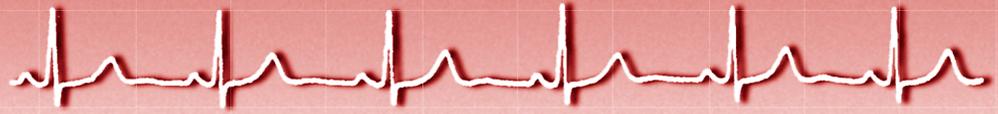


# The Framingham HeartBeat



Winter 2005

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## OFFSPRING EXAM 8 TO START SOON

In March, 2005, the eighth exam cycle of the Offspring generation will begin. The clinic exam will be similar to the previous seven Offspring exams. In mid-February, Framingham Heart Study Offspring Coordinators Marian Bellwood, Maureen Valentino and staff will start telephoning Offspring participants to schedule morning clinic visits. The visits will continue through 2007.

Since its inception in 1948, the Framingham Heart Study has pioneered research on the risk factors for heart disease and stroke. In more recent years we've also studied lung disease, osteoporosis, osteoarthritis and dementia. We are now focusing

on the genetics of these and other diseases. This innovative research has been possible because of the dedication of the thousands of loyal and enthusiastic participants who have generously given their time for periodic clinic exams and call-back visits. Now we are looking forward to their return visit for Offspring Exam 8.

If you are part of the Offspring study and you live outside of Massachusetts but plan to visit Framingham, please contact Marian Bellwood (1-800-451-0260) or Maureen Valentino (1-800-536-4143) to schedule an appointment at your convenience. The Framingham Heart Study is located at 73 Mt. Wayte Avenue, Perini Complex, Framingham, MA 01702. ♥

## THREE GENERATIONS

We are extremely gratified by the success of the Third Generation exam cycle. The response to the recruitment effort has been tremendous. To date, we have enrolled and examined 4,000 participants. We will continue exams into June, 2005. The Framingham Heart Study staff has been overwhelmed by the enthusiasm and dedication of our newest study participants!

We are deeply indebted to the first two generations of the Framingham Heart Study for instilling in the Third Generation a sense of commitment. The success of the Framingham Heart Study would be impossible without the unwavering effort of all our participants to attend each and every exam.

With three generations of participants, the Framingham Heart Study is uniquely qualified to pursue family patterns of disease and risk factors and to identify their genetic causes. We hope this information will lead to new treatments that will benefit future generations, just as the lessons learned in Framingham over the past 50 years have helped countless millions of people live longer and healthier lives today. This is our ongoing mission. ♥

## FRAMINGHAM HEART STUDY RESEARCHERS SEARCH FOR GENES UNDERLYING CARDIOVASCULAR DISEASES

Framingham Heart Study (FHS) researchers have recently reported that early onset of cardiovascular disease, coronary heart disease, and atrial fibrillation (a heart rhythm abnormality) occurs much more commonly in children whose parents suffered from these conditions. Indeed, the U.S. Surgeon General recently recommended that Thanksgiving Day be designated "family history" day to highlight that many common diseases run strongly in families. The familial predisposition to cardiovascular diseases suggests that the risk for these diseases is increased by changes in the genetic material—deoxyribonucleic acid or DNA—that is inherited by children from their parents. This year, it was determined that the entire length of DNA, or "genome", of each human being contains about 25,000 genes. A major focus of the FHS has been to identify and understand the genes that contribute to increased risk for diseases. Because the Framingham Heart Study has so many families containing three generations, we have a good opportunity to successfully identify

relevant genes. Several large research projects are now underway.

**1. "Linking" regions of DNA to risk factors and cardiovascular diseases:** Funded by the National Heart, Lung, and Blood Institute, FHS researchers have tested DNA from participants for about 400 genetic "markers" along the strands of DNA. These markers allow the researchers to search for "linkages" to cardiovascular diseases. Initial analysis of this "genome scan" was completed in the year 2000, allowing FHS researchers to focus on a number of areas of the genome that may harbor genes responsible for high blood pressure, obesity and abnormal cholesterol levels. Now, this genome scan is being expanded to include DNA from several thousand more men and women, including all members of the "Third Generation". This will allow a much more powerful search for genes linked to these and other diseases.

**2. DNA variations associated with diseases:** A team of researchers based in the

Department of Genetics and Genomics at Boston University School of Medicine, in collaboration with FHS researchers and researchers from the Harvard School of Public Health, is using a new technique for identifying disease-causing genes. The work builds upon an interesting observation about DNA in human beings. The DNA of all human beings is about 99.9% identical. However, it has been discovered that frequent natural variations in the genetic code, called single nucleotide polymorphisms (SNPs, or "snips"), account for the remaining 0.1% of our genetic makeup and determine each individual's unique genetic identity. These differences account for genetic traits, such as eye color and height, and for diseases. Using the new technique, the researchers will scan about 100,000 different SNPs simultaneously to find those that could explain cardiovascular and other diseases and their associated risk factors.

