DCM beat

DCM Research Project

Newsletter of the Dilated Cardiomyopathy Research Project at The Ohio State University

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Family history can provide important health information

Families are an important part of our lives. Some may be born into their family while others may be adopted in. Relatives may live close by and others may live far away. Family relationships are constantly changing and look different for every individual. There are multiple factors that can impact how family members communicate with each other and what information they share with each other. This was in part the rationale for the randomized trial of the Family Heart Talk tool in the DCM Precision Medicine Study, which some of you may have seen as a part of your participation (Box 1).

The shared genetics of our biological relatives and our lived experiences help shape who we are. The genes we inherited from our parents are important for health. A disease-causing genetic change can result in the development of shared health problems in a family, or appear to "run in families." While some individuals may be the first in their family to face a specific health problem, 20-35% of individuals who develop DCM for unknown reasons are found to have at least one relative with DCM once family members have a heart check. In addition, most DCM is silent and without symptoms until late stages of the disease, highlighting the importance of periodic heart checks to detect early DCM in those at risk.

Discussing genetics and personal health information with relatives can be difficult for many reasons. These conversations may be emotional, and can include feelings of guilt, fear, or uncertainty. Care providers such as genetic counselors and cardiologists can help provide resources and support on how you can begin talking to your family about their genetic risk.

The Family Heart Talk booklet is a part of a randomized-controlled study of the DCM Precision Medicine study and may look familiar to those whom participated. Daniel Kinnamon, Ph.D. recently presented on the positive findings of this study at the Annual American Society of Human Genetics Conference.

DCM Project Portal

The DCM Project Portal is an IRB-approved web interface for participants of all DCM Research Project studies.

We welcome any study participants interested in using the DCM Project Portal to create an account while we continue to test and refine this tool.

If you are interested, please email DCM.research@osumc.edu for instructions.

Study Participant Spotlight: Carla Dunton

Carla Dunton is a participant in the Dilated Cardiomyopathy (DCM) Precision Medicine Research Project and a recently enrolled member of the Cardiac Magnetic Resonance (CMR) ancillary study.

Ms. Dunton's enrollment in the DCM Research Project followed her mother's diagnosis with DCM. While Ms. Dunton has not been diagnosed with DCM herself, she has seen first-hand the impact DCM can have on an individual's everyday life and how families share risk information. Her mother's diagnosis "took [her family] by storm." However, the diagnosis of DCM shifted how her family communicated—"setting the tone for [her family] to be open about [their] health."

> "For me, just being able to be a part of something… just being able to participate… You want to be a part of something for the good… and in medicine, you can only find out things if people are willing to participate. If you do not have any participants, you cannot learn. So, that's why I do it."

While her mother's diagnosis of DCM resulted in open discussion about each other's health, the severity of her mother's condition and the new understanding of her family's medical history brought about emotions of fear. Ms. Dunton detailed how her mother's journey to her diagnosis drastically changed her once active lifestyle to an early retirement. As Ms. Dunton stood by her mother through her medical therapy and cardiac rehabilitation, she and her family looked for ways to be involved and understand DCM further. Being involved, understanding their risk, and learning how to monitor for symptoms and reduce risk factors were ways Ms. Dunton and her family sought to improve their health and help reduce some of the feelings of anxiety. Ms. Dunton and her mother enrolled in the DCM Research Project, as well as becoming involved with the American Heart Association through offered programs and fundraising.

While Ms. Dunton and her family are actively engaged in the DCM community, her mother's path to a diagnosis was complicated and emotional. Through their experiences they learned how to advocate for their health, and highlighted the importance of a positive relationship between patients and their medical providers, emphasizing open communication, trust, and respect. In addition, DCM education from a trusted medical provider became a helpful tool for understanding the genetics of DCM. It was also a positive motivating factor to determine the status of her own heart health and continued participation in the DCM Research Project.

Ms. Dunton and her family's experience with DCM highlight the impact the severity of this disease can have on one's day-to-day life. Further research is needed to determine optimal heart screening tools to identify signs of DCM before advanced stages. Ms. Dunton's story also highlights the importance of comprehensive education, a positive patient-provider relationship, and being aware of one's family medical history when possible.

By Katie Parker, MS, Licensed Genetic Counselor and Team Member in the DCM Precision Medicine Study.

The DCM Research Project is grateful for the Dunton family and for each one of our study participants who help us advance understanding of the genetics of DCM.

AN UPDATE TO NIH GRANT TO BE SUBMITTED

Exciting developments are happening with the DCM RESEARCH PROJECT. An application to renew the DCM Precision Medicine Study National Institutes of Health grant will now be submitted in **July of 2023** due to exciting new data and progress on paper production. Stay tuned! In this grant, we will propose to bring family members back to DCM Consortium clinical sites for two clinical re-screenings (medical history, exam, ECG, echocardiography) during the 5 years of NIH support. The study will also propose to enroll additional family members not yet enrolled and conduct clinical screening. We still have an enormous amount to learn about DCM genetics, how to detect it, its genetic makeup, and how to prevent it! **THANK YOU TO ALL** the probands and family members enrolled in the DCM Precision Medicine Study.

