### Thomas Dawber Memorial Scholarship

Last year, the Friends of the Framingham Heart Study awarded scholarships to two high school seniors planning to attend college. Friends President John Galvani and the board members announced two scholarships for 2015 based on an essay contest: a \$1,000 scholarship and a \$500 scholarship.

**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 Fall 2015.

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 *"How does FHS help improve public health."* Applicants are welcome to tell a story, conduct an interview, or pursue any angle of interest. Please fact-check and proofread before submitting.

Please email the essay as an attachment to Emily Manders (emanders@bu.edu) by <u>Thursday, April 23, 2015</u>. We'll confirm receipt of all essays within one business day. If you don't receive a confirmation, please call (508) 935-3443.

The Friends will review the essays and notify recipients by May 29, 2015. Recipients will be invited to accept their awards at the FHS research center.



2014 Dawber Scholarship recipient, Hailee Gelinas, is pictured with (left to right) Friends of the Framingham Heart Study treasurer, Peter Allen and president, John Galvani. Hailee is a freshman at Quinnipiac University, studying nursing and then plans on pursing her MD degree.



2014 second-place Dawber Scholarship recipient, Katelyn Springsteen, pictured with (left to right) Friends of the Framingham Heart Study treasurer, Peter Allen, and president, John Galvani. Katelyn is a freshman at New Hampshire Technical Institute, Concord's Community College in Concord, NH with a major in Radiologic Technology.

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

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 clinic visits. With your help, we'll be able to do more to support FHS in its ground-breaking 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) non-profit organization supported solely by donations. We invite you to contribute in the memory of or in honor of a family member or friend. No donation is too small or too large and all are tax deductible.

#### To make a donation, please mail a check, made out to "Friends of the FHS" to:

Lynda Norton, ATTN: Friends of the FHS, 73 Mt. Wayte Ave., Suite 2, Framingham, MA 01702.

#### Trustees of Boston University National Heart, Lung, and Blood Institute Framingham Heart Study

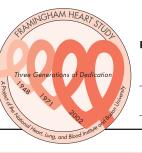
73 Mt. Wayte Avenue Framingham, MA 01702

RETURN SERVICE REQUESTED

# Medical History Update -

Why is it Important? One of the most important ways you can contribute to the Study is by providing us with your medical history information. In FHS research, knowing whether and when a disease developed brings us closer to learning, for example, the link between high blood pressure and stroke. Without your examinations and medical history updates, our estimate of these relationships are unclear. Your regular visits and medical history updates make our understanding of disease more accurate and focused. Even if you feel well or your health has not changed in several years, these updates help us document your health status.

If you receive a mailed Medical History Update form, a password is enclosed and you have the option of completing the form online. You still have the option of returning the form by mail or completing it on the telephone with one of our staff. Please call Mary Ann Crossen (508-935-3430) if you have any questions about the form or would like to complete it on the phone. We greatly appreciate your efforts to keep our records current. NONPROFIT U.S. POSTAGE PAID FRAMINGHAM, MA PERMIT NO. 325



**The Framingham Heartbeat** 

e annual newsletter for the participants of the Framingham Heart Study | **Spring 2015** 

The Framingham Heart Study is a project of the National Heart, Lung, and Blood Institute and Boston University.

# **Current Projects**

#### For Original participants:

• FHS/Health eHeart Study Pilot Project 3

Page

- Medical history update
- Electronic Device Survey Update

# For Offspring (Second Generation) and Omni 1 participants:

- FHS/Health eHeart Study Pilot Project 3
- Medical history update
- Brain MRI and cognitive testing
- Osteoporosis study
- Sleep study
- Electronic Device Survey Update

# For Third Generation and Omni 2 participants:

- FHS/Health eHeart Study Pilot Project 3
- Medical history update
- Electronic Device Survey Update

# The Framingham Heart Study Staff is here for you!

Please call us at (508) 872-6562 or (800) 854-7582 if we can be of any assistance to you.



NHLBI to fund FHS for another 5 years via new contract!! Next examination of Gen 3 cohort to begin in 2016!

