



## **An Insight into Hereditary Breast Cancer for Black Women**

# **B-GREAT CONNECTIONS**

### ***Welcome >>>***

## ***Welcome to Connections***

Welcome to the first edition of the B-GREAT Connections newsletter. Our goal is to keep you up to date on B-GREAT happenings. This includes advising you of future events, reporting on previous events, and sharing research updates. Feedback on this publication is most welcome. We would love to hear from you.

Please forward all correspondence to [info@bgreatinitiative.com](mailto:info@bgreatinitiative.com)



## ***Advocacy 101: Becoming an Advocate for Breast Cancer in your Community***

Since the inception of the B-GREAT Initiative, countless women have contacted the study team with one common question. How can I become an advocate for breast cancer in my community? Although seemingly straightforward, the answer to this is often quite complex. Breast cancer advocacy can be as simple as speaking to a group of friends about your experiences, passing out a flyer or brochure, or writing a letter in support of a program or law. Want to do more? Those seeking a higher level of responsibility may consider becoming a community outreach worker. What is involved in being an outreach worker? For the answer to this and many other questions, we turned to one of our Community Advisory Panel Members, Linda Paige. The role of the Community Advisory Panel within the B-GREAT Initiative is to provide guidance and direction to the study team in areas of cultural sensitivity, cancer survivorship, recruitment efforts, and community outreach efforts. Ms. Paige has been at the forefront of community-based cancer education programs for the past decade and knows exactly what it takes to be a community outreach worker.

### **What inspired you to become a Community Outreach Worker?**

L.P.: I don't believe anything in particular inspired me to become a community outreach worker. I've always had a desire to help those in need if I could. Furthermore, I was brought up in an environment that nurtured the belief in lending a hand no matter who it might be. So, my current position falls in line with who I am. I began this journey by volunteering through the Witness Project® of Tampa Bay; however, I was unaware of the needs in the community. While volunteering in the community I learned about the lack of information, cultural myths, unavailable services and disparities in our local areas that affect many people including the underserved populations. When I was presented with the opportunity to oversee the Witness Project® program this gave me a strong opportunity to reach out to the community with information and resources, so I moved forward with this effort.

*"Being a 'real' advocate for others with the willingness to empower them is not a learned skill."*

# *New to B-GREAT?* Get to Know Us!

## **Who Are We?**

We are research team based upon a community and academic partnership. Our team includes researchers at the Moffitt Cancer Center, community leaders, breast cancer survivors, healthcare providers, and patient advocates, many of whom are members of the Black community. This partnership has been instrumental in the development of our educational materials to improve the awareness about inherited breast and ovarian cancer in African American women. In addition, through our research studies, we are interested in learning more about why young black women are developing breast cancer.

## **What does B-GREAT stand for?**

B-GREAT is an acronym for Breast Cancer Genetics Research and Education for African American Women Team. The "team" represents the academic-community partnership (consisting of community leaders and researchers) that was developed to address breast cancer health disparities in Black women.

## **Our Objectives:**

The B-GREAT Initiative seeks to educate and inform the African American community about the role of genes in breast and ovarian cancer that "runs 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.

## **Moffitt Team**

Tuya Pal, MD  
Susan T. Vadaparampil, PhD., MPH  
Patrice J. Fleming, BS  
Alison Nelson, BS  
Veronica Harville, BS  
Devon Bonner, BA  
Alyssa Schmidt, BS  
Sharland Johnson  
Germane Limage, BS

## **Academic Partners**

Tamandra Morgan, BA  
Desiree Rivers, PhD. MPH

## **Community Advisory Panel**

Joyce Austin  
Cheryl Clinton  
Khariah Fleming, MPH, CHES  
Sue Friedman, DVM  
Benita Hayes  
Julie Kornfeld, PhD. MPH  
Linda Paige  
Evora Pimento  
Peggie Sherry  
Donald Temple, MD  
Gloria Wood, BSN, RN  
Deneen Wyman  
Gwendolyn Dawson



## *Directors' Corner*

As part of the B-GREAT Initiative, we are dedicated to working with the African American community, particularly those women who are at increased risk for breast cancer due to their family history. We hope that this newsletter provides you with updated information as well as inspiring stories. Whether you are a patient, advocate, survivor, family member, health care provider, or researcher, we appreciate and thank all of your efforts throughout the year.

