



BioNews

FOR PARTICIPANTS OF THE MAYO CLINIC BIOBANK

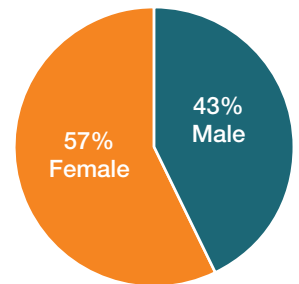
ISSUE NO. 5 | FALL/WINTER 2011



Recruitment Stats Update

Gender of Participants

The current total enrolled biobank participant count is 22,499. 12,863 are female and 9,636 are male.



It's Time to Celebrate!

We are celebrating because we have reached our target of 20,000 participants enrolled into the Biobank! This represents a major achievement and is a real credit not only to the Biobank staff members, but most importantly to each of our participants. Please note that, while we have reached our target, we are still enrolling new participants.

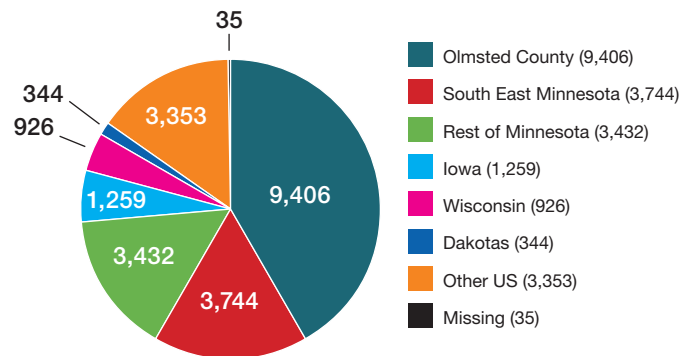
In addition to enrolling 20,000 participants, we have many other reasons to celebrate, such as the approval of seven more studies to use the Biobank, a publication in the medical literature of the first study to use Biobank samples, and improvements to our website. You can find out more about these and other topics inside this edition of BioNews, where we provide updated participation statistics and a summary of the most recent Community Advisory Board meeting. We have also included some interesting facts about the Biobank as we look back at our journey of meeting our goal of 20,000 participants.

Finally, we are in the process of considering expanded plans for the next five years – there will be more to come on that in the next BioNews. We look forward to your continued participation and, in the meantime, we hope you enjoy this edition of BioNews.

Sincerely,
The Biobanking Team

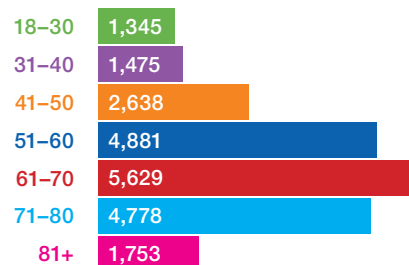
Demographic of Participants

The Biobank participants are from these areas.



Age of Participants

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





CELEBRATING THE RECRUITMENT OF

20,000

BIOBANK PARTICIPANTS

The Mayo Clinic Biobank reached a monumental event in the last few months. We have surpassed our original goal of recruiting 20,000 participants. We recruited our 20,000th participant in June of 2011. Huge thanks to all of you who agreed to participate in this valuable research resource at Mayo Clinic. We would not have been able to do this without you.

To celebrate the successes of the Biobank, we held an event on the Mayo Clinic Rochester campus for all of the Mayo Clinic employees involved in the biobanking efforts as well as our valuable Community Advisory Board members. The event was held on September 23 from 11:00 a.m.-1:00 p.m. in the Kahler Plaza Hotel Heritage Room near the downtown Mayo campus. Approximately 40 staff members and Community Advisory Board

members were able to attend the event. Dr. Stephen Thibodeau, Ph.D. (Chair, Biospecimen Trust Oversight Group) and Dr. James Cerhan, M.D., Ph.D. (Principal Investigator, Mayo Clinic Biobank) thanked the group for all of their work throughout the years in supporting the day-to-day efforts of the Mayo Clinic Biobank. The group enjoyed socializing and reflecting upon many milestones we have reached over the years. Dr. Janet Olson, Ph.D. (Project Director, Mayo Clinic Biobank) gave a quiz

that contained some fun facts about the Mayo Clinic Biobank. A few of the sample quiz questions can be seen on page 5 in this issue of BioNews with answers to be found on page 7. We hope you enjoy these interesting facts about the Biobank.