# What's New and What's Next at the FHS?

The past twelve months were busy times at FHS. Offspring Exam 9 and Omni-1 Exam 4 were completed and the data from these exams are being studied. Over 200 scientific papers were published in 2014, authored by our own FHS faculty and by investigators far and wide who apply to use FHS data and frozen samples from our repository. FHS investigators continue to successfully obtain research funding for ground-breaking studies including several American Heart Association Cardiovascular Genome-Phenome Study (CVGPS) awards to investigate new areas of interest in cardiovascular disease research. New research ideas are proposed every month. Some of the topics of current FHS research include investigations into heart failure, atrial fibrillation, stroke, cognitive decline, diabetes, sleep disorders, osteoporosis, lung disease, and other diseases. New approaches to studying these diseases at the FHS include analyses of genetic data, social networks, imaging data, and information collected from participants by mail and internet.

Plans are underway for Exam 3 of the Third Generation and Omni group 2 participants. In addition to measures of glucose and cholesterol, several exciting research applications have been reviewed favorably at the National Institute of Health to study blood vessel stiffness, risk factors for bone loss, and new measures of cognitive function to better understand the brain and find ways to prevent Alzheimer's disease. Investigators are considering using electronic technologies to monitor diet, exercise, blood pressure and heart rate to investigate whether this approach may lead to ways to prevent heart disease. The FHS staff plan to use electronic technologies in the research clinic to make the exam more efficient. **Stay tuned for an exam start date in March 2016.** The FHS staff will continue to contact all participants for medical history updates and opportunities to participate in additional research studies.

We hope we can continue to rely on your participation in these new projects. *You* are the Framingham Heart Study.



### Contact Us

# **Receptionist** (508) 872-6562 or (800) 854-7582

#### **Brain Donation**

Linda Farese (508) 935-3488, (800) 248-0409 or lfarese@bu.edu

#### **Maureen Valentino**

Original, Offspring (Second Generation) Third Generation Participant Coordinator (508) 935-3417, (800) 536-4143 or maureenv@bu.edu

#### Paulina Drummond

Omni Coordinator (508) 935-3485, (888) 689-1682, or pautras@bu.edu

#### Linda Farese

Brain MRI, Cognitive Testing, Stroke Coordinator (508) 935-3488, (800) 248-0409 or Ifarese@bu.edu

# www.framinghamheartstudy.org

# Whole Genome Sequencing at FHS Underway

Great news!! FHS has been selected for inclusion in a new National Heart Lung and Blood Institute (NHLBI) project to analyze the complete DNA sequences of participants in a collaboration involving several ongoing population studies. Whole Genome Sequencing (WGS) helps us determine the complete DNA sequence of an individual's genome to characterize differences in the sequence of bases that form the building blocks of our DNA. This effort represents a major step in the genome wide research begun in FHS over a decade ago and will produce far more detailed genetic information about individuals than previous genotyping endeavors. When the new genetic information is linked to FHS data on the observable traits that have been measured over the years, researchers can discover new links between genes and traits measured in FHS participants such as risk factors and heart, lung and brain diseases. Some DNA specimens from FHS storage at the Boston University FHS genetics lab have been shipped to a specialized laboratory for whole genome sequencing. FHS consent restrictions will be followed; DNA will be included in the WGS project only from among individuals who have previously consented to participate in FHS genetic studies.

FHS investigators plan to continue their collaborations with other scientists to make important discoveries. FHS WGS data will be made available along with similar data from other NHLBI studies to investigators world-wide with appropriate approvals and protection of confidentiality. The Framingham Study is especially valuable in this new project because of the participation of so many family members and the great number of traits that have been measured over the years and stored in our data repository for research. With this WGS project, FHS continues to be a leading study in the personalized genomic research into health and common diseases promoted by the recently announced Precision Medicine Initiative. Thank you for your tremendous and precious contribution to health science and genetic research.

# **Noteworthy News**

The American Heart Association awarded its 2014 Population Research Prize to Vasan S. Ramachandran, M.D., of Boston University School of Medicine and Principal Investigator of The Framingham Heart Study, "for brilliantly seizing upon opportunities to translate cutting-edge bench science into an epidemiological context, thereby making fundamental contributions to identifying systemic markers for cardiovascular risk, both here and in developing countries." Dr. Ramachandran has made many important contributions to cardiovascular epidemiology. These include systemic markers of cardiovascular risk, hypertension, congestive heart failure, risk re-classification and diseases in developing countries. A native of India, the Boston scientist continues to collaborate and conduct research there. Dr Ramachandran's findings recognizing four stages of risk leading to symptomatic heart failure have been incorporated into AHA's informational materials. "This appreciation of heart failure progression represents a critical step toward preventing its emergence."