**Tuya Pal and Susan Vadaparampil**

# Advocacy 101

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## **What is involved in being a Community Outreach Worker?**

L.P.: You must have a “true heart” for people. Being a “real” advocate for others with the willingness to empower them is not a learned skill. Sure you can take classes and gain knowledge about social behaviors and cultural differences, etc., but these skills only enhance your natural ability to care for others. In my case I had some knowledge of early detection of cancers through my previous employment. Through the Witness Project® of Tampa Bay I was trained to learn even more about cancer and the different affects that it can have on individuals. It is important to have some cultural competency skills, recognizing that we have communities made up of many different people, languages, social economic status and academic levels. All of these different types of communities need services. You can make one statement to a group of people and that statement would be understood in many different ways based on the community you are addressing. As a community outreach worker you become an “information station”, a resource for the community. It is important to have an open mind and to prepare yourself for growth.

## **How can I become a Community Outreach Worker?**

L.P.: There are so many ways that you can be a Community Outreach Worker, but again you must first have an inner desire to care for others. You should begin by doing a self examination of the following:

- ◆ What is my motive for helping the community?
- ◆ In what ways can I help in the community?
- ◆ Am I willing to get intricately involved in the community (face-to-face vs. a monetary or material donation)?
- ◆ Am I able to talk candidly to leaders of community organizations and community gatekeepers about their community needs?
- ◆ What areas of need do I want to, or am I able to focus on (cancer, diabetes, infant mortality, etc.)?
- ◆ Is there a specific population that I desire to work with (men, women, children)

Once you decide what works best for you then you can begin to search for organizations and programs that have areas of need that you are able to help address.

## **Where can I find reputable resources that are easy to read and understand?**

L.P.: When you take the time to research you will find that there is a wealth of reputable information available to us. Some of the websites that we use for material and information are:

American Cancer Society  
National Cancer Institute  
Centers for Disease Control  
Komen Suncoast Affiliates  
Hillsborough County Breast & Cervical Cancer Early Detection Program

## **How can I get involved in the Witness Project®?**

L.P.: The Witness Project® of Tampa Bay is part of the Moffitt Diversity’s M-Power Department (Moffitt’s Program for Outreach, Wellness, Education and Resources). To find out more please contact Linda Paige at (813) 745-4304 or by email at [Linda.Paige@Moffitt.org](mailto:Linda.Paige@Moffitt.org).



## *Connect with Linda*

[Linda.Paige@bgreatinitiative.com](mailto:Linda.Paige@bgreatinitiative.com)

Linda Paige, a native of Boston, Massachusetts, lived in Atlanta for many years prior to her move to Tampa, Florida. Over the last 20 years her background in human resources and office management has opened opportunities for her to work with people from many walks of life. Her first position in Florida with one of the well known healthcare organizations inspired her to learn more about health disparities and how to bring health awareness to the community. She currently provides health education through the Witness Project® of Tampa Bay, a national faith-based breast and cervical health program that teaches survivorship. Linda serves on the National Witness Project® Steering Committee to assist in duplicating early detection, screenings and healthy lifestyle choices to Witness Project® sites across the country. In addition she provides other types of oral presentations and facilitates a healthy lifestyles group for women age 40 and up, teaching on how to control their overall health and well-being by learning how to make positive choices while going through mid-life. Her passion is to raise health awareness in the community and as a result of these endeavors she collaborates with churches, community centers, businesses, and a variety of health and civic organizations to encourage healthy living.





