



Greetings From the Biobanking Team!

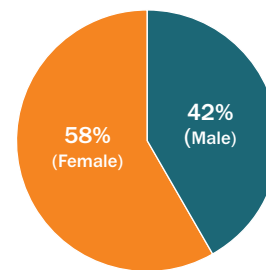
This is our third newsletter, and we have a lot of exciting things to tell you. First, we are more than halfway to our goal of recruiting 20,000 people for the Biobank — and we are ahead of our recruitment timeline. Second, more studies are applying to use Biobank resources, and we highlight some of these within this newsletter. Third, we had a Community Advisory Board (CAB) meeting to discuss our policies on the sharing of research results with other researchers. We received excellent input and are now incorporating their suggestions into our policies. Also, at that most recent CAB meeting, we gave members a tour of the Mayo laboratories used for biobanking. From this tour, we developed an article for this issue of the newsletter that includes pictures to show what happens to blood samples from the time they are drawn to the time when they are stored in one of our freezers. We hope you enjoy this issue, and we thank you again for your participation and continued support.

*Sincerely,
The Biobanking Team*

Current Participant Statistics

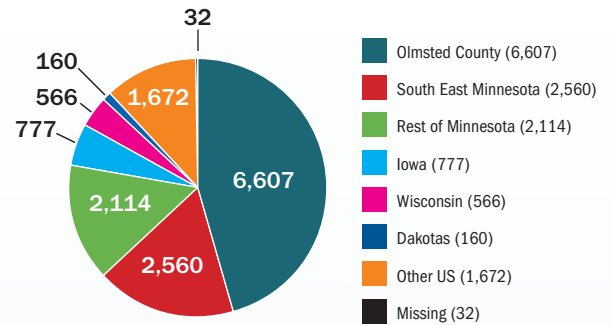
GENDER OF PARTICIPANTS

The current total enrolled biobank participant count is 14,488. 6,073 are male and 8,415 are female.



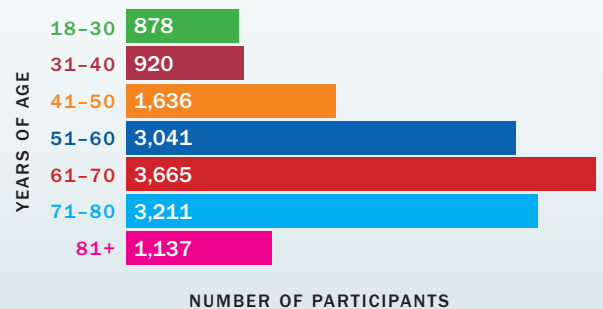
DEMOGRAPHIC OF PARTICIPANTS

The Biobank participants are from these areas.



AGE OF PARTICIPANTS

This graph represents the different age ranges of all participants of the Mayo Clinic Biobank.



Studies Approved for Use of Biobank Samples

The purpose of the Biobank is to enable research. We are pleased that many Mayo Clinic researchers have already made use of samples and data for new research projects on important problems.

GENETIC RISK FACTORS INVOLVED WITH CARDIORESPIRATORY FITNESS



Iftikhar J. Kullo, M.D. is researching genetic risk factors involved with cardiorespiratory fitness, a measure of the ability to perform aerobic exercise. Impairment of cardiorespiratory fitness is associated with an increased risk

of cardiovascular disease, type 2 diabetes, and metabolic syndrome. He has requested samples from 2,000 Biobank participants who have undergone a special type of exercise testing. He is attempting to identify specific genes or DNA sequences that influence cardiorespiratory fitness. His goal is to improve the design of new drugs and to develop new treatment strategies relevant to aging, insulin resistance and cardiovascular outcomes.

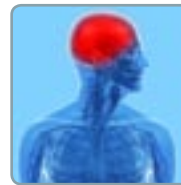
GENETICS OF MULTIPLE MYELOMA



Celine M. Vachon, Ph.D., is studying the genetics of multiple myeloma. She has requested samples from 1000 Biobank participants without a history of multiple myeloma to compare results of genotyping certain genetic variation to patients that

have this disease recruited through a separate study. She is attempting to identify specific DNA sequences and genes that increase a person's risk for the development of multiple myeloma. Her goal is to better understand the origin of this cancer.

GENETICS OF GLIOMA



Daniel H. Lachance, M.D., Robert Jenkins, M.D., Ph.D., and colleagues are studying the genetics of glioma, one type of brain cancer. They have requested samples from 500 Biobank participants without a history of glioma to compare results of testing to patients who

have newly diagnosed glioma. They are attempting to identify specific genes or DNA sequences that predispose individuals to the development of this particular form of brain cancer. Their goal is to understand the role of genetic susceptibility among glioma patients that do not have a family history of this disease.

GENETIC RISK FACTORS FOR PREECLAMPSIA



Vesna D. Garovic, M.D. is testing for the presence of genetic risk factors for preeclampsia, a major source of maternal and fetal morbidity and mortality worldwide. She has requested samples from 14 Biobank participants whom have never been pregnant and have no history

of hypertension. She is researching whether a specific type of DNA modification (methylation) is present and changes over the course of pregnancy and whether these modifications correlate with the development of preeclampsia. Her goal is to better understand the cause of preeclampsia with the long-term goal of improving treatment for these women.

