



**Tigerlily**  
Foundation

YOUNG WOMEN'S  
METASTATIC BREAST CANCER DISPARITIES

# *Fireside Chat*

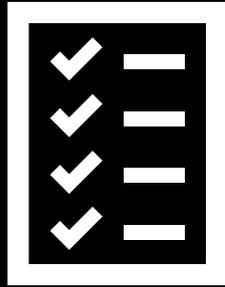
San Antonio Breast Cancer Symposium

December 10, 2019

7:00 – 11:15 AM

*#ListenUpMBC*





## Ground Rules

Respect.

Honesty.

Speak-up.

Agree to disagree.

Build Trust.

Heart.



## Wi-Fi Information

Password: Cavalier

*#ListenUpMBC*



**Getting Connected**

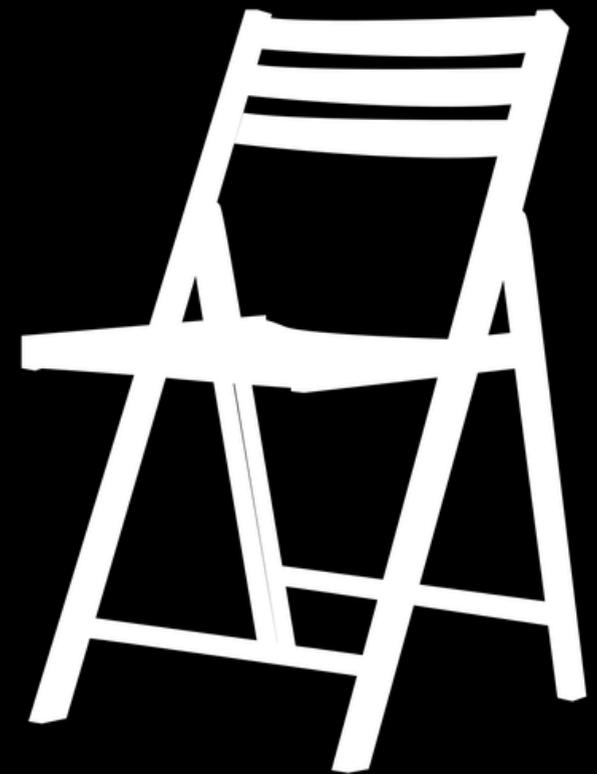


# Opening Remarks

Zora Asberry

If they don't give you  
a seat at the table,  
bring a folding chair.

-Shirley  
Chisholm





# Welcome Remarks

Maimah S. Karmo

**#ListenUpMBC  
Setting the  
table for change.**

**ATA**



# Why? MBC Disparities

**MBC ANGEL Advocates will combat disparities for black women in the U.S. who:**

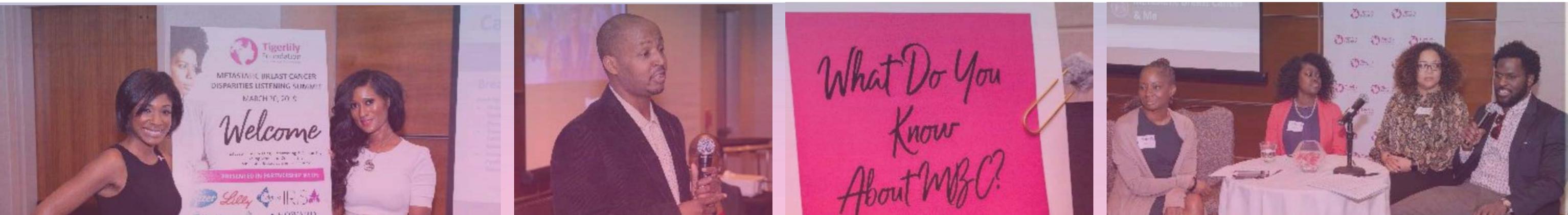
- **Get breast cancer at about the same rate as white women, however black women are nearly 40% more likely to die from breast cancer than white women.** In some areas this rate can be as high as 70% more.
- **Often go underrepresented in the conversation on the unique needs of women living with stage 4 breast cancer.**
- **Are more likely to be screened at lower resourced and non-accredited facilities** and experience longer intervals between mammograms, and between abnormal results and follow-up.
- **Due to a long history of injustices, mis-trust the scientific and health care system,** resulting in alarming outcomes, barriers to health care, lower participation in clinical trials and genetic testing.
- **Are more likely than white women to be diagnosed younger and develop more aggressive forms of breast cancer such as triple-negative.**



# What? Young Women's MBC Disparities Initiative

## Young Women's MBC Disparities Initiative's Objectives:

- Build a global platform that will end breast cancer disparities among young women of color in our lifetime.
- Facilitate conversations with MBC patients, experts & partners to educate young women of color on MBC disparities.
- Demonstrate the importance of access to innovations in MBC treatments including clinical trials for women of color record the barriers & misperceptions faced by young women of color.
- Create partnerships, tools, content, messages, & methods to lower black breast cancer mortality rates.
- Mobilize a network of diverse MBC ambassadors and experts to partner with Tigerlily on how to best meet the needs of their community.





# How? Defining Impact: 3 Phases. 1 Focus.



## LISTEN

P  
H  
A  
S  
E  
1

Listen to identify needs, priorities, barriers, partners & methods

Local & National Listening Summit

Launched at MBC Disparities Listening Summit Washington, DC in March 2019



## CREATE

P  
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2

Create a metastatic breast cancer disparities advocacy, education & outreach campaign

MBC Disparities Alliance

Launched at Young Women's Breast Health Day on the Hill in Washington, DC in November 2019



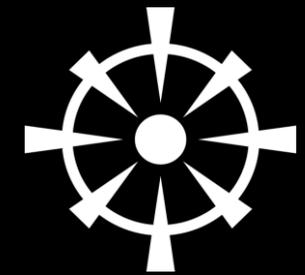
## MOBILIZE

P  
H  
A  
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3

Mobilize young women of color to lower African-American breast cancer mortality rates

MBC ANGEL Advocates

Launch at San Antonio Breast Cancer Symposium in December 2019



## FOCUS

Tigerlily will **listen** to gather insights to **create** a metastatic breast cancer disparities advocacy, education and outreach campaign to **mobilize** young women of color to build a global platform that will end breast cancer disparities among young women of color in our lifetime.

# METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT

## By the Numbers

MARCH 20, 2019 | WASHINGTON, DC



**1st** Metastatic Breast Cancer (MBC) Disparities Listening Summit for young Women of Color (WOC)



## 5 Recommended Next Steps

- MBC Disparities Mentorship Programs
- MBC Disparities Advisory Committee
- For Us by Us Activism & Conference
- MBC Targeted Legislation & Advocacy
- Partner with Existing Support Programs



**1,030+**

Social Posts Using #ListenUpMBC



### Voices At the Table



### Summit Overview

- 2 Breakouts
- 6 Facilitators
- 1 Media Advisory
- 4 Panels
- 1 Press Release
- 7 Recorders
- 15+ Resources Shared
- 1 Workbook



### Attendees by Interest

- 86% BC Disparities
- 79% MBC Young WOC Ed
- 64% MBC Patient Advocacy
- 64% BC Leader Networking
- 64% Tigerlily Partnership
- 50% MBC



### Industries

- 16% Advocacy
- 12% Business
- 8% Campus
- 6% Caregivers
- 8% Community/Faith
- 10% Health Care
- 31% Patients
- 9% Pharma



Young Women's Metastatic Breast Cancer Disparities Advocate, Now to Grow, Empower & Lead ANGEL Advocates



Young Women's Metastatic Breast Cancer Disparities Alliance



**99%**\*



OF ATTENDEES INTERESTED IN DEVELOPING NEXT STEPS

*\*of survey respondents*



# 7<sup>th</sup> Annual Young Women's Breast Health Day on the Hill

## By the Numbers

November 21, 2019  
LIBRARY OF CONGRESS

**1<sup>st</sup>** Young Women of Color Metastatic Breast Cancer (MBC) Disparities Alliance

**50** Patients, experts, caregivers, partners policymakers & community leaders

**1** Goal to establish priorities to form an alliance to end MBC disparities.

**4** Cs of Coalition Building In Communities of Color

**CREATE** | Activities recommended to plan and initially organize

- Recruit a core planning committee
- Put relationships first
- Identify initial vision & common concerns

**CONNECT** | Help group to become grounded as an organization

**COMMIT** | How the group will function effectively over time

**CELEBRATE** | Importance of celebration to the coalition's success



## Next Steps

**Action plan.** Working group to draft a plan with proposed deadline for full Alliance review.

**Next Meeting.** January 28, 2019 | 12 – 1 PM ET  
Virtual alliance meeting to develop the goals & objectives.

**Follow Up Date.** December 20, 2019  
Hill Day follow up with meeting minutes, materials & next steps.





# Who? MBC ANGEL Advocate's Role

Together, MBC ANGEL Advocates Will:



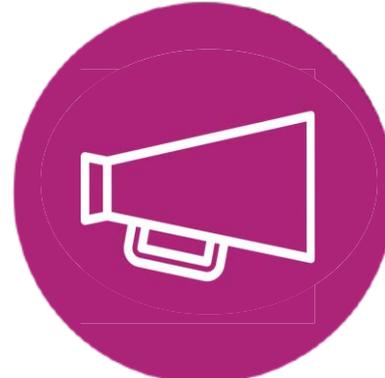
## COMMIT

Commit to advocacy program to learn, share, grow, host events & other outreach activities to educate your community.



## ATTEND

Attend and actively participate in all Tigerlily Advocate trainings and at least 1 to 2 conferences with travel support.



## AMPLIFY

Amplify the conversation on social media via Facebook, Instagram, Twitter, LinkedIn, and blogging.



## HOST

Host at least 3 Tigerlily supported educational or outreach events to engage and educate community members.



## PARTICIPATE

Participate in monthly Advocate calls for training, updates, partnerships, and opportunities.

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**+60** Local MBC Education & Outreach Activities

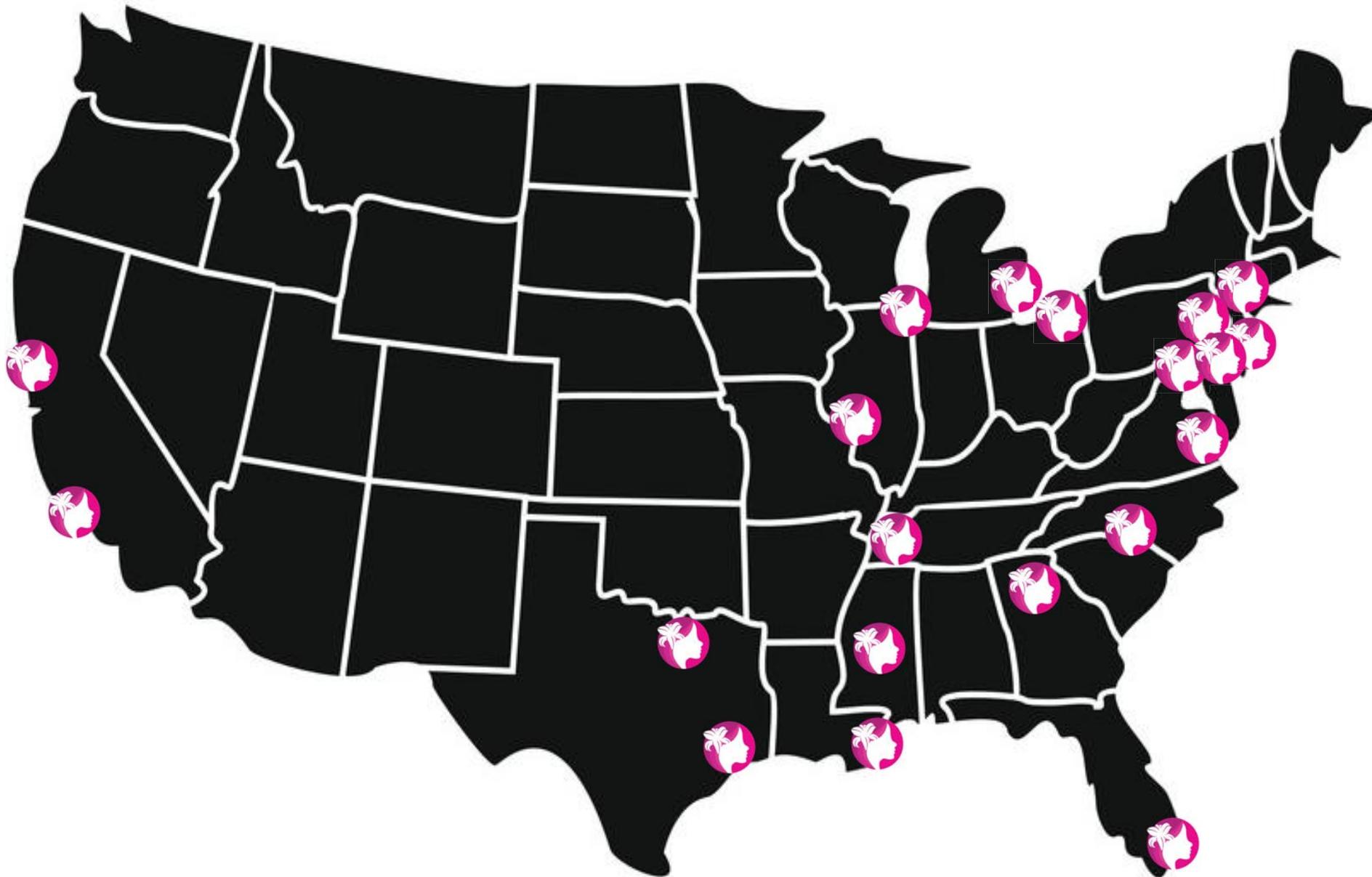
**8** MBC Advocate Modules & Training Sessions

