

The Framingham Heartbeat

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THE HONORABLE MICHAEL O. LEAVITT, UNITED STATES SECRETARY OF HEALTH AND HUMAN SERVICES, THANKS PARTICIPANTS OF FRAMINGHAM HEART STUDY

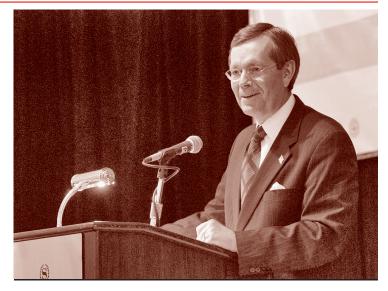
On November 29, 2007, The Honorable Michael O. Leavitt, U.S. Secretary of Health and Human Services, (HHS), came to Framingham to express the nation's appreciation to participants of the Framingham Heart Study (FHS). Their many years of dedication has made possible the SHARe (SNP Health Association Research) project, the phase of scientific research previously described in the Winter 2007 newsletter. The SHARe project was launched on October 1, 2007. FHS genomic data have been organized and are being distributed to researchers worldwide by the National Heart, Blood and Lung Institute, Boston University and the National Library of Medicine. With the approval of both a SHARe Data Access Committee as well as the institutional review boards of their local universities and medical centers, researchers are beginning to access and analyze the data. The goal is to find patterns within the extensive FHS three-generational data sets that will lead to improved health and disease prevention.

The event on November 29th celebrated the upcoming 60th anniversary of the Framingham Heart Study and included as guests Dr. Elias Zerhouni, Director of the National Institutes of Health. Dr. Elizabeth Nabel, Director of the National Heart, Lung and Blood Institute, Dr. Robert Brown, President of Boston University, Dr. Karen Antman, Dean of Boston University School of Medicine, Dr. Daniel Levy, Director of the Framingham Heart Study, and Dr. Philip Wolf, Principal Investigator of the Framingham Heart Study, as well as several local and state public officials. Every participant of the Heart Study was invited to attend this event. Below are excerpts of the remarks by Michael Leavitt.

"...I asked Dr. Zerhouni and Dr. Nabel for this opportunity to come and talk with you because there are so many things to acknowledge and be thankful for here, as this Study begins its 60th year. ... This is the Study that first pointed us toward the risk factors for cardiovascular disease that are so familiar to us all today.

For a health care researcher, the Framingham data looks like 24-carat gold. The reliability and the depth that researchers see in this data come from your consistency and openness over more than half a century. Here today in Framingham — I am honored to have the opportunity today to say "thank you" to all those who take part in medical research everywhere. ...

There's another reason to recognize the participants in the Framingham Heart Study at this point in time — and that's your willingness to take a new leap into the future. I believe you're on the cusp of giving much more. I'm talking about Project SHARe. And if this new research succeeds as we expect it to, it will help us achieve a new level of effectiveness in medical care. I call the goal "Personalized Health Care," and it means making health care much more individualized and precise for every patient. Personalized Health Care depends on learning much more about the genetic basis of our health.



Today, our medical knowledge is tied to our anatomy. We talk about lung cancer and heart disease. But in the future, we'll be talking about diseases at a much different level. We'll be talking about molecular-based diseases. That will give us all kinds of new treatments that are effective for very specific conditions in individual patients. Personalized Health Care can help us know our individual vulnerabilities. It can make health care more preventive. It can help us spot the onset of disease at a much earlier stage. And it can help us prescribe new therapies that are much more targeted and more effective.

One of the fundamental building blocks for achieving Personalized Health Care is the kind of information that can be gathered from existing studies. In Project SHARe, you've agreed to provide access to genetic data that has been collected as part of the Framingham Study. In Project SHARe, some of the best clinical data available to us has been collected over three generations — and you are sharing that data with researchers. Large samples will be a key to "personalizing" our findings.

