



# BLACK WOMEN'S HEALTH STUDY



*Working together  
to improve the health of  
Black women*


- BWHS 25th birthday
- BWHS—Why, When, How?
- Benefits and risks of research
- A Researcher in training
- Prostate cancer in Black men
- Current research in the BWHS

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**Did you know that the BWHS will be celebrating its 25th birthday next year?**

Birthdays are a time for looking back and looking forward. As indicated in the last newsletter, a year ago the National Institutes of Health funded the BWHS for another 5 years. Why did the reviewers and officials at the National Institutes of Health think that it was important to continue the BWHS? What does the BWHS contribute? How do BWHS participants benefit? This newsletter gives some thoughts on how the BWHS has been important to the health of Black women and why the BWHS will continue to be important. Since you, the participants, are the lifeblood of the BWHS, your views on these issues are of crucial importance. Please let us know your thoughts about what the BWHS contributes and what more we could be doing. Are there other health issues that the BWHS should be studying? This newsletter also describes a new study of prostate cancer, undertaken by a different research group, that some of the men you know may be interested in, a young researcher working with the BWHS, and descriptions of some ongoing research in the BWHS.

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# BLACK WOMEN'S HEALTH STUDY

About fifty years ago, back in the 1970s, health-related research focused much more on men than women. Gradually, reviewers and funders of research studies recognized that more study of women's health was needed. By the early 1990s, many studies of women were in progress. For example, multiple studies of risk factors for breast cancer were in progress, but they were almost entirely among White women. Black women were dying from breast cancer at a much higher rate than White women. The time was overdue for studies of the health of Black women. With that in mind, we submitted a grant proposal to the National Institutes of Health to establish the Black Women's Health Study. The idea was to invite a large number of Black women to participate and to then follow them. Over the passage of years, as women developed particular illnesses, we could use the collected data to study risk factors for those illnesses. Since the initial focus was on breast cancer, we proposed a study large enough to begin assessing, in five to ten years, risk factors for this disease. Gathering health-related information on so many women (it turned out to be 59,000) also allowed for the study of many other serious illnesses, such as type 2 diabetes, which affects twice as many Black women as White women. The National Institutes of Health provided funding for the BWHS in 1995 and has renewed funding every five years since then.

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**The goal of the Black Women's Health Study is to identify factors that increase or decrease the risk of a wide range of illnesses that are important in the lives of Black women. Now that participants are older, it is increasingly important to also study well-being after disease and to identify factors that contribute to healthy aging. In addition, the BWHS is committed to contributing to the training and career development of young Black researchers. Our efforts involve mentoring, providing data for their research, helping with scientific manuscripts, and assisting with grants and other opportunities.**

# BENEFITS AND RISKS OF RESEARCH STUDIES

Institutional Review Boards (IRBs), which include researchers and members from the community, review research studies to be sure that potential benefits outweigh potential risks and burdens. Participants generally take part in scientific research because they want to contribute to improved health for others. A study that identifies a new risk factor for diabetes, for example, may not help the diabetics in that study but the results could help prevent diabetes for others in the future.

Some studies, especially those with high burdens in time, risk, or discomfort, may pay participants for their contributions. Very large studies like the BWHS generally do not pay participants—even a payment of a few dollars per participant could come to hundreds of thousands of dollars in total. There may be reimbursement for travel and time spent for some specific activities, like giving a blood sample. However, even when participants receive payments, the IRBs require that payments are not so large that someone participates in the study just for the payment.

Over a period of almost 25 years, BWHS participants have repeatedly provided health and personal data, have allowed access to medical records, have provided biologic samples (such as saliva, blood, tumor tissue), and have in other ways made possible a highly productive study of health and illness in Black women. The value of these contributions has been very large, and we hope that participants think that the benefits have far outweighed the burdens. The efforts of BWHS participants have resulted in measurable contributions to knowledge about health. The BWHS has contributed to more than 250 scientific papers that have advanced understanding of how numerous factors, such as psychosocial stressors, dietary intake, and exercise, affect a range of illnesses. Assays of DNA from saliva and blood samples of participants have increased understanding of the genetics of several types of cancer and conditions that include diabetes, lupus, and sarcoidosis. Assessments of the microbiome (microscopic organisms that live in the body of every human being) are contributing to understanding causes of lung and pancreatic cancer. Tumor samples are permitting studies of mutations in the tumors. Cancer survivors are being followed to identify factors that contribute to healthier survival. Young Black researchers have had opportunities for training and career development. All of this has been possible because of the dedication of BWHS participants.



