



ISSUE 13 SUMMER 2016

BioNews

> FOR PARTICIPANTS AND FRIENDS OF THE MAYO CLINIC BIOBANK

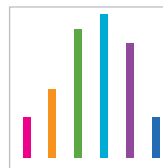
Welcome to *BioNews*. Recruitment is now complete for the Mayo Clinic Biobank. The Biobank first started recruiting on April 1, 2009. In the past 7 years, 56,880 participants have become part of the Mayo Clinic Biobank. We extend our sincere gratitude to all of our participants; because of your contributions, over 160 research projects have been facilitated across all health disciplines.

Recruiting 50,000 participants was just the beginning of the Mayo Clinic Biobank. Now our focus shifts from recruitment to maintenance and enhancement of the Biobank. Projects such as sequencing the genomes (all of an individual's genetic information) of all participants will make the samples contributed by participants that much more valuable for researchers.

In this edition of *BioNews*, we share an inside look at Senator Klobuchar and Secretary Burwell's visit to the Mayo Clinic Biobank, updates on the Community Advisory Board efforts, and highlights of some of the recent studies approved for use of Biobank samples.

As always, we enjoy hearing from participants of the Mayo Clinic Biobank and encourage you to contact us by phone (866-613-2386) or email (biobank@mayo.edu) if you have a question or comment.

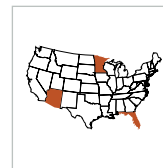
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INTERESTED IN SPEAKING ABOUT YOUR EXPERIENCE AS A MAYO CLINIC BIOBANK PARTICIPANT?

Occasionally, the Mayo Clinic Biobank gets requests from the media to speak with a Biobank participant about their experience as a Biobank participant. If you are interested in helping with these requests, please call or email the Biobank. We will add your name to a list and reach out to you in the future as we receive requests. As always, your personal information will never be released without your permission.

UPDATES ON RECRUITMENT STATS

The current total enrolled biobank participant count is 56,880.

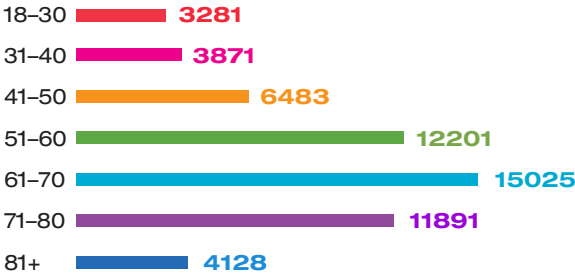
DEMOGRAPHIC OF PARTICIPANTS

The Biobank participants are from these areas.

- Olmsted County: **15,079**
- SE MN: **6,295**
- Rest of MN: **8,019**
- Iowa: **3,306**
- Wisconsin: **4,449**
- Florida: **9,075**
- Other US: **10,622**
- Missing: **35**

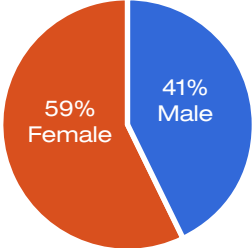
AGE OF PARTICIPANTS

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



GENDER

Total: **56,880**
Female: **33,404**
Male: **23,476**



SECRETARY BURWELL AND SENATOR KLOBUCHAR VISIT THE MAYO CLINIC BIOBANK



Stephen Thibodeau, Ph.D., Biorepositories Program Director, greets Secretary Burwell and Senator Klobuchar, with John Noseworthy, M.D. and Keith Stewart, M.B.Ch.B.

On Oct. 16, U.S. Department of Health and Human Services Secretary Sylvia Burwell and Minnesota Senator Amy Klobuchar came to Mayo's Rochester campus to tour the Mayo Clinic Biobank and discuss the national Precision Medicine Initiative with Mayo Clinic leaders. This was Senator Klobuchar's second visit to the Mayo Clinic Biobank.