In all of this, Framingham is a leader. We'll need new analytical tools and new structures to understand the large amount of patient data that will become available. This Study will have new lessons to teach us about aggregating and analyzing large amounts of patient data, getting sound results, and doing it securely.

If you have any questions about the SHARe project or any other aspect of participation in the Framingham Heart Study, please contact Maureen Valentino at 800-536-4143.

MEMORABLE COMMENTS



"The [Framingham] Study has moved medicine from a paradigm of diagnosis and treatment to prediction and prevention."... Dr. Karen Antman, Dean of Boston University School of Medicine

"And through Framingham, the National Institutes of Health recognized the irreplaceable role that public participation must have in any successful biomedical research program." ..."I thank you for making NIH what it is today."...Dr. Elias Zerhouni, Director, National Institutes of Health.





"...Thus evolved a wonderful symbiotic relationship [between staff and participants]...We have always trusted that, whatever we are asked to do, our best interests were always considered first and foremost ..." Dr. David Anghinetti, Offspring Cohort Participant, Framingham Heart Study

"...They [clinic staff] treated me great ... they showed me all the attention ... I was so grateful for all they did for me ... I am going to be 91 and I still can spell 'world' backwards!" Helen Vaughan, Original Cohort Participant, Framingham Heart Study.





"On this occasion of the celebration of the 60th year of the Framingham Heart Study as well as the celebration of entering into a new phase, the SHARe project, I would want you to know that I am honored to 'Stand and Be Seen' ... I am happy to be seen as a participant of the Omni Cohort of the Framingham Heart Study. Thank you for the inclusion of myself as well as

the hundreds of other [minorities] from Framingham who have not only benefited from the Study by enabling them to be proactive in their own health care management, but also by giving them an opportunity to contribute to the furtherance of research in the field ... "Rev. Dr. J. Anthony Lloyd, Omni Participant, Framingham Heart Study.

TO CONTACT US:

We maintain several local and toll free numbers for our participants to reach us here at the Framingham Heart Study:

Receptionist: 508-872-6562 or 800-854-7582.

Linda Clark: Original Cohort Coordinator, Brain Donation Program Coordinator: 508-935-3426 or 800-248-0409. lindac@bu.edu

Maureen Valentino: Offspring, New Offspring Spouse and Third

Generation Coordinator:

508-935-3417 or 800-536-4143. maureenv@bu.edu

Paulina Drummond: Omni Coordinator:

508-935-3485 or 800-854-7582 ext 485. omni@bu.edu

Marian Bellwood: Participant Coordinator and

Recruitment Supervisor:

508-935-3429 or 800-451-0260. bellwood@bu.edu

If you leave a voicemail message, please include a good time for us to return your call.

Please call or write us if you have a new street address, telephone number (home, work, or cell) or email address. Thank you!

ORIGINAL COHORT

The 30th exam cycle for the Framingham Heart Study's Original Cohort will begin in 2008. This will mark 60 years of participation for these dedicated men and women. Our original members had their first exams between 1948 and 1951 and have continued to have exams approximately every two years.

We see many of our participants here in the clinic. We also see many at their homes or in nursing homes if it is more convenient for them. For participants who live too far away for us to visit, we keep in touch by telephone, doing health updates and keeping track of medical events that occur

Our Original Cohort's long commitment to the work of the Framingham Heart Study is extremely gratifying. Their enthusiasm and dedication have influenced their children and grandchildren to participate as well, and we cannot thank them enough.

KEEPING IN TOUCH BY COMPLETING HEALTH HISTORY UPDATES

Once every two years, between clinic visits, Heart Study participants are asked to complete a health update either by mail or by phone. We ask for information about their health since their last exam or health update. Any new health information is reviewed by a panel of three physicians and becomes a valuable part of the data base used for FHS research. Please help us collect this information by completing and returning the form when it is mailed to you or by calling an FHS participant coordinator when you receive the form to provide this information by phone. Thank you!

