



# Knowledge is power

THE BLACK BREAST  
CANCER EXPERIENCE

  
**LIVING BEYOND  
BREAST CANCER®**

ORGANIZATIONAL PARTNERS



# What does Black breast cancer look like?

**Knowledge is power: The Black breast cancer experience** explores the disparities in breast cancer care. In addition to discussions about disparities in care, the program covers topics including self-care, body image, and breast reconstruction.

In this resource guide, we've pulled together highlights from each session and additional resources to help you live well, beyond your diagnosis.

*Statistics sourced from: Susan G. Komen and American Cancer Society*

About 1 in 3 Black women report experiencing racial discrimination at a healthcare provider visit

Black women tend to be diagnosed at a younger age than white women

Black women have a higher rate of receiving a triple-negative diagnosis, which is a more aggressive breast cancer subtype

Black women have about a 40% higher death rate than white women in the U.S.

**WE HAVE TO DO BETTER.**

## THANK YOU TO OUR PARTNERS & SPONSORS

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### SUPPORTER

AmeriHealth Caritas  
AmerisourceBergen Corporation Foundation

### FRIEND

Abramson Cancer Center (ACC) at Penn Medicine  
Basser Center for BRCA  
Sidney Kimmel Cancer Center (SKCC) – Jefferson Health  
Univest

SESSION I

# Our voices, our stories



A candid conversation with Black women from all walks of life about their breast cancer diagnosis, experiences with implicit racial bias and health inequalities, and how they overcame these obstacles to receive standard of care.



**MONIQUE GARY, DO, MSC, FACS**

Breast surgical oncologist and medical director  
Grand View Health/Penn Cancer Network cancer program



**RACQUEL JONES, MA** Early Childhood Education  
Diagnosed with DCIS in 2020, Breast Cancer Survivor



**BRITTANY SHOOK**

Metastatic breast cancer thriver



**SHELLI CLAY**

Breast Cancer Survivor and Thriver

**KEY TAKEAWAYS**

- You know your body best. Speak up and advocate for yourself to receive the care, services, and interventions you require
- Request copies of your medical records and tests to read and review
- It's ok to get second opinions if you aren't getting the care you deserve!

**ADDITIONAL RESOURCES**

[Young Advocates, Strong Friendships](#)

[The Importance of Communicating Well with your Doctors: Francess Register-Joyner](#)

[Addressing disparities in breast cancer care, with Tisha M. Felder, PhD, MSW](#)

[Speaking out: Taking time for myself helped me get the care I need](#)

# Radical self-care: Body, mind, and soul



**NATUROPATHIC RECOMMENDATIONS TO REDUCE SIDE-EFFECTS**

- Appetite
- Constipation
- Fatigue
- Hot flashes
- Lymphedema
- Nausea
- Neuropathy
- Sleep

**WATCH NOW**

LIVING BEYOND BREAST CANCER

Self-care can make a significant difference to women during and after breast cancer treatment. In this session you will learn about the principles of self-care and healthier living that can help you cope and manage the emotions of your diagnosis, and improve your energy levels and your overall sense of well-being.



**AISHA CHILCOAT, ND, FABNO**

T32 Postdoctoral Research Fellow  
University of North Carolina at Chapel Hill  
Program on Integrative Medicine



**JACCI THOMPSON-DODD, MA, MSSW, LASW**

Creator in Chief, LiveThrivorship.com

## KEY TAKEAWAYS

- Listen to your body. Do not suffer in silence. Pain, mental anguish, sleeplessness, and other symptoms should not be ignored
- Gather your tribe. Refresh your circle of support to better respond to your current needs
- Love yourself, be gentle with yourself

## ADDITIONAL RESOURCES

[Methods of self-care to deal with stress and anxiety](#)

[Mindfulness meditation for resilience with Anusha Wijeyakumar, MA, CPC, RYT](#)

[Fueling resiliency](#)

[Yoga to start your day](#)

# Loving the skin you're in: Breast reconstruction, body image, and body positivity



Racial disparities have been documented in many areas of healthcare, including plastic and breast reconstructive surgery. In this session our experts talk about these disparities and provide practical information that will help you make an informed decision about breast reconstruction, as well as how to improve body image, self-love, and body positivity.



### ERICKA HART, MD

Black queer femme activist, writer, and speaker  
Adjunct faculty at Widener University's  
Center for Human Sexuality



### JULIA C. STEVENSON, MD

Board Certified Plastic Surgeon  
Owner & Founder of Cardinal Plastic Surgery

### KEY TAKEAWAYS

- Anything having to do with your breasts from cancer diagnosis on is NOT COSMETIC...even if you had nothing done to the other breast...and there is no expiration date on that fact...and it's covered by insurance.
- You lose nothing by waiting to pursue reconstruction. Take all the time you need to figure out what is best for you.
- Loss of part, whole or both of your breasts is not a trivial thing. It can affect you physically, mentally, spiritually, intimately, and emotionally. Do not feel guilty about these feelings.