MAYO CLINIC BIOBANK'S CELEBRATION OF THE ENROLLMENT OF OVER 10,000 PARTICIPANTS



The Mayo Clinic Biobank reached a monumental event in the last few months. We have now reached and exceeded recruiting 10,000 participants, halfway to our 20,000 goal. We recruited our 10,000th participant in June of 2010. A tremendous thanks to all of you who have agreed to participate in this valuable research resource at Mayo Clinic! We would not have been able to do this without you.

To mark the successes of the Biobank, we held a celebration on September 9 on the Mayo Clinic Rochester campus. The event included the Mayo Clinic staff who work on the Biobank, researchers who use the Biobank, and Mayo leaders who have supported the Biobank from its inception. Attendees were able to enjoy a short presentation from Dr. Steve Thibodeau (Chair, Biospecimen Trust Oversight Group; pictured

far right), Dr. Jim Cerhan (Principal Investigator, Mayo Clinic Biobank; pictured far left), and Dr. Frank Prendergast (Director, Center for Individualized Medicine; pictured right center) as well as peruse through Biobank materials and enjoy refreshments. It was a successful event. We look forward to additional celebrations to commemorate our progress and activities for the Mayo Clinic Biobank in the future.

WHAT HAPPENS TO YOUR BLOOD SAMPLE ONCE YOU DONATE TO THE BIOBANK?

Many Biobank participants have asked what exactly happens to their blood sample once it has been drawn. Recently, our Community Advisory Board (CAB) had an opportunity to tour the laboratory where most of this processing of blood samples takes place. The CAB members found the tour very helpful, and we hope you do as well.



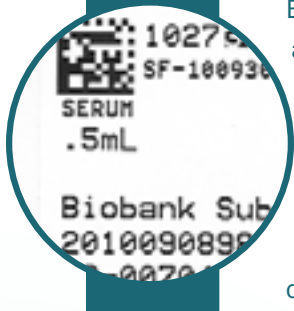
Mayo Clinic Biobank participants can have their blood drawn at many locations throughout Mayo Clinic. In order to deliver the samples to the lab for processing once they have been drawn in a clinical area, blood tubes are placed in cushioned transport containers (pictured left) and placed into a tube station (pictured right) which whisks them to their destination in a matter of seconds. Once they are received in the laboratory, a technologist in the lab will begin the processing of these samples.



Karla Kopp, a project manager for the Biospecimen Accessioning and Processing (BAP) laboratory, the lab where the Biobank samples are processed and stored, describes how each sample is entered into the lab database so that stickers can be printed to label all the tubes used to store a patient's blood sample. Each sticker has a unique ID on it and is barcoded so that the movement of the sample throughout the lab can be tracked. No patient information (name, date of birth, clinic number, etc.) is recorded on the labels, only the Biobank ID (a unique code number) is printed. Those stickers are placed on the patient blood tubes as well as smaller tubes that will hold plasma, serum, or DNA.



Karla then puts samples into a high-speed centrifuge (pictured far left) which will spin the Biobank blood collection tubes. The high-speed spinning allows for the separation of the plasma and serum from the whole blood. The serum and/or plasma will then be transferred to smaller tubes specifically labeled for that patient and later frozen.



Each Biobank participant's blood collection results in up to 21 smaller tubes which are frozen at -80 degrees to prevent degradation. Over 200,000 serum and plasma tubes have already been created from Biobank participants thus far.



During processing, lab assistants check frequently to ensure that each sample is within the correct tube. To do this, the barcodes on the tubes are scanned in and compared to the barcodes on the blood collection tubes. If the two ID's don't match, the system will not allow the lab assistant to continue processing. Quality in the BAP lab is of the upmost importance to ensure high-integrity samples are generated for research. Multiple checks exist throughout the blood processing. Once the bloods are processed and barcodes are checked, the plasma and serum are placed into storage boxes.

Each Biobank participant's sample has a 2D barcode (example pictured top) on both the side of the tube and the top of the tube. Mayo's Department of Engineering created a way to "capture" a whole box's worth of IDs with one click of a digital camera (pictured bottom). The camera image is then processed by the lab database software which electronically stores the locations of each sample within the box. This facilitates future collection of those samples from the freezer.



Karla holds a box of frozen plasma and serum samples. The lab has over 1.2 million tubes in storage. Each tube is given a "home" location which the lab database stores. Once a study is given approval to use that particular sample, a list of locations is given to the lab assistant, and they pull the sample from the box.

Once scanned, the last step of the process is to store the tubes in heavy-duty -80° Celsius freezers (pictured above right) to prevent degradation of the sample. These samples are kept at this temperature and can be stored securely for decades.

CAB members stand beside an automated DNA extractor. A portion of a Biobank participant's blood is utilized for extracting DNA which can later be used in gene analysis for hundreds of different genetic studies. This machine extracts DNA from the blood samples and can process 40 blood samples in about four hours. The extracted DNA is then frozen for later use.