**+12** MBC Advocate Social Media Resources

**+20** MBC Advocates Participate in Conferences

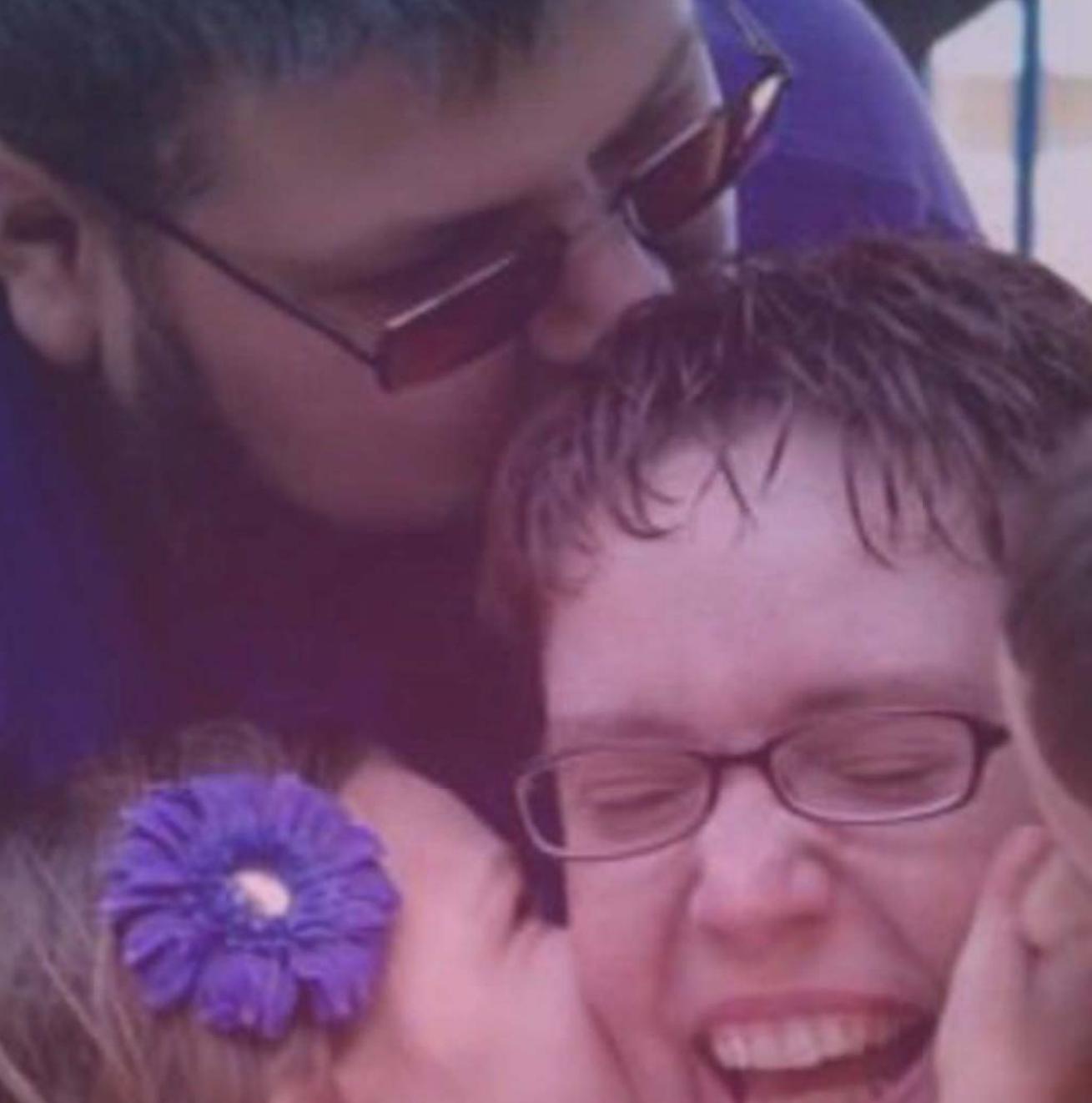


# Where? Our Areas of Impact



**20 CITIES.  
20 MBC ANGEL ADVOCATES.  
OUR AREAS OF IMPACT**

<b>Memphis</b>	<b>Detroit</b>
<b>St. Louis</b>	<b>Cleveland</b>
<b>Dallas Fort-Worth</b>	<b>Miami</b>
<b>Los Angeles</b>	<b>Charlotte</b>
<b>Virginia Beach</b>	<b>Oakland</b>
<b>Atlanta</b>	<b>New York</b>
<b>Chicago</b>	<b>New Orleans</b>
<b>Houston</b>	<b>Jackson, MI</b>
<b>Washington, DC</b>	<b>Camden, NJ</b>
<b>Philadelphia</b>	
<b>Baltimore</b>	