### ADDITIONAL RESOURCES

[For Black women, a special chemo challenge: finding a wig that works](#)

[Making Decisions About Reconstruction: Siata Swaray](#)

[Difficult Decisions: Breast Reconstruction](#)

[BC Worksheet: Questions to ask your doctor about breast reconstruction](#)



# LIVING BEYOND BREAST CANCER®

## MARK YOUR CALENDAR

### Ask the expert: Metastatic breast cancer

Wednesday, December 15, 2021

## GET SUPPORT

### Breast Cancer Helpline

Get matched with a trained volunteer who has a similar experience to you for peer-to-peer support. [LBBC.ORG/HELPLINE](https://www.lbbc.org/helpline)

### Reading for Reassurance

Make the cancer conversation easier by requesting free books for kids and teens who have a parent recently diagnosed with breast cancer.

[LBBC.ORG/READING](https://www.lbbc.org/reading)

### Living Beyond Breast Cancer Fund

LBBC offers one-time financial assistance grants to cover expenses such as rent, mortgage, utilities, and car payments. [LBBC.ORG/FUND](https://www.lbbc.org/fund)

## PRIVATE FACEBOOK GROUPS

[Breast Cancer Support for All Ages, All Stages](#)

[Breast Cancer Support for Young Women](#)

[Support community for high risk](#)

## CONNECT WITH LBBC

[mail@lbbc.org](mailto:mail@lbbc.org)  
855-807-6386



Share how you live well beyond your diagnosis on social media and be sure to tag @LivingBeyondBC and #LiveBeyondBC.

## ABOUT LBBC

Living Beyond Breast Cancer is a national nonprofit organization that seeks to create a world that understands there is more than one way to have breast cancer. To fulfill our mission of providing trusted information and a community of support, we offer on-demand emotional, practical, and evidence-based content that is meaningful to those newly diagnosed, in treatment, post-treatment, and living with metastatic disease.

For 30 years, Living Beyond Breast Cancer has imparted wisdom and connection via conferences, events, a peer-to-peer helpline, and more. Today, we remain committed to creating a culture of acceptance—where sharing the diversity of the lived experience of breast cancer fosters self-advocacy and hope.



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# FOLLOW-UP APPOINTMENTS DURING COVID-19? CANCER SURVIVORS CAN'T WAIT.

KANESHA  
BREAST CANCER SURVIVOR

## TALKING TO HER DOCTOR GAVE KANESHA THE CONFIDENCE SHE NEEDED TO KEEP HER APPOINTMENT.

Due to worries about COVID-19, people skipped their cancer screenings or follow-up appointments. That's understandable. But delaying or even canceling your appointments could put you at an increased risk for missing a diagnosis.

Doctor's offices, local hospitals, and clinics around the country are likely taking steps to make visits safer by using virtual visits and other telehealth services.

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Call your doctor to find out what steps they're taking and visit [GetCancerScreened.com](https://www.getcancerscreened.com) to prepare for your follow-up appointment.

CANCER  
SCREENING.  
GET IT DONE.™



  
LIVING BEYOND  
BREAST CANCER®

# Partner Resources

For more resources on Black breast cancer and places to find support, check out these inspiring organizations.

