



The MSK Pancreatic Tumor Registry Study Participant Newsletter

Greetings from the Pancreatic Tumor Registry at Memorial Sloan Kettering!

We hope this newsletter finds you well and in good health. Our study is undergoing some big changes and we wanted to share these updates with you!

- Notes of thanks and upcoming study changes
- What have we been up to?
- Team introductions
- Other study announcements

IN THIS ISSUE...

A NOTE FROM DR. ROBERT KURTZ

Dear colleagues: Thank you for your continued dedication to our Familial Pancreatic Tumor registry. I am writing to tell you about several changes to our study. As you may know, this study was initiated in 2002 by Dr. Sara Olson and me to learn about what risk factors are at work in the development of pancreatic cancer and if and how we could detect pancreatic cancer in an early and more treatable stage. Over the last 20+ years we have learned a great deal, and look forward to contributing many more years to find early pancreatic cancer and significantly extend the lives of individuals who have developed this disease. Our focus has recently shifted to the study of biomarkers, found in blood, that may help us achieve this goal. More than 2,500 individuals have participated in our study during this 20 year period. For this I am extraordinarily grateful.



Several changes are being planned for our study. I am retiring from clinical medicine and will no longer be the study's Principle Investigator, although I will still act as a consultant to the study. I will be passing my role to Dr. Vineet Rolston, a Gastroenterologist and member of the GI, Nutrition and Hepatology Service at MSKCC, whose focus is on the diagnosis and early detection of pancreatic cancer. She was recruited with this role in mind and is a wonderful clinician and clinical scientist who will be an extraordinary member of our team. Sara, who has co-led this study with me since its inception, retired at the end of 2018. Her role in epidemiology has been passed to Dr. Mengmeng (Margaret) Du, who will also be the study's new Principal Investigator. Margaret is a Cancer Epidemiologist who has been working with us for the last 3 years and has been crucial in continuing to move this study forward.

It has been my distinct privilege to be a part of this exciting program, spending time and caring for you and collaborating with colleagues throughout MSK and in the scientific community that is dedicated to finding a way to detect early pancreatic cancer. I have come to the realization that it is time for me to move on.

I wish to thank the members of our team, and especially thank you all, the participants in our program. I am honored to have been able to work with you and greatly appreciate your continued participation in this important research.

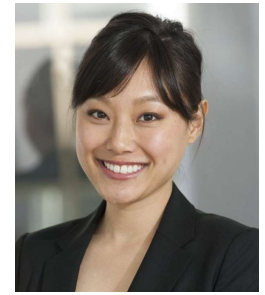
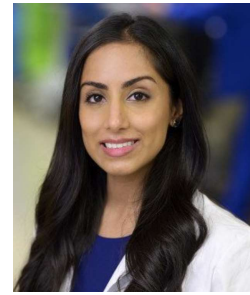
Thank you.

If you have any questions, please contact my office at 212-639-7620.

Sincerely Yours,
Robert C. Kurtz, MD
Principal Investigator
Gastroenterologist

A NOTE FROM DRs. VINEET ROLSTON & MARGARET DU

It is a great honor to become the new lead investigators of the Familial Pancreatic Tumor registry. The incredible work done thus far by Drs. Kurtz and Olson and the entire team has led to impactful and important contributions for at-risk individuals as well as the greater scientific community. Your active involvement and engagement in the study made these efforts possible. We look forward to meeting you all and thank you directly for granting us the opportunity to assist in your care as well as work towards our common goal of improving the prevention, early detection, and treatment of pancreatic cancer.



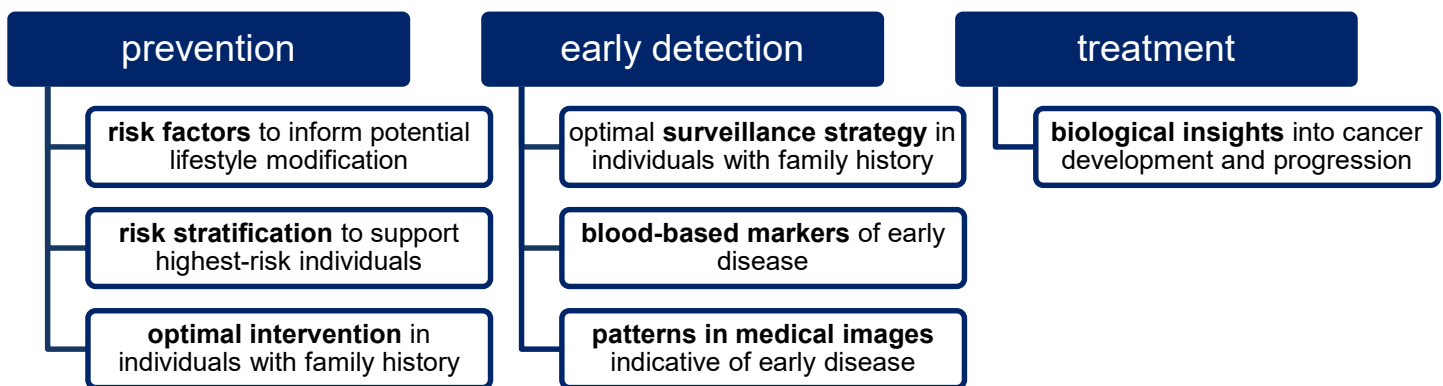
Warmest regards,

Vineet S. Rolston, MD
Co-Principal Investigator
Gastroenterologist

Margaret Du, ScD
Principal Investigator
Epidemiologist

WHAT HAVE WE BEEN UP TO?

