

The Black Women's Health Study

CELEBRATING 10 YEARS



*Take good care of yourself. Good health
is everyone's major source of wealth.*

- Anonymous

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THANK YOU

Perhaps it's night time or a calm Sunday afternoon. In either case, it is that point in the day when you have set aside some time to sort through your large pile of mail. As you methodically go through the letters, deciding which will be fortunate enough to deserve your undivided attention and which will find its way to the waste basket, you come across a large white BWHS envelope. You open it and discover another questionnaire with a series of circles that require bubbling, bubbling, bubbling. You decide to complete the questionnaire right then and there, or you put it aside to be completed at a later time. Whatever the situation may be, you are one of the many women who have, for 10 years, continued participating in the BWHS in the hope that you are contributing to the improved health of black women. The study would not exist without you. The BWHS thanks you for your time and your cooperation.

Some of you have written asking about what your contributions have achieved. We have tried to keep you informed through the newsletters sent to you every 6 months. It is our hope that this anniversary newsletter will make even clearer what has been accomplished already and what we plan to accomplish in the future. As you know, the BWHS began in 1995. 59,000 participants from across the United States have been followed since then through mail questionnaires. More than half of the study participants were younger than 40 when the study began. This means that many illnesses that affect younger women – such as fibroids – could be studied early on in the follow-up. As time has passed, it has become possible to study illnesses that affect older

women such as cancer, and rarer illnesses such as lupus. What are the findings so far? We have learned about some of the risk factors for heart disease, breast cancer, lupus, and fibroids. We have studied racial discrimination in relation to preterm birth. We have identified factors that influence whether women exercise, or whether they go for screening mammograms, or whether they get hysterectomies. The list is long, and we have included a listing of some of the publications from the BWHS later on in this newsletter.

The findings from health studies are not etched in stone. The understanding of causes of illness and predictors of health will increase as we are able to examine issues in greater depth and as scientific knowledge of human physiology and genetics increases. For these reasons, the BWHS continues and its contributions will become even more valuable in the future. Again, our heartfelt thanks.

PRIVACY STATEMENT

Your privacy is very important to us. You have trusted us by providing personal information, and we are very careful to have the highest standards for safekeeping that information and your privacy. Only statistical analysis of the questionnaire data are carried out. The data are identified by code only and stored separately from personal identifiers. There are never case reports and the results cannot be linked to any individual. All activities are approved and overseen by the ethical review boards of Boston and Howard Universities. The study is further protected by a certificate of confidentiality from the U.S. Department of Health and Human Services.



THE NEED FOR THE BWHS



Dr. Linda Clayton, member of the BWHS Advisory Board, was one of the early African-American graduates of Duke University Medical School. While a medical student she observed that "Black patients seemed to be sicker, presented at later stages in their disease processes, and fared worse than White patients." She and her husband, Dr. W. Michael Byrd, have documented the poorer health of African-Americans and the failures of the American health care system in their acclaimed books, "An American Health Dilemma, A Medical History of African Americans and the Problem of Race, Beginnings to 1900" and "An American Health Dilemma; Race, Medicine and Health Care in the United States 1900-2000".

