B-GREAT MILESTONES

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WELCOME MESSAGE

The Breast Cancer Genetics Research and Education for African American Women Team (B-GREAT) was formed as an academic-community partnership to develop strategies to reduce breast cancer health disparities in inherited cancer testing in the Black community. Now in our 8th year, the B-GREAT Program seeks to educate and inform the African American community about the role of genes in breast and ovarian cancer that "run in families." By increasing knowledge about hereditary breast cancer, we strive to empower those at risk to make the most informed decisions regarding their health care options. Please visit the B-GREAT website for more information: bgreatinitiative.inheritedcancer.net.

Through this newsletter, we wanted to give you updates on our studies among young breast cancer survivors, our activities to disseminate our brochure to increase awareness about inherited breast cancer across the United States, and bring awareness to male breast cancer and its importance in thinking about inherited cancers.

To make it easier to share information, we post on multiple social media platforms including Facebook, Instagram, and Twitter (@inheritedcancer) and LinkedIn (linkedin.com/company/inherited-cancer-registry/). We encourage you to follow us on your favorite social media platform. Examples of some of our posts are included on the back of our newsletter.

Sincerely,
B-GREAT Co-Founders

Tuya Pal, MD
Vanderbilt-Ingram Cancer Center

Susan Vadaparampil, PhD
Moffitt Cancer Center

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ICARE Inherited Cancer Registry

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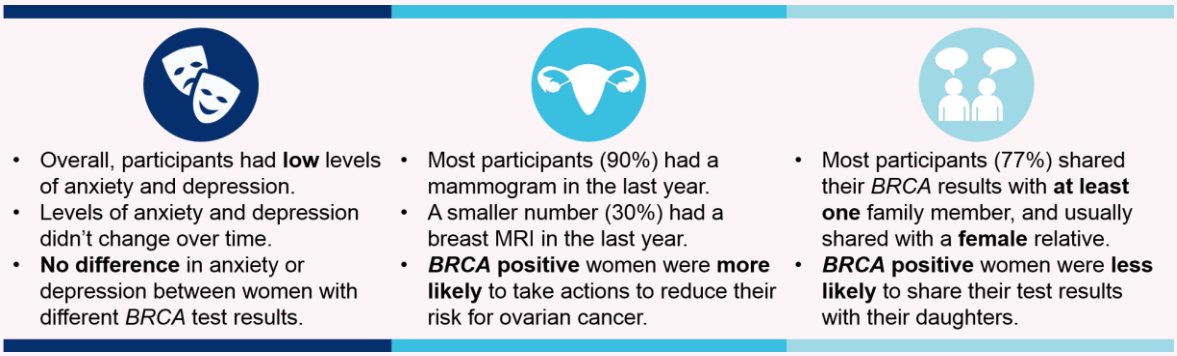
BENITA: What Participants Taught Our Team

We are thrilled to share that we have finished analyzing data from the BENITA (Behavioral and EmotioNal Impact of Testing in African Americans) study! In this study, 360 young Black breast cancer survivors from Florida received genetic testing to see if they had a mutation in the Breast Cancer (*BRCA*) genes. They completed surveys before and after they had genetic testing. We wanted to answer three big questions about *BRCA* testing.

1. Does a *BRCA* test result affect women's well-being after testing?[1]
2. Does a *BRCA* test result affect what women do for breast and ovarian cancer prevention after *BRCA* testing?[2]
3. Does a *BRCA* test result affect which family members women share their *BRCA* test results with?[3]

The infographic below tells you what we found out about these important questions!



Please contact Kenisha Avery with the BENITA study team to learn more about this research: Kenisha.avery@moffitt.org

[1]Gonzalez B.D., et al. Psychosocial impact of *BRCA* testing in young Black breast cancer survivors. *Psycho-Oncology*. 2018 Dec. PMID: 30207419. [2]Conley C.C., et al. Impact of *BRCA* testing on risk management behavior in Black breast cancer survivors. *Annals of Surgical Oncology.* In Pres. [3]Conley C.C., et al. The big reveal: Family disclosure patterns of *BRCA* genetic test results among young Black women with invasive breast cancer. Under review.

