

ISSUE 8 SPRING/SUMMER 2013

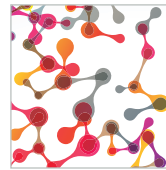
BioNews

> FOR PARTICIPANTS OF THE MAYO CLINIC BIOBANK

Hello from the Biobank Team!

We have many things in this issue to tell you about. One important update is that we will begin sending a “follow-up” health questionnaire to all of the original participants in the Biobank on approximately their 4th anniversary after enrolling in the Biobank. We kept this questionnaire very short (much shorter than the original one), and we hope that you will complete it when it arrives, but as always, it is your choice. It is very helpful for researchers using the Biobank to hear directly from you whether or not your health has changed since you enrolled in the Biobank. Also in this issue is an article on our new robotic freezers, which greatly facilitate the storage and retrieval of Biobank samples. There is also an article about the Community Advisory Board’s discussions of a new technology called “whole exome sequencing,” and the implications of using this technology with the Biobank samples. These discussions are particularly important because Mayo Clinic researchers are increasingly using this technology to help them better understand the genetic causes of health and disease. As always, we hope you enjoy this issue of BioNews, and thank you for your long-term support of the Biobank.

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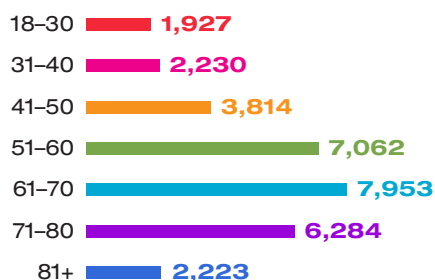
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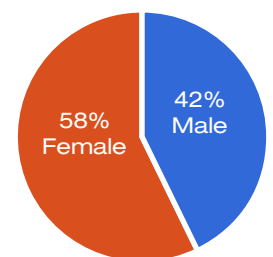


