



BLACK WOMEN'S HEALTH STUDY

25 Years Together



*Working together
to improve the health of
Black women*

- Coronavirus outbreak
- A film about the BWHS
- BWHS 25th anniversary
- New BWHS studies on brain health
- BWHS research news
- Endometrial cancer action group for Black women

THE CORONAVIRUS: As we go to press with this newsletter, the coronavirus has moved rapidly through the United States, causing tens of thousands of cases of COVID-19. BWHS staffers are working remotely to keep the work of the BWHS going. We hope that you are safe, well, and managing to tend to all the needs of you and your family, and that by the time this reaches you, the spread of the virus has slowed. The U.S. Centers for Disease Control is a good source of trustworthy information on the virus: www.cdc.gov/coronavirus/2019-ncov/index.html. We will keep you informed of any BWHS research on COVID-19.

Happy Anniversary to the BWHS

The BWHS turns 25 this year—the largest study of Black women yet conducted is still going strong. Invitations to participate in the BWHS were mailed in March of 1995. By the end of that year, the 59,000 women—that’s YOU—who make up the BWHS study cohort had returned completed questionnaires and indicated willingness to take part in a long-



term study. None of us knew exactly what “long-term” meant. As time has passed, it has become clear that long-term means the decades needed to get answers that short-term studies cannot. For example, what is the effect, later in life, of having had a preterm birth at age 20? Do experiences of racism earlier in life affect cognitive function, such as memory, as women reach their 60’s, 70’s, and 80’s? These important questions require long-term studies. Fortunately, many of the women who joined the BWHS almost 25 years ago are still on board, completing questionnaires, allowing access to medical records and tumor tissue—the list goes on. Please read on and learn about plans for a BWHS 25th anniversary celebration and what might come next in the way of research in the BWHS.

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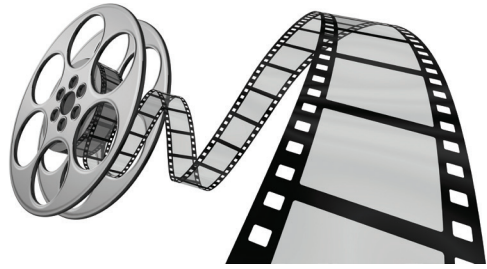
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Additional copies of this newsletter are available on a first come, first served basis.

A FILM ABOUT THE BWHS

As a start to celebrating the 25th anniversary of the BWHS, we took the opportunity to make a short film about the study. The film describes the study goals and selected accomplishments. It was shown in November at the 2019 annual meeting of the American Public Health Association. This meeting is attended by many thousands of researchers, public health officials, and government policy makers. The film was a way for them to learn about work relevant to the health of Black women in the U.S. In the BWHS film, several investigators spoke about the work and goals of the study, and four BWHS participants gave their thoughts about what the BWHS means to them. To view the film, go to the BWHS website (www.bu.edu/bwhs) and click on the link to the film. We have received numerous comments from participants who viewed the film. Here are some of those comments:



“Wonderful!! I am honored to have made my contribution to this monumental study. Blessings to all that have enabled this work to continue and the lives that will be improved as a result.”

“My mother was a 30+ year breast cancer survivor who died at age 87 of complications due to Alzheimer’s. So to hear that research is gearing in that direction is encouraging.”

“Hoping my info can eventually help some other woman.”

“I am humbled to know that I am a part of this mammoth undertaking.”

“It was empowering to see the impact of the data collected by the BWHS and how it has contributed to and furthered research specific to Black women’s health.”

“I plan to share this video with other family and friends.”

“I am SO proud to be part of this study.”

“I pray that my contributions will have an impact on the generations of Black women who come after me.”

BWHS 25TH ANNIVERSARY CELEBRATION

We had been planning to mark the 25th anniversary of the BWHS by holding an interactive event in Boston this fall. However, the coronavirus makes any plan for the future uncertain. Assuming for now that the event will take place, we will let everyone know by email and letters when the date is set. BWHS participants reside across the country and the world. When the study began in 1995, almost all participants lived in 17 states in the continental United States, with the largest numbers from California, Georgia, Illinois, Indiana, Louisiana, Maryland, Massachusetts, Michigan, New Jersey, New York, South Carolina, Virginia, and the District of Columbia. Now, 25 years later, participants live in 49 states and 15 foreign countries. This means that, unfortunately, we cannot all meet in person for the celebration. However, we will live-stream the proceedings so that participants from around the country and world will be able to join in the celebration. We are planning presentations on health issues of concern, contributions of the BWHS to Black women's health, and plans for future studies. We plan to offer many opportunities during the event for participants to provide feedback and discuss their experiences and thoughts about the study. What are your ideas about how to celebrate the BWHS 25th anniversary? What are your ideas about strengths and weaknesses of the BWHS? What would you like to see in the future in the BWHS? Please let us know. Send an email to bwhs@bu.edu or call us toll-free at 1-800-786-0814.



