



ISSUE 7 FALL/WINTER 2012

# BioNews

> FOR PARTICIPANTS OF THE MAYO CLINIC BIOBANK



## ABOUT THE MAYO CLINIC CENTER FOR INDIVIDUALIZED MEDICINE

> At the Center for Individualized Medicine, we find answers to diseases based on new ways to use your genome to provide you with an accurate diagnosis and best treatment available. Unlocking the mysteries of your genome leads to improved health. We achieve this result through a team of experts working to stop diseases before they start, find you the right drug at the right time, and enable faster and better outcomes.

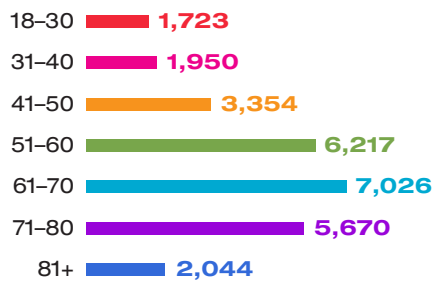
### Greetings from the Mayo Clinic Biobank Staff

We are excited to share with you another busy year of biobank activities. As you may notice we have a new look for *BioNews* that we hope you enjoy! We are very excited to announce that we have opened our Mayo Clinic Biobank in Jacksonville, Florida. In addition, we have been working hard to implement a new system for storage and handling of our samples which will ensure that our samples are stored in the most efficient and safe way, with easy access for investigators. In this issue, we further explore these new initiatives as well as share what the Community Advisory Board has been discussing recently. It is hard to overstate how valuable your participation has been to advancing medical knowledge on a growing number of fronts. We hope you enjoy this issue of *BioNews*, and we thank you for your continued support.

-The Biobank Team

## PARTICIPANT RECRUITMENT STATS

### Age

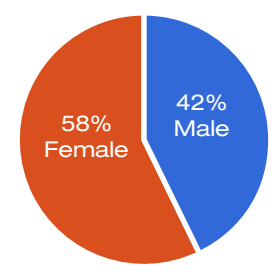


### Demographics

- Olmsted County: 11,220
- SE MN: 4,456
- Rest of MN: 4,431
- Iowa: 1,605
- Wisconsin: 1,159
- Dakotas: 455
- Other US: 4,624
- Missing: 34

### Gender

- Total: 27,984
- Female: 16,131
- Male: 11,853



# Why a **BIOBANK**

## Moving into the fast lane for medical research

Just a reminder of why the Mayo Clinic Biobank is so important today. As we move into the fast lane for medical research at the protein and DNA level, it becomes more and more important to have a way to compare findings between groups of people with a certain disease with groups of people who do not have that disease. Although those of you who chose to enroll in the Biobank may have a variety of medical issues like any other group of people, as a whole enrollees represent the general community, not a particular disease group. Researchers cannot interpret their research without comparing their findings to such a “control” group. Since the Biobank was established, researchers have been coming in great numbers to apply for use of the samples and information that you have so generously agreed can be used for this sort of purpose.

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YOU MAY HAVE NOTICED THE

## *design update*

We have a new look to the *BioNews* newsletter. We are currently in the process of updating the look and feel of our Biobank communications. As you may recall from our last issue of *BioNews*, we discussed the Center for Individualized Medicine (CIM). CIM facilitates genomic, molecular and clinical research and finds ways to deliver these medical innovations into the clinical practice with the goal of improving health care for every Mayo Clinic patient. The Mayo Clinic Biobank is at the core of CIM. In an effort to have consistent materials throughout the CIM program, but also to keep some of our existing look, a new design, incorporating images from our previous Biobank design and current CIM design was developed. We intend to slowly establish this design when new materials need to be printed for the Biobank and as we make edits to our website in the future. We hope you like it!



# Biobank Sample Storage

While Biobanking offers multiple benefits to researchers, it also creates challenges for storing and utilizing these samples. The Mayo Clinic Biobank has used this challenge as an opportunity to collaborate with Rutgers University Cell and DNA Repository (RUCDR), another prominent organization in the biorepository industry. DNA, plasma, serum, and whole blood need to be stored at -80 degrees Celsius to maintain greatest sample integrity. Up until recently, the samples for the Mayo Clinic Biobank have been stored in 2-millimeter tubes which are stored in boxes placed in upright freezers. To use these samples, a person

had to go into the freezer and look for the correct sample without allowing the sample to warm up or thaw. This manual process is time consuming with a risk of errors.

