



Participant Impact Beyond the Registry and Deep Phenotyping

You may be thinking that once you complete your Registry surveys and Deep Phenotyping visits, you've done all you can do for HeartShare. You'll be pleased to know that that is far from the truth! The information that you provide through your continued survey completion, along with the information being collected through the Deep Phenotyping visits is fruitful and ongoing.

The information provided through Deep Phenotyping visits allows researchers to continue learning and develop new ways to better the quality of care and life for the HFpEF community, hence HeartShare's ambitious goal of enrolling 1,000 participants in the Deep Phenotyping study. Researchers are aware that multiple days of strenuous testing can come across as an intimidating process to go through, which is why the HeartShare team values those who have contributed so far.

For this edition of the HeartShare Participant Newsletter, we've decided to shine a light on a true champion of the study, Ms. Janice Williams. On April 16, 2024, Ms Williams was invited to speak at an in-person HeartShare conference at Northwestern University to share her experience as a participant, as well as give some new insight on the impact of participant voices.



HeartShare values the thoughts and feedback from its participants, so Ms. Williams was asked what she thought was the biggest setback people have when it comes to joining the study. Ms. Williams mentioned that, specifically for minority groups, there has been a bridge in trust with the scientific field, and that may be a big reason why so many people turn away research opportunities or become very weary of the process. She went on to explain that one of the most effective ways that people would be more willing to participate is if they hear about it from not only someone who has gone through the process, but from someone that people trust. She explained that she feels a certain responsibility to share her experience as someone with heart disease participating in a study like this, and hopes that others with similar conditions will feel motivated to reap the same benefits that come with participating in HeartShare.

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Ms. Williams continued her sentiments about trust between minorities and the scientific field explaining that we can never truly break through our preconceived ideas and broken trust in the field until we actually get involved again and rewrite the history. She strongly advocated the importance of including minority groups in research and expressed the importance for initiatives to increase the diversity in not only HeartShare's participant pool, but in research overall.

Ms. Williams furthers her impact in the HeartShare study by sending a clear message to the people around her that none of this would be possible without them. The quality of life and care for HFpEF patients will never expand without the willingness of others to participate. At the in-person meeting, she also gave a number of new ideas, beyond the scientific field, to get the word out to more people to join the study. She went on to say that she feels a sense of responsibility to get the word out to other people that she thinks would also benefit from participation in HeartShare. Ms. Williams believes in the power of participants as one of many keys to get HeartShare to accomplish its mission.

At the end of the day, the HeartShare study is for the participants, and their continued support for the study is just as valuable as their active participation. The study team continues to work hard in order to gain as much information as possible in hopes that the HFpEF community feels more supported beyond completion of HeartShare.

Maintaining Health as Temperatures Rise

While it goes without saying, most of us know that rising temperatures pose higher threats to our health, and knowing how to prepare for these circumstances is crucial. Increasing temperatures means that our bodies have work even harder to maintain a healthy temperature.

Warmer temperatures usually call for higher rates of social drinking, and it is important to consider just how much we are consuming. Alcohol has a higher chance of dehydrating your body, so including a balance of alcohol and water is crucial during these times. Consuming cold foods like salads and fruits will also help your body regulate its temperature because of the high water content in natural foods, not to mention the health benefits that these foods already provide.

Spring/summer time are also common times for outdoor activities, which also increase the amount of work that our hearts have to put in in order to maintain our health. Taking mindful precautions such as wearing sunscreen can make a drastic difference in our overall health - one sunburn can make all the difference. Because sunburns delay the cool down process, we are at higher risk for dehydration, which then puts a strain on how much harder our body has to work to regulate itself (Solan, 2022).

Warmer weather is a time of fun, but having fun shouldn't mean putting our health on the back burner. One prevention step can make all the difference in the amount of fun you can enjoy!



HeartShare Research Fellows' Corner



Dr. Amogh Karnik

Dr. Amogh Karnik is a Cardiovascular Disease fellow at the McGaw Medical Center of Northwestern University, and Artificial Intelligence in Cardiovascular Disease fellow at the Bluhm Cardiovascular Institute at Northwestern Memorial Hospital. He obtained a Bachelor of Science in Biomedical Engineering and a Master of Science in Global Health at Duke University before earning his M.D. at the Geisinger Commonwealth School of Medicine. He completed his internship, residency, and chief residency at Dartmouth-Hitchcock Medical Center and the Geisel School of Medicine at Dartmouth.

His primary interests are focused on the ways that easily accessible, low-cost technologies can be leveraged to improve detection and diagnosis of cardiovascular disease using deep learning and multimodality imaging. He is hopeful that work in these areas can contribute to health equity and democratize access to specialized care not only in our local communities, but all over the world.

Registry Raffle Winners!



A big congratulations are in order for our first round of raffle winners! To our winning participants at UC Davis, Mass General, Wake Forest, and University of Pennsylvania - we greatly appreciate your continued participation in the HeartShare Registry! The information you provide for the study is truly invaluable.

As a reminder to anyone who may be interested in a chance to win on the next round, all you have to do is complete your Eureka surveys! Every survey submitted in a given quarter (every 3 months) is an automatic submission. The more surveys you submit, the higher your chances are for winning a \$100 Amazon gift card!