Disparities in *BRCA* Testing and Cancer Risk Management among Young Black Breast Cancer Survivors

In our Florida-wide study of young breast cancer survivors, including 440 Blacks, 897 non-Hispanic whites, and 285 Hispanics, we found providers were 16 times less likely to discuss genetic testing with Black women compared to non-Hispanic whites. Furthermore, among the subgroup of participants with a *BRCA* mutation, rates of oophorectomy (removal of the ovaries) was much lower among Black women compared to all other population groups. This is an important finding because women with a *BRCA* mutation have a high risk of developing ovarian cancer, and the only way to reduce these risks are removing the ovaries, because there are no reliable screening tests to detect ovarian cancer at an early stage. Moreover, our findings are particularly concerning because benefits of genetic testing can only happen when people act on positive results by being proactive with their health, and/or share their results with their family members so they too can be proactive. Our findings highlight the need to better identify and manage cancer risks across all populations to prevent widening disparities based on gene-based care.[1]

[1]Cragun D, et al. Racial disparities in BRCA testing and cancer risk management across a population-based sample of young breast cancer survivors. *Cancer*. 2017 July. PMID: 28182268

Developing a Brochure and Spreading the Word about Inherited Breast Cancer in the Black Community

Back in 2004, as we were starting to develop a brochure to publicize our study to offer genetic testing to young Black breast cancer survivors across Florida, we decided to get broad feedback.[1] What we came up with was very well received, to the point that our study's Community Advisory Panel (CAP) wanted to share the brochure with their friends and family. Recognizing the unmet need for information about inherited breast cancer in the Black community, we developed a new brochure by gathering feedback from various groups, in partnership with our CAP.[2] In addition to our team's efforts to distribute the brochure, we received an educational grant from the Florida Breast Cancer Foundation to distribute the brochure through CAP member events. This brochure has been disseminated across the United States and beyond, as shown in Figure 2 of the published article[3] and is available on the B-GREAT website: bgreatinitiative.inheritedcancer.net.

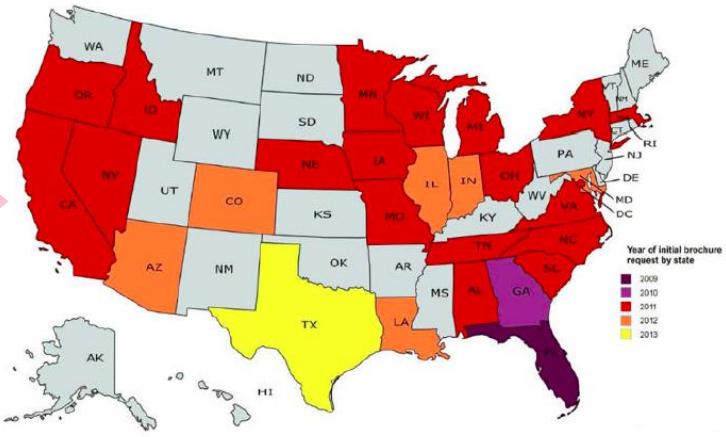


Figure 2. Year of initial brochure request by state

Valued CAP Members:

Joyce Austin
Charmettes Inc.

Dr. Gwendolyn Dawson
Ocala Housing Authority

Khaliah Fleming
TBCCN

Benita Hayes

Tracy Jacim
FL Breast Cancer Foundation

Linda Paige

Valerie Poindexter
Sigma Gamma Rho Sorority, Inc.

Peggie Sherry
Faces of Courage

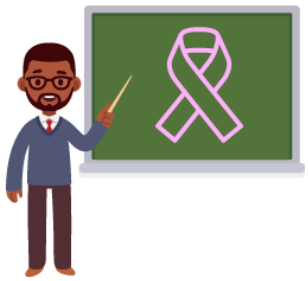
Viviam Sifontes
Moffitt

Gloria Wood
Moffitt

Deneen Wyman

[1]Vadaparampil S & T Pal. Updating and refining a study brochure for a cancer registry-based study of *BRCA* mutations among young African American breast cancer patients: lessons learned. *J Community Genet*. 2010 Jun. PMID: 22460206. [2]Vadaparampil S, et al. Development of a brochure for increasing awareness of inherited breast cancer in Black women. *Genet Test Mol Biomarkers*. 2011 Jan-Feb. PMID: 21275654. [3]Scherr CL, et al. Tracking the dissemination of a culturally targeted brochure to promote awareness of hereditary breast and ovarian cancer among Black women. *Patient Educ Couns*. 2017 May. PMID: 27866793

Increasing Awareness About Male Breast Cancer



DID YOU KNOW?