**3. In-depth study of important heart genes:** FHS investigators lead several ongoing large National Heart, Lung, and Blood Institute-

funded studies that will assess variations in key genes. The “CardioGenomics” project is designed to identify genes that can lead to increases in thickness of the heart muscle and size of the heart chambers. The “Genetics of Obesity” project is designed to examine the role of genes thought to cause obesity. The “Genetics of Inflammation” project is seeking to identify genes that are essential in the inflammatory process associated with heart and blood vessel diseases. In total, these projects will define the roles of several hundred important genes in heart disease risk factors and diseases.

In these ongoing and newly planned genetic studies, FHS researchers aim to present genetic research findings to investigators around the world who can test, confirm, and extend our findings. While genetic research is proceeding very rapidly, Framingham investigators have set up many safeguards to ensure absolute confidentiality of all participant data. In addition, several external advisory committees, including the Framingham Ethics Advisory Board (see article below), have been formed to advise the Study investigators about conducting research in the best interests of the FHS participants. It is anticipated that the genetic and nongenetic research made possible by the dedication of our FHS participants will directly help to develop new treatments and to provide insights into the prevention of risk factors for cardiovascular diseases. ♥

## FRAMINGHAM HEART STUDY ETHICS ADVISORY BOARD

As reported in our previous newsletter, a Framingham Heart Study Ethics Advisory Board was formed in the spring of 2004 consisting of professionals in the fields of medical ethics, genetic counseling, medicine, law, and religion, as well as representatives of the four cohorts of the Heart Study. The current members are:

Dr. Greg Koski, a physician and medical ethicist from Harvard Medical School and Massachusetts General Hospital, Boston

MaryAnn Whalen, a genetic counselor from Boston University

Dr. James Alderman, a cardiologist from MetroWest Medical Center, Framingham

Dr. Ralph Sherman, an internist from MetroWest Medical Center, Framingham

Rev. Dr. J. Anthony Lloyd, pastor of Greater Framingham Community Church, Framingham

Evelyn Langley, a representative of the Original Cohort of the Framingham Heart Study

David Whittemore, an attorney in Framingham and representative of the Offspring Cohort

Michelle Feinberg, an attorney in Framingham and representative of the 3rd Generation Cohort

Deborah Fuller, an ultrasonographer and representative of the Omni Cohort

The mission of this Board is:

- To consider complex questions posed by Study participants and Study investigators
- To provide the viewpoint of Study participants and community leaders in the process.
- To provide advice to the Executive Committee of the Framingham Heart Study
- To help the Framingham Heart Study conduct its activities in a manner that promotes and gives highest priority to the interests and well-being of Study participants.

In 2004 the Ethics Advisory Board met in April, June and October, to consider the reporting of test results to study participants. The following is a synopsis of the Board’s policy statement and recommendations to the Executive Committee:

“The Ethics Advisory Board believes that Study participants have an absolute right to know the circumstances under which information obtained in the Study will or will not be made available to them and the rationale for doing so or not. The practices of the Study should be governed by a uniform policy that is clearly expressed to participants at the time of the examination, and these policies must be appropriately described to the satisfaction of the participant during the process of making an informed decision to participate, as well as in the written consent form.

The actual decision of whether or not to provide information (i.e., test results) should be further governed by the ethical principle of beneficence, to do good. The Study staff should enter into a discussion with the participant to determine whether or not the individual wishes to be given the information, to have it provided to a third party, such as a physician or caregiver, or take other relevant action.”

In accepting this guidance, the Executive Committee has made several modifications to its procedures for notifying participants about the results of research tests. We also have modified the informed consent form for the upcoming Offspring Study exam in order to better inform participants about test results that may have implications for their health and treatment.

The Heart Study welcomes and greatly values your participation in the process of posing questions to the Ethics Board. If you have a question or comment for the Ethics Board, you may contact Esta Shindler at the Framingham Heart Study, at 508-935-3434. ♥

## BRAIN TISSUE DONATION PROGRAM

Since the Brain Tissue Donation Program’s inception in 1997, close to 600 Heart Study participants have enrolled. To date, we have analyzed brain tissue from 76 participants.

These detailed neuropathological analyses provide confirmation of stroke, Alzheimer’s Disease, Parkinson’s or other neurological illnesses, or may lead to the discovery of previously unsuspected conditions or diseases. It is hoped that comparing the brain tissue of mentally alert subjects to that of cognitively impaired individuals will lead to a clearer understanding of brain aging and cognitive decline. One important goal of this program is to increase the chances of preserving cognitive function into old age for the next generation. The Brain Tissue Donation Program has already contributed significant research information on the aging process.

Since our members have been coming to the Heart Study for so long (in the case of the first generation, well over 50 years) we have a wealth of data documenting physical and neurological conditions, life styles, and changes in cognition occurring over time. When we analyze brain tissue, we relate this detailed clinical data to the neuropathological findings. This is why our Brain Tissue Donation Program is open only to Framingham Heart Study participants. We handle all expenses in connection with the donation process.