In 2011, leaders within the Biorepository Program of the Center for Individualized Medicine at Mayo Clinic went to visit RUCDR in New Jersey. The Mayo team originally went to understand which best practices RUCDR has implemented for storage, quality assessment, and transferring DNA. This original meeting developed into a collaboration between the two organizations. In May, the DNA samples within the Biobank

underwent a transition by RUCDR to allow greater accessibility to these DNA samples. RUCDR transferred approximately 200,000 DNA samples into tubes which can then be used in the Mayo Clinic robotic freezers. During the transfer process, quantity and quality measurements were made. At this point, all DNA for the Mayo Clinic Biobank has been transferred and is being stored in the robotic freezers making handling of the DNA far more efficient and less error prone. This sample transfer will better allow for ease of use of these samples for all investigators using Biobank samples in the future.

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## COMMUNITY ADVISORY BOARD NEWS

Since our last issue of *BioNews* was published, the Community Advisory Board (CAB) has met twice to continue discussions concerning biobanking. In May, the CAB explored any hopes or concerns they had regarding an upcoming study. Furthermore, CAB members reviewed recruitment materials for the proposed study. A report was sent to the study investigators outlining the issues identified during this meeting. The investigators have incorporated much of this feedback into their study processes and documents.

When the CAB convened in July, members had the opportunity to meet a community representative on

Mayo Clinic's Institutional Review Board (IRB). The Mayo Clinic IRB is a governing body of scientists, doctors, and representatives of the community who review research projects in order to protect study participants. The community representative explained to the CAB the process that the IRB uses when reviewing proposed research studies. She believes that her primary responsibility as a community member on the IRB is to ensure that any communication materials that potential research participants will see are clearly written, contain the key information about the study, and accurately describe the potential risks of the study. ○○○○

# New research projects using the Biobank

We are pleased that many Mayo Clinic researchers have already made use of samples and data from the Biobank for studies at Mayo Clinic. Several new projects have been approved to use samples and information from the Mayo Clinic Biobank since the last issue of *BioNews*. Included are a subset of the recent studies that have been approved for Biobank sample and/or data use. Multiple investigators from previous project approvals have returned for additional sample and data approvals, due to their successes.

57

APPROVED  
RESEARCH PROJECTS

41,262

REQUESTED SAMPLES  
FROM PARTICIPANTS

## ***Right Drug, Right Dose, Right Time – Using Genomic Data to Individualize Treatment (The RIGHT Protocol)***

Suzette Bielinski, Ph.D., and colleagues were approved to utilize Biobank resources to contact and recruit 2000 Biobank participants who may consent to a new blood sample for use in a new project. For Biobank participants who agree to be part of this research study, a new blood sample will be drawn and genetic material will be extracted. The genetic material will be examined for variants in genes known to be important in how drugs are absorbed, activated and metabolized. Knowledge of these genetic variants may help physicians better prescribe the right drug at the right dose to their patients. This genetic information will be made available to the patients via the patient portal and in their electronic medical record for their physician at the time she or he begins the prescription of a new drug. The purpose of this study is to see if this reduces the problems related to some medications and improves medical outcomes.

## ***Hospitalizations and Emergency Room Use of Patients within the Mayo Clinic Biobank***

Paul Takahashi, M.D., will be studying the medical record information and questionnaire data from all the Biobank participants thus far, to determine the number of hospitalizations and emergency room visits within a six-month timeframe after enrollment in the Biobank. His goal is to determine the relationship between the health status of individuals and the number and timing of hospitalizations and emergency room visits. This will help to better understand the Biobank participants overall health as a cohort for future studies and in hopes to improve clinical practice.

## ***The Molecular Epidemiology of Renal Cell Cancer***

Alex Parker, Ph.D., is researching renal cell carcinoma (a type of kidney cancer). He has requested samples and data from 1,000 Biobank participants who report no history of cancer to compare to kidney cancer patients he has recruited from a separate study. Dr. Parker's goal is to examine the molecular causes that link smoking, obesity and other risk factors to renal cell cancer development. This study has the potential to enhance knowledge of causes for renal cell cancer and should help inform new prevention and treatment strategies.

## ***Genetic Contributors to Heart Failure***

Suzette Bielinski, Ph.D. is researching heart failure. Heart failure is a complex syndrome characterized by the inability of the heart to supply sufficient blood flow to the body. Understanding the cause of heart failure is challenging in that at least two distinct types exist that differ in their frequency, presentation, and outcomes. Because of this, Dr. Bielinski and colleagues have developed a set of rules to be followed to identify cases of heart failure using data from the electronic medical record. She will be reviewing medical record information from Biobank participants to determine whether this new set of rules may be of benefit in better defining heart failure patients for future work.

