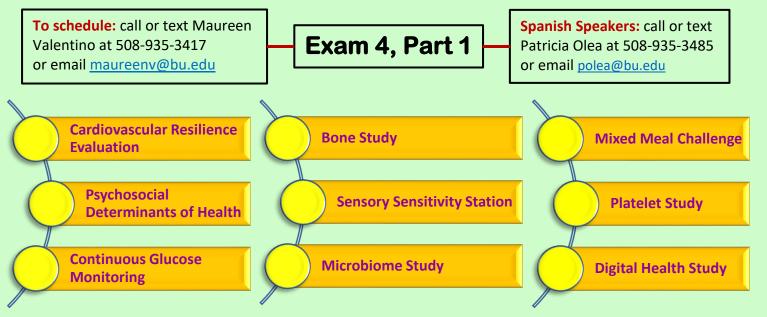


## Generation 3, Omni 2 and New Offspring Spouse

Exam 4 is off to a stellar start following its successful September launch. More than 500 participants have completed the onsite exam. Participant feedback is overwhelmingly positive.

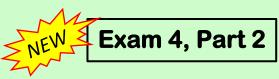
Framingham continues to collect the same core longitudinal measures we have used to study heart health for generations. These will include taking a small amount of blood, a urine sample, performing an EKG, taking body measurements and a medical history, and finally, asking you to complete a variety of surveys.

The studies listed below are part of Exam 4 and were described in the <u>Fall Newsletter</u>. (You can also view a slide show about the studies, just below the newsletter.) Since the fall, two new vascular studies (described on the next page) were funded to be part of Exam 4 and will likely launch this summer. We will be breaking Exam 4 up into two visits. Most of the testing will be completed in **Part 1**; the new studies will be completed during **Part 2** on a separate day, and at your convenience.



#### Why do we recommend doing Exam 4 in two parts?

Both studies in Part 2 require fasting. There also are two fasting stations in Part 1. If all these studies were completed on the same day, participants would need to fast for 4 additional hours while onsite for the exam. The two additional stations will take about an hour, adding to an exam that already lasts around five hours. We feel the length of time required to fast and complete the exam is too long and burdensome, and that a 2-part exam will be more comfortable and manageable for you.



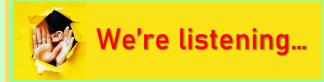
**Tonometry station is back.** As the population ages, the prevalence of Alzheimer's disease and other types of dementia will increase markedly. Excessive stiffness of the aorta—the main artery that connects the heart to the various organs—represents a potentially modifiable risk factor for dementia. Higher aortic stiffness increases pressure swings in the arteries each time the heart beats. This increase in pressure pulsatility can damage small blood vessels in the brain and elsewhere in the body. We will use measurements of aortic stiffness and brain blood flow to examine harmful effects of aortic stiffness on small vessels in the brain.

**Endothelial Cell Health.** The increase in cardiometabolic disease including Type 2 diabetes and obesity presents a critical cardiovascular challenge. Individuals with cardiometabolic disease experience accelerated vascular (blood vessel) aging, premature atherosclerotic disease (clogged arteries), and increased cardiovascular disease (CVD) risk. Endothelial cells may be used to help us assess vascular health. The cells line our blood vessels



and help them stay relaxed. For this study, we will place a flexible plastic catheter in a vein in your arm, then pass four soft wires through the catheter to collect endothelial cells, and finish by removing the catheter. This procedure is similar to having your blood drawn. Changes in endothelial function occur prior to clinical CVD, therefore, examining endothelial cells can tell us about the health of blood vessels and help us understand heart disease and diabetes risk.

### **If you have already completed Exam 4** *You are now eligible for Part 2!* Please call Maureen at 508-935-3417 for more information



We take your comments and feedback seriously (to heart (3)) and act upon them whenever possible. Below are things we have done in the last year in response to what we've "heard" from you.

- A **table describing the cohorts** will now be included in each newsletter (see table on page 3) so that you can figure out which cohort you are part of.
- We developed the *Participant Passport* so you know how many stations are in the exam and when you will complete each one.
- We are trying to provide **better snacks**. We have changed the gluten free options, and we're trying new snacks like popcorn and Kind bars (these have been a hit during Exam 4!).
- We purchased a **blanket warmer** because many participants reported being cold during the exam.
- We made it possible for you to complete some questionnaires and your medical history **online at home**, before coming in for the exam. This shortens your exam day.
- We wrote an article (page7) to explain why we ask you to complete so many surveys, some with the same/similar questions.
- We created an **At Home Activities** sheet that describes when things need to be done for studies that have at home components.