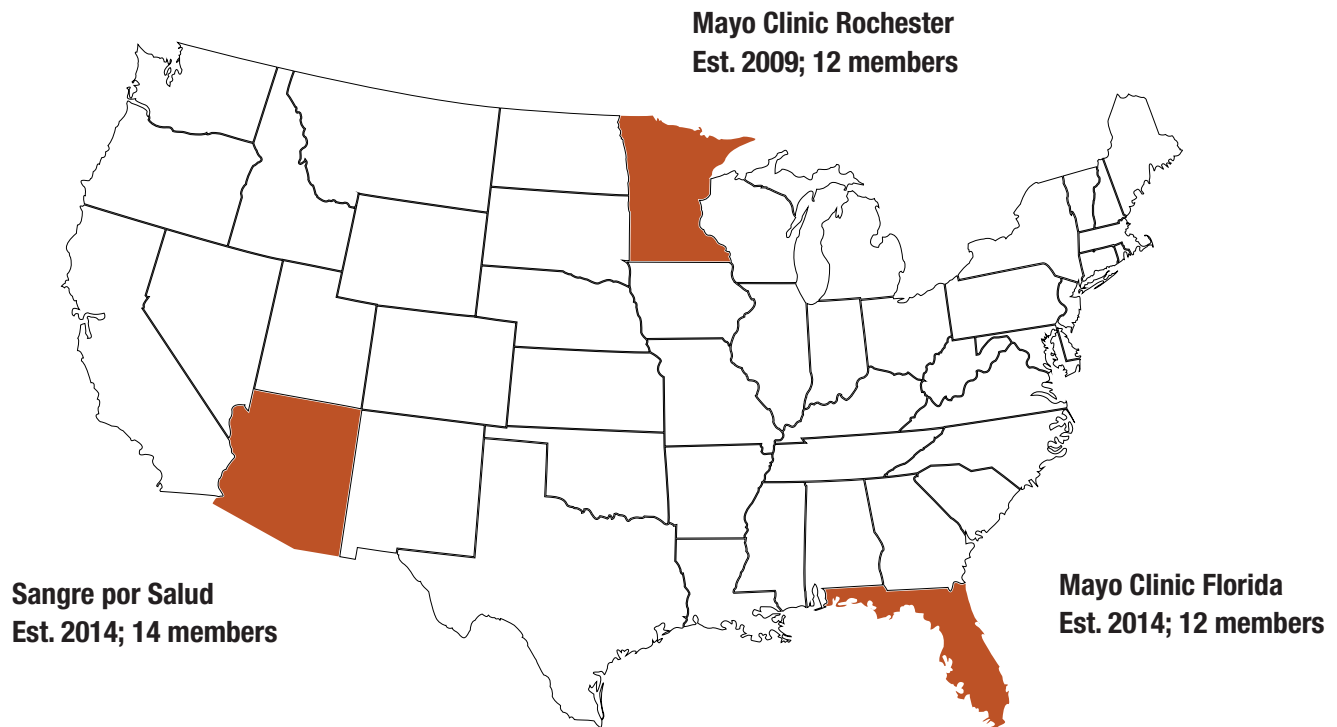
Secretary Burwell and Senator Klobuchar met with leaders from the Mayo Clinic Center for Individualized Medicine and Mayo Medical Laboratories. John Noseworthy, M.D., president and CEO, Mayo Clinic, and Keith Stewart, M.B., Ch.B., Carlson and Nelson Endowed Director of the Center for Individualized Medicine, guided the walking tour of the Biobank and Biorepositories Program.

The Precision Medicine Initiative (<https://www.nih.gov/precision-medicine-initiative-cohort-program>) was first

announced over a year ago in President Obama's 2015 State of the Union Address. This national initiative will allocate federal funding for cancer genomic research, as well as the creation of a 1 million participant national biobank, called the Precision Medicine Initiative Cohort Program. Recruitment efforts will begin nationwide later this calendar year. Mayo Clinic has submitted applications to be part of these efforts. Stay tuned for future announcements regarding Mayo Clinic's ongoing involvement with the Precision Medicine Initiative.

Secretary Burwell and Senator Klobuchar also discussed payment reform and delivery system reform with Mayo leaders during a roundtable discussion. Precision or individualized medicine — at the core of a major White House initiative — is a major focus of the National Institutes of Health.

COMMUNITY ADVISORY BOARD UPDATE: THREE-SITE NETWORK



Three Community Advisory Boards continue to meet separately every two months to discuss and provide important feedback on issues facing the Mayo Clinic Biobank. A framework is being established across the three-site network – MN, AZ, and FL – to improve broader coordination and communication between the existing Community Advisory Boards as an effort to maximize their benefit. This initiative will help establish a mechanism for soliciting CAB input

from all three sites on Biobank policies, consent and recruitment documents, and potential research projects. More pluralistic CABs allow divergent values and concerns among other populations to be represented.

MAYO CLINIC BIOBANK GOVERNANCE STRUCTURE

Institutional Review Board

- Monitors Biobank policies, procedures, and written materials
- Approves or denies all research proposals at Mayo
- Evaluates and minimizes risk to research study participants



Biospecimen Trust Oversight Group (BTOG)

- Approves or denies research projects seeking access to Mayo's biobanks
- Creates and enforces Biobank policies regarding security and access
- Oversees donor recruitment and their ongoing relationship with the biobank
- Consults and collaborates with various stakeholders



Community Advisory Board

- Reports to BTOG
- Provides community perspectives about Biobank policies, consent and recruitment documents, and potential research projects



Mayo Clinic Biobank

Why is the Biobank CAB important to you?

“ I think researchers are so passionate about curing disease that they sometimes have blinders on. I feel it is our responsibility to make sure they take the blinders off and be challenged to see things from a lay person's perspective. ”



Kathryn H., Rochester Mayo Clinic Biobank CAB member

Join the CAB

Recruitment for the Rochester Mayo Clinic Biobank Community Advisory Board (CAB) is currently underway. To apply for membership, send a letter of interest to the Mayo Clinic Biobank Community Advisory Board c/o Kylie Osterhus, Plummer 3, 200 First Street SW, Rochester, MN 55905, or send an e-mail to MayoBiobankCAB@gmail.com. There is no formal application, but the information provided should include: home address and daytime contact information, and a letter of interest telling us about yourself and why you are interested in becoming a member of the CAB.