We look forward to future events to commemorate our progress and activities for the Mayo Clinic Biobank. We will continue to share these with you through future newsletters and on our web site.

Mayo Clinic Biobank Featured at the Community Research Celebration

The Center for Translational Science Activities (CTSA), a Mayo Clinic group that seeks to speed the translation of research into therapies, tools and patient care practices that improve community health, recently invited the Mayo Clinic Biobank to share in an opportunity to thank research participants at a special event known as “The Community Research Celebration”.

The Celebration was held from 5:30 – 7:00 p.m. on Thursday, August 25 in Phillips Hall at Mayo Clinic Rochester. The Mayo Clinic Biobank was invited to share our research, and the community joined in helping us celebrate our achievement of enrolling 20,000 Mayo Clinic participants. The event began with a social hour including refreshments and research displays. Following



PICTURED ABOVE, LEFT TO RIGHT:

James Cerhan, M.D., Ph.D., *Principal Investigator, Mayo Clinic Biobank*

Susan Slager, Ph.D., *researcher using Biobank samples*

Wilma Lingle, Ph.D., *Director, BAP Lab*

Gail Onderak, *Community Advisory Board Co-Chair*

Kiley Johnson, M.S., C.G.C., *Biobank Genetic Counselor*

David Warner, M.D., *Chair, CTSA*

this, James Cerhan, M.D., Ph.D., Principal Investigator of the Mayo Clinic Biobank, gave a presentation entitled, “Celebrating Community Contributions to the Success of the Mayo Clinic Biobank”. Dr. Cerhan was happy to inform the community that through valuable community contributions and participation in this research project, the Mayo Clinic Biobank had enrolled over 20,000 participants, exceeding our original recruitment goal.

After the presentation, several Biobank team members, the Community Advisory Board co-chair, and a Mayo Clinic researcher who has used samples from the Biobank were available on a panel to answer questions from the community. The event was a great success and a tribute to all research participants at Mayo Clinic.



New Research Projects Using 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 studies at Mayo Clinic. Overall, we now have 28 approved projects requesting a total of approximately 17,500 samples from biobank participants. Several new projects have been approved to use samples and information from the Mayo Clinic Biobank since the last issue of BioNews.

An Integrated Approach for Discovery and Validation of Genomic Predictors of Bipolar Disorder

Joanna Biernacka, Ph.D., is researching bipolar disorder. She has requested samples from up to 1000 Biobank participants without a history of bipolar disorder or depression to compare to patients who have bipolar disorder who she has recruited through a separate study. She is trying to identify genetic contributors to bipolar disorder. Her goal is to use this information to develop a prediction model for bipolar disorder, which may be used to determine individuals at risk of developing this condition in the future.

Evaluation of the Role of Familial Pancreatic Cancer Genes in Minority Patients

Robert McWilliams, M.D., is researching genes proven to cause elevated risks for pancreatic cancer in some families. There is very little known about the frequency of mutations (gene changes) in certain genes in minority populations or the meaning of these gene changes in such populations. Therefore, Dr. McWilliams has requested up to 100 samples from Biobank participants to add to the group of individuals who he has recruited through a separate study. He is trying to determine if mutations in certain genes are more common in these ethnicities, and whether this plays a role in cancer development.

Biobank Whole Exome Sequencing Project

Stephen Thibodeau, Ph.D., has requested samples from 40 deceased Biobank participants (20 male and 20 female) without a history of any particular disease. The goal of his project is to perform DNA sequence analysis on all 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. For research laboratories, data from this study will be used to compare to information obtained from patients with a variety of different diseases to better understand the differences between health and disease. For the clinical laboratory, data from this study will be used to help build the next generation of tests that can be used by physicians world wide to diagnose different types of genetic disorders.

New Technology to Detect Lymphoma Biomarkers

Andrew Feldman, M.D., is researching new biomarkers and possible targets for therapy for T-cell Lymphoma. He has requested samples from 50 Biobank participants without a history of any type of cancer to compare to patients who have lymphoma who he has recruited through a separate study. His goal is to identify new biomarkers that might help with detection of T-cell lymphoma as well as identify potential targets for therapy for this cancer through new technologies.