Emelia J. Benjamin, M.D., ScM, professor of Medicine at BUSM, professor of Epidemiology at BU School of Public Health co-Principal Investigator of The Framingham Heart Study and attending cardiologist at Boston Medical Center, has been selected as the recipient of the prestigious 2015 American Heart Association (AHA) Paul Dudley White Award.

The award, named in honor of one of Boston's most revered cardiologists, Dr. Paul Dudley White, a founding father of the AHA, is given annually to a Massachusetts physician who has made a distinguished contribution to the Association's mission of building healthier lives, free of cardiovascular disease and stroke.

# **Reporting FHS Results:**

It is very important that you, as an FHS participant, understand the difference between the RESEARCH RESULTS that FHS generates and the CLINICAL TEST RESULTS your doctor sends you after your personal medical check-up. FHS research measurements are chosen to answer scientific questions. The FHS programs are not designed for monitoring health of individuals. However, FHS does eventually send some individual results to you and your doctor. Please look at the table below to see seven ways results from FHS visits differ from results of an annual check-up with your physician.

	FHS VISIT	ANNUAL CHECK-UP BY YOUR PERSONAL PHYSICIAN
1. Purpose	To collect information for research on a <b>population</b> to answer specific research questions.	To collect information about <b>you</b> for your health to guide health care recom- mendations and treatments.
2. Tests and Measures and Timing of Results	May include <b>novel</b> tests. May take <b>years</b> of FHS work to analyze information and arrive at research results.	<b>Standard</b> tests for overall personal health evaluation. Usually returned in a few <b>days</b> from testing.
3. Consent	FHS research is conducted according to the approved FHS informed consent for participation in the research and approved study protocols. Samples of FHS consent forms are displayed at www.framinghamheartstudy.org/researchers/concent-forms.php.	Patient care is conducted according to rules governing the physician-patient relationship, including consent to treatment. Confidentiality is often covered by The Health Insurance Portability and Accountability Act of 1996 ( <u>HIPAA</u> ).
4. Standards	Follows standards for high quality research.	Follows standards for <b>health care.</b>
5. Sending Test Results to Individuals	Most results are published in scientific journals based on the FHS population.	Your physician sends you results of standard tests from your annual check-up with recommendations for follow-up.
	Some individual test results such as blood pressure and cholesterol levels are sent to you and your physician to consider.	
6. Support	<b>Grants and contracts</b> with specific research objectives on the FHS population.	<b>Health insurance and you</b> . The objective is to provide personal health care.
7. Overall Value and Bottom Line	Moving SCIENCE forward. Many of the tests used today in health care were based on FHS research. WE CAN'T DO GOOD FHS RESEARCH WITHOUT YOUR PARTICIPATION!	Taking care of YOU. DON'T MISS YOUR CHECK-UPS WITH YOUR HEALTH CARE PROVIDERS!

### Framingham Heart Study/Health eHeart Study Pilot Project

FHS investigators are working with scientists at the Health eHeart Study based at the University of California in San Francisco to conduct a pilot study of 200 FHS participants. The purpose of the pilot study is to determine whether electronic data collection, including internet-based and wearable sensor data, is possible for some FHS projects. If possible, this would help pave the way for a larger study in all interested FHS participants.

To be eligible, FHS participants need to have a working email and an iPhone, and live within one-hour of FHS. Once recruited into the study, FHS participants will enroll either remotely by internet, or will come to FHS. Participants will complete electronic visits, and have the option to select up to 4 wearable devices, including a Fitbit activity monitor, a wireless scale and blood pressure device, and a wireless electrocardiography (ECG) device. FHS participants will be actively involved in the pilot for 3 months, and then we will continue to collect device data for up to one year. Please contact Emily Manders (emanders@bu.edu) if you are interested in finding out more about this pilot study.

# **Electronic Device Survey Update**

FHS investigators are thinking about using new electronic devices are mailed and can be set up without assistance. tools to conduct research on your heart and general health. We With your help we hope to show that small devices can be are interested in finding out what kind of electronic tools you used successfully in sleep medicine. use, including computers, internet, and cell phones. We are doing this to understand whether FHS participants would be Most Offspring (Second Generation) and Omni 1 participants interested in participating in research involving digital devices are eligible to participate and will be contacted in the coming and smart phones. Of course, we understand that mobile months. FHS thanks those who have already participated. technology isn't for everyone, and we want to reassure all of Alternatively, to see if you qualify for the FHS sleep study, you that no one will be left behind if you don't feel comfortable please contact Barbara Inglese at (508) 935-3451; toll free at with these kinds of technologies. Mobile health technology may (800) 601-3582, or via email at bji@bu.edu or Emily Manders represent a scientific advance. However, FHS investigators are at (508) 935-3489, or via email at emanders@bu.edu not working on behalf of any companies. We are also aware of potential security issues, and we are doing everything we can



Nancy Coppelman at FHS asking "What is the best way for me to reach you?"

to minimize the possibility of a security breach. Because this information is being collected remotely, we need to make sure that we can link your responses with your FHS data. This is the reason that we are asking for your date of birth.