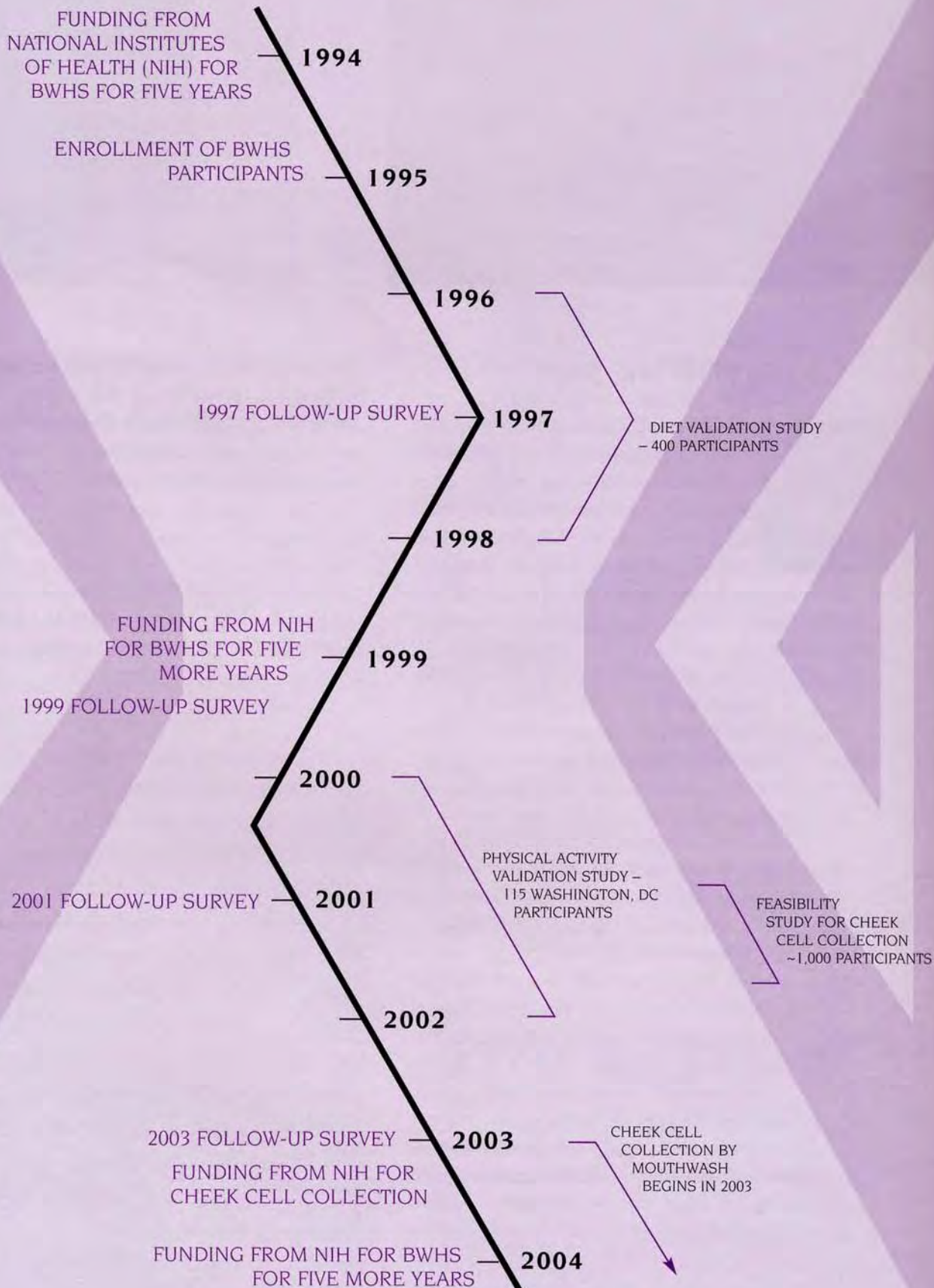
The idea for the BWHS grew out of an awareness of these health disparities. African-Americans were dying at greater rates – as infants, young adults, at older ages, at every age – than white Americans. This was so for every major illness – including cancer, heart disease and stroke. Black women were much more likely develop diabetes, high blood pressure, and lupus. Despite this heavy burden of illness, only small numbers of African-Americans were included in health studies. Large follow-up studies of the health of white women, but not of black women, were being conducted. Started 30 years ago in 1976, the first Nurses' Health Study included 120,000 nurses, of whom 98% were white. A second Nurses' Health Study, started in 1986, included another 120,000 nurses, almost all of whom were white. Both studies are still in progress. The BWHS, begun in 1995,

remains the largest follow-up study of the health of black women yet conducted. It will provide much needed answers about the causes of illness and the predictors of well being in black women. These answers should lead to better health and the elimination of health disparities.

A VOICE *from the BWHS*

"I have been a member of this project since its inception and always have taken pride in answering the survey questions and frankly get a little bent out of shape when I don't receive the survey on time. By participating in the survey over the years, I have become more aware of the different types of diseases that affect not only black women but all women. Lupus and breast cancer run on my mother's side of the family. I have made my goal in life not just to educate myself but others concerning these diseases. I now participate in fund raising walks and have, in the last five years, become a volunteer with the MS Foundation. In addition, after MANY years of being a couch potato I have now joined a gym and exercise at least 3 to 4 days a week."