# A Heart to Heart Conversation

J Caldwell

Maimah S. Karmo



# **MBC Disparities: Looking Back to Move Ahead**

Shawn Johnson

# How Patient Advocates Changed Me

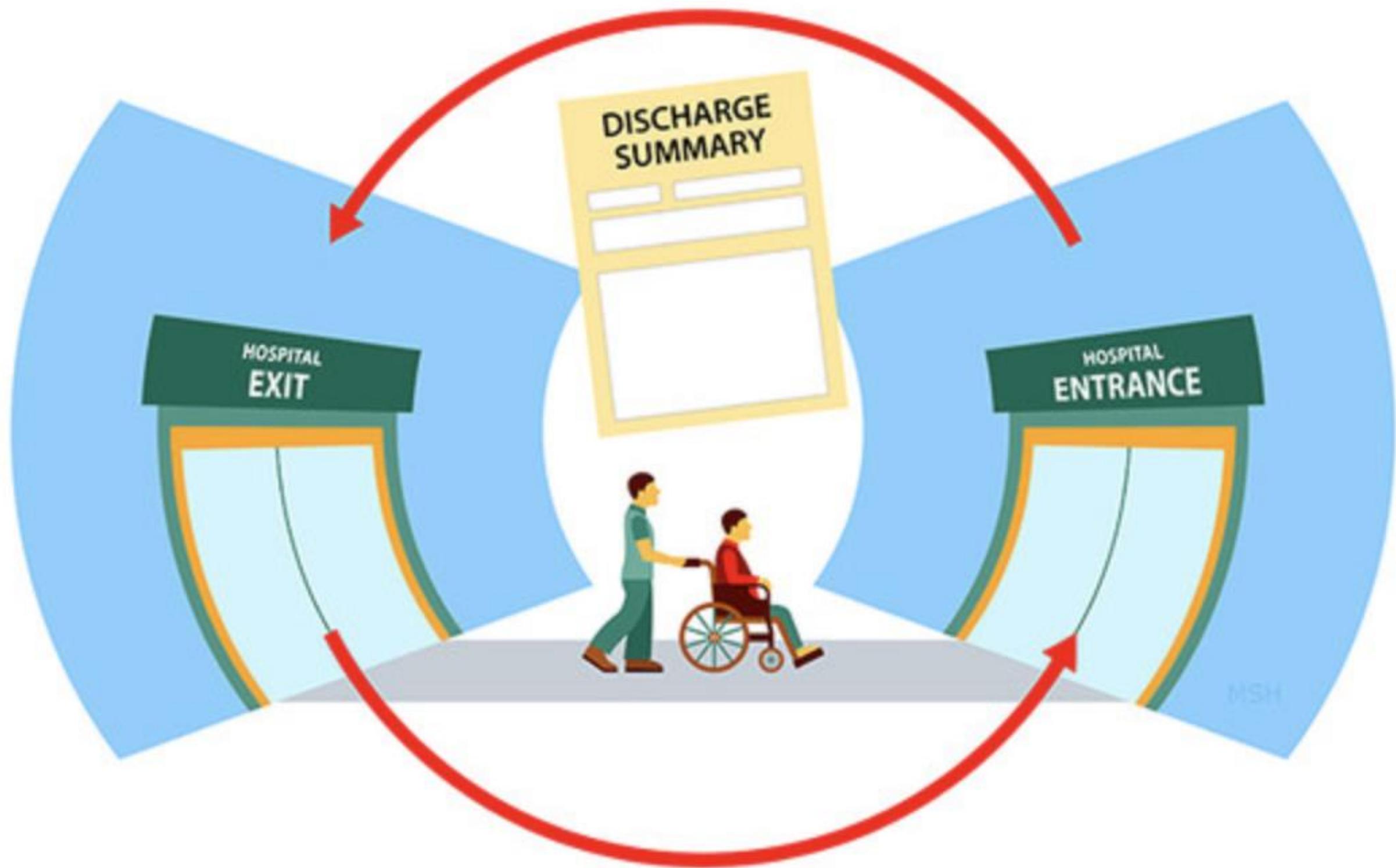
**“Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.” – Martin Luther King Jr.**



Shawn Johnson  
Harvard Medical School  
M.D. Candidate, Class of 2021







***“This isn’t a good patient to follow..you won’t learn anything from it.”***



# *My First Lesson – Whose voices do we prioritize?*



# *My First Lesson – Whose voices do we prioritize?*

## *Trump Administration Ends Protected Status for Thousands of Hondurans*

The New York Times



## *Trump Administration Says That Nearly 200,000 Salvadorans Must Leave*

Sections **The Washington Post** Democracy Dies in Darkness [Try 1 month for \\$5](#)

**Politics** Impeachment Inquiry White House Congress Polling The Trailer Fact Checker The Fix

Politics

## Trump administration announces end of immigration protection program for ‘dreamers’

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# *My First Lesson – Whose voices do we prioritize?*



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# *My First Lesson – Whose voices do we prioritize?*