### Offspring, Omni 1 and Others Studies you may be invited to participate in

*Muscle Study.* Age-related loss of muscle mass may cause falls and fractures. In the new Framingham Muscle Study, we will use a state-of-the-art method to assess the amount of muscle in your body by having you take a pill containing creatine, which is a building block of muscle. Three days later a urine test will be collected to measure creatine and quantify the amount of muscle in your body. Our first goal is to determine the genetic and non-genetic factors (diet and physical activity) that contribute to total muscle mass. The second goal is to determine if loss of total muscle mass causes falls and fractures. Using this easy and accurate way of measuring the amount of muscle, we hope to find ways of preserving this valuable tissue as we age. Preservation of muscle may also help to prevent falls and fractures that cause so much pain and disability. Contact: **Anjali Singh at (213) 249-0153 or** anjalisingh@hsl.harvard.edu

*Digital Cognitive Studies.* Digital technologies offer an alternative method for collecting brain aging data. The Digital Study will involve using a smartphone to use a set of applications that take about 15-20 minutes every 3 months for 3 years. The digital data will be compared to imaging (MRI, PET) and other clinical measures. Ultimately, the findings will help determine whether digital cognitive measures are more sensitive to detecting changes in cognition at a younger age compared to neuropsychological tests that are being collected through the Brain Aging Program. This project will invite all FHS participants from all cohorts. Contact: Lindsay Hathaway at (508) 663-4019 or <a href="mailto:lah3@bu.edu">lah3@bu.edu</a>

*Virtual Neurology Visits and PET/INRI Study.* The FHS Neurology Team is conducting virtual visits with participants for both cognitive testing and neurological examinations, using video and telephone capabilities to visit with you from the safety of your home. We hope to resume in-person activities for these visits when safe, at which time we will offer participants the option to complete their visit in-person or virtually, based on your preference. If you wish to learn more about our studies mentioned here, or to check your eligibility, please call **Vicki Peterson at (508) 935-3468 or** <u>vpeters@bu.edu</u>

Which cohort are you in?



Cohort	Short Name	Year Recruited
Original	Original	1948
Offspring	Gen 2	1971
Omni 1	Omni 1	1994
Third Generation	Gen 3	2002
Omni 2	Omni 2	2003
New Offspring Spouse	NOS	2003

### **REMEMBER:**

Framingham Heart Study evaluations are designed for research. They do not replace your regular check-ups with your own doctor(s)!

### **NEW** studies since the last newsletter





**C4R Wave 3.** Researchers from the Framingham Heart Study joined other cohort study investigators and began studying COVID-19 in 2021. Thus far, researchers have published 9 scientific articles using data collected during the C4R Study. We would like to thank the over 3,000 FHS participants who took part in Wave 1 and/or 2 of the C4R Study!

If you completed Wave 1 or Wave 2, you are eligible to take part in the next phase of the C4R Study, Wave 3. Wave 3 will begin in late spring, and you will be asked questions about your COVID-19 infection and vaccination history, symptoms you may have experienced, and the current state of your health. FHS is just one of many studies across the country whose data is working to help identify risk factors that predict the long-term health impacts of COVID-19. There is still so much to discover about COVID-19, but your contributions so far have played a huge part in the research process and helped us to better understand the impacts of COVID-19.

Contact: Laura Kurriss at 866-466-2040 or call Katelyn Kerr at 508-532-9312 or email us at <u>FHSC4R@bu.edu</u> Smartphone Cognitive Assessment. The goal is to identify cognitive assessments taken via smartphone that can best replicate the cognitive tests given at FHS. This study will be completely remote, and participants only need to complete assessments once. which the will take approximately 45-50 minutes. Participants will also be asked to provide their feedback at the end on the different cognitive assessments tested in this study in order to know which ones participants enjoyed using the most. To join, participants will need to have a smartphone with Internet connectivity in order to download the applications with the cognitive assessments onto their devices. Contact: Stephanie Li at (617) 358-0089 or email sgli@bu.edu



