BioNews

For participants and friends of Mayo Clinic Biobank

ISSUE 19 | SPRING 2021

In this issue

If you have a question or comment about anything in this edition of BioNews or the Biobank in general, please contact us. We like to hear from you.

Phone
866-613-2386 (toll free)

Email
biobank@mayo.edu

WELCOME TO THE 2020-2021 EDITION OF BIONEWS

It has been quite a year for all of us. Like many of you who were asked to change directions quickly the Mayo Clinic Biobank team responded and quickly helped to create a Mayo Clinic COVID-19 Pandemic Response Biobank in order to provide an immediate repository of samples for research in this area. This new biobank was formed in part with the advice of a Bioethics Task Force that considered the ethics of consenting donors during a public health emergency. We will report more on these COVID-19 related efforts in the next edition of BioNews.

In this edition, we will continue our conversation about a research collaboration we announced last year called Project Generation in which we will soon receive genetic sequencing data on most Biobank participants. We are also excited to highlight a new form of communication we are piloting, called a ChatBot, to help us schedule the genetic counselor visits needed to return the results. (Note, receiving results is optional.)

Finally, the Community Advisory Board will provide an update on both in-person and virtual activities they have been engaged in this past year kicking off a new BioNews series we are excited about called “Every Specimen Has a Story”.

The Mayo Clinic Biobank continues to support many active research protocols and make meaningful contributions to the scientific literature.

To date, 333 projects have been approved to use Biobank samples, including 7 COVID-19 related projects. There have been 217 publications that have come out of these research efforts. Thank you for your response to our most recent survey! Your information contributes to this important research.

56,000
Biobank participants

333
Projects approved to use Biobank samples

7
COVID-19 related projects

217
Publications from research efforts

Through Project Generation, participants could have an opportunity to learn about genetic results that may be important to their health.

Project Generation

WHAT YOU NEED TO KNOW

In the Autumn 2019 issue of BioNews, we announced the launch of Project Generation, a new collaboration between Mayo Clinic and Regeneron Genetics Center. DNA samples from all current Biobank participants and an additional 44,000 samples from other Mayo studies will undergo whole exome sequencing at Regeneron. Results of this sequencing will be returned to Mayo for research purposes. In exchange, the Biobank will share de-identified medical record data with Regeneron. (Participant identifying information will not be shared). This exchange of information is key for researchers to make progress on important medical questions related to our health and genetic code. All samples have been sent out for sequencing. We expect to start receiving data back in summer 2021.

About whole exome sequencing:

Whole exome sequencing refers to a genetic test that looks at specific regions of our DNA that code for genes. Genes are the genetic recipes for life that our cells use to make a variety of products (like proteins) for normal development and growth. Information about our risk for certain diseases is most likely to be located in our genes. The Biobank researchers can choose to look at certain genes within the exome known to be associated with their disease of interest specifically. See the Spring/Summer 2012 issue of BioNews, available on our website, for a description of exome sequencing.

Because this research study using the Biobank will have genetic sequencing data on most of its participants, we know that researchers will discover genetic information that could have significant implications for the health of some participants. For instance, a result could tell us a participant is at increased risk for a certain condition. It could tell us how to better manage a disease someone already has. And it could help us confirm a genetic cause for something in a participant's health history. Although we do not know everything or have the right tools yet to interpret all the important parts of the genetic code related to a participant's health, we are able to understand quite a bit.

QUESTIONS AND ANSWERS

Q: What type of results might the Biobank contact me about?

A: The Biobank will initially return results to participants who test positive for variants identified in a list of 59 genes. An expert panel from the American College of Genetics and Genomics (ACMG) previously identified a list of genes that are well studied and have clear disease associations. About half of the genes on the list are associated with increased lifetime risks for certain types of cancers. For example, one of these genes, called BRCA1, increases a woman's risk for breast cancer from about 12% to up to 85% during her lifetime. Other genes on the list cause an increased risk for heart disease due to genetic forms of high cholesterol, heart arrhythmia, and an enlarged heart muscle. There are genes on the list associated with metabolic disorders in which the body stores too much of a toxic substance that can lead to organ damage or disease. Fortunately, if a person is aware of their risk, there may be things that can be done to detect a problem early and in some cases prevent disease. It is estimated that ~3% of Biobank participants will test positive for a variant in one of these 59 genes.