Beyonce Knowles' father, Mr. Mathew Knowles, was recently diagnosed with breast cancer. He states, "*we used to think this was only an issue for women, but this is male or female*." According to CBS news, "*he is hoping that sharing his story as a man with breast cancer will shine a light on the risk men can face.*"

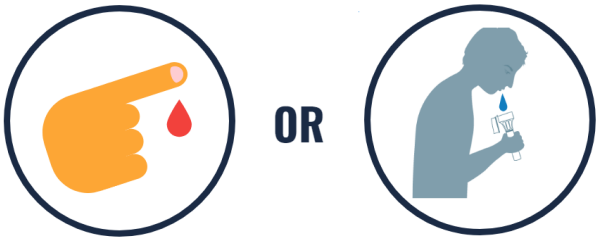
News report available at: https://www.cbsnews.com/news/mathew-knowles-breast-cancer-beyonces-dad-reveals-diagnosed-with-breast-cancer/

LET'S TALK FACTS:

Surprisingly, less than 20% of women diagnosed with breast cancer who are at high risk for a *BRCA* mutation are tested. Even lower rates of genetic testing are seen among African Americans, who are less aware of their risk for a *BRCA* mutation. All men with breast cancer should be offered *BRCA* testing. 6-8% of men with breast cancer will have a *BRCA2* mutation. Mr. Knowle's children have a 50/50 chance of inheriting this *BRCA2* mutation. Women with the mutation, have a 60-70% risk to develop breast cancer. The *BRCA2* gene raises the chance for ovarian cancer in women, aggressive prostate cancer in men and pancreatic cancer in both sexes.

HOW EASY IS GENETIC TESTING?

Genetic testing for inherited cancer genes (such as *BRCA1/2*) can be done through a simple **blood** or **saliva (spit)** sample. Detecting a mutation allows people to be proactive about their health by finding cancer early or preventing it all together.

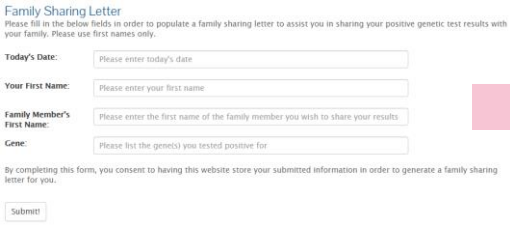


Introducing a New Resource to Share Genetic Test Results with Family Members

With the tremendous advances in gene-based care among those with inherited cancer risk, we are developing tools and strategies to help more people access genetic education and testing. We are proud to introduce **GeneSHARE**; a **FREE** online toolkit for YOU, to help share positive test results with your family members.

