# Black Women's Health Study





# January 1999 Newsletter

"The implementation of the Black Women's
Health Study means that the health of black
women is now a high priority.

I am glad to be able to play
a small role in it."

Ellen Grant Bishop, Ph.D., ACSW

Commissioner, Erie County

Dept. of Mental Health

and BWHS Participant

## WHAT'S AHEAD?

Every two years we send you a health questionnaire to update information about health and illness. This is how we find out who has had an illness in the previous two years — a heart attack, cancer, lupus, and so on. The questionnaire also updates information on weight, exercise, smoking, use of contraception, and other factors that might influence health. Once enough occurrences of an illness have been reported, we can then assess whether weight, exercise, smoking, or any of the other factors is related to the occurrence of the illness. Watch for the 1999 questionnaire. You will be receiving it in March of 1999. Please take 15 or 20 minutes to fill it out and return it to us. The cooperation of participants in the BWHS has been wonderful, and it is crucial for the success of the study that it continue. As always, if you have questions or concerns, call us toll-free at 1-800-786-0814.

The success of the Black Women's Health Study depends upon your continued participation. You will receive the 1999 BWHS questionnaire in March of 1999. Please fill it out and return it to us! Questions? Suggestions? Concerns? Call us, toll-free, at 1-800-786-0814.

#### **Confidentiality**

As soon as the questionnaires are received at our office, the sheet with personal information is detached from the rest of the questionnaire and stored separately. Published information provides group statistics only and never individual information. Furthermore, by law, the Black Women's Health Study is prohibited from providing participant information to outside sources.

#### **BWHS Logo?**

Do you think there should be a BWHS logo — an attractive graphic that would be associated with our study and appear on letters, newsletters, and questionnaires? Let us know what you think, and send us your ideas for a logo if the creative urge strikes you!

## SPECIAL STUDIES WITHIN THE BWHS

**Diet Validation Study.** 200 BWHS participants took part in a diet validation study. They reported what they had eaten several times over the course of a year, and they also kept food diaries for a week. Dr. Shiriki Kumanyika, a member of the BWHS Advisory Board and the BWHS expert on diet, conducted the study to find out how well the diet questions on the 1995 BWHS health questionnaire reflect what participants really ate. The study is a step toward the goal of finding out if certain foods cause or prevent particular illnesses.

Physical Activity Validation Study. A sample of BWHS participants will be invited to participate in a physical activity validation study. These women will be asked to report on their physical activity (walking, aerobics, etc.) and to keep physical activity diaries several times over the course of a year. The ultimate goal is to be able to assess how physical activity influences various illnesses. The study will take place during 1999 and 2000.

Medical Record Review. An important part of all health follow-up studies like the BWHS is to determine exactly what illnesses occur among the participants, and this requires review of medical records. The medical record information is used to determine how accurately diseases are reported, and to classify different types of particular diseases because different types might have different causes. We will be asking women with particular illnesses for written consent to review their records. We thank you in advance for your help. As always, the information will be kept strictly confidential and used only in statistical analyses. You are protected by a Certificate of Confidentiality from the U.S. Department of Health and Human Services. Medical record review will continue to be an ongoing part of the BWHS.

Check Swab Study. Cells obtained by rubbing a soft brush on the inside of the cheek contain genetic material. Recent scientific findings suggest that certain genes may play a role in how the body handles carcinogens. For example, people with one form of a particular gene might clear the body of carcinogens from cigarettes much faster than people with other forms of the gene. The BWHS will assess genes of this type. The ultimate goal is to be able to identify what makes some women more susceptible to particular illnesses. Starting in 1999, BWHS participants will be given the opportunity to provide cheek swabs.

# **Mammography and Breast Cancer**

#### New National Cancer Institute Mammography Guidelines

African-American women are less likely to develop breast cancer than white women but are more likely to die of the disease. Part of the reason is that black women tend to be diagnosed when the cancer is more advanced, and survival is worse the later the cancer is detected.

The screening mammogram — an X-ray of the breast for detecting growths — is a tool for diagnosing breast cancer at an early stage. Before 1995, the National Cancer Institute recommended that women have regular screening mammograms starting at age 50, because scientific studies had shown that this practice reduced deaths from breast cancer in women who are 50 or older. Regular mammograms were not recommended for younger women because the benefits were less clear. Younger women have denser breasts and growths are more easily missed. Mammography also sometimes detects growths that turn out not to be cancer, resulting in great anxiety before the benign nature of the lump is determined.

In 1995 the National Cancer Institute reconsidered the evidence and issued new recommendations — that regular screening mammograms begin at age 40 rather than 50.

### Mammography Use in the BWHS

BWHS participants were ahead of the National Cancer Institute recommendations for screening to begin at age 40! Based on questions about mammography use in the BWHS 1995 baseline health questionnaire, 85% of participants aged 40–49 had had a mammogram, and 45% had one in the previous two years. Among women aged 50 and older, 95% had undergone mammography, about half in the previous two years. Mammography rates were similar in various regions of the U.S. It was reassuring to see that younger women who had mothers or sisters with breast cancer had higher rates of mammography use than other women of the same ages.

In sum, BWHS participants across the country are making extensive use of mammography. This was so among women aged 40–49 even before the National Cancer Institute issued its new guidelines. The hope is that regular screening will pick up breast cancer early and result in a decrease in breast cancer deaths.

# **QUESTIONS AND ANSWERS**

How often are health questionnaires sent to BWHS participants? Every two years.

When will I receive the next BWHS questionnaire? In March of 1999.

I have a friend who wants to join the BWHS. Can she participate?

No. Only women who enrolled by completing the 1995 BWHS baseline questionnaire may participate in the BWHS. The study design involves following the same women over a long period. Fortunately, the information obtained from the BWHS will be useful to African-American women whether or not they have participated in the study.

If I have a medical question, can the BWHS help me?

We can help you to find sources of information, but we cannot give advice on specific medical problems. Only your doctors and nurses have sufficient information to help you make decisions about care and treatment. If you are in doubt about the care you are getting, it is useful to get a second opinion.

How can I find out about information that the BWHS has published?

Study findings are reported in the Newsletters that we send to you. If you have further questions, give us a call, toll-free, at 1-800-786-0814.

How often will I receive a BWHS Newsletter?

Twice a year, once in the summer and once in the winter.