BWHS Time Line



10th ANNIVERSARY

THE FIRST 10 YEARS

Selected BWHS Publications:

- The Black Women's Health Study: A follow-up study for causes and preventions of illness. (Rosenberg et al.) *J Am Med Wom Assoc* 1995;50:56-8.
- Postmenopausal female hormone use and venous thromboembolic disease in black women. (Rosenberg et al.) *Am J Obstet Gynecol* 1997;177:1275.
- Correlates of postmenopausal female hormone use among black women in the United States (Rosenberg et al.) *Obstet Gynecol* 1998;91:454-8.
- Obesity and hypertension among college-educated black women in the United States.(Rosenberg et al.) *J Hum Hypertens* 1999;13:237-41.
- Risk factors for coronary heart disease in African-American women. (Rosenberg et al.) *Am J Epidemiol* 1999;150:904-9.
- Correlates of hysterectomy among African-American women. (Palmer et al.) *Am J Epidemiol* 1999;150;1309-15.
- Descriptive epidemiology of physical activity in African-American women.(Adams-Campbell et al.) *Prev Med* 2000;30:43-50.
- Perceptions and experiences of racism among African-American women. (Cozier et al.) *Am J Epidemiol* 2000;151:S24.
- Height and breast cancer risk: results from the Black Women's Health Study. (Palmer et al.) *Cancer Causes Control* 2001;12:343-8.
- Recent mammography use among African-American women. (Cozier et al.) *Ethn Dis* 2001;11:188-91.
- Strenuous physical activity and breast cancer risk in African-American women. (Adams-Campbell et al.) *J Natl Med Assoc* 2001;93:267-75.
- Follow-up of a large cohort of Black women. (Russell et al.) *Am J Epidemiol* 2001;154:845-53.
- Relative validity of food frequency questionnaire nutrient estimation in the Black Women's Health Study.(Kumanyika et al.) *Ann Epidemiol* 2003;13:111-18.
- Patterns and correlates of alcohol consumption among African-American women. (Rosenberg et al.) *Ethn Dis* 2002;12:548-54.
- Perceptions of racial discrimination in relation to preterm birth in the Black Women's Health Study. (Rosenberg et al.) *Epidemiology* 2002;13:646-52.
- Onset of natural menopause in African-American women. (Palmer et al.) *Am J Public Health* 2003;93:299-306.
- Dual effect of parity on breast cancer risk in African-American women. (Palmer et al.) *J Natl Cancer Inst* 2003; 95:478-83.
- Smoking, alcohol consumption and risk of systemic lupus erythematosus in the Black Women's Health Study. (Formica et al.) *J Rheumatol* 2003;30(6):1222-6.
- Comparison of methods for collection of DNA samples by mail in the Black Women's Health Study. (Cozier et al.) *Ann Epidemiol* 2004;14(2):117-122.
- Assessment of strategies for identifying cases of systemic lupus erythematosus through self-report. (McAlindon et al.) *Lupus* 2003;12:754-759.
- A prospective study of the effect of childbearing on weight gain in African-American women. (Rosenberg et al.) *Obesity Res* 2003;11:1526-1535.
- Reproductive factors, hormonal contraception, and the risk of uterine leiomyomata (fibroids) in African American women: A prospective study. (Wise et al.) *Am J Epidemiol*, 2004; 159:113-123.
- A prospective study of induced abortion and breast cancer in African-American women. (Palmer et al.) *Cancer Causes Control* 2004; 15:105-111.
- Influence of body size and body fat distribution on risk of uterine leiomyomata (fibroids) in African-American women. (Wise et al.) *Epidemiol in press*, May 2005.
- Risk of uterine leiomyomata (fibroids) in relation to tobacco, alcohol, and caffeine consumption in the Black Women's Health Study. (Wise et al.) *Hum Reprod* 2004;19:1746-54.
- Age-specific incidence rates for uterine leiomyomata (fibroids) in the Black Women's Health Study. (Wise et al.) *Obstet Gynecol in press* March 2005.

You can find the full publication list on the BWHS website www.bu.edu/bwhs; click on Publications.

A VOICE *from the BWHS*

"Presently I am at a health institute detoxing and cleansing my body. After 7 months of chemo my body has been through many changes. I have had two bouts with cancer since 1998...I have fantastic doctors and each day I rise is truly a celebration."