Q: How will I know if I'm one of the participants that tested positive?

A: The Biobank will contact all participants who are found to have a variant in one of the 59 genes. We will only contact you if we find something.

Q: How will I be notified?

A: If we find something in your DNA, we will first send you a letter in the mail. This letter will invite you to talk to a genetic counselor over the phone to learn more about your specific result. Read the letter carefully for instructions about using a Chatbot to schedule your genetic counseling appointment.

We are excited to offer you an opportunity to brush up on your genetics, provide us some information, and schedule your appointment from your smartphone or computer. After you have received the initial letter, we will send you a link to a Chatbot via email or text message. This is an interactive application that will ask you questions and facilitate scheduling. It's easy, convenient and quick. Importantly, for both the Biobank and our participants, it will help us schedule the visits with the genetic counselors more efficiently. Our Community Advisory Board has reviewed the Chatbot and give it a thumbs up!

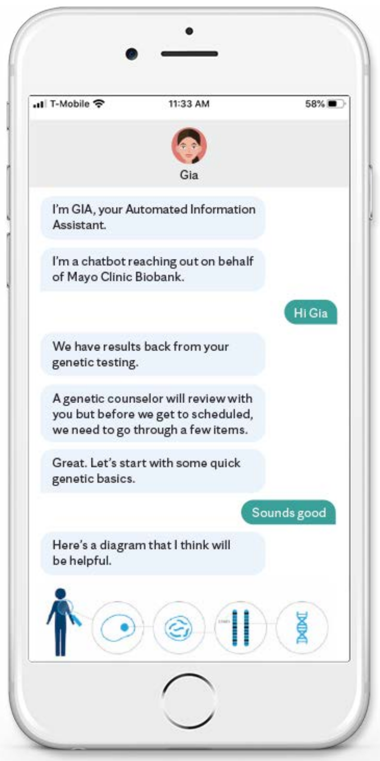
There will be instructions for scheduling a genetic counseling appointment if you do not have a cell phone or email on file with the Biobank. Additional information will be included in the initial letter you receive if you test positive. Importantly, you do not need to learn your results. You can fill out the refusal form included in the initial letter and return it us by mail.

Q&A continues on the following page

WHAT IS A CHATBOT?

A chatbot is an online computer program that simulates a human conversation. Chatbots are commonly used for customer service support when online shopping or booking a hotel. Chatbots can answer questions and collect information quickly. We hope the chatbot will make it easy and fast to schedule the phone call with the genetic counselor and make the genetic counseling appointment as beneficial as possible.

Our chatbot is accessible on any device with an internet connection, including a smart phone, iPad or desktop computer. The chatbot will provide education on genetics and genetic testing. It will also collect personal and family health histories for the genetic counselor to review ahead of the appointment. The chatbot follows guidelines from both Mayo Clinic and HIPAA (Health Insurance Portability and Accountability Act). ■



I'm GIA, your Automated Information Assistant.

I'm a chatbot reaching out on behalf of Mayo Clinic Biobank.

Hi Gia

We have results back from your genetic testing.

A genetic counselor will review with you but before we get to scheduled, we need to go through a few items.

Great. Let's start with some quick genetic basics.

Sounds good

Here's a diagram that I think will be helpful.