Test Development for Detection of Bullous Pemphigoid (an autoimmune skin disease)

Michael Camilleri, M.D., is working to develop a new test to detect a specific antibody known as anti-bullous pemphigoid IgE to detect a skin disease known as bullous pemphigoid. This skin disorder is an autoimmune condition most common in the elderly. It is characterized by intense itching and burning of the skin followed by blistering. He has requested serum samples from 50 Biobank participants without a history of skin disease, other immune disease or steroid treatments to compare to patients who have bullous pemphigoid who he has recruited through a separate study. His goal is to develop a new test that could be used clinically in the future to identify this disease and may help to guide treatment.

Effect of TCF7L2 Gene Alterations and Risk for Diabetes

Adrian Vella, M.D., is researching the effects of the TCF7L2 gene on Type II diabetes. Some studies have indicated that certain genetic changes within the TCF7L2 gene cause slight differences in risk for diabetes. He has requested samples from 1,000 Biobank participants without a history of diabetes to determine whether they have higher risk or lower risk factors for diabetes. Those with particular genetic variations may then be offered an opportunity to participate in further research studies with Dr. Vella's group to help to determine the role the TCF7L2 gene has in development of diabetes and potentially help to target therapies for diabetes in the future.

Genetic Variation of Beta 2-Adrenergic Receptor and Cardiovascular Response

John Eisenach, M.D., is researching the effects of certain genetic alterations in the β_2 - Adrenergic Receptor gene and how these changes influence heart and blood vessel function under controlled levels of sodium in the diet. He has requested samples from 1,000 young Biobank participants without a history of heart disease or diabetes to determine whether they have specific genetic alterations in the β_2 -Adrenergic Receptor gene. Those with these genetic changes may then be offered an opportunity to participate in further research studies with Dr. Eisenach's group to help determine the role this gene plays in cardiovascular disease.

Bioquiz

- 1** If all the blankets ordered for the Biobank were laid out flat with their edges touching, how much ground would this cover?

 - Two average city blocks
 - Eight football fields
 - The square footage of the retail space in the Mall of America (2.5 million)
 - Equal to the state of Rhode Island
- 2** How many envelopes have been ordered for the Biobank?

 - about 40,000
 - about 80,000
 - about 120,000
 - about 160,000
- 3** How many phone calls have been made and/or received (and recorded in the database) on behalf of the Biobank?

 - 18,101
 - 20,930
 - 37,234
 - 55,343
- 4** If all 20,000 signed consent forms for the Biobank were unstapled and the (double-sided) pages laid end-to-end (the long way), how long would it extend?

 - about 500 feet
 - about 2000 feet
 - about 1 mile
 - about 7 miles
 - about 21 miles
 - about 83 miles
- 5** If you lined up (end to end) the blood tubes collected for our 20,000 Biobank participants, it would span the distance from the Gonda entrance to the St. Mary's entrance how many times?

 - 1 time
 - 3 times
 - 8 times
 - 10 times
 - 17 times
 - 50 times

Community Advisory Board Activities

The Mayo Clinic Biobank Community Advisory Board (CAB) met once again on September 8, 2011, at the downtown Rochester campus. The CAB was updated on several important topics concerning the Biobank:

- 1 eMERGE Network Meeting Update
- 2 Return of Results Letters
- 3 Shortened Consent Form
- 4 Future CAB Topics

