



## In this Issue

**Page 2:**  
Participant Highlight  
Elizabeth Dolan

**Page 3:**  
NIH Grant Update  
DCM Project Portal  
Continued

**Page 4:**  
DCM Beat Bulletin  
Board

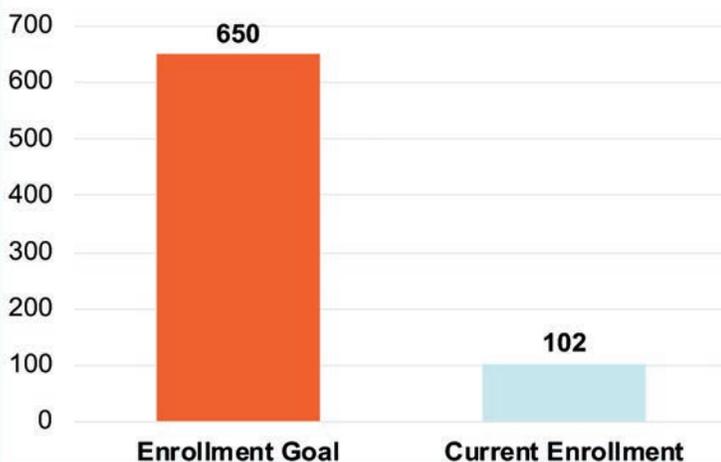
## The DCM Research Project goes electronic: Introducing the DCM Project Portal

With plans of expanding the number of DCM patients and families in the DCM Research Project, a web-platform has been developed for current and future study participants: The DCM Project Portal. As was highlighted in the last issue of The DCM Beat, The DCM Project Portal is a web-platform that allows users to create a password protected account, where they can directly communicate with study staff in a secure messaging platform, as well as invite family members to participate in the study with them through an automated email system. In addition, new family members or DCM patients can join the study electronically, with eligibility assessment and consent process built in for those who have not yet consented to participate. In September, we received approval from our Institutional Review Board at the University of Pennsylvania to use this web-based approach to invite and consent participants to the study. See page three for a figure demonstrating how you, your enrolled family members, and unenrolled family members will be able to use this platform.

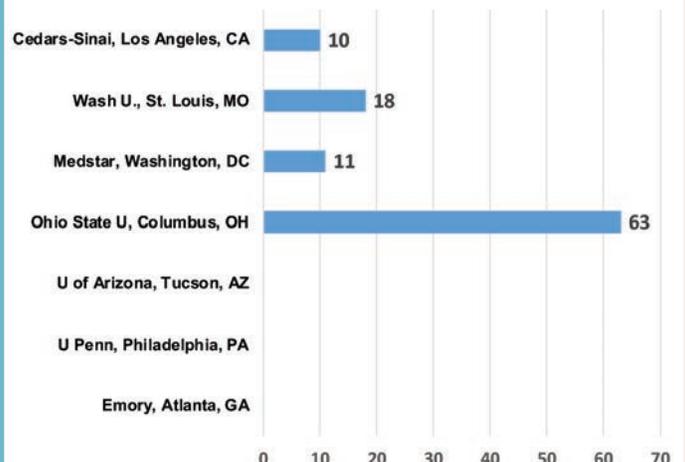
## DCM Precision Medicine Study Precision CMR Study

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](mailto:dcm.research@osumc.edu) or 877-800-3430. See graphs below detailing the number of family members enrolled by site and the total number of family members enrolled.

**CMR Study Family Member Enrollment**



**CMR Family Members Enrolled by Site**



# Study Participant Spotlight: Elizabeth Dolan

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



While Ms. Dolan has not been diagnosed with DCM, she is no stranger to the variable impact this heart condition can have within the same family. Ms. Dolan and her family were introduced to the study following her brother's diagnosis of DCM and placement of a left ventricular assist device (LVAD), a mechanical pump administered to individuals with heart failure. Since her brother's diagnosis multiple brothers and sisters, as well as extended family members, have been diagnosed with DCM and arrhythmias.

Understanding first-hand the importance of the earliest possible detection of signs of DCM, Ms. Dolan was eager to participate in the CMR study, which aims to utilize detailed imaging to monitor the hearts of at-risk relatives of individuals with DCM before more severe changes occur.

**"I jumped at the chance to be a part of it because I want to keep my heart healthy for one thing... By studying our family [researchers] might gain insight into what actually causes dilated cardiomyopathy and how to help that in other people."**

Prior to participating, she had not had conversations about how genetics play a role in heart disease. Despite Ms. Dolan's inconclusive genetic testing in her family, she has gained a deeper understanding of the genetics behind DCM. Ms. Dolan described gaining this knowledge and experiencing the impact of disease on her brother's health in particular as an "eye opener." Furthermore, while results from the CMR study positively reassured Ms. Dolan of her heart's health, participation sparked an increase of conversations

between relatives about their family history of heart disease and a shared appreciation of "staying aware of what heart problems might arise."

Many individuals, like Ms. Dolan may have a family history of DCM while they themselves are healthy. Similarly, many individuals with a family history of DCM may have different presentations and experiences with the disease—even between relatives in the same family. Ms. Dolan and her family's experience highlight the importance of understanding the genetics of DCM and the need for early detection and intervention. Studies such as the CMR ancillary study aid in advancing research in DCM as well as hopefully identifying opportunities for early detection to maximize the health of those with DCM before advanced disease.