### About Dr. Vadaparampil

Dr. Susan Vadaparampil is a behavioral scientist with an interest in uptake and outcomes related to genetic counseling and testing for hereditary breast cancer in minority communities. Her research program focuses on increasing awareness, knowledge, and risk appropriate utilization of genetics services among patients and health care providers. She is Principle Investigator of the BENITA Study and Co-Directs the B-GREAT Initiative alongside Dr. Pal.



### About Dr. Pal

Tuya Pal is a board-certified clinical geneticist, with an interest in the genetics of breast cancer in African American women over the last several years. She currently staffs all patients evaluated and tested through the Cancer Genetic Counseling and Testing Service at the Moffitt Cancer Center. She is the Principal Investigator of BEST Study, and Co-Directs the B-GREAT Initiative alongside Dr. Vadaparampil.

# Spotlight on Research:

## *B-GREAT Investigators Launch Two New Studies Exploring Hereditary Breast Cancer in Black Women*

One in eight women in the United States will have their lives affected by Invasive Breast Cancer. White women are more likely to develop breast cancer than Black women; however Black women are more likely to die from breast cancer. One possible reason for this disparity may be the higher incidence of aggressive breast cancer subtypes in Black women, such as Triple Negative breast cancer, which may be responsible for as much as 30% of breast cancers in Black women compared to approximately 12% in non-Blacks. To date, very little research has been done to investigate exactly why young Black women are developing this very serious and very hard to treat type of breast cancer. This is the core question that our study entitled “Black Women: Etiology and Survival of Triple Negative Breast Cancers (BEST)” led by Dr. Tuya Pal. As one of the first large scale studies of its kind, BEST will be testing uncharted waters in its attempt to recruit and enroll at least 600 Black women age 50 and under in Florida, over a 5 year period, that have been diagnosed with invasive breast cancer.

The study will collect detailed clinical, genetic, and lifestyle information on each participant over its five year course in an attempt to understand what it is about this specific population that is contributing to these grim cancer statistics. Unique to this study is its focus on the role of *BRCA* 1 and *BRCA* 2 mutations within the triple-

negative subtype. As a part of this endeavor, all participants enrolling into the study will receive complimentary genetic counseling and *BRCA* testing.

It is known that people who have changes in the *BRCA* genes have a higher risk of developing breast cancer. For women who have previously been diagnosed with breast cancer, having changes in the *BRCA* genes also puts them at increased risk for developing a second breast cancer and/or ovarian cancer. For this reason, *BRCA* genetic counseling and/or testing is typically offered to breast cancer patients with certain risk factors. Despite having these risk factors, Black women are less likely to have *BRCA* testing compared to White women. As a result, little known about the emotional impact of testing in women of color.

In an attempt to learn more about this topic, B-GREAT investigator Dr. Susan Vadaparampil recently launched and secured funding for a new study entitled: BENITA to evaluate the impact of *BRCA* testing on Black women’s cancer risk management behaviors, the psychological impact of testing, and the impact of testing on the family. Like the BEST study, BENITA is the first of its kind. Ultimately it is our hope that with the information collected in this study, the number of deaths due to breast cancer in Black women can be reduced and lives can be saved.

# Understanding Black Women's Response to Cancer Clinical Trials

Investigators: Desiree Rivers, PhD., MSPH, Gwendolyn Quinn, PhD.

## What was the purpose of this study?

To assess a framework for overcoming barriers including lack of trust and respect among Black women and the medical community regarding clinical trials, by building relationships based on mutual respect and trust between researchers and communities.

## What was the goal of this study?

To work collaboratively with community stakeholders to recruit 48 women without a cancer diagnosis living in the Tampa Bay area to participate in the project. The women in the focus groups discussed their knowledge, attitudes and beliefs about cancer clinical trials and assessed how an existing cancer clinical trials DVD could be culturally tailored for Black women.

## What were the results of this study?

Preliminary findings from the focus groups suggest that the representation of Black women should be increased in the DVD. A culturally-specific DVD should be developed and offered in a menu of

DVDs, addressing language and cultural variability, and including detailed descriptions of the process of participation in cancer clinical trials.