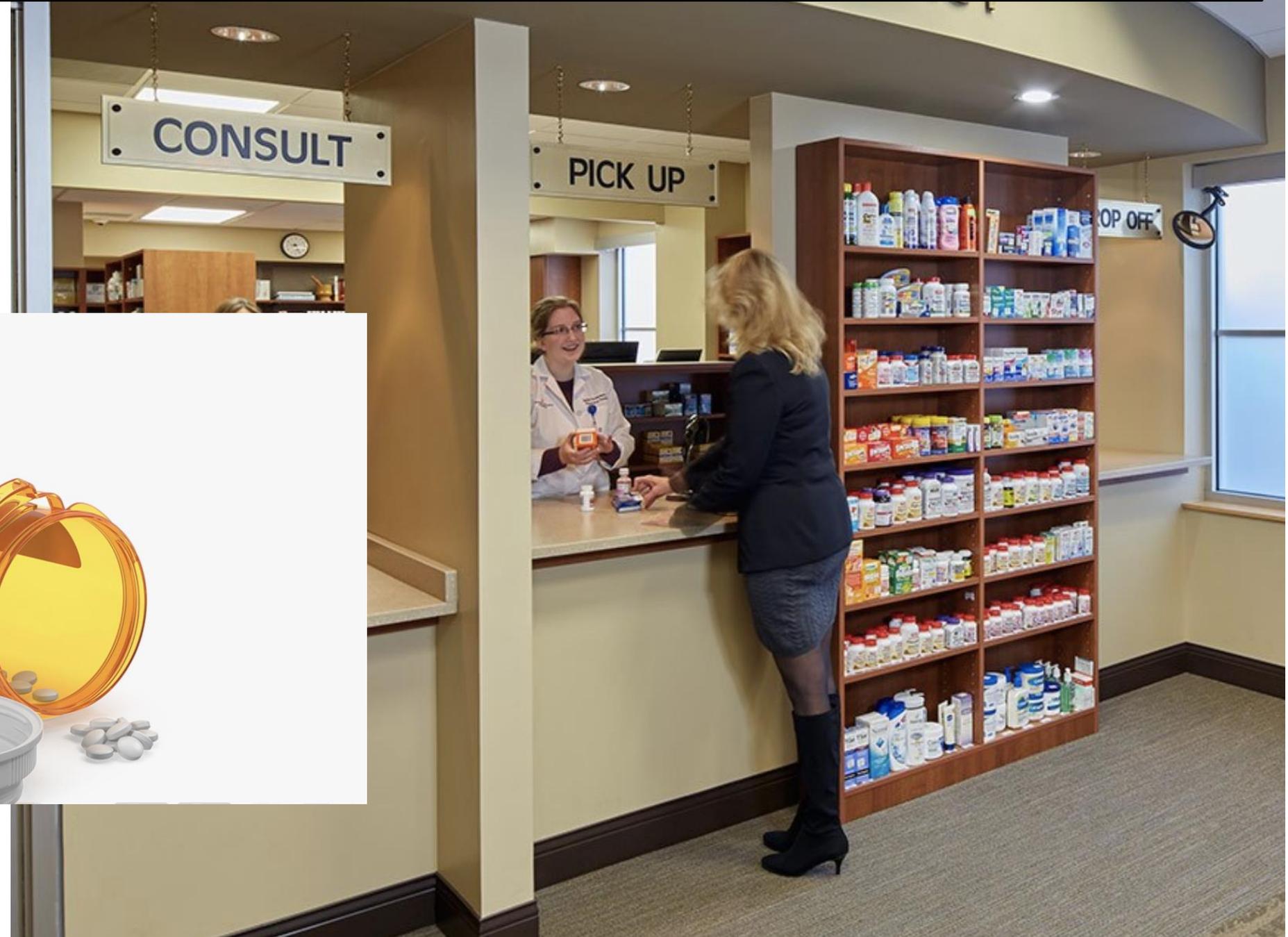
# ***My First Lesson – Whose voices do we prioritize?***



***“We can’t do that...it’s too complicated.”***



***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***



***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***

*The* **NEW ENGLAND**  
**JOURNAL** *of* **MEDICINE**

ESTABLISHED IN 1812

OCTOBER 20, 2005

VOL. 353 NO. 16

**Trastuzumab after Adjuvant Chemotherapy  
in HER2-Positive Breast Cancer**

***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***

**Table 1. Baseline Characteristics of the Patients, Tumors, and Primary Treatments (Intention-to-Treat Groups).\***

Variable	1 Yr of Trastuzumab (N=1694)	Observation (N=1693)
Region — no. (%)		
Western and Northern Europe, Canada, South Africa, Australia, New Zealand	1208 (71.3)	1222 (72.2)
Asia Pacific, Japan	203 (12.0)	202 (11.9)
Eastern Europe	189 (11.2)	175 (10.3)
Central and South America	94 (5.5)	94 (5.6)
Race — no. (%)†		
White	1411 (83.3)	1406 (83.0)
Asian	210 (12.4)	207 (12.2)
Black	12 (0.7)	8 (0.5)
Other	57 (3.4)	67 (4.0)
Missing	4 (0.2)	5 (0.3)

