



## NEWS FROM THE TISSUE DONATION PROGRAM

Volume 2, Issue 1

Fall 2008

### Dear Friend,

The past year has been a very busy and productive one for the Tissue Donation Program. We continue to enroll participants in our ongoing studies of brain, colon, lung, ovarian, and breast cancer, as well as our rheumatoid arthritis study. In addition, participation in the Feinstein Medical Research Registry continues to grow. Over 2,300 control participants have joined the Research Registry and we are striving to reach our goal of 10,000 participants.

We believe it is important to bring our science to the community, so that people outside of the hospital research family can better understand the purpose of our program and provide feedback on the fast-paced developments that are occurring in medical research and genetics. To this end, we are grateful for the opportunities we have had to participate in programs held at the Commack YMHA, the Friedberg JCC in Oceanside and the Forest Hills Library. These programs provided forums to discuss how scientists are applying new scientific and medical knowledge to understand human diversity and to explain how scientists identify genetic and environmental factors that contribute to maintaining health and treating disease.

On November 18 we proudly participated in the grand opening of the new addition to The Feinstein Institute. The four story addition houses 35,000 additional feet of research space and the Goldman International Conference Center, which will host international scientific meetings. The addition enhances the Feinstein's ability to carry on our mission, and make life changing advances in the fight against a wide range of diseases affecting millions of people.

The Feinstein Institute is "Where science meets the patient." We cannot do it without each and every one of our participants, and we thank you for your continued involvement. We hope you find this newsletter informative and we look forward to hearing from you with suggestions and feedback at 516-562-3491 or [researchregistry@nshs.edu](mailto:researchregistry@nshs.edu).

Sincerely,

Peter K. Gregersen, MD and Christine Metz, PhD

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### Did you know:

If the total DNA in one person was laid out in a straight line, it would stretch to the sun and back over 600 times!

## New Genetic Link Discovered for Rheumatoid Arthritis

Led by Dr. Peter Gregersen, scientists at The Feinstein Institute for Medical Research, in collaboration with colleagues across the country, have identified a critical gene that increases a person's risk for rheumatoid arthritis and systemic lupus erythematosus (SLE). Both rheumatoid arthritis and SLE are autoimmune diseases in which the body attacks its own cells, often causing significant complications. Together these two diseases affect over 2 million Americans.

The gene, named STAT4, is one of dozens, or possibly even more,

genes involved in triggering complex diseases like rheumatoid arthritis or SLE. Although STAT 4 has been found to only increase risk from approximately 1 in 100 to 1.6 in 100 over a lifetime, identifying such a 'risk gene' is important because it points scientists in many new directions that can ultimately help scientists unravel the triggers for the disease, help in the development of a test to confirm a diagnosis and perhaps even help predict who will respond to treatments.

With the help of participants in the Feinstein Medical Research

Registry, scientists are now working to better understand the role STAT4 plays in rheumatoid arthritis and SLE. By comparing unaffected control subjects enrolled in the Registry with patients who have rheumatoid arthritis or SLE, scientists hope to learn more about the molecular and cellular activities underlying the diseases, and ultimately improve treatments. For more information about this discovery go to <http://feinsteininstitute.typepad.com> (See Archives 9/2/07 to 9/8/07)

### Research is more fun with a friend!!

Zygmunt Kruk and Victor Kuras are in their 80s and healthy enough in all respects to continually volunteer for a number of studies conducted at The Feinstein Institute for Medical Research. In addition to patient populations, Victor and Zygmunt understand that it is equally important to have a large pool of healthy volunteers to help discover how diseases unfold. That is why they were among the first few hundred people to join the Feinstein Medical Research Registry.

The men met as volunteers at the Cradle of Aviation on Long Island and when they heard about the Feinstein Medical Research Registry Victor turned to his friend, who is unofficially called Ziggy, and asked whether he'd like to sign on for research. "What would it take?" Ziggy asked. "A bit of spit, maybe some blood... Pretty easy, right?"

Since signing up for the research registry both men have taken part in additional studies as healthy controls. One such study was

designed by researchers at the Litwin-Zucker Center for Alzheimer's Disease, part of the Feinstein. Scientists were looking for generally healthy older people to study the effects of normal aging on different brain functions such as memory, problem solving and language skills. Both Ziggy and Victor provided a blood sample, completed a battery of cognitive tests and had a brain MRI. Their results, compiled with those of many others, may help unravel the puzzle of Alzheimer's and possible risk factors that set the degenerative brain disease in motion.

Now, the men are back for another study of autoimmune diseases. There are many other studies, but in some cases – like an ovarian cancer study – these gentlemen won't qualify. Victor said he liked being a part of the brain scan study. "It was great. It made me feel important," he said. At 84, he added, "it gives me another reason for being a good person."

Indeed. At a recent get together,

Victor and Ziggy joked about their penchant for aviation, for shared meals and for science. "I am proud to be a part of this place," said Victor. Ziggy smiled and agreed, adding: "So what's next?"

If you are interested in supporting our research efforts and joining the Feinstein Medical Research Registry call us at 516-562-1175. If you are already part of the program, please consider asking a friend to join.



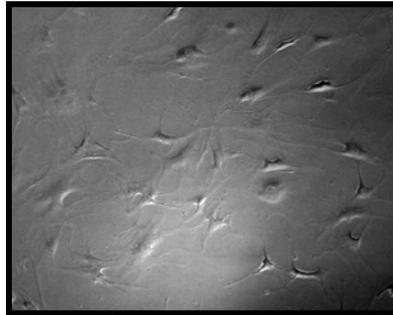
"I am proud to be a part of this place," said Victor Kuras (left), pictured here with Zygmunt Kruk.