## What are the implications of these research findings?

Findings from both the focus groups and the recommendations from the study's community advisory panel suggest:

- the need to develop more culturally relevant educational materials and events in regard to cancer clinical trials.
- the need for clinicians to be engaged in the development and dissemination of more culturally relevant and clinically descriptive educational materials.

Funding Agency: Center for Equal Health  
USF Moffitt Cancer Center

Year Conducted: 2011

More information about this study and other research from our Academic Partners can be found under the "Research" tab on our website, [www.BGREATInitiative.com](http://www.BGREATInitiative.com).



*Connect with Dr. Rivers*

[Desiree.Rivers@bgreatinitiative.com](mailto:Desiree.Rivers@bgreatinitiative.com)

Desiree Rivers is a USF faculty member and the Center Coordinator for a National Institute on Minority Health and Health Disparities-funded Center of Excellence, addressing cancer health disparities. As a behavioral oncology post-doctoral fellow at Moffitt, Dr. Rivers served as a research team member for the 'Population-Based' study. Dr. Rivers continues to collaborate with the B-GREAT Initiative, involving the CAP in research she is leading that assesses Black women's knowledge of and willingness to participate in cancer clinical trials. Dr. Rivers is an emergent independent investigator with expertise in health policy, health education and promotion, and health disparities research.

## Already Had Genetic Testing?

You may be interested in participating in our Inherited Cancer Registry! ICARE is a registry developed for individuals interested in taking part in studies on inherited cancer.



For more information about ICARE, who can participate, and what is required of participation visit [www.Moffitt.org/ICARE](http://www.Moffitt.org/ICARE) or connect with study coordinator Courtney Lewis by calling 813-745-6446.





# BRCA Testing: Is It Right for Me?

**Q:** *I have a strong family history of breast cancer. Should I have genetic testing?*

**A:** *The decision to pursue genetic testing depends on a number of factors. From a clinical standpoint, you might be recommended for genetic testing if you meet any of the following criteria:*

- *A personal diagnosis of breast cancer at or below age 50*
- *Two first-degree relatives with breast cancer, one of whom was diagnosed before age 50*
- *Three or more first- or second-degree relatives with breast cancer, diagnosed at any age*
- *Both breast and ovarian cancer in the family*
- *A first-degree relative with cancer in both breasts*
- *Two or more relatives with ovarian cancer*
- *One relative with both breast and ovarian cancer*
- *A male relative with breast cancer*

*Even if you meet multiple criteria, it is always a good idea to visit a genetic counselor before deciding to have a genetic test for inherited breast cancer. A counselor can help you weigh your options and discuss the impact (both medical and emotional) of testing on you and your family.*

*Need help locating a counselor in your area? The National Society of Genetic Counselors can help! Connect with a counselor in your area by logging on to [www.NSGC.org](http://www.NSGC.org) and clicking the "locate a counselor" tab.*

## Expanding our Reach >>>

### B-GREAT-ER (B-GREAT Expanding our Reach)

B-GREAT was recently funded by the Florida Breast Cancer Foundation Educational Grants Program to expand the reach of our initiative. Through this grant we will be able to increase our outreach and educational efforts related to hereditary breast cancer both in the Tampa Bay area and beyond! As a part of our new efforts, we are partnering with 30 new organizations in the state of Florida and 25 additional organizations throughout the country to disseminate

our brochure entitled The Family Link between Breast and Ovarian Cancer in Black Women. In addition, these funds will also allow us to strengthen our community partnerships by sponsoring 4 community education events developed by members of our Community Advisory Panel. We are excited to announce that these new efforts have been appropriately named B-GREAT-ER (Breast Cancer Genetics Research and Education for African American Women Team:

Expanding our Reach). If you are interested in obtaining this brochure to distribute to your organization please contact the B-GREAT Initiative via phone (813-745-6649) or by email at ([GeneticsResearch@moffitt.org](mailto:GeneticsResearch@moffitt.org)). It is absolutely free to request brochures and brochures will be mailed to distributors free of charge.