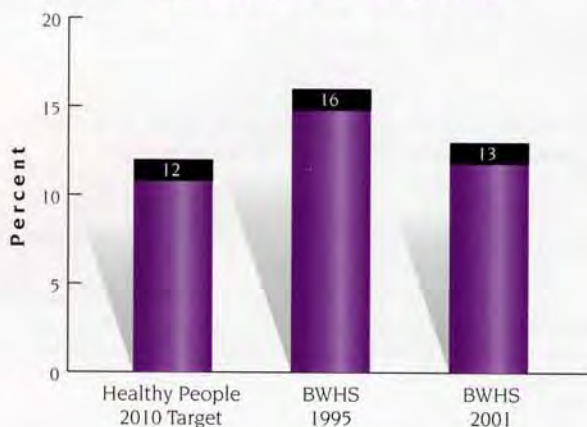
HEALTHY PEOPLE 2010

Healthy People 2010 is a set of health objectives for the United States to achieve during the first decade of the 21st century. It is used by communities, states, medical organizations and others to develop programs and guide research to improve health. The main goals are to improve life expectancy and the quality of life and to eliminate health disparities. This means improving the health of African-Americans who have lower life expectancies than whites (76 years among black women, 82 years among white women) and higher rates of almost every major illness. Leading health indicators that will be used to help measure the health of the nation include health care, cigarette smoking, overweight and obesity, and physical activity. How are BWHS participants doing in terms of these measures?

Health care: BWHS participants are on target with mammography screening for breast cancer. Almost all participants aged 40 and older have had a screening mammogram, and a high proportion have reported having had a mammogram on every follow-up questionnaire. The current recommendation for women aged 40 and older is to have yearly mammograms. High proportions of BWHS participants get Pap smears. The recommendation is to have a Pap every 1-2 years if you are under age 30, and every 2-3 years after age 30 until age 70. Because of the very high risk of high blood pressure among black women, having a blood pressure measurement at least every 2 years is important. When asked on the 1997 health survey, 97% of participants reported having had their blood pressure checked in the previous 2 years. Women who are age 50 or older should consider having a colonoscopy – this procedure lowers the chance of developing colon cancer by detecting polyps and early cancers.

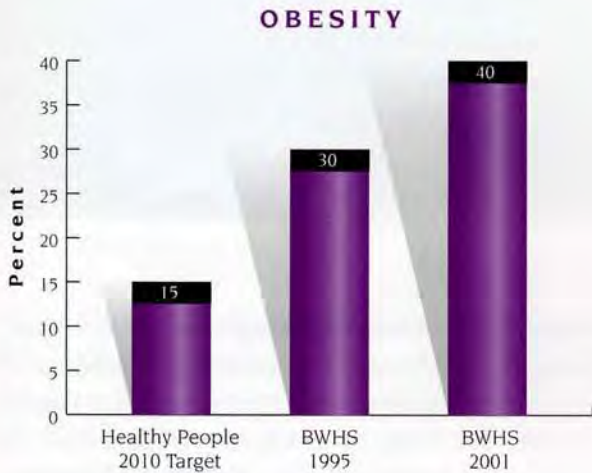
Cigarette smoking: Smoking is a leading cause of lung cancer, heart disease, and a long list of other illnesses. Black women smoke less than most other race/ethnic groups in the United States. The graph shows that BWHS participants are already close to the Healthy People 2010 target.

CIGARETTE SMOKING



Overweight and obesity: Obesity was recently named the second leading cause of preventable deaths in the United States. For example, being overweight is a leading cause of diabetes which in recent years has been affecting an increasing number of black women and even children. Obesity in adults is defined as a "body mass index" (BMI) of 30 or more and overweight is a BMI of 25 to 29. BMI is based on weight and height. Using the BMI table on the next page, you can estimate your own BMI. For example, if your height is 63 inches (that's 5 feet 3 inches) and your weight is 162 pounds, your BMI is about 29, in the overweight category. Americans tend to gain weight with increasing age. As

shown in the graph below, BWHS participants have gotten heavier since they entered the BWHS in 1995 and are far from the Healthy People target goal.