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



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

**This spotlight highlights the importance of early screening for DCM when you are at risk, even if you are not experiencing symptoms. DCM can be silent until late phase disease, which in most cases presents with heart failure. Parents, siblings, and children of patients with DCM need to undergo clinical screening periodically with echo or cardiac magnetic resonance imaging.**

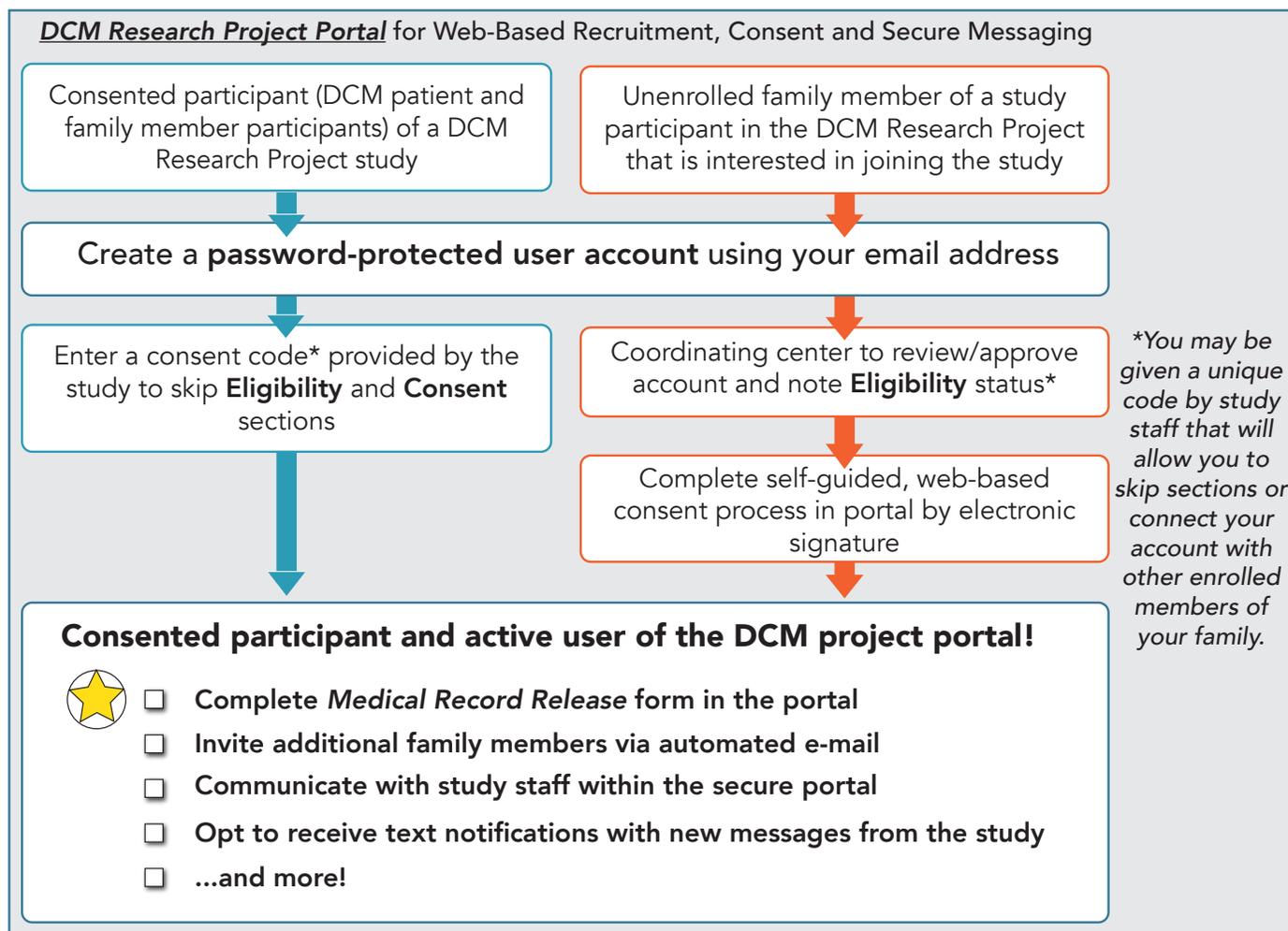


## AN UPDATE TO NIH GRANT TO BE SUBMITTED

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 March 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.

## The DCM Project Portal Continued

Final testing is ongoing with plans to open the portal for use to all participants in early 2023. We look forward to announcing the official launch of this tool very soon and we will encourage all participants of all DCM Research Project studies to sign up for a portal account. See figure below demonstrating how you, your enrolled family members, and unenrolled family members will be able to use this platform. Stay tuned!



The DCM Research Project Portal is a web-based platform for recruitment, consent, and secure messaging across all DCM Research Project studies. The portal will be used to continue to connect with and engage our currently enrolled families, from the 1990s to now, as well as new DCM patients and family members who will join our studies in the future. In the last issue of The DCM Beat, we shared a workflow of how the portal will be used by all types of users. In this issue, we have adapted this figure for you, our currently engaged DCM patients and families, to show how you and your family will use the portal.