## ***Using Electronic Medical Records to study Citalopram and Escitalopram Treatment Response***

Richard Weinshilboum, M.D., and colleagues are studying the effects of certain medications (Citalopram and Escitalopram) that are used to treat individuals who have major depressive disorder. The goal of this study is to understand the underlying genetics behind treatment response for these drugs in patients diagnosed with major depressive disorder. His study team will see if patients suffering from major depressive disorders (MDD) who have been administered an antidepressant show a treatment response that is influenced by the underlying individual genetic make-up. Therefore, his group is working to develop a medical records set of rules to identify such individuals. The hope is that this would translate to better understanding the genetic factors that may play a role in metabolizing these drugs.

## ***Characterization of Microvesicles from Plasma of B-Cell Chronic Lymphocytic Leukemia (CLL) Patients***

Asish K. Ghosh, Ph.D., is researching the relationship of microvesicles to CLL development. Microvesicles come from parts of the cell that make up different tissues in the body. Once formed, these vesicles can be shed into the blood stream. There appear to be elevated levels of microvesicles in CLL patients, the group of patients that Dr. Ghosh is studying. Therefore, Dr. Ghosh will study 100 healthy Biobank participants who have no known history of chronic disease to compare to a population of CLL patients that have been recruited through a separate study. He hopes to learn more about the association of microvesicles in relation to CLL to see if these may be predictors of disease or play a role in therapy in the future.

## ***Additional Whole Exome Sequencing (WES) Requests***

In our last issue of *BioNews*, we noted a study initiated by Stephen Thibodeau, Ph.D. In that study, Dr. Thibodeau and colleagues requested samples from 40 deceased Biobank participants (20 male and 20 female) without a history of any particular disease. The goal of his project was to perform DNA sequence analysis on most known genes (whole exome analysis) for these 40 Biobank participants. The results of the whole exome analysis will be used to help both research and clinical laboratories to compare genetic differences between health and disease. This genetic information has been generated, and greater than 20 investigators have requested access to the information. These investigators want to study this genetic information to better understand what the information looks like and how it may relate to the specific diseases they are studying. No additional samples were given to these investigators. They only received de-identified genetic results generated from whole exome sequencing for their review.

In addition, Dr. Thibodeau has expanded the whole exome sequencing to include an additional 50 samples from deceased Biobank participants. Having additional samples with this information will help develop systems for managing these types of data and for developing clinical tests for future patients.



# Mayo Clinic has opened a Biobank extension in Jacksonville

We are pleased to announce that the Mayo Clinic biobanking efforts have expanded to include Jacksonville, Florida!

Beginning in June of 2012, the Mayo Clinic in Florida began enrolling participants into the Mayo Clinic Biobank, and we expect to enroll at least 5,000 participants in the next five years.

Alexander Parker, Ph.D., an epidemiologist and Florida-based associate director of the Mayo Clinic Center for Individualized Medicine, is leading this effort.

This Biobank is an extension of the current efforts in Rochester, with the goal to further diversify the population of Biobank participants and extend the biobanking effort to other Mayo campuses. Participants who enroll in the Mayo Clinic Biobank are asked to grant access to their medical records, complete a 12-page lifestyle questionnaire and

donate a blood sample, from which DNA is extracted and stored for future use. Just like the Biobank started in Rochester, participation in the Biobank is currently limited to people with a Mayo Clinic ID.

The expansion of the Biobank to Florida will more fully support Jacksonville researchers. As one of the first Jacksonville researchers to

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use Biobank samples, Dr. Parker, a kidney specialist, says one study is looking at how frequently a genetic mutation found in kidney cancer patients occurs in healthy individuals.

“One of my goals is to understand how genetics interacts with the

environment to affect a person’s risk of developing kidney cancer,” he says. “Now, through a simple query of the Mayo Clinic Biobank, we are able to rapidly identify control individuals who have no history of kidney cancer and gain access to their DNA and lifestyle data. This essentially reduces the time needed to do the work from years to months, which moves the process along at a faster pace.”

Other benefits of opening the Mayo Clinic Biobank in Florida include access to more diverse populations outside the Midwest and allowing for better design of studies aimed at disorders that have a higher prevalence in southern states, such as skin cancer and kidney stones.

“Participating in an effort like the Biobank is an altruistic gesture on the part of these volunteers. It is a wonderful contribution to our efforts to improve medical treatment and disease prevention for all, now and into the future,” Dr. Parker says.

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# Visit us on the web!

[mayoresearch.mayo.edu/biobank](http://mayoresearch.mayo.edu/biobank)

As always, if you have any suggestions or feedback on our website, please contact us.



Use your smart device to scan the code to access the website



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MC6276-1112