NEW BWHS RESEARCH STUDIES: BRAIN HEALTH



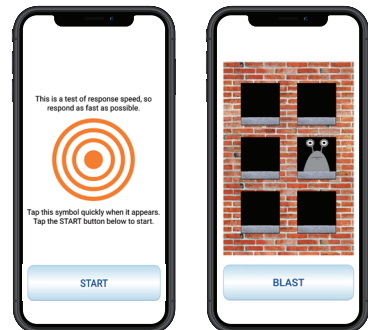
Lifestyle and health habits can contribute to brain health. As the BWHS population ages, it is desirable to study factors that contribute to healthy cognitive aging. We are taking several approaches.

First, we have established a new collaboration with an Alzheimer's Disease (AD) and brain-health researcher, Dr. Rhoda Au, who has worked

with the Framingham Heart Study for many years. A major focus of that study is AD and cognitive aging. We will learn from what they have done.

Second, studies of cognitive aging traditionally rely on in-person cognitive assessments to evaluate memory and brain function. There is a network of AD centers, funded by the National Institutes of Health, around the country. People living near those centers are able to go to the AD Center, take these assessments, and be referred for treatment if AD is present. We hope to start our research by collaborating with six of these Centers, which local BWHS participants would be able to attend if they wished to. We plan to study many of the factors on which BWHS participants have already provided information in relation to the cognitive assessment results. For example, how does a healthy diet influence brain function years later?

Third, standard assessments measuring cognitive function tend to be long and tiring. Recently, several brief cognition assessment apps for smartphones and tablets have been developed. Those with the app could take the test from time to time. If these short assessments could replace the long in-person assessments at AD Centers, it would be easier for patients and their caregivers. The BWHS is currently testing an app called DANA to find out if it accurately assesses cognitive health in Black women and if BWHS participants find it easy to use.



Screenshots of the DANA cognitive function assessment app

RECENT BWHS RESEARCH NEWS

Breast Cancer

Women who have the so-called breast cancer genes (BRCA1 or BRCA2 gene mutations) have a high risk of developing breast cancer. Rare genetic mutations from several other genes have also been shown to greatly increase risk. However, almost all of the data on these high-risk genes comes from studies of White women. Dr. Julie Palmer led an analysis of data on this topic from the BWHS and other breast cancer studies, including about 5,000 Black women with breast cancer and 5,000 Black women unaffected by breast cancer. The same genes that carry a high risk of breast cancer in other populations were found to be associated with high risk for Black women. This means that the available gene testing panels are appropriate for use in Black women. Genetic testing for high-risk breast cancer genes is currently conducted less often for Black women than for White women. At least one study showed that the difference was based on physician choice rather than patient choice. Our hope is that when health care providers learn of the new information from our study, they will be more likely to discuss and recommend appropriate genetic testing to Black women. *Palmer et al. Contribution of germline predisposition gene mutations to breast cancer risk in African American women, Journal of the National Cancer Institute, in press.*



Insomnia

Seven questions about difficulties with sleeping were included on the 2015 questionnaire. These are the questions often used by physicians to learn whether a person has symptoms of insomnia. About 15% of BWHS participants reported such symptoms. Dr. Traci Bethea analyzed the BWHS data to look at the relationship

between experiences of racism and experiencing insomnia. Women who reported more racism experienced more insomnia symptoms, suggesting that difficulty sleeping may be yet one more adverse effect of experiencing racial discrimination. *Bethea et al. Perceived racial discrimination and risk of insomnia among middle-aged and elderly Black women. Sleep 2019. doi: 10.1093/sleep/zsz208*



The Endometrial Cancer Action Network for African-Americans (ECANA) is a patient-driven organization founded in 2017 to promote community among Black women affected by endometrial cancer (the most common gynecological cancer), to provide educational resources, and to foster partnerships among clinicians, patients, researchers, and advocates. ECANA operates out of the University of Washington under the leadership of gynecologic oncologist, Dr. Kemi Doll, with a steering group of Black women who have had endometrial cancer and/or who are community advocates for Black health. Dr. Kimberly Bertrand represented the BWHS in ECANA's first National Conference for Community, Education, and Research Training, held in March 2019. We look forward to continued engagement with ECANA and future research collaborations. Find out more about ECANA at: <https://ecanawomen.org/ecanaconference>

Reminder: If you haven't done so already, please fill out the 2019 BWHS health survey—by mail, on the web (bu.edu/bwhs), or by telephone. An "R" after the 8 digit number on the lower left back cover of this newsletter means you've returned your questionnaire. Please call if you have questions (1-800-786-0814).

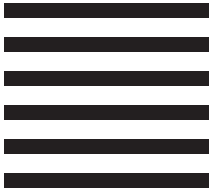


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