

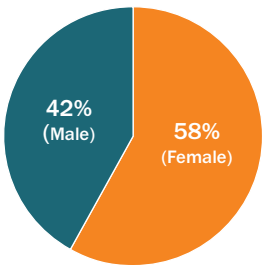


DISCONTINUED

Current Participant Statistics

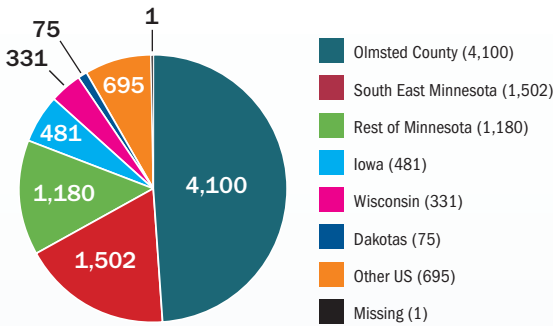
GENDER OF PARTICIPANTS

The current total enrolled biobank participant count is 8,365. 3,489 are male and 4,876 are female.



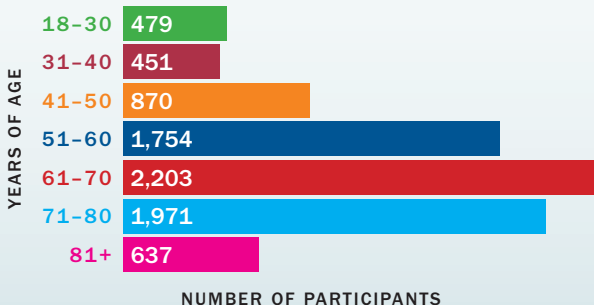
DEMOGRAPHIC OF PARTICIPANTS

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.



Greetings From the Biobanking Team!

We have updates on enrollment, projects, and other aspects of biobanking. April 1st was the first anniversary of the enrollment of our first participant. Over 8,000 participants have now enrolled, and we are on track toward our target of 20,000 participants. We have talked with researchers throughout Mayo about research opportunities using the Biobank. As a result, many new projects are being developed to use this resource. We also held our first meeting of the Community Advisory Board for the overall biobanking effort at Mayo. All of these are exciting accomplishments, but it all comes back to you, as a biobank is put together one participant at a time. We thank you again for your support!

Sincerely,
The Biobanking Team

The Mayo Clinic Biobank Community Advisory Board was Established, Holds First Meeting

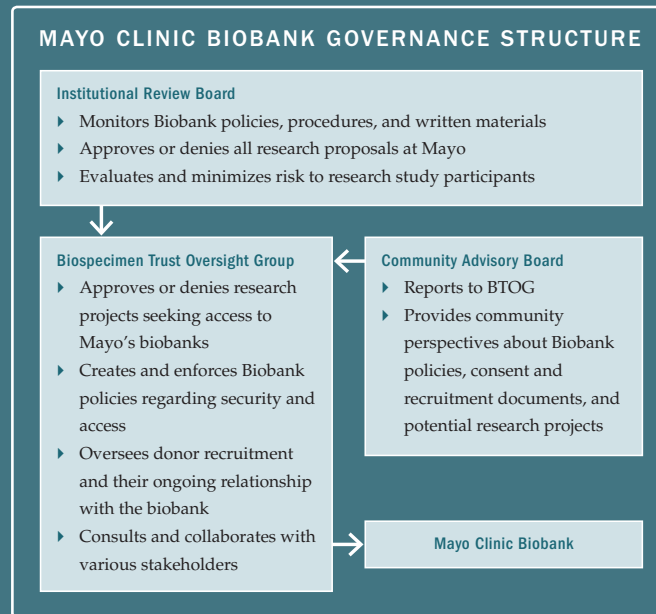
THE MAYO CLINIC COMMUNITY ADVISORY BOARD (CAB) WAS ESTABLISHED AS A UNIQUE RESEARCH RESOURCE TO ENSURE THAT THE VOICE OF THE COMMUNITY IS HEARD IN THE DEVELOPMENT OF BIOBANKING POLICY.

As you can see in the chart to the right, this governance structure is different from others in that the community voice directly informs the discussion of how best to govern the Mayo Clinic Biobank. This ensures your suggestions carry real power in this decision-making process.

The idea of creating a community advisory board to engage biobank research and development came from a trend in research known as deliberative community engagement. Community engagement is based on the assumption that citizens can (and must) play a role in the governance of research, offering suggestions and ongoing advice. This process ensures that the diversity of views in the Rochester community will be considered by the Biospecimen Trust Oversight Group (BTOG), the internal advisory group that supervises the Mayo Clinic Biobank.

The CAB has 20 members who reflect the diversity of community interests and backgrounds. Nine of our CAB members are from our original deliberative event in 2007, and the remaining eleven members were selected because of the unique employment, religious views, and cultural traditions they represent. All of our members were selected to represent the spectrum of diversity in SE Minnesota.

The CAB reports to the BTOG as a resource for voicing community suggestions. For instance, the CAB helps decide who may use the Biobank. At its next meeting, the CAB will appoint a community leader or co-chair to work with Mayo's co-chair, Dr. Barbara Koenig. This co-chair will review research protocols for how they may affect the community.