## A RESEARCHER IN TRAINING



### **A young researcher is conducting her doctoral work with the BWHS.**

Lauren Barber, MS, is a doctoral student studying epidemiology at the Boston University School of Public Health. In 2016, Lauren joined the BWHS as a trainee in the Susan G. Komen Graduate Training in Disparities Research program. She has conducted research on early life risk factors for breast cancer in the BWHS and has presented her findings at national scientific conferences. In addition to her

work on racial disparities in breast cancer, Lauren plans to expand her training and research to study risk factors for colorectal cancer in the BWHS as part of her doctoral dissertation project. She expects to graduate in 2021.



# RESPOND

African American Prostate Cancer Study

### **A new study of prostate cancer in Black men is recruiting participants.**

The BWHS is not involved in this study, but we are sharing information because of its potential importance for your family and friends. Black men in the U.S. die from prostate cancer at a rate double that of White men. A new study of prostate cancer among Black men is being conducted at 11 institutions across the U.S. The study, called RESPOND (Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress), will compare men with aggressive prostate cancer, which is often fatal, to men with milder prostate cancer. 10,000 Black men with prostate cancer will be recruited and asked for health information, saliva samples, and access to their prostate tumor samples. A focus of the study will be on social stress, such as discrimination and early-life adversity, which has been a focus of the BWHS for many years. **Please visit the Respond study website, [RESPONDstudy.org](http://RESPONDstudy.org), for more information.**

# CURRENT RESEARCH TOPICS IN THE BWHS

## Hair Loss

In 2015, a questionnaire about hair loss was included on the BWHS website and more than 6,000 BWHS participants completed it. Hair loss in Black women on the top of the head (central scalp hair loss) occurs much more commonly than in other racial/ethnic groups. To indicate their central scalp hair loss, BWHS participants selected from a group of photographs on the hair loss questionnaire that showed varying degrees of hair loss (see below). Our analyses estimated that women with type 2 diabetes had a risk of severe hair loss on the central scalp about 70% greater than that of women who did not have diabetes. This BWHS study is by far the largest and most definitive to date.



## Lupus

Lupus, an autoimmune disease that can damage skin, joints, and organs, affects Black women more than other racial/ethnic groups. Little is known about its causes. The BWHS has already published about associations of lupus risk with certain genes, smoking (increased risk) and being overweight at age 18 (increased risk). However, none of these factors is a strong predictor of risk. Current analyses are assessing physical and sexual abuse in childhood, reproductive factors, and dietary intake as potential risk factors. We will update you when the analyses are completed.

## Stroke

The stroke risk of Black Americans is about twice that of other Americans. The “standard” risk factors for stroke, such as high blood pressure, atrial fibrillation, diabetes, and smoking, explain only part of the excess of strokes among Black men and women. We have begun analyses of “nonstandard” risk factors for stroke in the BWHS. Aided by a physician who treats stroke patients and specializes in stroke research, we are reviewing the medical records of BWHS participants who have permitted access to the records of their stroke hospitalizations. We plan to study numerous risk factors that have not previously been assessed, such as pregnancy-related factors and early life exposures.

# RESEARCH TOPICS, CONTINUED

## Life Expectancy and Exercise

Black women have a life expectancy almost 3 years shorter than that of White women in the United States. One of the aims of the BWHS is to figure out what can be done to improve the life expectancy of Black women. Many studies indicate that exercise prolongs life in White women, but there is almost no information on whether this is the case among Black women. We have been examining the exercise habits of BWHS participants, such as vigorous exercise like aerobics and dancing, and milder exercise like walking. Our analyses to date provide very encouraging news: BWHS participants who exercise are more likely to live longer, and even small amounts of exercise have this effect.

## 2019 Health Questionnaire

The 2019 health update is in progress. You can complete the questionnaire online ([www.bu.edu/bwhs](http://www.bu.edu/bwhs)) or on paper and mail it to us. If you prefer to be interviewed on the telephone you can call us toll-free at 1-800-786-0814.

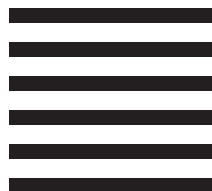


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