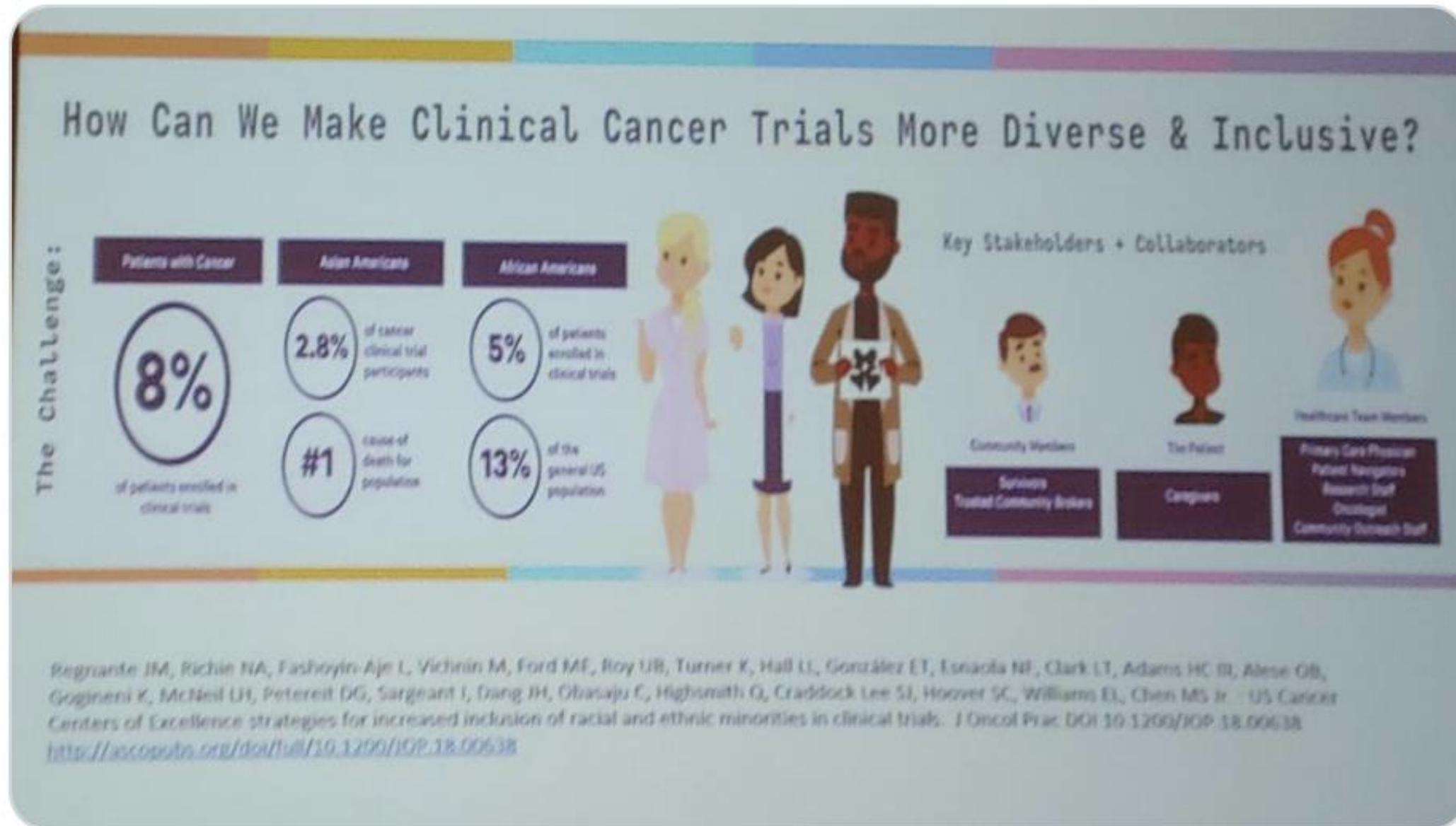
**2005**

# *My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc*

Age		
Median (range) — yr	62 (30–89)	61 (28–88)
<65 yr — no. (%)	263 (59.2)	141 (63.5)
≥65 yr — no. (%)	181 (40.8)	81 (36.5)
Race — no. (%)†		
White	344 (77.5)	172 (77.5)
Asian	65 (14.6)	30 (13.5)
Black	8 (1.8)	3 (1.4)
Other	27 (6.1)	17 (7.7)
ECOG performance status — no. (%)‡		
0	257 (57.9)	102 (45.9)
1	178 (40.1)	117 (52.7)
2	9 (2.0)	3 (1.4)
Disease stage at initial diagnosis — no. (%)		
I	51 (11.5)	30 (13.5)
II	137 (30.9)	68 (30.6)
III	72 (16.2)	39 (17.6)
IV	138 (31.1)	72 (32.4)
Unknown	36 (8.1)	12 (5.4)
Other or data missing§	10 (2.3)	1 (0.5)

**2016**

# ***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***

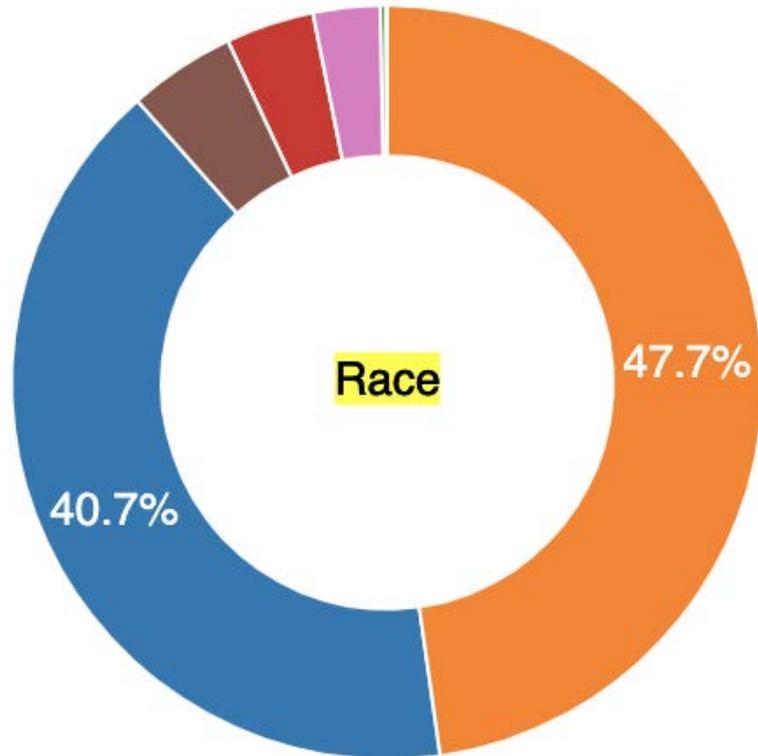


***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***

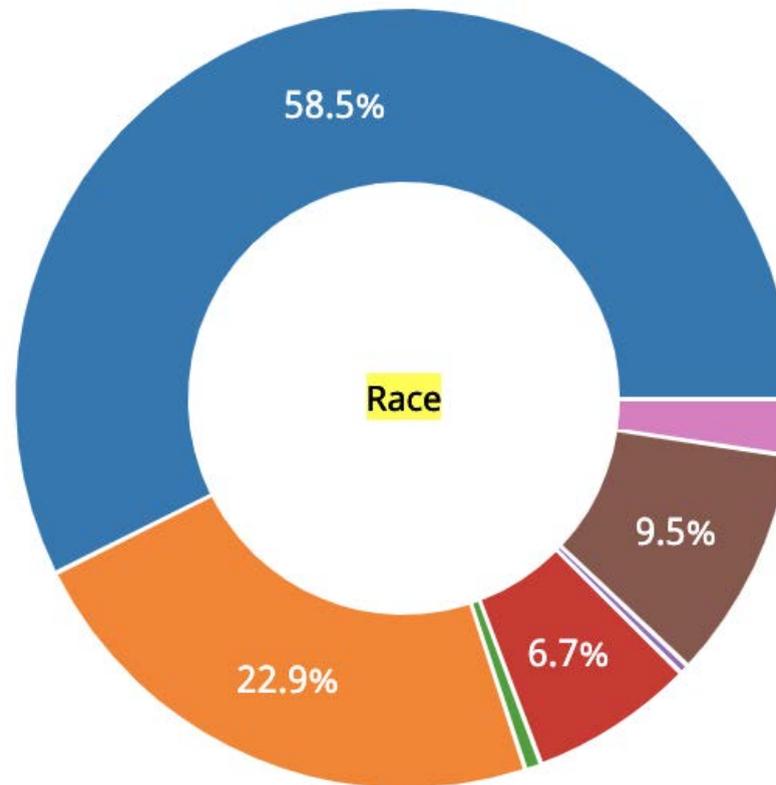
“Cancer Centers occupy a unique role in their communities. **They are expected to perform research of particular relevance to their catchment area and engage the populations within their catchment area in the research they conduct.** In order to facilitate this, Centers thoroughly analyze the demographics and cancer burden of their catchment area. In addition, Centers are expected to engage communities within their catchment area to decrease their cancer burden, **particularly among minority and underrepresented populations.**” — *National Institutes of Health*