BRAIN TISSUE DONATION PROGRAM

The Framingham Heart Study Brain Donation Program continues to contribute significant information on the aging process. We have analyzed brain tissue from 117 participants from 19 states, and currently almost 500 Study members are enrolled.

Neuropathology analysis may provide confirmation of stroke, Alzheimer's disease, Parkinson's or other neurological illnesses. We are particularly interested in exploring environmental and genetic links to neurological diseases, and postmortem analysis could provide a clearer picture of genetic risk. The donor's family receives a detailed report documenting our findings

We recently published a new finding that indicators of preclinical Alzheimer's disease seem to be found in the posterior regions of the brain, located near the back of the head. Prior research had hypothesized that the earliest stages begin in another region of the brain, the medial temporal lobe. Identifying the earliest markers of Alzheimer's disease is especially important because that is when treatment is most effective, and eventually when prevention may be possible.

To learn more about the Brain Tissue Donation Program, please contact Linda Clark, Research Coordinator, at 1-800-248-0409 or 508-935-3426, or email her at lindac@bu.edu. ♥

FRAMINGHAM GENETIC RESEARCH ACHIEVEMENTS

A team of Framingham investigators recently published a series of 17 linked papers that summarize a wide variety of genetic findings in our

Study. The publications of the Framingham Heart Study cover genetic studies of heart disease and stroke, high blood pressure, cholesterol, obesity, diabetes, blood chemistry results, lung function, kidney disease, and findings on the echocardiogram and electrocardiogram. This series of studies provides a glimpse of what to expect soon from the research we are conducting as part of the much larger SHARe Study (described on Page 1). Future Framingham genetic research will involve even more extensive analysis of alterations in the building blocks of DNA. In pursuing these projects we hope that Framingham will continue to contribute to the prevention and treatment of common diseases.

OSTEOPOROSIS RESEARCH AT THE FRAMINGHAM HEART STUDY

If you have completed a bone density test as part of your clinic examination, you have also made an important contribution to the Framingham Osteoporosis Study! Continuously funded by the National Institutes of Health since 1987, the Framingham Osteoporosis Study has performed close to 10,000 bone density tests for participants in the Original, Offspring and Omni 1 Cohorts.

Osteoporosis, which means "porous bone," is a disease characterized by weak bones and increased risk of fractures. Researchers study bone loss and fractures under the direction of Dr. Douglas Kiel, a physician specializing in geriatric medicine (the treatment and care of older people) and Director of the Institute for Aging Research at Hebrew Senior Life. Dr. Kiel and colleagues have found an important connection between bone and heart health. Using data collected from the Original Cohort since 1949, researchers discovered that women who experienced the greatest bone loss were those at greatest risk of developing plaques in the heart. Conversely, researchers found women with the strongest bones were less likely to develop heart disease than the women with weaker bones. Researchers also have identified that adequate amounts of dietary protein may be necessary to prevent osteoporosis. Previously it was widely thought that consuming too much protein was bad for bone health in older adults.

While it has long been established that levels of the hormone estrogen play a major role in the bone health of women, the impact of estrogen on the male skeleton was uncertain until Framingham Osteoporosis Study researchers investigated this highly important issue in men's health. The results showed that men with low estrogen levels were at increased risk of having low bone density as well as increased risk of hip fracture.

The Osteoporosis Study also found that hip fracture rates have been increasing. For example, rates were lowest in participants born 1887-1900, intermediate in those born 1901-1910, and highest in those born 1911-1921.

Investigators from the Osteoporosis Study have published more than 100 articles in leading medical journals and are also part of the new genetics initiative, the SHARe Project, to discover genes that might explain why bone fragility and fractures tend to occur in families.

Thanks to all Framingham Heart Study participants and to the collaboration of the Framingham Heart Study and Osteoporosis research teams, important progress will be made in improving our understanding of the causes and ways to prevent osteoporosis and fracture.