As you can see there are multiple steps to preparing a participant's blood sample for storage and use in the Mayo Clinic Biobank. Once all of these steps are complete, the final samples are kept in the freezer until a researcher at Mayo Clinic is given permission to access to this sample for a particular research project. Access is only gained after the Biobank Access Committee has thoroughly reviewed the researcher's project and determines that it is a high-quality project. If approved, a sample is removed from the freezer, and only the amount of sample required to perform that particular research project will be given to the researcher. The samples donated by you, the Biobank participants, are very highly valued, and therefore, the Mayo Clinic Biobank Access Committee works hard to ensure that the samples are being used to their fullest potential and that no sample is wasted. Stay tuned for our next newsletter, where we will more extensively discuss the duties of the Mayo Clinic Biobank Access Committee and the current process used to allow researchers access to this valuable Biobank resource.

The Mayo Clinic Biobank Community Advisory Board Meeting Summary

On May 13, 2010, we held a tour of the Mayo Clinic Biobank as well as our second Mayo Clinic Community Advisory Board (CAB) meeting at the downtown Rochester campus. During this meeting, we talked about three distinct issues:

1 How to go about data sharing

We began the meeting with a discussion about data sharing and how the Biobank should address the issue. Data sharing is what happens when a researcher gives data that he or she collected to another investigator for use. Its appeal lies in the fact that sharing allows multiple investigators to study and analyze one common data set, which is more efficient than paying for each investigator to independently collect their own data. Three experts knowledgeable about data sharing in genetic research provided background information and answered questions. Joel Wu, a post-doctoral fellow in the Mayo Clinic Bioethics program, spoke about federal government rules and regulations regarding data sharing. Dr. Gloria Petersen, a Mayo Clinic epidemiologist engaging in pancreatic cancer research, summarized some of the scientific benefits of data sharing. Following these presentations, the CAB had the opportunity to question the experts in panel format. John Mills, an attorney at the Mayo Clinic, joined Mr. Wu and Dr. Petersen in answering questions concerning protection of privacy, what happens to data when a scientist relocates to another institution, and Mayo's historical view on data sharing.

During these discussions, CAB members made several recommendations regarding how Mayo Clinic can make the Biobank a stronger and more collaborative resource. One such recommendation was for Mayo to outline the differences between the Mayo Clinic Biobank and clinical genetic testing versus private direct-to-consumer genetic testing kits and resultant biobanks. This would educate the public about the scientific value and rigor that is behind the biobanking research here at Mayo and to dispel any misunderstandings between what is happening here as opposed to other

2 What new research/projects are making use of the Biobank resource

privately backed ventures. A second recommendation was to post informational videos and podcasts about the Biobank on the Mayo Clinic external website as well as make use of the Mayo Patient Portal to electronically keep Biobank volunteers abreast of recent developments.

After the discussion of data sharing our Biobank Genetic Counselor, Kiley Johnson, MS, CGC, presented new research projects making use of the Biobank. Currently, many Mayo Clinic investigators are engaging this resource to study such diseases as breast, lung, and colon cancer; hypertension; cardiovascular diseases; multiple myeloma; and others. Please see our Newsletter section entitled "New Research Projects Using Biobank Samples" or our web site for further information on each of these studies.

Finally, Matt Durski presented the procedures for selecting the CAB co-chair and summarized the responsibilities the co-chair will hold. The co-chair will be charged with the following responsibilities:

- ▶ Helping establish meeting agendas
- ▶ Attending oversight committee meetings
- ▶ Serving as a voice of the CAB to the Mayo Clinic Biobank
- ▶ Helping run/chair regularly scheduled meetings.

Again we wish to thank the CAB members for the hard work of ensuring community voices are involved in this important and ongoing task. We are committed to sustaining and further developing community involvement in the decision making process of this Biobank.

3 The procedure for selecting the CAB's co-chair

Visit Our Web Site for More Information

We have a Web site for our current or prospective participants. Please visit the site to learn more about the following topics:

- ▶ GENERAL INFORMATION ABOUT BIOBANKING
- ▶ PLANNING THE BIOBANK
- ▶ GOVERNING THE BIOBANK
- ▶ FREQUENTLY ASKED QUESTIONS ABOUT THE BIOBANK
- ▶ EXPECTATIONS OF YOU AS A PARTICIPANT NOW AND IN THE FUTURE
- ▶ UPDATES ON THE STUDIES USING THE BIOBANK
- ▶ ISSUES OF THIS NEWSLETTER (PRINTER FRIENDLY)
- ▶ OUR CONTACT INFORMATION



If any donors have suggestions for the CAB or topics they would like the CAB to consider, they can contact one of the Biobank staff members at:

507-293-0203 (local)
1-866-613-2386 (toll free)
biobank@mayo.edu (e-mail)
<http://mayoresearch.mayo.edu/biobank>

or via mail to:

Ethics and Community Engagement
Mayo Clinic, 200 First Street SW,
Plummer Building, Room 3-20-9
Rochester, Minnesota 55905

Contact Us

If you have questions or need more information about the Mayo Clinic Biobank, please contact one of our staff members at:

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