Diet and physical activity: The two main individual behaviors linked to overweight and obesity are increased caloric intake and decreased physical activity. A poor diet (high in saturated fat and calories and low in fruits and vegetables) and lack of physical activity can lead to overweight and obesity. A good way to improve diet, and also to protect against some diseases, is to substitute fruits

and vegetables for other foods so as to meet the U.S. government's recommendation of 5 or more servings a day. On the 1995 diet questionnaire, BWHS participants reported an average of 2-3 servings of fruits and vegetables a day. A quick way to lower calorie intake is to stop drinking sugary drinks like sodas and Kool-Aid and to decrease intake of fast foods. Being physically active is one of the best ways to control weight or lose weight, and it protects against a long list of conditions, such as heart disease, diabetes, thin bones, and perhaps even breast cancer. There is also a great deal of scientific evidence that staying active is the key to maintaining a sharp mind. Walking is the most popular physical activity in the United States and in the BWHS. As shown in the graph based on responses to the 2001 questionnaire about exercise in the past year, about 30% of BWHS participants did no walking for exercise, 25% walked less than an hour a week, and 15% walked 1-2 hours a week. Current recommendations are to walk at least 3 hours a week. Some BWHS participants reported participating in other activities like aerobics or swimming but even so, about 15% of participants did no walking or exercise at all. It can be difficult to find time in the day and a place to exercise, but the effort is worth it. Perhaps the place to start is walking to the store, church or work. The payoff will be improved well being.

BMI	"Healthy Weight"						Overweight						Obese	
	19	20	21	22	23	24	25	26	27	28	29	30	35	40
Height (in.)	Weight (lb.)													
58	91	96	100	105	110	115	119	124	129	134	138	143	167	191
59	94	99	104	109	114	119	124	128	133	138	143	148	173	198
60	97	102	107	112	118	123	128	133	138	143	148	153	179	204
61	100	106	111	116	122	127	132	137	143	148	153	158	185	211
62	104	109	115	120	126	131	136	142	147	153	158	164	191	218
63	107	113	118	124	130	135	141	146	152	158	163	169	197	225
64	110	116	122	128	134	140	145	151	157	163	169	174	204	232
65	114	120	126	132	138	144	150	156	162	168	174	180	210	240
66	118	124	130	136	142	148	155	161	167	173	179	186	216	247
67	121	127	134	140	146	153	159	166	172	178	185	191	223	255
68	125	131	138	144	151	158	164	171	177	184	190	197	230	262
69	128	135	142	149	155	162	169	176	182	189	196	203	236	270
70	132	139	146	153	160	167	174	181	188	195	202	207	243	278
71	136	143	150	157	165	172	179	186	193	200	208	215	250	286
72	140	147	154	162	169	177	184	191	199	206	213	221	258	294
73	144	151	159	166	174	182	189	197	204	212	219	227	265	302
74	148	155	163	171	179	186	194	202	210	218	225	233	272	311
75	152	160	168	176	184	192	200	208	216	224	232	240	279	319
76	156	164	172	180	189	197	205	213	221	230	238	246	287	328

To use the table, find the appropriate height in the left-hand column. Move across the row to the given weight. The number at the top of the column is the BMI for that height and weight.



WHAT'S IN STORE IN THE COMING YEARS?

Funding for the BWHS is set for the next 5 years.

- ☼ Health questionnaires will be sent every 2 years (2005, 2007, etc.)
- ☼ Newsletters will be sent every 6 months to tell you about new study findings and to provide information on health issues.
- ☼ We will respond to your individual questions and comments.
- ☼ We will ask for permission to review specific medical records when serious illnesses occur.

Cheek Cell Collection: We thank the thousands of BWHS participants who have provided cheek cell samples (by swishing with mouthwash and sending the mouthwash to our laboratory at Howard University) in the past year. Over 60% of women invited so far have sent a sample. Over the next 3 years, we will be asking those of you who have not yet been approached to provide a sample if you feel comfortable doing so. These samples are a resource for assessing the role of genetic markers in the development of various diseases. For example, different forms (polymorphisms) of genes may have different effects on estrogen levels in the body which may influence disease risk. While the results of the genetic studies are for research purposes only, the expectation is that the research will contribute to understanding the mechanisms of disease development, thereby leading to better prevention and treatment in the future.

Cancer: Death rates from breast cancer, the most commonly occurring cancer in American women, are higher among black women than among white women. Colon cancer occurs more often in black women than white women. In the next 5 years we plan to assess whether BWHS participants can make changes in their lives to prevent these cancers. A major issue to be assessed is whether physical activity reduces the occurrence of these cancers. What types of exercise? Is walking as effective as more strenuous exercise? How much exercise is required? Another major issue is whether the composition of the diet influences risk. Does the percentage of animal fat, the type of carbohydrate, or the amount of fruits and vegetables consumed affect risk? Other important issues are the influence of oral contraceptive use, postmenopausal female hormone use, cigarette smoking, and body size on risk.