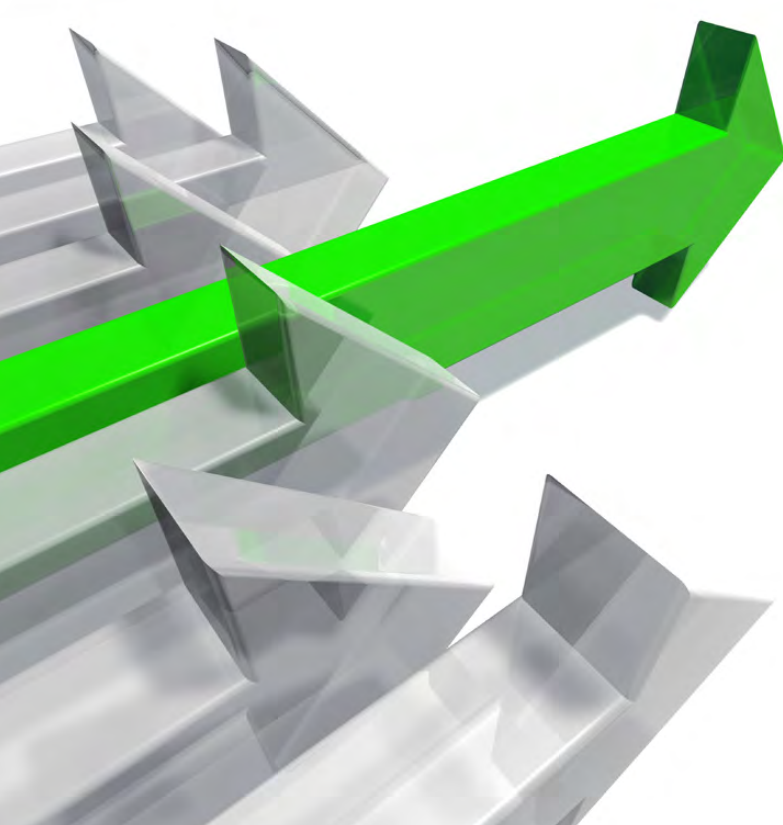
The meeting began with a presentation from CAB community co-chair, Gail Onderak. She had the opportunity to attend an eMERGE Network meeting in Washington, D.C., at the end of July. Organized by the National Human Genome Research Institute (NHGRI), the eMERGE Network is a national consortium formed to develop and apply approaches to research that combine DNA biorepositories with electronic medical record (EMR) systems for genetic research. The consortium is composed of seven sites including Group Health Cooperative in Seattle; Geisinger Health System in Danville, Penn; Marshfield Clinic in Marshfield, Wis; Mayo Clinic in Rochester, Minn; Mount Sinai School of Medicine in New York; Northwestern University in Chicago; and Vanderbilt University in Nashville, Tenn. At the eMERGE meeting, all seven sites were represented, and Onderak learned how each site handles community engagement as it relates to their biorepository. After hearing from each of the eMERGE sites, it was evident that community involvement at each site varies greatly.

After Onderak's presentation, CAB members reviewed a final draft of the letter some participants may receive regarding return of results. CAB members helped to revise an earlier version of this letter as well as provided input on the overall return of results process as was summarized in earlier newsletters.

In addition to the return of results letter, CAB members also reviewed a shortened Biobank Informed Consent Form which is currently being used in a Biobank research study. Several new Biobank participants will receive this shortened consent form and will then be contacted in follow-up. Researchers hope to find out which form is more effective and easily understood: the current consent form or the more abbreviated consent form.

Finally, CAB co-chair Karen Maschke, Ph.D., mentioned several potential CAB discussions for the future. Karen is a researcher at the Hastings Center, a bioethics institute in Garrison, N.Y. Future discussion topics include the use of samples from deceased persons, requests for samples from commercial (for-profit) organizations, and pediatric biobanks. CAB members offered a good deal of input regarding these topics, and the issues will be explored at future meetings.

Once again, we thank the Community Advisory Board members for their dedication and commitment to ensuring that the community's voice is heard. Community engagement is vital to the decision-making process of the Mayo Clinic Biobank.



Visit us on the web!

mayoresearch.mayo.edu/biobank

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



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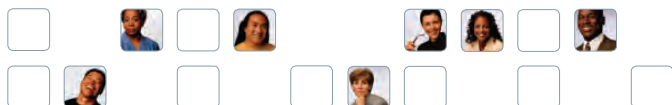
Contact Us

If you have questions or need information about the Mayo Clinic Biobank, please contact us at:

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1-866-613-2386 (toll free)
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The Mayo Clinic Biobank is part of the Center for Individualized Medicine, dedicated to discovering and integrating the latest genomic, molecular and clinical science into personalized care for each Mayo Clinic patient.



Bioquiz

ANSWERS

1. **B**, Eight football fields
2. **D**, About 160,000
3. **D**, 55,343
4. **E**, About 21 miles
5. **D**, 10 times

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