We are pursuing a multi-pronged approach and working with international, cross-disciplinary teams towards our goal of reducing pancreatic cancer morbidity and mortality. Your contributions to our study enables us to answer core questions as well as expand to new areas of research. Below are some areas we have been tackling in the last few years:



Your participation has led to over 50 published studies across many research areas! We've highlighted a sampling of findings below to show the broad scope of the scientific questions we've been able to answer thanks to your contributions:

You can access the full text of these studies at no cost by clicking on the underlined PMC or PMID following each description (if viewing this in PDF form). Alternatively, you can visit <https://www.ncbi.nlm.nih.gov/> and enter the "PMC" or "PMID" number in the search bar to locate the article.

1. Genomic risk factors that predispose individuals to inflammatory intestinal diseases—particularly ulcerative colitis, Crohn disease, inflammatory bowel disease, and chronic pancreatitis—are associated with pancreatic cancer. [PMC7861352](#)
2. Results of surveillance for pancreatic abnormalities on imaging are similar regardless of *BRCA1/2* mutation status. [PMC6726560](#)
3. Compared with cancer-free controls, the oral microbiota of pancreatic cancer and IPMN patients possess similar bacterial diversity, but different proportions of various bacterial groups. [PMC5709151](#)
4. Weight loss, often severe, and new-onset diabetes frequently occur together before diagnosis of pancreatic cancer. Fatigue and depression are also potential precursors of diagnosis. [PMC4912937](#)
5. Pancreatic cancer patients who report a history of allergies experience more favorable survival after diagnosis. [PMID:20143395](#)

MEET THE NEW MEMBERS OF OUR TEAM!



We are thrilled **Marygrace Corral** (left) and **Kelli O'Connell** (right) have joined our team. Marygrace is our new **Clinical Research Coordinator**; she speaks with participants and physicians about the study and assists Drs. Kurtz and Rolston at clinic. She looks forward to meeting you! Kelli is our **Biostatistician**; she carefully handles the data you generously contribute. You may remember our previous Clinical Research

Coordinators, **Molly** and **Nicole**. They have moved on to new, exciting things! Molly is back at school to prepare for medical school, and Nicole received her degree in Public Health and is now working as a research coordinator in London. We are grateful for their contributions and wish them the very best in their future endeavors!

THE MOLECULAR EPIDEMIOLOGY LAB HANDLES YOUR SAMPLES WITH CARE!

These hardworking lab members process the saliva and blood samples that you provide to our research study

The Molecular Epidemiology Lab, led by Dr. Irene Orlow and located at the heart of MSK in Manhattan, is involved in research to help understand what molecules modify the risk for developing cancer and/or the risk for cancer progression. The Lab has been involved with our study since 2003 by processing samples from patients, relatives, and healthy controls. In the early years, they have tested these samples and have contributed to several scientific publications describing the effect of allergies, the microbiome, and genetics.



Who is Who in The Lab?

Keimya Sadeghi, Research Assistant, is excited to exercise her passions in genetics, epidemiology, and biotechnology while contributing to this study. She is the primary laboratory member processing biospecimens and sample-related data for the MSK Familial Pancreatic Cancer Registry, and together with her lab-mates takes care of specimens and samples-data collected from over 2500 study participants.

Emily Ali, Research Technician, processes samples obtained at various clinics, extracts DNA and prepares samples for testing. She looks forward utilizing genetic applications to help advance cancer research through the field of Epidemiology.

Jessica Kenney, Research Assistant, has ample experience working in research laboratories, and contributes to studies by testing genes and proteins in relation to cancer risk and progression, and by ensuring that the laboratory equipment is properly maintained.

Isidora Autuori, Research Assistant, participates primarily in melanoma studies and contributes to other ongoing research with ideas and by developing new assays. Isidora is eager to contribute to the fight against cancer within our Lab and the MSK community.

Irene Orlow, DSc, MS, BA/BS. Attending Biologist & Laboratory Member, joined MSK in 1991 and the Department of Epidemiology & Biostatistics in 2000. She oversees all the activities of the Lab and is passionate about obtaining accurate information that can help diagnose and/or treat patients, while avoiding side-effects.

OTHER STUDY ANNOUNCEMENTS



Our research study coordinators are contacting participants by phone and mail to complete the **2-year follow-up survey**. The purpose of this survey is to update your health and family history information. The survey will only take 10 to 15 minutes of your time.



For those of you who have questions about genetic counseling and testing, please note that our study staff are unable to schedule these types of appointments. Please contact the **MSK Clinical Genetics** office directly at 646-888-4050 for more information.



If you have questions about or need to reschedule your clinic appointment with **Dr. Vineet Rolston**, please call her office at 212-639-4822.



Want to learn more? If you would like more information about our research, the results of our study, or have any other questions, please contact our team at FPCRegistry@mskcc.org.

CONTACT US!

Vineet S. Rolston, MD

212-639-4822

Participants may call Dr. Rolston's office to schedule appointments.

If you are a former patient of Dr. Kurtz, you may also call this number regarding your appointments.

Marygrace Corral, Clinical Research Coordinator

646-888-8319

Contact Marygrace about eligibility, to update contact information and participant status, and for other questions about the study. You may also contact Amethyst Saldia, Clinical Research Supervisor, at 646-888-8310.

E-mail

FPCRegistry@mskcc.org

Website

www.mskcc.org/departments/epidemiology-biostatistics/epidemiology/pancreatic-family-registry

Visit our website to view the current eligibility requirements and to download past newsletters.

Postal Mail

Attention: Marygrace Corral, Epidemiology Service
Memorial Sloan Kettering Cancer Center
485 Lexington Avenue, 2nd Floor
New York, NY 10017

You received this newsletter because you or a loved one participate in the MSK Pancreatic Tumor Registry study.