Diabetes: Black women are at high risk of developing diabetes. In fact, there is currently an epidemic of diabetes among black women. Research on diabetes in the BWHS will focus on clarifying the influences of activity patterns, dietary patterns, and weight upon the development of diabetes. In addition, we will assess whether characteristics of the neighborhoods in which participants live influence their risk.

Cardiovascular Disease: High blood pressure more commonly strikes black women, and at younger ages, than white women. Death rates from heart disease are higher in black women. Despite this burden of illness, a great number of questions about factors that affect these illnesses in black women are unanswered. With BWHS data, we plan to assess how exercise and weight loss influence the occurrence of high blood pressure and heart disease. Just as for cancer, a key question is whether the form of exercise that is most popular and most convenient – walking – cuts the risk. How much exercise is enough? Is exercise protective even among women who are overweight?

A VOICE *from the BWHS*

"I was motivated to participate in the BWHS to help improve the health information available to empower women on their own behalf. I joined my first gym when I was 18 and know the huge benefit of exercise as well as healthy nutrition."

- ☼ We will review cancer registry records for women who develop cancer.
- ☼ We will carry out studies of cancer, diabetes, heart disease and other illnesses as described on these pages.



Blood Collection: Certain biological markers in the blood may be important predictors of heart disease and other conditions, but there has been almost no study of them in black women. We are currently evaluating ways in which BWHS participants who are willing can provide blood samples for future studies.

Glaucoma: Glaucoma is an eye disease that is the leading cause of blindness worldwide, and it disproportionately affects black women. Very little is known about its causes. We will assess a long list of potential causes and preventives. They include diabetes, high blood pressure, cigarette smoking, intake of antioxidants in foods and supplements, body mass, and use of cholesterol-lowering drugs.

Autoimmune Diseases: Systemic lupus erythematosus (lupus) and sarcoidosis occur more commonly in black women than other women. These and other autoimmune illnesses such as rheumatoid arthritis and multiple sclerosis occur with a range of severity and can lead to serious disability and even death. We plan to assess possible risk factors for these conditions, including the role of genes.

Studies of Men or Children: The 2001 and 2003 questionnaires asked if BWHS participants thought their male relatives or their children might wish to participate in studies like the BWHS. There were some positive responses but not enough to make such studies feasible at the present time.

Other Studies: BWHS participants have asked that we study the effects of religion, depression, stress and violence. They will be a part of the BWHS agenda in the coming years.

Many of the questions we are studying have come from BWHS participants. Please continue to send your ideas.

REVIEW OF MEDICAL RECORDS

BWHS participants who report a new diagnosis often receive a request for permission to review medical records concerning that diagnosis or to allow us to write to their physicians and ask them to complete a medical checklist about the diagnosis. For cancers, we may review cancer registry data. Review of medical records is an important part of research because there can be useful information about treatment and diagnosis that is available only in the original record. Specific information allows for more informative analysis of the data. For example, pathology records will indicate whether the breast cancer was estrogen receptor positive or estrogen receptor negative. We are very grateful to the many women who have helped the BWHS by permitting the confidential review of medical records about their diagnoses. We also thank those who have answered extra questions about their symptoms and other aspects of their illness.



A STORY FROM THE BWHS: Sylvia S. Johnson



Sylvia Johnson is one of many BWHS participants who are an inspiration to all of us. She calls from time to time to keep us informed of her activities and to make sure that we are studying the causes of sarcoidosis, an autoimmune condition that affects African-Americans much more often than other Americans. Sylvia wrote to us: "I am a 67 year old African-American with sarcoidosis. I have had the disease approximately 34 years. I still have night sweats and occasional chronic coughs but try to maintain

good health habits and not take prednisone treatment that has caused my other friends so many problems. I belong to the Sarcoidosis Awareness Foundation founded by Janie Chunev here in Detroit to help bring more awareness and help to others with sarcoidosis... We have a clinic opening here in Detroit, in partnership with Wayne State University. Our hope is to make a difference and give hope to others. We have monthly meetings as a sort of support informational group." Sylvia was instrumental in getting that clinic started. Many BWHS participants have written to us, sometimes about what they have done to improve their own health and sometimes about what they have done to improve the health of others. As the great African-American poet, Maya Angelou, wrote "Nothing will work unless you do."