We thank the nearly 4000 FHS participants who have already responded, including almost 1300 Offspring, 2400 Third Generation, and 283 Omni participants. We will be mailing paper versions of the questionnaires, so there is still a chance to respond if you haven't filled yours out yet! If you would like more information about this, please contact Maureen Valentino (maureenv@bu.edu or 800-536-4143).

# **Ongoing Sleep Study** with Easy-to-Use Home Monitors

The FHS Sleep Study is investigating factors that affect sleep quality using an experimental, FDA-approved monitor. The M1 recorder identifies stable and unstable sleep by detecting changes in your heart rate and breathing patterns. The study hopes to identify metabolic and cardiovascular changes linked to sleep quality.

Previous sleep studies performed in the 1990s required bulky equipment and significant setup time. The new equipment is the size of an iPod and wristwatch. These



The Nonin WristOx (left) measures blood oxygen during sleep. The M1 recorder (right) measures the electrical activity of the heart.

### **Brain MRI and Cognitive Testing**

The Framingham Study Neurology team thanks all participants who have volunteered for brain MRI, cognitive testing and a neurological examination. Using this data in 2014 alone, over 40 papers have been published, describing new risk factors, genes and blood markers for Alzheimer's disease and stroke. Also, the Heart Study data are crucial to a national effort to identify possible new drug targets for these diseases.

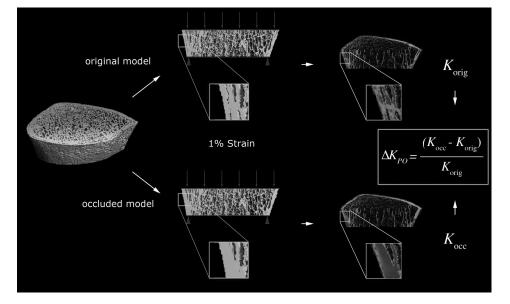
We will be reaching out to you to obtain one more MRI and cognitive test; this will help us understand how the brain changes over time. If you have not had a brain MRI since 2009, please call our coordinator Linda Farese at 508-935-3488 and she will be happy to schedule one for you.

Over 200 participants will also be selected at random and invited to have sophisticated PET scans for brain amyloid; these scans will be done at the Massachusetts General Hospital Please call Linda Farese at 508-935-3488 if you would like to learn more about this new test.

# Have you had a recent Stroke? **Please let us know**

Over the years, your participation has helped researchers at FHS study the factors that lead to strokes, how they occur, and what can be done to prevent them over a lifetime. Stroke is an emergency, and anyone with symptoms such as facial weakness, sudden difficulty speaking, weakness on one side of the body, or sudden vision loss should call 9-1-1 and get immediate help.

If you have had a recent stroke or received medical care for stroke symptoms, FHS would like to know as soon as you or a family member can contact us. Participants are asked to call The Framingham Stroke Study at 508-935-3488. We would like to talk to you and set up an in-person appointment when it is safe and convenient for you. We greatly appreciate your efforts to help us monitor for and research this disabling disease.



# **Osteoporosis Study Measures 3D Bone Architecture**

In a preliminary analysis of 381 Offspring participants seen in 2012-2013, we found that individuals with greater amounts of fat in their abdomen tended to have more small holes in the outer shell of bone in their forearm. The analysis suggests that having too much fat may be bad for parts of the skeleton; another good reason to shed those holiday pounds.

We are scheduling Offspring and Omni 1 participants for this important callback visit, and hope many participants will join our study in its final year. We thank those of you who have already participated. As before, the exam will also include the traditional bone density "DXA" test and the results will be provided. Please call Linda Farese for an appointment for the FHS Bone scan and Neurology/MRI testing at: 508-935-3488.

# **Interesting fact**

Osteoporosis is a silent disease that can result in fractures and loss of independence. Yet less than 25% of the U.S. population over 65 years of age have their bone density tested for osteoporosis.