



## WELCOME NOTE

Welcome to the HeartShare Study! Whether you are considering participation in the HeartShare Study or are already a participant, our hope is that the HeartShare Newsletter will provide you with valuable information about the heart failure medical condition and the HeartShare Study. The HeartShare Data Translation Center at Northwestern University oversees the administration and coordination of all aspects of the HeartShare Study. On behalf of our team here at Northwestern and all the HeartShare investigators across the United States, I would like to express my heartfelt gratitude to each of our future and current study participants for their selfless contributions to the HeartShare Study. Advances in medical care for all medical conditions, including heart failure, are due to individuals like yourselves who generously give their time and energy to helping scientists like us discover new treatments to promote health and reduce suffering.

— Sanjiv Shah, MD,  
Principal Investigator  
HeartShare Data Translation Center  
Northwestern University



## What is Heart Failure, and What is Heart Failure with Preserved Ejection Fraction?

Heart failure occurs when the heart is unable to keep up with the body's demands. In most patients with heart failure, the heart is not "failing", but it is having trouble performing properly, leading to symptoms of breathlessness, fatigue, leg and/or abdominal swelling (fluid retention), and inability to do activities such as walking, climbing stairs, and exercising. Several common medical conditions, including obesity, high blood pressure, diabetes, coronary artery disease, and chronic kidney disease can lead to heart failure. Heart failure is extremely common, especially in older individuals, and is a leading cause of hospitalization.

Heart failure is typically classified into categories based on the ability of the heart to pump, which is termed "ejection fraction." The heart's ejection fraction is the percentage of blood that is ejected

from the heart into the body with each heartbeat. A normal or "preserved" ejection fraction is typically defined as  $>50\%$ , mildly reduced  $40-50\%$ , and reduced  $<40\%$ . Although much is known, and several treatments exist, for patients with heart failure and a reduced or mildly reduced ejection fraction, comparably less is known about heart failure with preserved ejection fraction (HFpEF – often pronounced "heff-peff"). In addition, many treatments that have worked for heart failure with reduced ejection fraction have not been effective in HFpEF.

Presently, approximately half of all patients with heart failure have HFpEF, and the number of patients with HFpEF is growing because of the aging of the population and the epidemics of obesity and diabetes. Patients with HFpEF are often debilitated, have poor quality of life, and are at risk for getting hospitalized for their heart failure. Therefore, HFpEF represents a major challenge for patients, their healthcare providers, and the healthcare system.

### Contact Us

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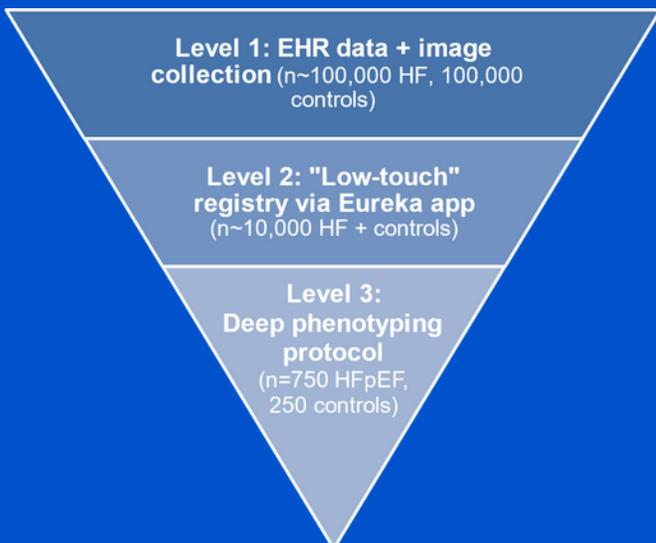


## Goals of HeartShare

We now know that HFpEF not only affects the heart but several other organs such as the lungs, kidneys, blood vessels, and skeletal muscles. It is a complex medical condition that is unique to each individual patient and therefore will likely require a “precision medicine”, personalized approach to diagnosis and treatment. The major overarching goal of HeartShare, a research study funded by the National Institutes of Health (NIH), is to take the heterogeneous HFpEF syndrome and better classify it into subtypes that are more effectively diagnosed and treated. One of HeartShare's primary objectives is to leverage existing knowledge about HFpEF and expand upon it using a variety of cutting-edge tools, including molecular testing, sophisticated imaging tests, comprehensive exercise testing, and artificial intelligence (AI). By studying patients with HFpEF and comparator patients without HFpEF, the HeartShare investigators will gain a better understanding of the biological mechanisms underlying HFpEF and its subtypes, which will lead to improved diagnostic tests and personalized treatments.

The preceding figure illustrates HeartShare's 3 main components: (1) collection of anonymized historical electronic health record data on >100,000 patients with heart failure and an equal number of comparator patients; (2) 10,000 patients (mostly with HFpEF, but some with other types of heart failure, and some comparator patients without heart failure) of all backgrounds, races/ethnicities, and health histories who are participating in the HeartShare Registry, which involves surveys about their health; and (3) 1,000 patients (750 with HFpEF, 250 comparators without heart failure) who will undergo in-person testing over a 2-3 day period as part of the HeartShare Deep Phenotyping Study.

Patients who give their consent to join the HeartShare Registry first complete health surveys after which a subset are invited to join the HeartShare Deep Phenotyping Study. Due to its time-intensive, comprehensive nature, only 1,000 participants will participate in the Deep Phenotyping Study, but the HeartShare investigators will be able to use what they learn from these 1,000 patients and apply those learnings to other patients involved in HeartShare.