***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***

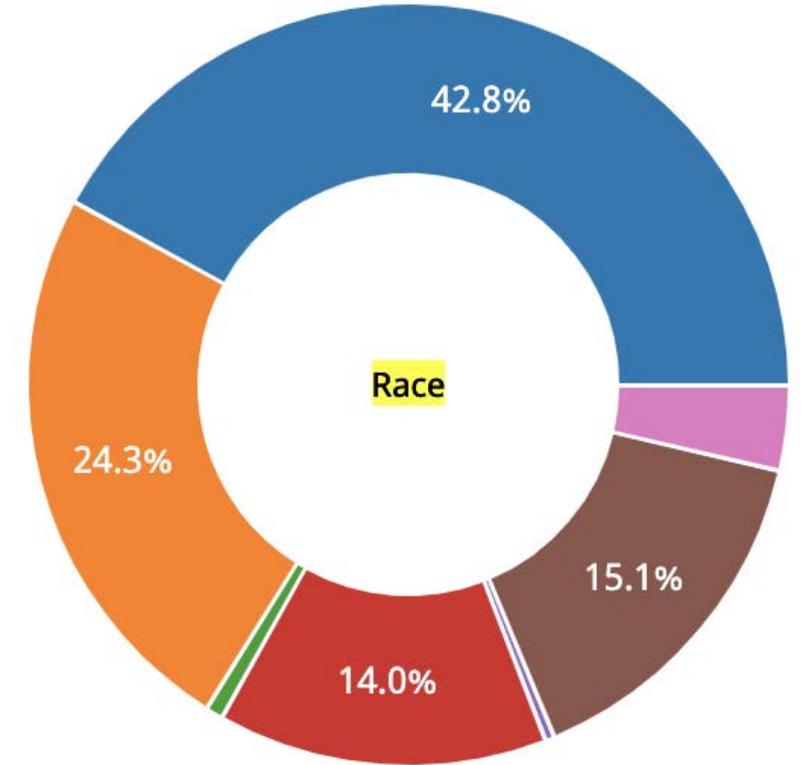
**Washington, D.C.**



**Houston**

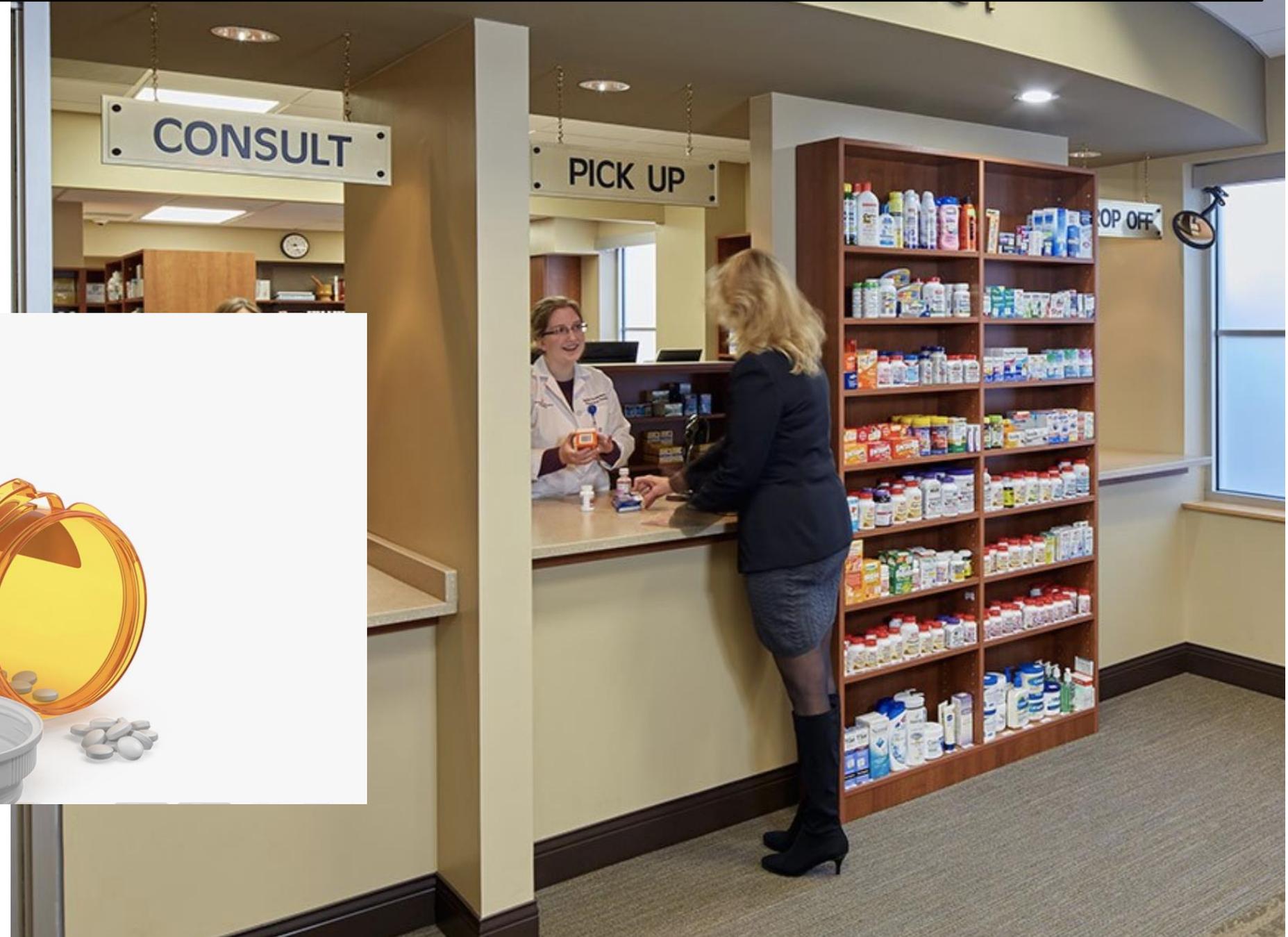


**New York City**



- White
- Black or African American
- American Indian and Alaska Native
- Asian
- Native Hawaiian and Other Pacific Islander
- Some Other Race
- Two or More Races

***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***



***My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc***



***My Third Lesson – The “Impossible” Can Be Changed  
When Patients Have A Voice***



# My Third Lesson – The “Impossible” Can Be Changed When Patients Have A Voice

## Featured Speakers



Sheila McGlown  
MBC Advocate



Dr. Lori Wilson  
Oncologist & MBC Advocate



Ricki Fairley  
Patient Advocate