# WORD SEARCH: HEREDITARY BREAST CANCER



[Word List >>>](#)

- |            |           |               |
|------------|-----------|---------------|
| BRCA       | CANCER    | COUNSELING    |
| FAMILY     | GENE      | GENETICS      |
| HEREDITARY | MAMMOGRAM | MUTATION      |
| NEGATIVE   | PEDIGREE  | TRIPLNEGATIVE |

S	R	G	Y	J	B	E	O	W	Q	J	F	J	A	V
L	E	A	N	L	C	S	P	O	Y	B	I	J	S	H
C	C	Q	F	I	I	E	R	U	M	Q	T	E	P	L
B	N	E	Y	G	L	M	N	R	F	P	V	L	G	U
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C	K	I	A	A	A	X	P	G	C	K	S	G	D	O
Y	F	C	T	G	E	N	E	O	L	V	N	D	E	N
M	R	I	L	O	N	H	U	U	G	S	O	H	R	L
B	V	P	D	L	T	M	F	H	G	B	G	U	E	C
E	T	W	N	R	E	L	M	W	M	E	L	R	H	L

## SPOTLIGHT TESTIMONY: SHARE YOUR STORY IN THE NEXT NEWSLETTER!

The B-GREAT Initiative is looking for a breast cancer survivor who has had genetic counseling and/or testing to share their story( in their own words) for the next Connections newsletter. If you are interested in having your story published, email us at : [info@bgreatinitiative.com](mailto:info@bgreatinitiative.com) or give us a call at **813-745-6649**.





# NewFaces

*Our Initiative is Growing...*

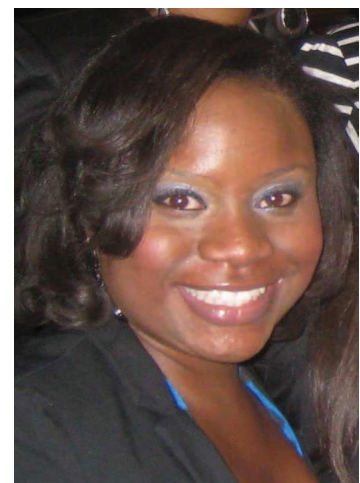
*Meet our new additions*



**Khaliah Fleming** is a community health educator with the Tampa Bay Community Cancer Network at Moffitt Cancer Center. She is a 2004 graduate of Spelman College where she majored in English and a 2010 graduate of the University of South Florida where she obtained her Masters of Public Health. She is interested in exploring the use of non-formal educational strategies and techniques to influence community ownership of healthy lifestyles and practices. Khaliah joins the B-GREAT Initiative as a member of the Community Advisory Panel.



**Tamandra Morgan** is a second year genetic counseling student at The Johns Hopkins/NHGRI training program interested in exploring how African American families communicate about hereditary cancer risk as part of her thesis project. Originally from Southern California, Tamandra is a 2009 graduate of Stanford University with a major in Human Biology. She first became interested in the field of genetic counseling after completing a summer internship at the City of Hope Cancer Center in Duarte, CA. Tamandra joins the B-GREAT Initiative as an Academic Partner



**Alison Nelson** is research assistant at Moffitt Cancer Center. She is currently a Master's of Public Health student at the University of South Florida concentrating in Maternal Child Health & Epidemiology. Her interests include the reproductive health of adolescent cancer patients, health disparities, and health care access to children with special health care needs. Alison joins the B-GREAT Initiative as an Outreach Coordinator for the greater Tampa Bay area.

**coming soon >>>**

## *In The Next Issue*

*Changing the Face of Genetic Counseling*

*Intro to Breast Cancer Genetics*

*Breast Cancer Screening*

*Telephone-based Genetic Counseling*

## **About B-GREAT Connections:**

*B-GREAT Connections is a newsletter produced by the Breast Cancer Genetics Research & Education for African American Women Team (B-GREAT) Initiative. For more information on B-GREAT or Connections please visit our website at [www.BGREATInitiative.com](http://www.BGREATInitiative.com) or give us a call at 813-745-6649.*

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