NOTIFICATION PROCESS

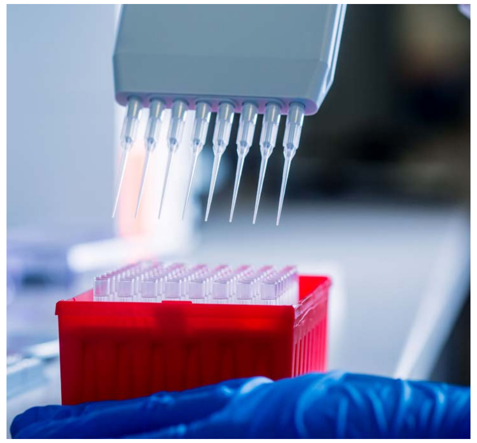
If you have a positive test result:

1 Receive and read initial contact letter from Mayo Clinic Biobank

2 Receive text message or email with a link to Chatbot

3 Click on the link to interact with Chatbot's Genetic Information Assistant (GIA)

4 Receive genetic education and schedule a genetic counseling appointment



It is our hope that studies using the Mayo Clinic Biobank will advance our understanding of disease.

Q: If I am not contacted, does this mean I don’t have to worry?

A: If we don’t contact you, this could mean a few things:

1. It could mean we did not find any variants in the genes tested. These genes were derived by experts because they are known to affect clinical care. If you are not contacted, this doesn’t completely rule out your risk for hereditary cancer, heart disease or other genetic conditions because we are only looking at 59 genes. There are other genes not on this list that may be linked to health risk and disease. We also know that most types of common disease are not caused solely by our genes and that lifestyle and other non-genetic factors are important as well.
2. It could mean we may no longer have a sample to test. We may have used up all of your sample in a previous research study or we were not able to extract viable DNA from your sample.
3. It could mean you live outside of the United States. We are only returning results to United States residents at this time.
4. It could mean your sample may not have been included in one of the first batches of samples tested for Project Generation, therefore your results may be arriving at some future point. Stay tuned for future newsletters announcing completion of the Project Generation return of results process through 2022.

Q: I know I signed a consent when I provided my sample to the Biobank but what if I don’t want to know my result?

A: That’s ok! You can contact our staff by emailing us at biobank@mayo.edu or calling us toll-free at 866-613-2386 and letting us know you do not want us to contact you if we find something. You can do this now or wait until you are contacted. If you are contacted, you can refuse to receive your specific result before or during your genetic counseling phone appointment.

Q: What if I’m unsure about whether I should learn my result?

A: We encourage you to meet with the genetic counselor. This phone appointment is a free consultation provided by the Biobank for all individuals who have a medically significant result. The genetic counselor can tell you more about the genetic testing that was done and answer your specific questions about the study. If after speaking with the counselor you decide you do not want to learn your result, you can decline at that time.

Q: What kinds of things will the genetic counselor talk to me about?

A: The genetic counselor will answer your questions about the study and confirm that you want to learn your result. They will then provide you with the gene and the variant you tested positive for. They will tell you the specific risks and diseases associated with the genetic variant and what can be done about it.