An article from:

THE MICHIGAN CHRONICLE

October 20-26, 2004

Harper University Hospital to open Michigan's only center for sarcoidosis

State Rep. Artina Tinsley Hardman recently joined leaders of the Detroit Medical Center (DMC) and Wayne State University School of Medicine and the Sarcoidosis Foundation to announce the development of Michigan's most comprehensive center for the diagnosis and treatment of sarcoidosis. The announcement was timed with Hardman's Michigan House Resolution No. 275, which recognizes National Sarcoidosis Awareness Day on Sept. 24.

"Sarcoidosis is an autoimmune systemic disease with no known cause or cure that can affect any part of the body," said Safwan Badr, Medical Director for Sarcoidosis at Harper University Hospital and professor of internal medicine at WSU. "The disease affects 20 to 50 of every 100,000 individuals in the United States. Most victims are between 20 and 40 years of age and while anyone can contract the illness, African-Americans are affected at least 10 times more often than Caucasians."

The center will offer diagnostic services, testing and evaluation, treatment and research, support groups and education for both the general public and medical community. One of the multiple goals of the center is to educate physicians and health care workers about the disease. While diagnosis dates back 135 years, sarcoidosis often goes undiagnosed in many patients because too often health care providers are not trained to recognize the symptoms.

For more information about The Center for Sarcoidosis at Harper University Hospital or to schedule an appointment, please call 1-888-HRC-2588. More information about Sarcoidosis will soon be available at the Sarcoidosis Awareness Foundation website at www.sarcoidosisfoundation.org and at Harper's website: harperhospital.org.

INTRODUCING TWO NEW INVESTIGATORS ON THE BWHS



Yvette Cozier has been with the BWHS during its entire first decade, starting out as a research coordinator. Her time on the BWHS has been busy – while working and raising 2 children, now 9 and 8, Yvette completed a doctoral degree in epidemiology at Boston

University. She studied whether the risk of hypertension is affected by the neighborhoods in which people live and by experiences of racism and racial discrimination. She also supervised the study that demonstrated the feasibility of collecting cheek cell samples for genetics studies from BWHS participants by mail. Dr. Cozier is now involved in collecting BWHS mouthwash samples from as many participants as are willing to give them and she will continue her work on hypertension.



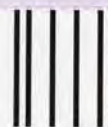
Lauren Wise began as a research assistant and then became the chief data analyst on the BWHS while completing her doctoral work in epidemiology at Harvard University. Lauren's work has focused on factors that may cause or prevent uterine

fibroids and her three thesis papers have already been published. Future analyses will include the study of dietary and genetic risk factors for uterine fibroids. Her other interests include reproductive health, the health effects of depression and of violence, and predictors of multiple sclerosis. Dr. Wise now supervises all analysis of BWHS data and assures that the statistical procedures are appropriate.

Watch for the 2005 Questionnaire: Start the New Year off with less paperwork. You can complete the 2005 questionnaire online soon and avoid getting the questionnaire mailed. The online questionnaire will be available by the middle of March 2005 on our website: www.bu.edu/bwhs/. We will be mailing out the 2005 questionnaire in May 2005. Thank you for your continued participation in this important research.

Please check the other side of this postcard to see if it 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.

Do we have your email address? From time to time we'd like to send you late breaking news. If you wish to be reached by email in the future, please email your address to bwhs@slone.bu.edu.



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“Walking is the nearest activity to perfect exercise.”

– PROFESSOR J MORRIS AND DR. ADRIANNE HARDMAN, 1997

Are you interested in walking but don't know where to begin?

There may be an established walking group in your city or town, or you might form your own. Here are some links to various walking groups throughout the country:

www.walking.about.com/od/walkamerica/

www.walkertownusa.com

www.thewalkingsite.com/clubs.html/

While walking on a regular basis is needed to obtain the health benefits, it's fun to take part in local fundraising walks as well. Juanita Hope, BWHS research assistant (on left in photo), involved staff and friends in a 20 mile walk to raise money for food banks in Massachusetts and they had a great time.



“I have two doctors, my left leg and my right.”

– GEORGE TREVELYAN, 1913



Artwork by Monica Stewart

The Black Women's Health Study

CELEBRATING 10 YEARS

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