

Black Women's Health Study



BOSTON UNIVERSITY
SCHOOL OF MEDICINE



HOWARD UNIVERSITY
COLLEGE OF MEDICINE

Fall 1997 Newsletter

INFORMATION ON:

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- Investigators
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- Results

Background

Large follow-up studies of the health of white women have been in progress for many years. Finally there is recognition of the need for information on causes of illnesses in black women, who have higher rates of many illnesses, such as hypertension, stroke, and lupus. The Black Women's Health Study (BWHS) is designed to provide that information.

The 65,000 BWHS participants come from all parts of the U.S. and have an average age of 40 years. About 8,000 reported that they have hypertension, 700 have had breast cancer, 600 lupus, and 500 heart attacks.

Dr. Lynn Rosenberg and Dr. Julie Palmer, Boston University, and Dr. Lucile Adams-Campbell, Howard University, head the study. Other investigators include Dr. Shiriki Kumanyika, providing expertise on diet;

Dr. Tim McAlindon, lupus; Dr. Camara Jones, health effects of racism; Dr. Michael Corwin, premature birth. Advice is provided by an Advisory Board composed of a diverse group of black women, both laypersons and scientists.

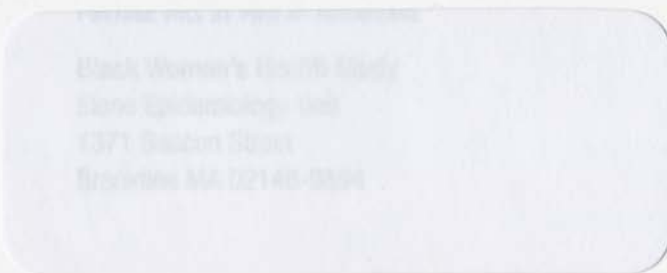
The BWHS is funded by a 5-year grant from the National Institutes of Health. At the end of that period we will seek funding for another 5 years. Previous health studies have received funding in this manner for decades.

Participants completed a baseline health questionnaire in 1995. Every two years, questionnaires will be sent to update information on your health. Permission will be sought to review medical records in order to properly classify serious illnesses that are reported. So far, 49,000 participants have completed the 1997 follow-up questionnaire.

Confidentiality is assured by removing identifying information from the questionnaires, identifying the data by code number only, protecting computer files with security passwords, and shredding documents. All employees have signed a confidentiality statement. A Confidentiality Certificate from the federal government protects the data from access by outsiders.

The success of follow-up studies is dependent upon the continued participation of the people in the study. We are grateful to all of you for your willingness to participate, your enthusiasm, and your helpful suggestions. ■

The success of the Black Women's Health Study is dependent upon your continued interest. We are grateful to all of you for participating. If you have any questions about the BWHS please call our toll-free number at 1-800-786-0814.



What We've Been Doing Since 1995

We edited the 1995 baseline questionnaires and fed the 910,000 pages through an optical scanning machine to enter the data onto computer file. We then checked the computerized data for errors.

We have been sending out the 1997 follow-up questionnaires. To date, 49,000 BWHS participants have completed them. If you have not received one, please let us know. Call toll-free at 1-800-786-0814.

We have been trying to locate participants for whom we do not have forwarding addresses. If you move or change your name please let us know.

We are conducting special studies of randomly selected BWHS participants. Dr. Kumanyika is looking at how well the 1995 questions on diet

correspond to women's actual diets. 400 BWHS participants have taken part in special diet interviews. Dr. McAlindon has contacted 50 women who reported having lupus and 100 women without lupus to determine how well questions about symptoms distinguish between them. He is also reviewing medical records to assess how well self-reports correlate with physician notes. Because valid results depend on accurate diagnosis, we are also reviewing medical records for other serious illnesses.

We have conducted a series of analyses of the BWHS data. The results are given in the section *RESEARCH RESULTS*. ■

Health Concerns Of BWHS Participants

The most frequently asked questions from you concern uterine fibroids, diagnosed in about 20,000 BWHS participants. This benign tumor is thought to be much more common in black women than in white women. The occurrence increases with age. Causes are largely unknown. Diagnosis is usually through a routine pelvic exam or ultrasound. Fibroids often cause no symptoms and do not require treatment, but they do sometimes lead to excessive bleeding during periods, bleeding between

periods, frequent urination, pain, and infertility. Treatment options include hormone therapy, myomectomy (surgical removal of the fibroids which leaves the uterus intact), and hysterectomy (removal of the uterus). For more information on fibroids you can call the National Institute of Child Health and Human Development, 301-496-5133, or the National Women's Health Resource Center, 202-293-6045. Future newsletters will provide information on other illnesses. ■

Research Results

Heart Attacks

Preliminary BWHS results were published in the *American Journal of Epidemiology* in 1997. Cigarette smoking, hypertension, diabetes, being overweight, and having a parent who had a heart attack were related to an increased risk of heart attacks. A detailed report has been submitted for publication. ■

Blood Clots in the Leg or Lungs

Recent studies of white women suggest that blood clots in the legs or lungs may occur more often among women who take postmenopausal female hormone supplements. Our results, to appear in the *American Journal of Obstetrics and Gynecology*, indicate that this may be the case in black women as well. This illness is rare, but it should be considered when making the decision about whether to take hormone supplements. ■

Lupus

Little is known about the causes of lupus (systemic lupus erythematosus), which affects black women more than other women. Our preliminary findings, to appear in the journal *Arthritis and Rheumatism*, suggest that cigarette smoking is related to an increased risk. It is important to see if this result holds true for new occurrences of lupus reported by BWHS participants in the future. ■

Hypertension

A high proportion of black women are affected by hypertension, including almost half of BWHS participants in their 60's. The BWHS data confirm the importance of overweight in increasing risk. The results have been submitted for publication. ■

Hysterectomy

The hysterectomy rate among U.S. women is very high and some of these operations may be unnecessary. We have found that rates among BWHS participants differ according to where women live. Differing medical practices may explain this result, and it underscores why it is a good idea to get a second opinion when hysterectomy is suggested. ■

Breast Cancer

Presently there are no simple ways in which women can modify "lifestyle" to lower the chance of developing breast cancer. Recent studies have raised the possibility that exercise may lower the risk. We are conducting detailed analyses to assess this possibility among BWHS participants. It will be necessary to confirm what we find, which is a major reason for continuing the BWHS in the future. ■

Questions & Answers

Q. Who can I contact if I have questions about BWHS?

A. You can call our toll-free number, 1-800-786-0814, to reach study investigators and research assistants.

Q. Can participants have input into the decision about what health issues will be studied?

A. Yes. For example, in 1995 many participants commented on the need for studies of factors related to the high rate of premature birth of black infants. A section on reproductive health was included in the 1997 questionnaire. If you have suggestions please let us know.

Q. Are other large follow-up studies of the health of black women in progress?

A. No. The BWHS is by far the largest study ever conducted and will be the most informative.

Q. How will we learn of study results?

A. Our regular newsletters will continue to update you as new findings emerge.

Q. Is my response to the questionnaire important?

A. Yes, it is crucial. The accuracy of scientific studies like the BWHS depends critically on the participation rate. If the rate is low, there will be doubt that the results are correct.

Q. In 1995, who was invited to participate in the BWHS?

A. Questionnaires were mailed to subscribers to Essence magazine and members of several professional organizations.

Q. Can new people join the BWHS?

A. No. Because of the study design, it is limited to the 65,000 women who enrolled in 1995.