Last January 28, we held our first CAB meeting over dinner at the Mayo Clinic Rochester campus. Dr. Janet Olson, director of the Mayo Clinic Biobank, presented to the CAB about the history and development of the Biobank. Also, Dr. Cathy McCarty from the Marshfield Clinic presented on differences between the Mayo Clinic and Marshfield Clinic Biobanks. One such example is that at the Marshfield Biobank recruitment is for all citizens over 18 years old, whereas at Mayo, recruitment is for Mayo

Clinic patients 18 and over only. You can access Dr. McCarty's Marshfield Clinic personalized medicine project by visiting this site: http://www.marshfieldclinic.org/chg/pages/default.aspx?page=chg_pers_med_res_prj.

Topics the CAB will consider at future meetings include, but are not limited to, whether we should:

- ▶ Include children in the biobank? If so, how often?
- ▶ Re-contact participants for more information?
- ▶ Share research data with other institutions. If so, when?
- ▶ Return any genetic results to Biobank participants? If so, when?

Thanks again to CAB members for their work and efforts of ensuring the community is involved in this important task. We are committed to sustained and meaningful community involvement in the development of this Biobank. We will continue to have CAB meetings several times a year to ensure involvement is ongoing.



If any participants have suggestions for the CAB or topics they would like the CAB to consider they can contact:

Matt Durski

Ethics and Community Engagement Coordinator
507-284-3132 (tel)

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

Technical/research questions or genetics questions should be directed to our genetic counselor at: biobank@mayo.edu



New Research Projects Made Possible by the Biobank

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 projects on important problems like cancer and heart disease. Several new projects have been approved to use samples and information from the Mayo Clinic Biobank since the last issue of BioNews. These include the following:



LUNG CANCER

Mariza de Andrade, Ph.D. is researching genetic causes for familial lung cancer. She has requested samples from 150 Biobank participants without a personal or family history of lung cancer to compare to those from patients who have lung cancer that she has recruited through a separate study. She hopes to identify specific genes that might increase risk for the development of lung cancer.



HYPERTENSION

Lilach Lerman, M.D., Ph.D. is researching kidney disease in patients with high blood pressure (hypertension). She has requested samples from 50 Biobank participants without a history of hypertension to compare to those from patients with hypertension that she has recruited through a separate study. She would like to know how kidney disease is affected by the presence of hypertension for a given patient.



MICROVESICLES

Muthuvel Jayachandran, Ph.D. is researching the presence of microvesicles in blood and how they relate to disease. 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. However, not much is known about what these vesicles are made of or how many of these are in a healthy individual. Once this is known, it will be possible to look at patients with disease to see if the number and make-up of these microvesicles are different. The goal is to see if these blood particles can be used to detect the presence of disease very early, for example before symptoms develop, or to see if they can be used to predict that a patient will develop disease later in life. To study microvesicles, Muthuvel Jayachandran, Ph.D. is requesting samples from 50-100 healthy Biobank participants who have no known history of chronic disease.

Ways We are Making Participation and Data Collection Easier

CHANGES TO OUR WEB SITE

We have recently made some changes to our web site. Please log on to view the web site to stay up to date:

[HTTP://MAYORESEARCH.MAYO.EDU/BIOBANK](http://MAYORESEARCH.MAYO.EDU/BIOBANK)

We have also updated our "Studies Using the Biobank" page to include all of the current researchers and a brief discussion of their projects which have approval for use of biobank samples and information.

We have added a Newsletter left navigation bar so that you can quickly find all of the *BioNews* Newsletters (available in PDF).

On our home page we have added a section entitled "What's New?". This is to better keep you informed of the recent changes or new information for participants of the Biobank.



As always, please feel free to e-mail us with any suggestions or comments that you have for the continuous improvement of our web site: Biobank@mayo.edu.



SCANNABLE QUESTIONNAIRE

Remember being a kid and filling in all those little bubbles on the standardized tests? While taking tests may not be your best memories, bubble-coded technology is still the most cost effective way to collect large amounts of data from a large group of people. That is why the newly revised Mayo Clinic Biobank questionnaire is being converted to a bubble-coded format. We have used a format that required Biobank staff to type the data into a computerized database, but at five minutes per questionnaire, our staff has spent about 700 hours entering the data from the old-style questionnaires. Data can be extracted from the new version in less than a minute, helping us to use our limited resources more wisely. We expect the new version to come out this summer and hope to have a web-version of the questionnaire available then also. So, if you have not yet returned the Biobank Questionnaire, you may be asked to fill out the newly designed version. Thank you for helping us to achieve our goals.

Speakers Bureau Available

Are you interested in having a Biobank staff member speak to a group about the Mayo Clinic Biobank progress and efforts? If so, please contact us by e-mail or phone. We will try to accommodate all appropriate requests.

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Contact Us

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

507-293-0203 (local)

1-866-613-2386 (toll free)

biobank@mayo.edu (e-mail)

<http://mayoresearch.mayo.edu/biobank>



PLEASE UPDATE YOUR CONTACT INFORMATION

Please let us know if you have changed your home address, phone number or e-mail address. We would like to be able to contact you so that we can send you updates about Biobank activities and have a means to reach you should we need any additional information regarding your sample and participation. You may contact us at any of the following to provide us with your updated contact information:

507-293-0203 (local)

1-866-613-2386 (toll free)

biobank@mayo.edu (e-mail)

200 First Street SW
Rochester, Minnesota 55905
www.mayoclinic.org