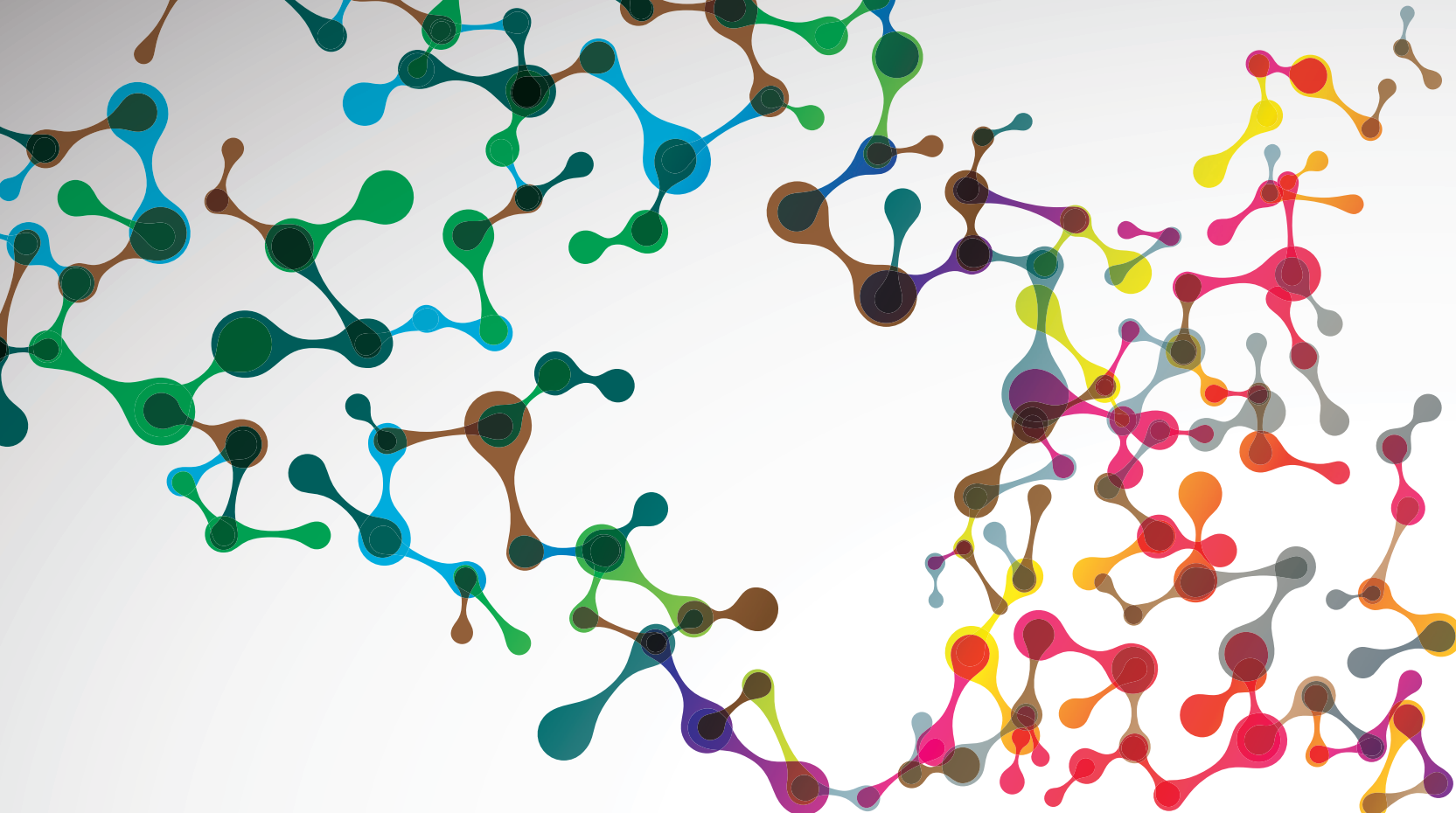
DEMOGRAPHICS

Olmsted County: **12,147**
 SE MN: **4,817**
 Rest of MN: **5,029**
 Iowa: **1,871**
 Wisconsin: **1,316**
 Dakotas: **521**
 Other US: **5,757**
 Missing: **35**

GENDER

Total: **31,493**
 Female: **18,186**
 Male: **13,307**





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 **66 approved projects** requesting approximately **71,907 samples or data** 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, and a subset of these projects are summarized here.

MECHANISM OF A BLOOD PRESSURE MEDICATION AND ITS EFFECT ON THE INTESTINE

Joseph Murray, M.D. has identified in previous research that the commonly prescribed blood pressure medication olmesartan causes severe gastrointestinal issues such as nausea, vomiting, diarrhea, weight loss and electrolyte abnormalities in a small percentage of individuals. Interestingly, these symptoms are also common among those who have celiac disease. Mayo Clinic is conducting a study to explore why this is happening to some people on this medication and why the symptoms are so similar to celiac disease, despite a demonstrated lack of gluten sensitivity in these individuals. Although the number of individuals who take olmesartan is low, the symptoms that some people face with this medication may be severe if left untreated. Therefore, Dr. Murray has asked for up to 200 Biobank blood samples from participants for his study, some of whom are on this medication (cases) and some of whom are not (controls). This will help determine more about the effects of this medication in patients and if there are genetic markers that could identify these individuals who have significant gastrointestinal issues from this drug, before they develop the symptoms.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE AND LUNG CANCER

Ping Yang, M.D., Ph.D. is researching lung cancer and Chronic Obstructive Pulmonary Disease (COPD). She has requested samples from 1720 Biobank

participants who do not have lung cancer. Dr. Yang will compare the genetics of these individuals to individuals that have COPD and/or lung cancer whom she has recruited through a separate study. She is trying to identify the genetic changes that may contribute to the development or risk of development of COPD and/or lung cancer, so that this information could be used for at-risk patients in the future.

THE EFFECTS OF DIETARY SUPPLEMENTATION ON HEPATIC INSULIN ACTION AND GLUCOSE TOLERANCE IN PRE-DIABETES

Rita Basu, M.D. is researching the effects of dietary supplementation on liver fat content and glucose metabolism in pre-diabetic subjects. Seventy million people have either pre-diabetes or type 2 diabetes. People with pre-diabetes have up to a 50 percent chance of developing diabetes within five to ten years. Dr. Basu is recruiting Biobank participants with a history of impaired fasting glucose or HbA1c levels within the pre-diabetic range for a 12-week feeding study. In this study, subjects will be assigned to one of three diets: 1) a diet high in monounsaturated fat, 2) a diet high in fiber, or 3) a standard diet. Dr. Basu's research group wants to determine whether dietary changes reduce liver fat, improve liver insulin action, and help prevent progression to type 2 diabetes. They also plan to quantify liver fat using liver scan software that will provide further insights into the type and kind of liver fat. This study will provide important preliminary data for lifestyle interventions in people with pre-diabetes.

GENETIC EVALUATION OF CARDIOVASCULAR DISEASE RISK

Iftikhar J. Kullo, M.D. is researching communication of genetic risk of coronary heart disease and how it affects participant motivation to make lifestyle changes such as increased exercise and decreased dietary fat intake. He has requested DNA samples from 1,300 Biobank participants who do not have a history of coronary artery disease, peripheral arterial disease, abdominal aortic aneurysm, and statin use. Genetic testing of coronary heart disease risk will be performed, communicated to some of the study participants, and participants will be assessed for motivation to make lifestyle changes. This study is also a pilot investigation about including genetic information in participants' electronic medical record.

THE IMPACT OF CYTOMEGALOVIRUS ON RHEUMATOID ARTHRITIS: A PILOT STUDY

John Davis, III, M.D. is researching Rheumatoid Arthritis (RA). He is trying to determine whether history of exposure to cytomegalovirus, a common virus with few symptoms, has any bearing on development of RA. He has requested samples from 100 Biobank participants for his study, some of whom have RA (cases) and some of whom do not (controls).