DCM Precision Medicine Study

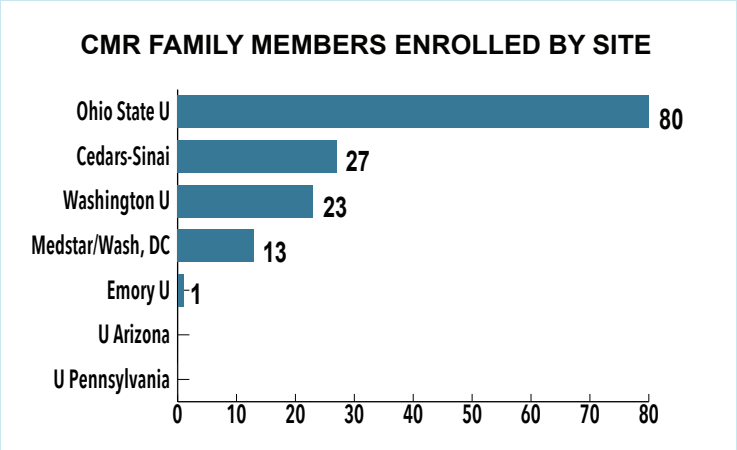
Precision CMR Study

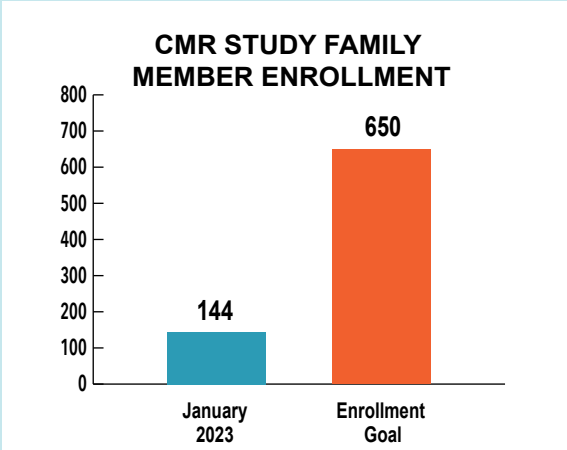
The Cardiac Magnetic Resonance (CMR) Study is now screening genetically at-risk family members from the DCM Precision Medicine study at select sites. The goal of the study is to identify the earliest signs of DCM using cardiac MRIs. Research staff will contact eligible family members over the next year and invite them to participate in the study.

If you have questions or would like to participate now, please contact the OSU Coordinating Center at dcm.research@osumc.edu or 877-800-3430.

Many at-risk relatives enrolled in the DCM Precision Medicine Study have already been contacted regarding their eligibility for the CMR Study. In addition, at-risk relatives from any site who have not yet been contacted, if willing to travel to one of the sites in the graphs below, may also be eligible for this study. If you or your relative is interested in participating, please contact the OSU Coordinating Center to determine eligibility.

See graphs below detailing the number of family members enrolled by site and the total number of family members enrolled.





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ADDRESS SERVICE REQUESTED

TO:

DCM BEAT NEWSLETTER

You are receiving this DCM Research Project newsletter because you are a consented participant in the DCM Precision Medicine, Discovery, or Legacy Study. The aim of the Project is to discover the genetic basis of DCM and to translate newly found knowledge into the practice of medicine. Your continued participation is vital to our research effort, please help us by updating us with new developments in your family.

DCM Beat BULLETIN BOARD

CLINICAL GENETIC TESTING?

While our research continues even after a research result is identified in a family, we recommend that all individuals with DCM consider undergoing clinical genetic testing. Clinical genetic testing is done similarly to any other blood test that is ordered by your doctor and sent out to a laboratory. Your results would be provided to your doctor. Clinical genetic testing can be a complex process. Therefore, referral to a center expert in genetic evaluation should be considered. We can help you identify a clinic that offers genetic counseling and testing for DCM.

If you have undergone clinical genetic testing outside of this study and have results, please provide us with a copy of your results for our database. You can share these by contacting the study or by uploading to your DCM portal account.

Please contact us (toll-free) at 877-800-3430 or email the DCM Research Project at *DCM.research@osumc.edu*.

MEDICAL UPDATES

If anyone in your family is newly diagnosed with heart problems, please let us know. Similarly, if you or anyone in your family has had heart or genetic tests performed outside of the study, regardless of results, we would be interested in receiving copies. Please contact us and we will send you a medical records release form. If we have already sent you medical record release form(s), please send us the completed form(s) as soon as possible. You may also complete medical record release forms and upload medical records in your DCM portal account.

CONTACT INFORMATION UPDATES

If you have moved, have a new phone number, or new email address, please let us know. Call 877-800-3430 or email us (DCM.research@osumc.edu), or update your information through your DCM portal account directly. This way we can get in touch with you for any follow-up and continue to send you our newsletter.

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