ORGANIZATIONAL PARTNERS	FOLLOW	CONTACT
 <p>Launched in 2019, The Chrysalis Initiative provides patients with mentoring, resource navigation and equips women of disparate groups with the opportunity to assess their breast cancer care intelligently. TCI pushes patients and providers to examine how racism and bias shows up in the way care is administered and guides participants into a responsive and inquiry-based space, empowering both the provider and patient through the cancer treatment process.</p>	<ul style="list-style-type: none"> <li> @chrysalisinitiative</li> <li> Chrysalis Initiative</li> <li> @chrysalisinit</li> <li> Chrysalis Initiative</li> <li> Chrysalis Initiative</li> </ul>	<p><b>Jamil Rivers</b> Chief Executive Officer 1.800.929.4979 info@thechrysalisinitiative.org</p> <p><b>RaeAna Saenz</b> Executive Administrative Assistant 1.800.929.4979 ext. 102 rsaenz@thechrysalisinitiative.org</p>
 <p>My Style Matters is a 501c3 grassroots non-profit organization, dedicated to improving the lives of underserved and disadvantaged individuals affected by cancer by offering supportive services and providing healthy lifestyle coaching and educational programs with a focus on cancer and cancer prevention.</p>	<ul style="list-style-type: none"> <li> @mystylematters</li> <li> @mystylematters</li> <li> @mystylematters2</li> <li> @mystylematters</li> <li> @mystylematters</li> </ul>	<p><b>Tiah Tomlin, Co-Founder &amp; CEO</b> 804.400.6082 Info@mystylematters.org Ttomlin@mystylematters.org</p> <p><b>Join our sisterhood on Facebook:</b> My Breast Years Ahead</p>
 <p>Tigerlily Foundation supports young women before, during, and after breast cancer. We envision a future where breast cancer diagnosis doesn't inspire fear, but ignites hope for a future.</p>	<ul style="list-style-type: none"> <li> @tigerlily_foundation</li> <li> @tigerlilycares</li> </ul>	<p><b>Shanda Cooper</b> shanda@tigerlilyfoundation.org</p>
 <p>Touch, The Black Breast Cancer Alliance drives the collaborative efforts of patients, survivors, advocates, advocacy organizations, health care professionals, researchers, and pharmaceutical companies to work collectively and with accountability towards the common goal of eradicating Black Breast Cancer. Our vision is to eradicate Black Breast Cancer!</p>	<ul style="list-style-type: none"> <li> @touchbbca</li> <li> @touchbbca</li> <li> @touchbbca</li> <li> @touchbbca</li> </ul>	<p><b>Ricki Fairley</b> 443.758.1924 Ricki@touchbbca.org</p>
 <p>The Triple Negative Breast Cancer Foundation strives to be a credible source for triple negative breast cancer information, a catalyst for science and patient advocacy and a caring community with meaningful services for patients and their families.</p>	<ul style="list-style-type: none"> <li> @TNBCFoundation</li> <li> @TNBCFoundation</li> <li> @TNBCFoundation</li> </ul>	<p><b>Arlene Brothers</b> arlene@tnbcfoundation.org  #tnbcfoundation</p>

# Partner Resources

For more resources on Black breast cancer and places to find support, check out these inspiring organizations.

COMMUNITY PARTNERS	FOLLOW	CONTACT
<p><b>2FOR2 BOOBS</b> mission is to help save Black lives from breast cancer by educating, engaging and empowering women, men and teens to know their risk and preventive factors, address barriers and disparities to allow for managing their health proactively for better outcomes.</p>	<ul style="list-style-type: none"> <li> @2for2Boobs</li> <li> 2for2Boobs Private Group</li> <li> @2FOR2BOOBS</li> <li> 2for2ShadesPink</li> </ul>	<p><b>Tallulah Anderson</b>            Founder &amp; CEO            301.219.2287            2for2Boobs@gmail.com</p>
<p><b>FOR THE BREAST OF US</b> is the first inclusive online community for Women of Color diagnosed with breast cancer empowering women to make the rest of their lives their best lives through education, connection, and community.</p>	<ul style="list-style-type: none"> <li> @forthebreastofus</li> <li> For the Breast of Us</li> <li> @thebreastofus</li> </ul>	<p><b>Marissa Thomas</b>            253.229.6629            marissa@breastofus.com</p>
<p><b>AFRICAN AMERICAN BREAST CANCER ALLIANCE, INC.</b>            Educating and supporting African American/Black Americans in the survivorship of breast cancer.</p>	<ul style="list-style-type: none"> <li> @AABCALnc.org</li> </ul>	<p><b>Reona Berry</b>            612.462.6813            info@aabcainc.org</p>
<p><b>CANCER IN THE KNOW</b> is a growing community where we share knowledgeable information to help people navigate their cancer journey with access to education and resources for advocacy.</p>	<ul style="list-style-type: none"> <li> @roberta.albany</li> <li> @CancerInTheKnow</li> </ul>	<p><b>Roberta A. Albany</b>            Cancer In The Know, Founder            robertaalbany@cancerintheknow.com</p>
<p><b>CANCER AWARENESS NETWORK FOR CHILDREN, INC., (CAN)</b> is a grassroots community organization. Our mission is to inform, educate, motivate, and enlighten underserved individuals of all ages who have been diagnosed with cancer. In addition, we provide supportive services, eliminate fears associated with a cancer diagnosis.</p>	<ul style="list-style-type: none"> <li> @CancerAwarenessNetwork</li> </ul>	<p><b>Loretta Herring</b>            205.516.1044            lorettaherring70@gmail.com</p>

**CHECK OUT ADDITIONAL RESOURCES RECOMMENDED BY OUR SPEAKERS AND COMMUNITY MEMBERS >**