The Feinstein Institute for Medical Research
North Shore-Long Island Jewish Health System
North Shore LIJ

NEWS FROM THE TISSUE DONATION PROGRAM

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Dear Friend,

We are pleased to share with you the inaugural newsletter of the Tissue Donation Program. The Tissue Donation Program (TDP) is a critical component of the research conducted at The Feinstein Institute for Medical Research, part of the North Shore-LIJ Health System. In addition to providing high-quality medical services to our community, the North Shore-LIJ Health System supports medical research to gain a better understanding of a wide range of diseases. The Tissue Donation Program plays an integral part in this effort. The mission of the TDP is to bridge the gap between scientists conducting basic medical research in the laboratory and the everyday clinical practice of medicine. Working with individuals, we collect biological samples – blood, urine, saliva and surgical tissue – from patients and volunteers from the community. This has become a valuable resource for scientists studying the molecular basis of disease. As new knowledge is gained, it is used to improve the care and outcomes for patients within our community and beyond.

This first newsletter is being mailed to more than 2000 people who have participated in our research studies. We have enrolled participants in studies of many types of cancer, including lung, colon, breast, brain and ovarian as well as studies of rheumatoid arthritis. Many others have supported medical research by joining the Feinstein Medical Research Registry as control subjects. Please know that your participation remains critical in our search for knowledge – and ultimately this can lead to improved diagnoses, new treatments and even cures for these diseases.

We hope you find this newsletter informative. We look forward to hearing from you with suggestions and feedback at (516)562-3491 or **researchregistry@nshs.edu**.

Sincerely,

Peter K. Gregersen, MD and Christine Metz, PhD

Inside this issue:

Did you know:

Nine of the top 10 leading causes of death, including diseases such as cancer, heart disease and Alzheimer's Disease have a genetic component that influences the risk of developing the disease.

Meet The Staff Of The Tissue Donation Program

Left to right:

Suliaman Sebro – Research Assistant

Peter K. Gregersen, MD – Medical Director

Mike Ryan – Research Technician

Christine Metz, PhD – Assistant Director

Mike Willock – Research Assistant

Mary Keogh, ANP – Project Coordinator

Cathleen Mason, RN – Research Nurse

Susan Abelson, MA – Research Coordinator

A Powerful New Tool – Genome Wide Association Studies

We have come of genetic age. As a result, you will hear about genetic findings as a steady diet – and you'll probably be amazed, surprised and confused at the same time. Not to worry. The idea of unraveling the genome is simply to figure out what genes are involved in specific diseases. Then, scientists can use this information to design drugs that target the genes and the proteins they make and hopefully prevent or reverse the disease process.

There are different ways to go about studying genes. Traditionally, scientists would collect DNA from families beset with an illness and compare any differences between the family members with the disease and those without. While this is a good technique for diseases like Huntington's disease and cystic fibrosis, where a single gene does damage, more common diseases in the population probably involve dozens or hundreds of different genes.

Figuring out this puzzle is far more complicated – and requires a different set of genetic tools. Enter the genome wide association study. This involves hundreds – and better yet – thousands of individuals with a particular disease who donate a blood or saliva sample to allow scientists to screen for genetic variances within this population and compare it to a control group of individuals who are alike in some ways – except they do not have the disease. Volunteers without the disease being studied, are called "matched controls."

Just 5 years ago, thinking about studying genetic variance in 2,000 individuals would have been a laboratory nightmare. That would be a billion tests!

Until recently this wasn't an easy task. There are 3 billion bits of genetic information on the human genome and individuals vary by about 0.1 percent. But that means 3 million differences in the code, or string of letters, that make up each individual. Just 5 years ago, thinking about studying genetic variance in 2,000 individuals would have been a laboratory nightmare. That would be a billion tests!

But today, thanks to major advances, scientists have access to kits that allow them to study 500,000 markers at a clip. These 500,000 marker chips are powerful enough to create a virtual genetic barcode to read changes in variants between individuals and to help isolate disease genes.

