCH

In 2003, the Gastrointestinal Cancer Rapid Medical Donation Program (GICRMDP), led by Dr. Christine Iacobuzio-Donahue, was initiated at The Johns Hopkins Medical Institutions to supplement ongoing research of pancreatic cancer. The aim of this research program is to learn more about late stage pancreatic cancer by studying terminal pancreatic cancer patients. To date, more than 20 patients have participated and have agreed to undergo an autopsy for research purposes. Dr. Iacobuzio 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 is being used for research directed towards the creation of new drugs to specifically target late stage pancreatic cancers, and the study of patients with familial pancreatic cancer will provide an invaluable resource for researchers hunting for the familial pancreatic cancer gene.

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 strongly 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



**Dr. Christine Iacobuzio-Donahue and Lab**

voluntary and it may help other patients and their families in the future.

If you would like to learn more about the program, please contact Dr. Iacobuzio at [ciacobu@jhmi.edu](mailto:ciacobu@jhmi.edu) or call 410-955-3511 Monday through Friday.

## PATIENT DESIRE FOR GENETIC COUNSELING AND TESTING

Jennifer Axilbund, M.S., C.G.C., reported in the previous newsletter about her study assessing patient perspective on the value of genetic counseling for familial pancreas cancer. Her completed data analysis confirmed preliminary results that participants were overwhelmingly in favor of genetic counseling. This is despite the limited information currently available. The survey also found that most participants found the session to be helpful and would be interested in another session when more is learned. Eighty-seven percent of respondents want to be genetically tested once a predisposing gene is discovered. Such desire is great motivation for the many scientists hunting this elusive gene! Jennifer was able to present her research at the 2003 American Society of Human Genetics conference in Los Angeles, and the 2004 meeting of the Lustgarten Foundation in San

Francisco. She hopes that her findings will encourage physicians to refer their patients with pancreas cancer and their at-risk relatives for genetic counseling. Next, Jennifer plans to assess the psychosocial effect of genetic counseling for pancreas cancer as part of a multi-center consortium. If you have questions regarding genetic counseling, please contact Jennifer Axilbund at 410-614-0378 or via email at [axilbund@jhmi.edu](mailto:axilbund@jhmi.edu).



**Jennifer Axilbund**

## FANCONI GENE ABNORMALITIES IN PC: AN UPDATE

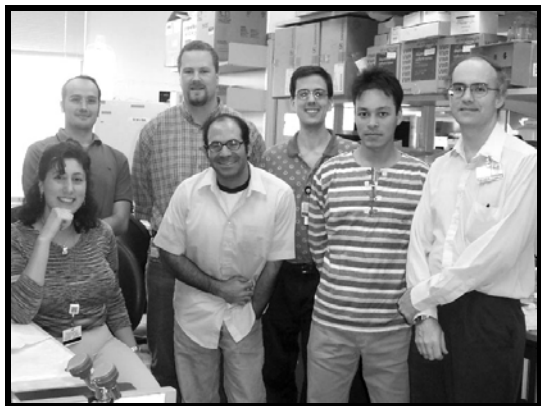
The Kern lab continues to work on a promising new idea for individualized therapy for some patients with certain forms of familial pancreatic cancer. In 1995, the lab reported the first mutation (genetic change) of the second breast cancer gene (BRCA2) in a pancreatic cancer. Additional studies at Johns

Hopkins confirmed that inherited BRCA2 mutations often play a role in the development of pancreatic cancer, including some pancreas cancer-prone families that had registered in the NFPT. This research has accelerated within the past two years as additional discoveries from  
(Continued on Page 4)

*( FANCONI GENES Continued from page 3)*

the Kern lab found changes in genes related to the BRCA2 gene in pancreatic cancers. These related genes in the past were best known for being involved in a childhood illness termed "Fanconi Anemia". Interestingly, cells from Fanconi Anemia patients are especially sensitive to certain drugs, including the well-known anticancer drug "mitomycin C" that is sometimes used to treat pancreatic cancers. The Hopkins team investigated the attractive possibility that certain pancreas cancers, those in persons harboring BRCA2 mutations in particular, might also be highly responsive to treatment with mitomycin C.

They recently published their studies, done initially on cell lines in tissue culture, that confirm that mitomycin C was highly toxic to Fanconi-type pancreatic cancer cells, including BRCA2-mutant pancreatic cancer cells. More recently, they have been actively exploring this mitomycin sensitivity to treat human cancers grown in mice. It is hoped that clinical trials of mitomycin C might be initiated soon to treat carriers of the BRCA2 mutation that develop pancreatic cancer. The NFPTR Newsletter will keep you posted as this approach is developed further.



The Kern Lab

## WELCOMING NEW FACULTY: DR. ALISON KLEIN

Dr. Alison Klein had joined the faculty of the Johns Hopkins School of Medicine and will focus on pancreatic cancer research. She has been actively involved in the NFPTR for over 7 years. This is a wonderful opportunity for her to become more involved in the NFPTR. While her research has been included in past editions of the NFPTR news, as faculty Dr. Klein will be able to devote more of her time to her pancreatic cancer research.



Dr. Alison Klein

Dr. Klein plans to examine if cancers other than pancreatic cancer occur at a rate significantly greater than expected in Familial Pancreatic Cancer families. Given that many of the known cancer-causing genes increase risk to several cancer types, this work may help us better identify families who may have a pancreatic cancer gene. These results may help us find the genes involved in pancreatic cancer.

Additionally, Dr. Klein is helping to develop statistical models to estimate an individual's risk of having a gene that increases the risk of pancreatic cancer in collaboration with Dr. Giovanni Parmigiani. Hopefully, these models will be an important aid for genetic counselors and help identify individuals who are in need of pancreatic cancer screening.

*(FROM THE DIRECTOR continued from page 1)*

Finally, please remember to complete the enclosed research update card. We sincerely appreciate your time and effort in filling this out. The information you provide is very important to our research.

**Ralph H. Hruban, M.D.**

Please Remember To  
Complete and Return Your  
Research Update Card.

Thank You for Your  
Assistance!