### **ONGOING RESEARCH EFFORTS**

#### FOR ALL PARTICIPANTS

FHS BRAIN AGING & DONATION PROGRAMS. The Brain Aging Program continues the cognitive assessment and brain MRI scans that began in 1999 and is open to all participants from all cohorts. New to this project is the addition of a neurology examination. While we will offer these examinations at the FHS Research Center as has been done in the past, we will also offer the option of doing it in your home, whether in person or through videoconferencing. One way our research is unique has been the use of digital recordings of written and spoken responses, which has allowed us to find new ways to measure cognition and mood-related behaviors. We are using this unique data to help detect changes that could someday be used to trigger interventions that will reduce risk or progression of dementia/Alzheimer's disease. We are continuing the **Brain Donation Program** that allows for neuropathological examination of brains and provides important insights about risk factors, biomarkers, and genetic factors related to those who do and do not have dementia/Alzheimer's disease. Brain donations can also help provide families with a definitive diagnosis if their loved one was known to have suffered from a neurological illness. To learn more about these programs, contact **Sophie Donohue at (508) 663-4078 or** <u>sdonohue@bu.edu</u>

HAVE YOU HAD A RECENT STROKE? PLEASE LET US KNOW! Stroke is a medical emergency, and symptoms can include facial weakness, sudden difficulty speaking, weakness on one side of the body or sudden vision loss. Anyone with symptoms of stroke should call 911 and get immediate help. *If you had a stroke or received medical care for stroke symptoms, FHS would like to know as soon as you or a family member can contact us.* Reach us at the *FHS Stroke Hotline at (617) 630-3627.* If you live out of state or are unable to be seen in person, we may also schedule an evaluation over the internet by video teleconference. This is a research evaluation only and is not meant to provide any medical care or advice. We greatly appreciate your efforts to help us monitor and research this disabling disease; your participation has helped us reduce the risk of stroke and TIA and we are studying how to also reduce the risk of memory and thinking problems after a stroke.

**GENETIC NOTIFICATION UPDATE - TOPMED AND POPSEQ** The NHLBI TOPMed and PopSeq projects study the results of FHS genetic testing. Many FHS participants opted to receive genetic information when found at FHS. Every year, more is learned about genetic associations with disease. When treatable medical conditions are identified in consented participants, Dr. Jodi Hoffman, Boston Medical Center medical geneticist, contacts participants to discuss this important information. If you receive a message from Dr. Hoffman (or from her FHS assistant, Barbara Inglese), please respond. FHS has not found reportable variants for most participants. The search continues and additional participants may be notified in the future. If you received a PopSeq survey, there's still time to complete it and send it to FHS.



## Medical History Update 2023

The Framingham Heart Study is like a puzzle, we collect your health information in pieces and then try to organize them to see the whole picture.

When you complete a Medical History Update (MHU) each year, you are contributing to a vital piece of the puzzle by keeping your information up to date. The MHU allows us to collect information on various health conditions such as heart attack, stroke, or diabetes that you may have experienced since the last time you shared your health information with us. The data is then made anonymous and shared with our researchers who use it to track trends in diseases and health outcomes. Collecting this information annually keeps the data accurate, bridges the time between exams, and provides greater insight into health progression. The more we know, the more we can determine how to prevent and treat these issues in the future.

In 2022, researchers published over 180 scientific papers based on data collected from Framingham Heart Study participants. This demonstrates just how impactful your participation is in furthering health knowledge. With your contribution to the puzzle, we can continue working towards making discoveries that can improve health worldwide.

The MHU can be completed online, by phone, on paper or in-person. If you have a preference, let us know. Contact Laura at 866-466-2040 or call Katelyn at 508-532-9312 or email us at <a href="mailto:fhsmhu@bu.edu">fhsmhu@bu.edu</a>

## HIGH SCHOOL SENIORS: ENTER THE 2023 \$1,500 DAWBER ESSAY CONTEST

John Galvani, President, and the Board Members of the Friends of FHS, announced two scholarships for 2023 based on an essay contest: First place \$1,500 and Second place \$750.

**Eligibility:** Open to children, step-children, and grandchildren of FHS participants. Applicants must be graduating from high school this year and planning to attend college in the fall 2024.

To apply, only two items are needed: an email with the applicant's name, address, telephone number, and college and career plans (roughly a two-sentence description), and a 1,000-word essay titled *What it means to be a participant in medical research in the Framingham Heart Study*. Applicants tell a story, conduct an interview, or pursue any angle of interest. Please fact-check and proofread before submitting. Email the essay as an attachment to Rebecca Bennett (<u>rlbennet@bu.edu</u>) by Friday, May 5<sup>th</sup>, 2023. We will confirm receipt of all essays within one business day. If you do not receive a confirmation, please call (508) 935-3486. The Friends will review the essays and notify recipients by May 19, 2023. Recipients will be invited to accept their awards at the Framingham Heart Study.