## Patient Tissue Sheds New Light On Inflammatory Arthritis

The TDP continues to enroll patients with rheumatoid arthritis, osteoarthritis and psoriatic arthritis undergoing joint replacement surgery. Percio S. Gulko, MD, Director of the Laboratory of Experimental Rheumatology at the Feinstein Institute, and his team are studying the mechanisms that cause and regulate rheumatoid arthritis.

In people with inflammatory arthritis, such as rheumatoid and psoriatic arthritis, the synovial tissue, which lines the joints, is usually thickened and inflamed leading to pain, cartilage and bone destruction, and deformity in the affected joint. At the time of joint replacement surgery diseased synovial tissue is collected and delivered to the research lab. Examination of donated tissue allows the researchers to compare the pattern of gene

expression and destructive properties of the synovial tissues, comparing tissue from inflammatory arthritis patients with that from patients with the non-inflammatory disease osteoarthritis.



**Synovial cells** shed light on how abnormal synovial tissue grows in the joints of patients affected with rheumatoid arthritis

Researchers isolate and grow synovial cells from the tissue samples.

These cells help the researchers better understand the mechanism regulating the abnormal growth of synovial tissue in inflammatory arthritis.

Ultimately, Dr. Gulko aims to bring laboratory discoveries into clinical care to improve the lives of patients with inflammatory arthritis.

The synovial tissue collection protocol has been supported by Dr. Kraus, Dr. Asnis and other Orthopedists at the North Shore-LIJ Health System.



Staff from the TDP and the laboratory of Brain Tumor Biology participated in the Little Louie Foundation walk on June 28, 2008. The Foundation has provided support to Dr. Marc Symons' ongoing research on medulloblastoma, the most common malignant pediatric brain tumor, and glioblastoma, the most common primary brain tumor in adults.

Thanks in part to this funding, as well as funding from Project To Cure, the lab is now studying signals from the brain tumor environment that stimulate the growth and survival of malignant stem cells. There is accumulating evidence that brain tumors originate from these stem cells; therefore it is crucial to examine their malignant properties.

## Genetic Information Non-discrimination Act Passed

The Tissue Donation Program considers protecting the confidentiality of our participant's personal data our top priority, and this Spring important legislation that bolsters our efforts was signed into law. The Genetic Information Non-discrimination Act (GINA) passed after thirteen years of legislative review. This law makes it illegal for health insurers or employers to discriminate against individuals based on their genetic information.

Specifically, GINA prevents health insurers from denying coverage or adjusting premiums on the basis of genetic information, or requesting that an individual undergo a genetic test. Similarly, employers are prohibited from using genetic information to make hiring, firing or promotion decisions.

Prior to passage of this law there was a patchwork of individual

state laws that protected individual's genetic information to varying degrees. Although New York State laws were some of the strictest, GINA now establishes a unified standard for protection of genetic information for all Americans. This advanced protection permits people to take advantage of genetic services and become part of the promise of personalized medicine without fear of discrimination.

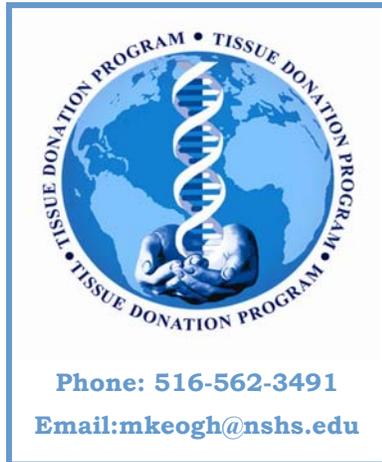
The TDP never shares confidential research information with anyone outside of our program, and within the program, processes exist to assure that no one on our staff is able to match subject identity with genetic research data. Your trust is essential to the success of our program and we welcome GINA's additional protection for all of our participants.

# The Feinstein Institute for Medical Research



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## Significant Research Milestone!!

### The Feinstein Medical Research Registry is proud to announce that we have reached another significant milestone- 2300 participants!!

The Feinstein Medical Research Registry continues to expand and provide critical support for ongoing research studies through recruitment of control or comparison subjects. This year we have enrolled an additional 800 people into the program, pushing our total enrollment over 2,300 participants.

People who have joined the program have completed a mouthwash collection to provide a DNA

sample, and expressed a willingness to help support medical research studies by serving as a control subject. For example, if a scientist is studying heart disease, he or she will often seek to study people without heart disease to better understand the condition. Having an available pool of people willing to be contacted about serving such a role is an invaluable resource that expedites a scientist's work, and could bring results sooner.

During the past year the Registry has been instrumental in enrolling subjects interested in participating as controls in research investigating ovarian cancer, autoimmune diseases (such as rheumatoid arthritis), and the effects of normal aging on brain functions such as memory and language skills. We want to extend a special thanks to

those who have taken the time to support this research.

The scientific value of the registry multiplies as participation increases. If you know someone who may be interested in receiving an enrollment kit, ask them to contact us at 516-562-1175 or [researchregistry@nshs.edu](mailto:researchregistry@nshs.edu).

[Inside - read the story of two Feinstein Medical Research Registry participants.](#)