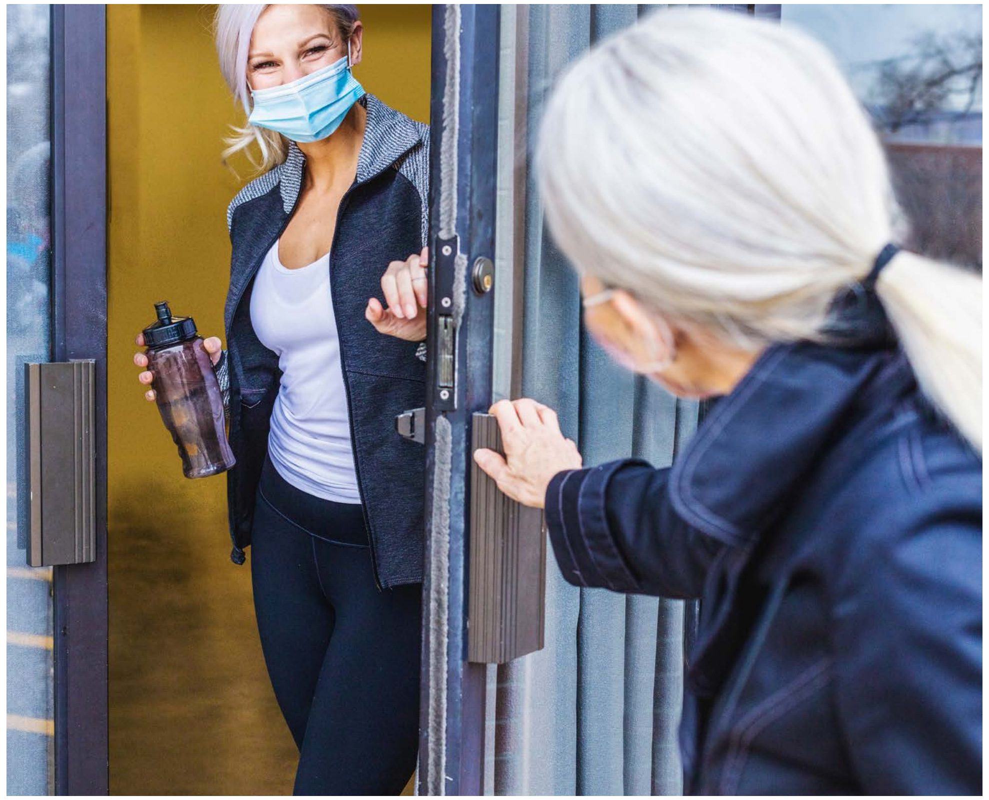
Q: If I find out I have an increased risk for a certain disease, should I call my doctor and tell them?

A: It will be important for your doctors to know about and understand how these results impact your health. However, the genetic counselor will talk to you about first confirming the result using a fresh blood sample from you. This is a standard procedure and is strongly recommended following the identification of a medically significant research finding. The genetic counselor can help you with this step. Only clinically confirmed results should be used by physicians to make decisions about your healthcare.

Clinical confirmation typically takes 1-2 weeks. Once the result is confirmed, the genetic counselor will help you talk to your primary care physician about your result and facilitate referrals to physicians who specialize in managing the risks identified through genetic testing. They will also provide you with resources to help you communicate your results to your family members.

If you are not able or elect not to proceed with clinical confirmation during the appointment, the genetic counselor will provide you with a letter and instructions for getting this done later through a local provider. ■

If we can understand the underlying genetics we can develop better ways to prevent, treat and cure disease.



Over the years, the CAB network has expanded and now includes three distinct boards made up of people from the surrounding local communities.

Community Advisory Board

UPDATE

The Community Advisory Board (CAB) network includes three distinct boards from the local communities of Rochester, Minnesota; Jacksonville, Florida; and Phoenix, Arizona to provide ongoing guidance to the Mayo Clinic Biobank based on views of individuals from their region and the Biobank participant populations. The Sangre por Salud (SPS) Biobank from Phoenix area Latinx donors is made possible through collaboration with the Mountain Park Health Center and Arizona State University.

Since the last issue of BioNews, each site held four in-person CAB Meetings reviewing a broad range of topics and seeking community advice and recommendations. Topics included privacy protections provided by the biobank's "certificate of confidentiality." The community members' role play activity on this topic was helped out at the Jacksonville site by a visiting retired FBI agent! Due to the pandemic, the Network explored virtual community engagement in 2020—hosting two virtual socials, and combining Rochester and Jacksonville CABs site meetings for lively zoom meetings. Recent CAB meetings included discussion of past project results and community advice for new projects, including biobank research on electronic consent and polygenic diseases.

Summary of recent CAB network meeting topics:

- Explored virtual options of engaging members in multi-site socials and joint meetings
- Provided feedback on Chatbot technology, anticipating Project Generation return of results
- Gave public views and community input on Biobank research of addiction genetics

SEEKING MEMBERS

Community advisory board members are tasked to represent their community's values and diverse peers in regular meetings where Biobank research projects are presented for input and guidance. We are seeking additional members with diverse backgrounds to join the CABs in Rochester, MN and Jacksonville, FL. If you are interested, email mayobiobankcab@mayo.edu c/o Sara Watson. Please include the experiences and community values that you could bring to the community advisory board.