DAWBER MEMORIAL SCHOLARSHIP

In memory of Dr. Thomas R. Dawber, Director of the Framingham Heart Study from 1949 to 1966, the Friends of the Framingham Heart Study award a \$1,000 scholarship to a deserving high school senior upon graduation. The contest is open to all children of Framingham Heart Study participants who will be graduating in the spring of 2008 and going on to college. The prize will be awarded to that student whose

1,000 word essay is judged the winner of the competition. The topic is "What It Means to be a Participant in Medical Research". Essays should be sent as Word documents attached to an e-mail to Esta H. Shindler at eshindle@bu.edu no later than June 13, 2008. Include name, address and phone number, as well as college and career plans. Applicants will receive e-mail acknowledgement. If you do not receive an acknowledgement, please call Esta Shindler at 508-935-3434.

Last year Aliza Becker received the Dawber Memorial Scholarship. Portions of her deserving essay follow.

What it Means to be a Participant in Medical Research

... I feel like our family is very special because of the Framingham Heart Study. Not every family has the opportunity to make a difference in the world in the way that participating in a multigenerational medical research study does. ...

It is very satisfying to know that people are healthier and live longer than they would have if there had been no medical research and that my family was able to be part of a study which helped society in such a great way.

But not only has the Framingham Heart Study made a difference in the health of other people, it has also positively affected my family and our lives. We personally are healthier than we might have been due to this Study...

... I think that it would be interesting to discover how much of a person's chance of getting heart disease depends on genetics and how much it depends on environment. I think that my data could help in determining the answer to this question and continuing the understanding of a human's most vital organ, the heart.



FRAMINGHAM, THE TOWN THAT CHANGED AMERICA'S HEART

It's been said that the Framingham Heart Study put the town of Framingham on the world map. In keeping with this sentiment, ten years ago, at the time of the Heart Study's 50th anniversary, the phrase "Framingham, the town that changed America's heart" was created. As the Heart Study approaches its 60th anniversary, thanks to the efforts of the Friends of the Framingham Heart Study, along with the support of the Department of Public Works and the Board of Selectmen, six prominent signs have been strategically posted throughout the town to remind all those who live in or pass through the town that the participants of the Framingham Heart Study have indeed put the town of Framingham on the national and world map.

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

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THIRD GENERATION EXAM 2 AND NEW **OFFSPRING SPOUSE EXAM 2**

WE LOOK FORWARD TO SEEING YOU IN CLINIC!

The second cycle for the Framingham Third Generation Study and the New Offspring Spouses will begin in May 2008. Exams are scheduled each morning, Monday through Friday. We are located on the first floor of the Perini building at 73 Mt. Wayte Avenue. Please take advantage of our reserved participant parking. The clinic is under the direction of Dr. Joanne Murabito. Our participant coordinators, Maureen Valentino, Marian Bellwood and Sandy Bittenbender will be contacting you to schedule Exam 2. We look forward to seeing you in clinic!

If you live out of town and are planning to visit the Framingham area soon, please call Maureen at 800-536-4143 so she can arrange a clinic appointment for you at a convenient time.

OMNI STUDY

We have successfully completed Omni Gen 1 Exam 3 and would like to thank all of our participants who took part. We are preparing for Exam 2 of Omni Gen 2 participants, which will begin in the near future.

RECRUITMENT STAFF

The recruitment staff (Participant Coordinators) schedule Framingham Heart Study visits when a new examination cycle begins. The Coordinators track name and address changes, contact information, and reported medical events to keep data current. The Coordinators are the first people at the Heart Study with whom participants speak when they call with questions, requests, or special needs; they make certain participants have access to the appropriate Heart Study department or staff member. Coordinators are the advocates for our participants, keeping the lines of communication open at all times while staying within the guidelines of the Study requirements. >



(L to R) Mary Marinofsky, Maureen Valentino, Linda Clark, Linda Farese, Paulina Drummond, Marian Beliwood, Barbara Inglese, Deborah Foulkes, Sandra Bittenbender