## HeartShare Deep Phenotyping Study

The HeartShare Deep Phenotyping Study is a comprehensive and long-term observational study, comprised of a group of individuals currently participating in the HeartShare Registry. Its primary aim is to collect a wealth of different and complementary data types to understand how multiple organs in the body are working to better understand how HFpEF affects patients. The information gathered through the HeartShare study will serve as a valuable resource for further research and a deeper understanding of HFpEF and its subtypes, ultimately aiming to enhance the quality of life for patients.

At 7 sites across the United States, participants who have provided their consent will be recruited to participate in the Deep Phenotyping Study. These participants will undergo 2-3 days of testing, including exercise testing, imaging tests, and collection of biospecimen samples. Deep Phenotyping Study participants are also expected to return to their clinical site one year after the baseline visit for a shorter Deep Phenotyping Study follow-up research visit.

While the deep phenotyping aspect of the HeartShare Study is time-consuming and occurs over a few days, it plays a crucial role in ensuring we learn as much as possible about how HFpEF affects the body so that we can identify effective, personalized treatments. To express gratitude for their participation, Deep Phenotyping Study participants are compensated for their time and effort during their initial participation in the study.

## HeartShare Research Fellows' Corner

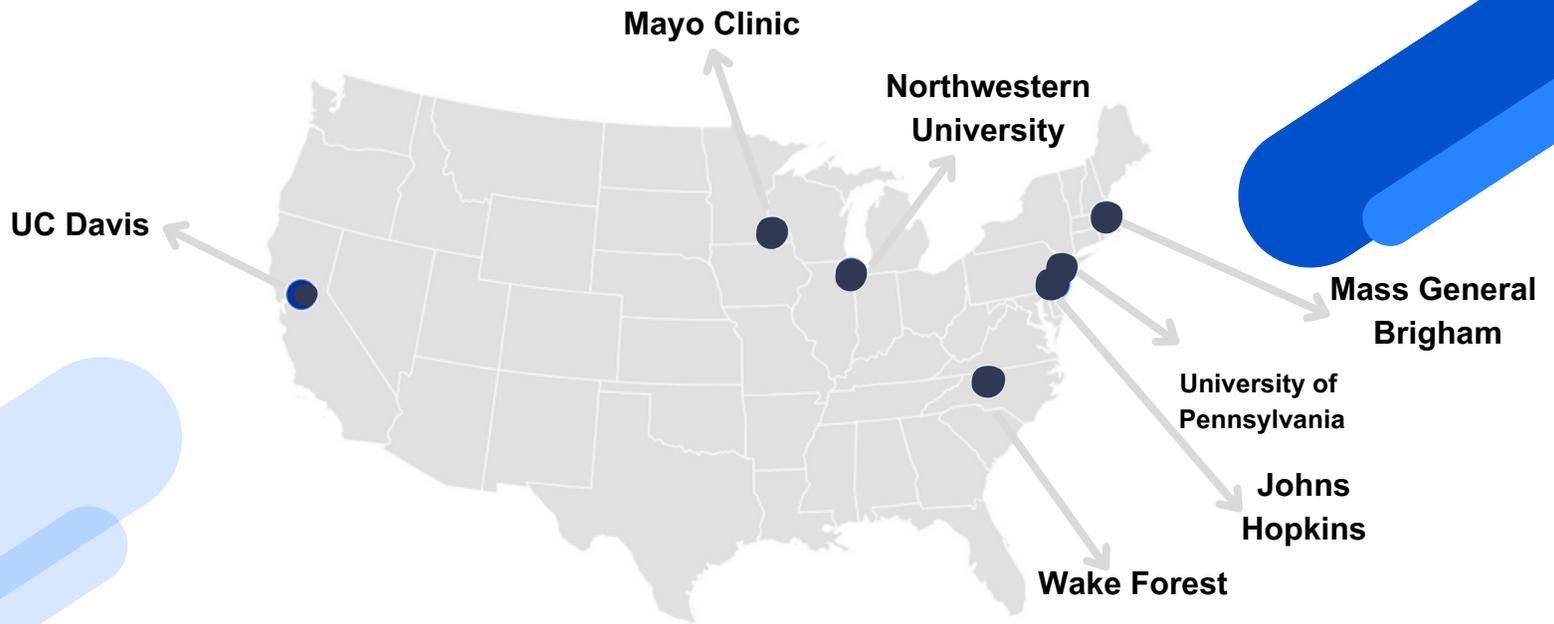


**Dr. Laura Cohen**

Every year, the HeartShare Research Skills Program trains the best and brightest scientists for careers in heart failure research that use the latest AI and machine learning techniques. Dr. Laura Cohen, one of this year's fellows (trainees), is a cardiologist who specializes in echocardiography (heart ultrasound) at Massachusetts General Hospital in Boston. She completed her undergraduate studies at Washington University in St. Louis and her medical degree at Harvard Medical School, where she jointly earned a master's degree in public policy from the Harvard Kennedy School. Her research interest is in risk factors associated with the development and progression of HFpEF. Her work is particularly focused on behavioral and lifestyle patterns that contribute to the disease process, and evaluating echocardiographic parameters associated with HFpEF subtypes.



## Who is involved?



## HeartShare Registry Raffle

The HeartShare team recognizes that completing the surveys in the HeartShare survey does take effort, and we know that our participants' time is extremely valuable and essential to the success of the study. Consequently, the HeartShare Study has implemented a registry raffle, in which registry participants are offered the opportunity to win a \$100 Amazon gift card! All registry participants who complete all initial (baseline) study surveys will be eligible for the raffle, which will occur monthly. Once a participant completes their baseline surveys for the registry, they will be entered once. Subsequently, participants will be entered once more for every monthly survey completed in a given quarter. Best of luck to all of our generous participants!

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Contact Us

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