BIOBANK CAB NETWORK

Minnesota (Est. 2009)

- 13 members

Florida (Est. 2014)

- 11 members

Arizona (Est. 2014)

- 11 members

Sara E. Watson
Mayo Clinic Biobank Coordinator
Rochester, Minnesota
Jacksonville, Florida
SPS Collection, Phoenix, Arizona

EVERY SPECIMEN HAS A STORY

The CAB Network welcomed a new coordinator, Sara Watson. Sara joined the Biomedical Ethics Research Program at Mayo Clinic in October 2019 as a research coordinator and is excited to support Dr. Karen Meagher and the Mayo Clinic Biobank.

The CAB team is thrilled to bring you a new interview series, titled *Every Specimen Has a Story*, wherein we share the value of public engagement in biobanking and biospecimen research. We will learn that each person who donated a biospecimen has an interest in the research being done with the Mayo Clinic Biobank.

Our first installation in the new series is a question and answer interview with Rochester CAB member, Randy Moger:

Q: How long have you been a CAB member?

A: 12 years (I was on the original panel/focus group about establishing a board—been on the board since day 1!)

Q: Share your history and experience with the Community Advisory Board. How did you learn about the CAB? What interested you about the CABs goals and mission? Why did you want to join?

A: I have been on the Board 12 years. Got a phone call out of the blue, asking if I was interested in being on a community discussion on Mayo Clinic forming a Biobank. After hours on the panel, hearing reasons for and against collecting specimens and also hearing from the Marshfield Biobank and that they have a Community Board, thought it would be good idea for Mayo Clinic to also start one. Asked for volunteers and I agreed to be one. I have enjoyed it greatly!

Q: What is it like being a CAB member?

A: It is exciting to be a CAB member! With new technology and research, everything is always changing. Something new comes up all the time. It is exciting to hear about new medications and treatments for certain diseases in the works by using the Biobank samples.

Q: What do you enjoy most at CAB meetings?

A: The speakers and Research PI's [Principal Investigators] that come to the meetings and explain their studies and what they are looking for and then we give them our feedback. We have great discussions.

> The goal of "Every Specimen Has a Story" is to elevate and highlight the importance of and experiences of community members.

Q: What are some positive reflections on the importance of community advisory boards based on your experience? Why is research public engagement important to you?

A: Surveys have been rewritten, letters have been rewritten, and studies have been reviewed because of the CAB feedback. The CAB is the public's voice. We are not afraid to ask questions, mostly "Why?" and/or "What if?"

Q: What would you like Biobank participants to know about the CAB?

A: I feel a lot of pride being on the board. I feel like my concerns are taken seriously and will be addressed. Everyone on the CAB has a chance to give their feedback and everyone is treated as an equal. It is great to hear other ideas that I never thought of before. ■

FEATURED CAB MEMBER

Randy D. Moger
Community Advisory Board Member
Rochester, Minnesota

Mayo Clinic
200 First Street SW
Rochester, MN 55905

About Mayo Clinic Biobank

Mayo Clinic and the Center for Individualized Medicine have made a significant commitment to building a world-class, scalable biorepository infrastructure, which includes two specimen processing core laboratories and several large centralized biospecimen collections.

One of these biospecimen collections is the Mayo Clinic Biobank, a collection of samples, including blood and blood derivatives, and health information donated by Mayo Clinic patients. Unlike many biobanks in existence at Mayo Clinic and elsewhere, the Mayo Clinic Biobank is not focused on any particular disease. Rather, the Biobank collects samples and health information from patients and other volunteers regardless of health history. Once a participant becomes a part of the Biobank, he or she becomes a part of ongoing health research.

> “The glory of medicine is that it is constantly moving forward, that there is always more to learn.”
>
> – William J. Mayo, M.D.

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