If you would like to learn more about this important program, please contact Linda Clark at 1-800-248-0409 or 508-935-3426, or email her at [lindac@bu.edu](mailto:lindac@bu.edu). ♥

## DO YOU KNOW SOMEONE WHO COULD BE AN OMNI PARTICIPANT IN THE FRAMINGHAM HEART STUDY?

The Omni Study began in 1994 when we recognized the need to better reflect the ethnic diversity of the Framingham community. Originally 500 men and women of African-American, Hispanic, Indian, Asian and/or Pacific Islander and American Indian origins were enrolled. Now we are opening minority enrollment again, to increase the number of our Omni participants.

In this new effort, we hope to see a total of 400 participants by July, 2005. So far we have seen over 250. We need your help to recruit more Omni participants to the Framingham Heart Study!

If you have any family or friends that may be eligible (20 years of age or older and who meet the ethnic criteria) please contact Paulina Drummond, Omni Study Coordinator at 508-935-3485 or 800-854-7582 ext 485, or Maureen Valentino at 508-935-3417 or 800-536-4143. ♥

### TO CONTACT US:

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

Receptionist: **508-872-6572 or 800-854-7582**

Marian Bellwood, Offspring Coordinator, Cardiac MRI Coordinator:  
**508-935-3429 or 800-451-0260**

Maureen Valentino, Third Generation Coordinator:  
**508-935-3417 or 800-536-4143**

Linda Clark, Original Cohort Coordinator, Brain Donation Program Coordinator:  
**508-935-3426 or 800-248-0409**

Paulina Drummond, Omni Coordinator:  
**508-935-3485 or 800-854-7582, ext 485**

Patricia Kelly, New Offspring Spouse Coordinator:  
**508-935-3403 or 800-854-7582, ext 403**

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

Please call or write us if you have a new address or new telephone numbers where we may contact you (home, work, or cell) or email address which you would like us to use. Thank you!

## CALLING ALL ELIGIBLE NEW OFFSPRING SPOUSES

The opportunity to join the Framingham Heart Study as a New Offspring Spouse (NOS) is ending soon. If you are the spouse of an Offspring participant and have two or more biological children who have come into the clinic for a Third Generation exam, we would like you to enroll. We may have left you a message, or you may have just recently become eligible with the enrollment of your second child. In the next few months we will be contacting all of the remaining eligible spouses. If you are interested, please call Patricia Kelly, NOS Coordinator at 508-935-3403 or for those out of state at 800-854-7582 ext 403. ♥

## CT STUDY WILL END MAY, 2005

The CT Scan Study, which measures the amount of calcium deposits in the artery walls of the heart and aorta, is coming to a close. This important Study will help us better understand the link between high coronary calcium scores and heart disease. Over 3,000 participants in the Third Generation and Offspring Study groups have taken part in this Study. Eligible men are age 35 years and older and eligible women are 40 years and older. Results that may be clinically important are forwarded to your physician. The CT scan takes only 15 minutes and is performed at Massachusetts General West Imaging Center in Waltham, MA.

You will be contacted by Barbara Inglese, the CT Study Coordinator, if you are eligible for the CT Scan Study. Barbara Inglese can be reached at 508-935-3451 or 800-854-7582, ext. 451. ♥

## FRIENDS OF THE FRAMINGHAM HEART STUDY

The Friends of the Framingham Heart Study was formed in 1991 as a community-based organization to provide supplemental support for the research activities of the Framingham Heart Study and advocacy for the participant population. It is a non-profit organization with tax-exempt status and is supported solely by donations. The Friends are pleased to announce their new officers. They are:

Karen LaChance, President  
Peter Allen, Treasurer  
Jim Gordon, Clerk

The Board of Directors are participants in the Heart Study and represent each of the four cohort: the Original Cohort, the Offspring Cohort, the Third Generation Cohort, and the Omni Cohort. Esta Shindler is the Administrative Manager of the Friends and welcomes any questions you may have. She can be reached at 508-935-3434.



Friends of the Framingham Heart Study from left to right: Dr. Philip A. Wolf, Principal Investigator, Framingham Heart Study; Nancy Spinale, Board Member; Karen LaChance, President; Jim Gordon, Clerk; Peter Allen, Treasurer; Dr. Daniel Levy,

Director, Framingham Heart Study. Additional Friends Board Members are Jay Lander, John Galvani, Noreen Murphy and Deborah Fuller. ♥

## DR. FREDERICK BRAND, FORMER RESEARCH INVESTIGATOR

We are sad to announce the death of Dr. Frederick Brand and wish to extend our sympathy and condolences to his family. Dr. Brand retired in 1998 and will be warmly remembered for his 25 years of dedication to the Framingham Heart Study and Boston University School of Medicine. He was actively involved as a research investigator and had also spent much of his time examining participants in our clinic to help generate the data that forms the basis of our research. ♥

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## EMPLOYEE SPOTLIGHT

Marian Bellwood (right) and Emily Manders (left) have been working at the Framingham Heart Study for 30 and 23 years, respectively. Marian has been involved with the Offspring Study as the Coordinator and with scheduling the Cardiac MRI appointments. Emily (left) has worked in many of the clinics, including the Family Study, as well as on many other projects at the Heart Study. The gratification from knowing and working with our wonderful participants and supportive staff has been integral to Marian and Emily's continuing tenure at the Heart Study.