Members are expected to commit to a three-year term and attend a minimum of 4 meetings each year (out of 6), which last 2-3 hours. Since CAB members will represent the community with their time and expertise, they will be compensated \$75 for attending each meeting and event. It is not required that members be Biobank participants. New membership will be determined by current CAB members.

NEW RESEARCH PROJECTS USING THE BIOBANK

The purpose of the Mayo Clinic Biobank is to enable research. We are pleased that the Mayo Clinic Biobank continues to be used for a wide variety of research projects. Overall, we now have over 160 approved research projects requesting samples and data from Biobank participants. Several new projects have been approved since the last issue of BioNews. Included below are a subset of the recent studies that have been approved for sample and/or data use. For a complete list of projects, visit our website (<http://www.mayo.edu/research/centers-programs/mayo-clinic-biobank/projects>).



Plasma autoantibody responses as clinical correlates in malignant melanoma immunotherapy

Aleksandar Sekulic, M.D., Ph.D. is researching cancer immunotherapy. He has requested samples from 50 Biobank participants without a history of melanoma or other cancers and autoimmune conditions to compare to patients with melanoma that are undergoing melanoma immunotherapy that he has recruited through a separate study. He is researching autoantibody profiles of healthy individuals in comparison to patients undergoing melanoma immunotherapy. His goal is to understand if these patients have a specific antibody response that targets their tumors.

Whole Exome Sequencing in neurodegeneration

Owen A. Ross, Ph.D. is researching neurodegenerative disorders including Parkinson's disease, Lewy body disease, Pick's disease, multiple system atrophy, progressive supranuclear palsy, essential tremor and restless legs syndrome. He has requested whole exome sequence data from 89 Biobank participants without a history of neurodegenerative disorders to compare to whole exome sequence data from patients who have neurodegenerative disorders that he has recruited through a separate study. His goal is to identify genes related to neurodegenerative disease.

Molecular Regulation of Muscle Glucose Metabolism

Lawrence J. Mandarino, Ph.D. is researching glucose metabolism and obesity. He has requested whole exome sequence data from 89 Biobank participants. He is researching whether genetic variation in a gene called VWA8 causes differences in body mass, lipid levels, and glucose measures. His goal is to learn how genetic variations regulate how the body burns fat. This knowledge will help us learn why some people burn more fat than others and will have a major impact on our understanding of the origins of obesity.

International Consortium for Prostate Cancer Genetics Controls

Stephen N. Thibodeau, Ph.D. is researching the genetics of prostate cancer. He has requested samples from 500 Biobank participants without a history of prostate cancer to compare to patients who have prostate cancer that he has recruited through a separate study. His goal is to identify genes associated with increased prostate cancer risk that may be used to better screen men for prostate cancer and reduce the significant morbidity and mortality associated with this disease.

Genome-wide association for progressive supranuclear palsy and parkinsonism

Owen A. Ross, Ph.D. is researching Parkinsonian disorders, including Progressive Supranuclear Palsy (PSP) and corticobasal degeneration. He has requested genetic data from 818 Biobank participants without a history of neurological disorders to compare to patients who have PSP and corticobasal degeneration that he has recruited through a separate study. His goal is to identify or confirm common DNA variation and regions of the genome that may influence the disease susceptibility.

CARRIERS Study

Fergus J. Couch, Ph.D. is researching breast cancer genetics. He has requested DNA samples from 2500 Biobank participants without a history of breast cancer or any other type of cancer to compare to patients with breast cancer that he has recruited through a separate study. He is researching 1) breast cancer risk in the general population; 2) risk of cancer in individuals with particular genetic variations; and 3) the clinical relevance of new genetic variants in known cancer genes. His goal is to establish health care recommendations for individuals who have an increased genetic risk for breast cancer, a critical unmet need.

Inflammatory Bowel Disease Metabolomic Profiling

William A. Faubion, M.D. is researching Inflammatory Bowel Disease (IBD). He has requested to collect new urine samples from 75 Biobank participants without a history of IBD to compare to patients who have IBD that he has recruited through a separate study. He is researching the role of diet on maintaining remission in patients with IBD. His goal is to identify differences in the metabolomic profile (small particles of metabolism) that will identify IBD.

Genetics of Kidney Cancer

Alexander Parker, Ph.D., and Jeanette Eckel-Passow, Ph.D. are researching clear cell renal cell carcinoma, a type of tumor that occurs in the kidney. They have requested genotype data from 800 Biobank participants without a history of cancer to compare to genotype data from patients who have been diagnosed with renal cell carcinoma from a national collaboration called The Cancer Genome Association (TCGA). They are researching new genetic risk factors for kidney cancer. Their goal is to verify previous preliminary results and to generate data for funding renewal to support continued research.

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



CONTACT US

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

507-293-0203 (local)

1-866-613-2386 (toll free)

biobank@mayo.edu (e-mail)

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

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