## A Message from the Friends of the Framingham Heart Study



To make a donation please mail a check made out to: "Friends of the FHS." Address it to:

> Rebecca Bennett ATTN: Friends of the FHS 73 Mt. Wayte Ave., Suite 2 Framingham, MA 01702

Greetings, fellow participants. We are participant volunteers from the Offspring (Second Generation), Third Generation, and Omni cohorts who meet periodically throughout the year as members of the Board of Trustees for the Friends of the Framingham Heart Study. With funds donated to the Friends, we provide support for items and activities at FHS, such as occasional travel grants to FHS investigators attending scientific conferences, audio-visual equipment for long-distance conferencing with collaborators, annual scholarships to high-school graduates going to college and the ECG cards sent to participants after examvisits. With your help, we will be able to do more to support FHS in its

groundbreaking research for improving public health related to heart disease, diabetes, cancer, sleep disorders, aging and Alzheimer's disease.

*The Friends of the FHS is a 501(c) (3) nonprofit organization supported solely by donations.* We invite you to contribute a personal donation or one in the memory of, or inhonor of, a family member or friend. No donation is too small or too large and all aretax deductible.



# why so many questions?

During your years in the Framingham Heart Study, you have answered many hundreds - probably thousands! of questions about your health and potential risk factors that may affect your health. We ask you questions in many ways...in-person with a staff member, via paper surveys and online questionnaires, and sometimes by phone interview. This may leave you wondering: "Why so many questions?", "Why do I answer some questions multiple times?".

There are several reasons.



FHS research is vast. From the original focus on heart disease, FHS has expanded its scope to study aging, stroke and other brain diseases, lung disease, metabolic diseases such as diabetes, bone diseases such as osteoporosis, and other conditions.



The scientific importance of using standardized and validated questionnaires. We want to collect the best data possible. The accuracy and reliability of information collected depends on the questionnaire having been validated by previous research. When using a validated questionnaire, researchers are required to ask every question and in the same order as the original questionnaire. If two studies are using different validated questionnaires to collect information about eating habits, there may be a couple of

questions that are asked on both questionnaires.



Some FHS research is part of larger multicenter projects. Data from these projects must be collected in the same way at multiple sites. For example, FHS is part of the Collaborative Cohort of Cohorts for COVID-19 research, or C4R, a nationwide study of the health effects of COVID-19. For data from the different research sites across the US to be combined, it is crucial that questionnaires about COVID-19

illnesses and subsequent symptoms be asked in the same way at all sites. In some cases, this may result in repetitive questions with those asked previously by FHS.



Different questions about the same topic can complement each other when asked in a slightly different way. By combining responses, researchers may be able to improve the accuracy of the research data.

We cannot thank you enough for the substantial time and effort you put into thoughtfully answering FHS questions and completing questionnaires. The information obtained is a crucial component of the research data collected by FHS, just as important as what we learn from a blood draw, EKG or any other testing, and represents a huge contribution to health research.

## It is time to celebrate and honor your 75 years of commitment to FHS



FHS 75<sup>th</sup> Anníversary planníng has begun!



Information about the fall event will be coming soon.





If you will be coming to Massachusetts or New England in the spring or summer, please call us to see if you are eligible for Exam 4 or any of the other studies that are ongoing.

### How to contact us

FHS Core FHS Main Number

(508) 872-6562 (800) 854-7582

**FHS - All Participants** 

Maureen Valentino Call or Text (508) 935-3417, Call (800) 536-4143 Email <u>maureenv@bu.edu</u>

FHS - Spanish Speaking Participants Patricia Olea-Fichtel Call or Text (508) 935-3485 or <u>polea@bu.edu</u>

### FHS Neurology Team

Stroke Study, Neuropsychology Testing, MRI & PET Scan Studies Vicki Peterson (508) 532-6498 or <u>vpeters@bu.edu</u> **FHS Brain Aging Program** 

Non-urgent Brain Donation Inquiries Sophie Donohue (508) 663-4078 or <u>sdonohue@bu.edu</u>

URGENT Brain Donation Inquiries 1-877-99DONOR (1-877-993-6667)

**Cognitive Testing, Neurology, and Brain MRI** Sophie Donohue (508) 663-4078 or <u>sdonohue@bu.edu</u>

Digital Health Study Lindsay Hathaway (508) 532-6505 or <u>lah3@bu.edu</u>

PET Scan Studies Rebecca Finney (508) 663-4078 or <u>rifinney@bu.edu</u>