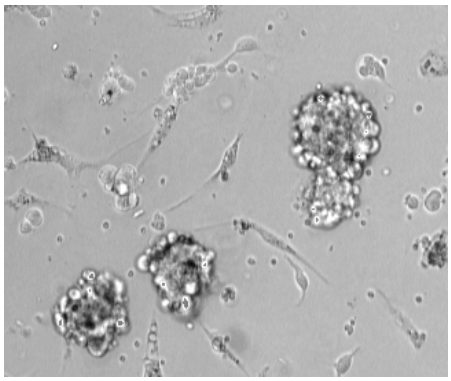
At The Feinstein Institute for Medical Research, scientists process genetic information on 400 people a week. This is helping identify genes for rheumatoid arthritis, lupus and a host of other conditions. It's one thing to have all the genetic data, but managing and mining the data has also come of age. Computers can store the information and allow scientists to easily access and analyze it.

Patient Tissue Sheds New Light On Brain Tumor Invasion

The TDP has recently extended its reach to patients undergoing brain surgery to remove tumors. At The Feinstein Institute, Marc Symons, PhD, Head of the Laboratory for Brain Tumor Biology, and his team have been studying how tumor cells get into the normal brain and spread. This process, called "invasion," is largely responsible for the malignancy of the disease. Currently, there are no anti-invasion therapies available to treat these brain tumors.

Dr. Symons' laboratory has been focusing its research on two brain tumors, medulloblastoma and glioblastoma. Medulloblastoma is the most common malignant pediatric brain tumor and accounts for over 20% of all pediatric brain tumors. Glioblastoma (grade IV glioma) is the most common primary brain tumor in adults.

Over the past several years, Dr. Symons and colleagues have identified two key signaling proteins -- Rac1 and Cdc42 -- that play critical roles in the invasive behavior of both medulloblastoma and glioblastoma. By studying and learning more about the signaling events that are controlled by these proteins, Dr. Symons' research could pave the way to developing new therapeutic targets for these brain cancers. The Brain Tumor TDP is an integral component of these research efforts. Examination of the donated tissue allows the researchers to determine whether signaling proteins that have been identified in the laboratory are malfunctioning in the tumor. The laboratory also isolates brain tumor stem cells from fresh tumor samples. There is accumulating evidence that brain tumors originate from these stem cells and thus it is crucial to examine their malignant properties.



***Glioblastoma stem cells**. Like their normal counterparts, brain tumor stem cells tend to grow in spherical colonies, called neurospheres*

The Brain Tumor TDP was initiated in collaboration with Steven Schneider, MD, of the Department of Neurosurgery at Schneider Children's Hospital and Alexis Demopoulos, MD, of the Department of Neurology at North Shore University Hospital.

Protecting Your Privacy

The staff of the Tissue Donation Program maintains the confidentiality of our participants' personal data. This is a top priority. In addition to the rigorous steps already taken to protect your confidential information, we recently obtained a Certificate of Confidentiality from the US Department of Health and Human Services.

With this certificate, we cannot be forced to disclose information that may identify you, even under court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceeding. However, the certificate does not prevent you from voluntarily releasing information about yourself or your involvement in a research study.

Your trust is essential to the success of our program and we will continue to safeguard your data with the utmost care.

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Significant Research Milestone!!

The Feinstein Medical Research Registry is proud to announce that we have reached a significant milestone- 1500 participants!!

We are living in an exciting era of biomedicine. Scientists are studying the genetic factors involved in hundreds of human diseases. The Feinstein Medical Research Registry allows scientists to recruit control subjects based on identified common genetic variants, in addition to more traditional criteria such as age, gender or ethnicity.

People who have joined the program have provided a mouth-wash-DNA sample and expressed a willingness to help support medical research studies by serving as a control or comparison subject. For example, if a scientist is studying diabetes he or she will often seek to study people without diabetes to help 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 scientists' work, and hopefully brings results sooner.

Seeing the registry in action is really impressive. In the past two years we have sent letters to approximately 175 people in the Feinstein Medical Research Registry, asking them to consider participating as a control subject in a new study. The response we received was tremendous. Close to sixty people contacted us and eventually participated as controls in a study of rheumatoid arthritis and related autoimmune diseases. We want to extend a special thanks to those who have taken time out to support this research.

The scientific value of the registry multiplies as participation increases.

Ultimately, we aim to enroll 10,000 people in the Feinstein Medical Research Registry. People interested in receiving an enrollment kit can contact us at 516-562-1175 or researchregistry@nshs.edu.