Black Women's Health Study

Summer 1998 Newsletter

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Vivian Pinn, MD
Associate Director for Research on Women's Health
Director, Office of Research on Women's Health National Institutes of Health

Inside: The latest information on the Black Women's Health Study
We are pleased to share with you the following letter from Dr. Vivian Pinn, who is among the highest ranking African-American officials in the National Institutes of Health.

Dear Dr. Rosenberg,

Thank you for informing me about the progress of the Black Women's Health Study (BWHS). The study has my enthusiastic support. Its goals are of direct relevance to the mission of the Office of Research on Women's Health - to conduct research that will lead to improvement in the health of all women.

African-American women bear a greater burden of morbidity than white women in the United States. I am very supportive of a study that may well help to lessen or eliminate these differences. I applaud the 64,500 women who are participating in the BWHS. With their continued participation in this unique long-term study, I have every confidence that the BWHS can provide results that will contribute to the improved health of Black women. Their contribution as volunteers in this landmark study are, and will be, appreciated by Black women and their families for years to come.

Sincerely yours,

Vivian Pinn, MD
Associate Director for Research on Women's Health
Director, Office of Research on Women's Health
National Institutes of Health

The success of the Black Women’s Health Study is dependent upon your continued interest. So far, over 50,000 BWHS participants have completed the 1997 8-page pink questionnaire. If you have not, we hope you will do so soon. If you need a new questionnaire or have questions about the BWHS, please call our toll-free number 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.

Any contact with friends or relatives whose names have been provided by participants is solely for the purpose of locating the participant in the event she cannot be reached by mail or by phone. No personal study information about the participant will be disclosed to friends or relatives.
Design of the BWHS

The BWHS is a “follow-up” study. The follow-up design is one of the best ways to determine whether a factor causes a disease. For example, to learn if smoking causes a particular disease we would enroll a group of people and determine their smoking habits. Then we would follow them over time to learn about changes in their smoking habits and who had developed the disease. Once enough new cases of the disease had occurred (for example 500), we would compare the rate of disease in smokers to the rate in nonsmokers. A higher rate in smokers (after taking into account other factors that might also influence the rate of that particular disease) would suggest that smoking might be a cause. This study design requires that the same people be followed over time. It also requires that the study go on for as many years as necessary for sufficient cases of specific diseases to develop. Even for a relatively common disease such as stroke, it would take at least 5 years for sufficient numbers to occur for a valid study. For rare diseases, such as ovarian cancer, it might take 10 years. The reason for using a follow-up design is that results are reliable if it is well done, and many factors and diseases can be studied at once. However, this design takes time and requires the dedication of the participants.

Study Publications

In the last newsletter, we told you about some of the analyses underway based on the data collected in 1995. Below you will find a list of articles published so far.


- **Associations of cigarette smoking and alcohol with systemic lupus erythematosus (SLE) among participants in the Black Women’s Health Study.** McAlindon T, Felson D, Palmer J, Zhang Y, Rosenberg L. Arthritis Rheum 1997;40:S162.


A Personal Journey to Improved Health

Rosemary Graham is a Lupus/Myositis/Fibromyalgia patient and Advisory Board member of the BWHS. She also serves as the Seventh-day Adventist Representative for the National Council of Churches in the Christ Committee on Disability. We asked her a few questions about diet and exercise.

Rosemary, we hear you’ve lost 105 pounds! How long did it take and how did you do it?
I refined my diet, and included exercise. I joined Lee Haney’s World Class Fitness Center in June, 1996. Three years ago I weighed 365. Now I weigh 260. I have 100 pounds to go.

What changes did you make in your diet?
My diet initially changed in 1984 when I was diagnosed with lupus, myositis, (muscle inflammation), pulmonary fibrosis and fibromyalgia. I have been on steroids since ‘84 and methotrexate since ‘91. Despite the changes, I prepared foods wrong, and continued eating high fat foods. I didn’t drink enough water. In 1996, I refined my diet, started eating low-fat, reduced salt and sugar, and began drinking more water. 75% of my meals are vegetarian.

You’ve been on steroids since 1984 and you still lost weight? What was the major factor?
Exercise – and being consistent with it. I work out 4 days each week and alternate doing cardio and weight training. I don’t have a personal trainer, but the staff and men in the gym help me. Even when I’m sick and can’t do my regular routine, I still go and do a “little something”.

How have your emotions changed since you’ve lost weight?
I always suffered from low self-esteem and depression. I grew from a fat child to adult and went on/off diets for years. Although my depression and low self-esteem have changed, sometimes I’m frustrated because of weight plateaus and slowing exercise routine when I’m sick. I get discouraged because I think I should have lost more than I actually have.

What advice would you give women who are trying to change their diets?
Set consistent lifestyle changes. Drink at least 6-8 glasses of water daily (not including juice, sodas or teas). Eat low-fat, and reduce salt and sugar. Most importantly, exercise! Stick with it – don’t quit! Even if you slip and eat something fattening, get back on track. Don’t weigh every day because your weight will plateau and the scales will disappoint you. Last year I didn’t lose weight for 9 months, but I was consistent going to the gym, even when I felt bad. You have to take one day at a time.
A Profile of the BWHS Investigators

The BWHS is headed by the team of Dr. Lynn Rosenberg and Dr. Julie R. Palmer at Boston University and Dr. Lucile L. Adams-Campbell at Howard University.

After working as a chemist, Lynn Rosenberg returned to school to earn a doctorate in epidemiology at Harvard. Her work has focused on the effects of oral contraceptives, postmenopausal female hormone supplements, and other medications on the risk of cancer and heart disease.

Julie Palmer worked as a nurse before earning a doctoral degree in epidemiology at Harvard. Her recent research has focused on reproductive outcomes and on the health effects of certain drugs taken by mothers during pregnancy on the later health of their children.

Lucile Adams-Campbell earned her doctorate in epidemiology at the University of Pittsburgh. Her early work focused on cardiovascular disease, physical activity, and obesity. In recent years, she has turned her attention to causes and preventives of cancer.

Long before it became fashionable, these investigators were concentrating on women's health. Lynn and Julie have worked together for over 10 years. The collaboration with Lucile began after Lynn and Lucile served together on a committee that was reviewing a women's health study. The investigators have produced over 300 scientific publications, 5 children and 1 grandchild – Lynn has 2 married sons and a granddaughter, Julie a daughter aged 4, and Lucile a 9-year old son and a 5-year old daughter.

A Snapshot of BWHS Participants

Based on information given on the 1995 questionnaire, BWHS participants live in all 50 states. The most common medical conditions reported are uterine fibroids, hypertension, high cholesterol, and diabetes. Some other characteristics of the group are:

- 35% are currently married or living as married;
- 19% live alone;
- 40% have childcare responsibilities;
- 12% help in the care of parents or other relatives;
- 44% have completed college;
- 16% currently smoke cigarettes;
- 82% have used oral contraceptives;
- 24% have gone through menopause;
- 15% have used menopausal female hormone supplements;
- 50% have had a screening mammogram for breast cancer; and
- 14% perform self-examination of the breast at least once a month.
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INFOGRAPHIC ON:
- Participants
- Confidentiality
- Investigators
- A Personal Story
- Study Design
- Publications

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Please check to see if this label is correctly addressed.

If your last name or address has changed from that on the mailing label, please fill in the correct name and address and mail it to us on this prepaid postcard.

Can new people join the BWHS?
No. Because of the study design, it is limited to the 64,500 women who enrolled in 1995.

Has your last name or address changed?

If so, please make changes and mail.

Name

Street

City State Zip

Telephone Number

If there are no changes, please do not mail this back.