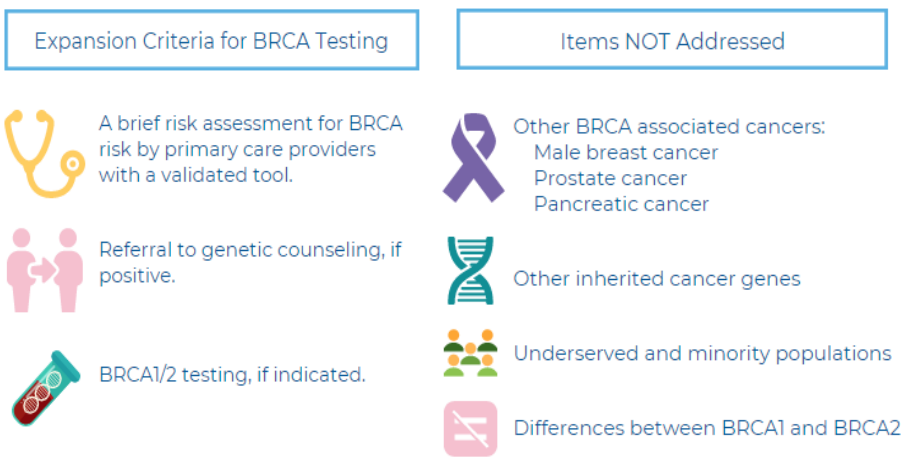
Available at: geneshare.net

Visit our website to use the personalized family sharing letter generator!



New *BRCA* Testing Guidelines Issued by the U.S. Preventive Services Task Force (USPSTF)

A few weeks ago, the USPSTF came out with **new guidelines** for *BRCA* genetic testing. The **substantial update** now covers more women who are at-risk for a *BRCA* mutation, including those with a history of breast, ovarian, fallopian tube, and peritoneal cancer who are disease-free, as well as those from certain ethnic backgrounds or communities who have a greater number of individuals who carry the *BRCA* mutation.[1] This update is featured in the Inherited Cancer Registry (ICARE) Summer 2019 Newsletter available at: inheritedcancer.net/newsletters/



[1]US Preventive Services Task Force, Owens et al. *JAMA*. 2019 Aug. PMID: 31429903. Available at: https://jamanetwork.com/journals/jama/fullarticle/2748515

Inherited Cancer Registry (ICARE) Community Spotlight

Life was great at 45. I had nothing more than a few headaches and was a tad overweight. After a friend was diagnosed with breast cancer, I realized I had not had a mammogram in a couple of years, so I scheduled an appointment. One mass was found, but it was benign and nothing to worry about. The mass continued to grow, and again, a biopsy confirmed it was benign. The mass was removed, and I went on with my life. A few months later, I returned for a follow-up appointment. It felt like a blow to my chest as the doctor confirmed I had a rare malignant phyllodes tumor in one breast. Because of the rarity of this type of cancer, I was offered genetic testing. A few months later, I was diagnosed with Li-Fraumeni syndrome (due to a *TP53* mutation), a rare condition that greatly increases the risk for many types of cancers.

I have three children ages 11, 22, and 27. My 11-year-old was diagnosed with autism at age 3, which has prepared me to advocate like no other. Although there is so much more to my story, when faced with challenges, I prefer to come through and share the answers I have collected throughout my journey. I'm just starting, but here are a few tips I have used to cope:

1. Brainstorm your thoughts in a journal. I have learned there are so many things I can't control, but so many more that I can.
2. Get your life in order and encourage your family and friends to do the same. With or without Li-Fraumeni syndrome, we are all guaranteed a death which can happen at any moment. As crazy as it sounds, while journaling, I realized that death was not my real fear. My real fear was leaving my son, and what his life would look like if I was not here to take care of him. Insurance policies, wills, trusts, and written expectations for my son are no longer something just on a to-do list.
3. Get organized. I'm still figuring this out, but the appointments and test results can take over your life quite literally. Getting a calendar and establishing systems that work for you is a must.
4. Research solutions and take an active role in your care. Ask questions no matter how silly they may seem. Always ask, "Is that the best we can do, and what are my other options?"
5. Take your time when making decisions. Never allow anyone to pressure you into making a decision. Sometimes you have to take a step back and seek wise counsel.
6. Create a "worry" section in your journal. As things pop up in my mind, I write them in the "worry" section of my journal and tell those thoughts that we can talk about them later during my worry time. "Worry time" is time I set aside to worry so that my day is not consumed with worry, which helps me stay focused on positive things. Typically, by the time "worry time" comes around, I have either found a solution, or I'm over it!
7. This probably should have been number 1 on the list but seek therapy. A few weeks in I realized the thoughts about "what if" were consuming me. Depression is real. Get a good therapist. It may take several sessions with several therapists but talking it out can be a game changer.

Hope this helps because I'm out of space. Sending great vibes and love your way!

—ICARE participant, Angela Watson, from Memphis, Tennessee

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