COMMUNITY ADVISORY BOARD ACTIVITIES

In a recent meeting of the Biobank Community Advisory Board (CAB), director Stephen Thibodeau explained genomics using a helpful metaphor involving something you can probably find in every kitchen: a cookbook. You can think of your genome as a cookbook. Just as a cookbook contains many different recipes that outline how to make particular dishes, your genome is made up of many different genes that contain the specific instructions for how to build your body. Extending the metaphor a little further, recipes are made up of words and numbers in the same way as genes are made up of segments of DNA. Now imagine what would happen if your cookie recipe contained a typo, and “1 teaspoon salt” read “1 tablespoon salt” instead. Your next batch of cookies might not turn out so well! In the same way, differences in your DNA can have a profound impact on your health. Advances in whole genome sequencing are giving scientists the ability to find those typos, “proofreading” your genetic cookbook to identify typos. Although these technologies hold promising possibilities in identifying and treating diseases, they also raise significant ethical questions about how we manage healthcare and research.

“ Now imagine what would happen if your cookie recipe contained a typo, and “1 *teaspoon* salt” read “1 *tablespoon* salt” instead. Your next batch of cookies might not turn out so well! In the same way, differences in your DNA can have a profound impact on your health. ”

What if your Biobank sample was used in a research project that conducts whole genome or whole exome sequencing? Researchers may discover genetic variants that affect your risk of developing numerous health conditions. What information would you want to know about your genetics? What information would you not want to learn? The data obtained from your genome can have significant repercussions for not only you, but also your relatives.

What should be the Biobank’s policy on returning these results to you, the Biobank participant? To gain insight on these dilemmas, the Biospecimen Trust Oversight Group consulted the CAB, a group made up of individuals from a variety of backgrounds that provides different perspectives on these issues. In March, CAB members dedicated one of their Saturdays to spend the day hashing out the ethical, legal, and social challenges involved in genomic research. As policies are developed and as genomic research advances, the CAB will remain actively engaged to ensure that the voice of the community continues to be heard on these complex ethical issues.



IT’S BEEN OVER FOUR YEARS SINCE PEOPLE BEGAN ENROLLING IN THE MAYO CLINIC BIOBANK AND WE’RE WONDERING, “WHAT’S BEEN GOING ON IN YOUR LIFE?”

That’s why we’ve started sending out a short (8-page) follow-up questionnaire to all participants. The purpose of this questionnaire is to find out about certain health conditions that may have developed since you first enrolled in the Mayo Clinic Biobank. It includes a series of questions about gastric symptoms that would help us identify if you have an undiagnosed GI condition called irritable bowel syndrome. In addition, there are general health questions that your doctor would not typically ask.

We will use this information to determine if your data and samples are appropriate for use in various studies. For example, if you have developed a particular disease since you enrolled

in the Biobank, we would know not to use your sample as a “control” (someone without the disease). However, we could use your sample as a “case” (someone with the disease). Although some of this information may be in the Mayo medical records, we know that many people enrolled in the Biobank seek medical care at non-Mayo Clinic facilities. This questionnaire will allow us to collect the same information from everyone.

You can expect to receive this questionnaire at about four years after you enrolled. If you enrolled in 2009, you can expect to receive the questionnaire in 2013. If you enrolled in 2010, you will receive your questionnaire in 2014, and so on.

IT IS VERY IMPORTANT THAT YOU COMPLETE THIS QUESTIONNAIRE IF YOU ARE WILLING AND SEND IT BACK TO US WHEN YOU RECEIVE IT. IT WILL HELP US TO CONTINUE ADVANCE MEDICAL RESEARCH IN MANY AREAS.

THE BIOBANK INVESTS IN ROBOTIC FREEZERS

As a Mayo Clinic Biobank participant, your blood was drawn to help facilitate research. Have you ever wondered, exactly what happened to your blood and how it was stored? All blood samples from Mayo Clinic Biobank participants go through several processes and are divided into different blood products, such as serum, plasma, DNA and white blood cells. Researchers need these different sample types depending on what downstream research they plan to do. From each participant's blood sample, over twenty small vials at exact volumes are created. These samples are stored in specialized robotic-friendly tubes for use in high-capacity, ultra-cold freezers. The current Biobank freezer can store over 600,000 individual tubes. Additional freezers will be added in late 2013 to expand our storage capacity to 2.25 million tubes.

Robotic storage and retrieval of Biobank samples in high-capacity, ultra-cold freezers, without human intervention, helps to reduce the risk of errors in sample processing. All sample information (storage location, volume, sample type, sample ID) is recorded in a laboratory computer system. When the Biobank Access Committee grants approval to a researcher to receive samples from the Biobank for his or her research study, the laboratory staff is told which samples need to be pulled and where they need to be sent. The robotic freezer retrieves these samples for the lab staff who can then quickly get these samples to the researcher.

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mayoresearch.mayo.edu/biobank

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