YOUNG WOMEN'S METASTATIC BREAST CANCER DISPARITIES

# Fireside Chat

Together, we will end breast cancer disparities among young women of color in our lifetime.  
Join the conversation. Follow [@TigerlilyCares](#) and share using:

*#ListenUpMBC*

DECEMBER 10, 2019 | 7:30 - 11 AM CST  
LIVE FROM SAN ANTONIO BREAST CANCER SYMPOSIUM

PRESENTED IN PARTNERSHIP BY:

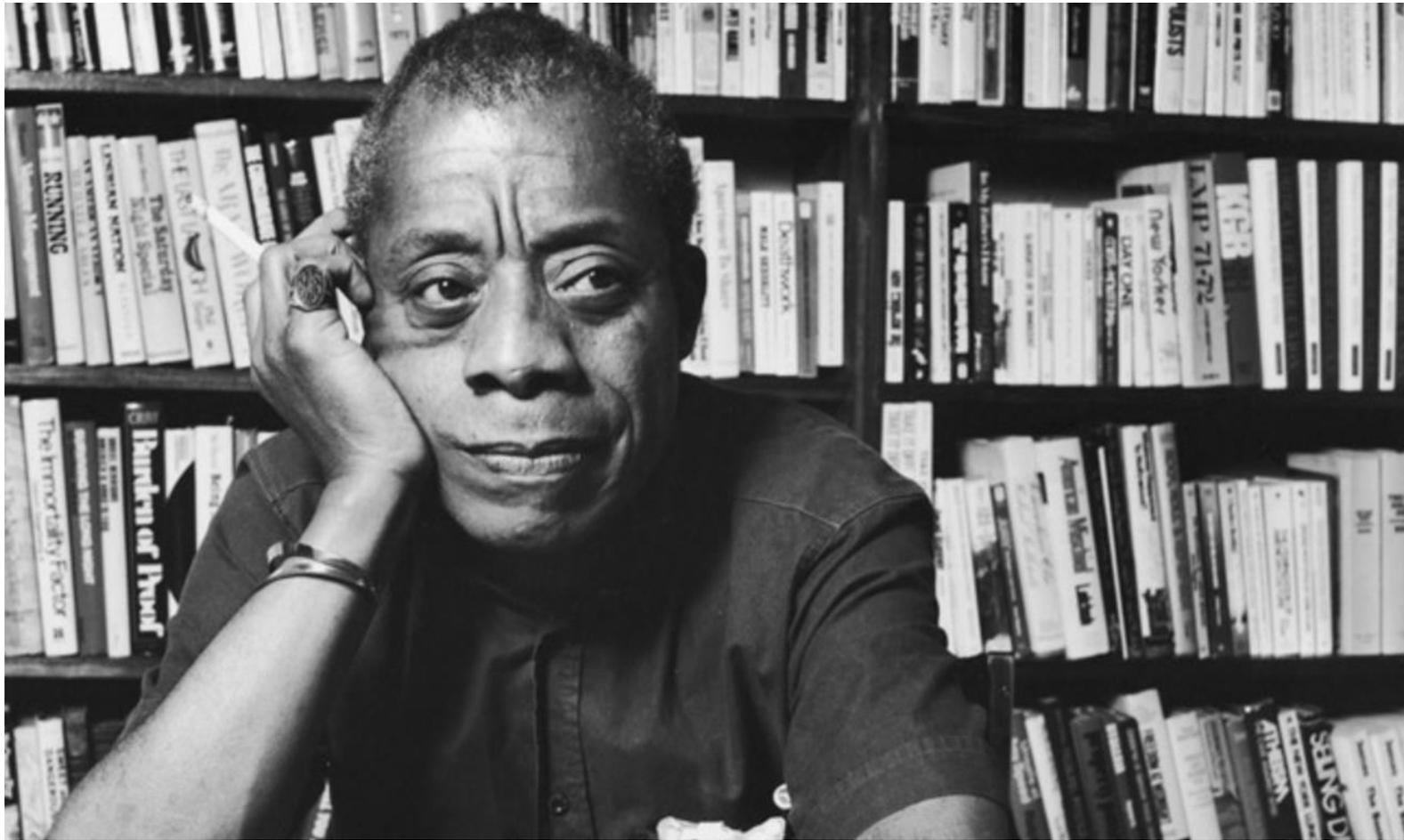




Still, it is a mistake to attribute African Americans' medical reluctance to simple fear generated by the Tuskegee Syphilis Study, because this study is not an aberration that single-handedly transformed African American perceptions of the health-care system. The study is part of a pattern of experimental abuse, and many African Americans understand it as such, because a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians.

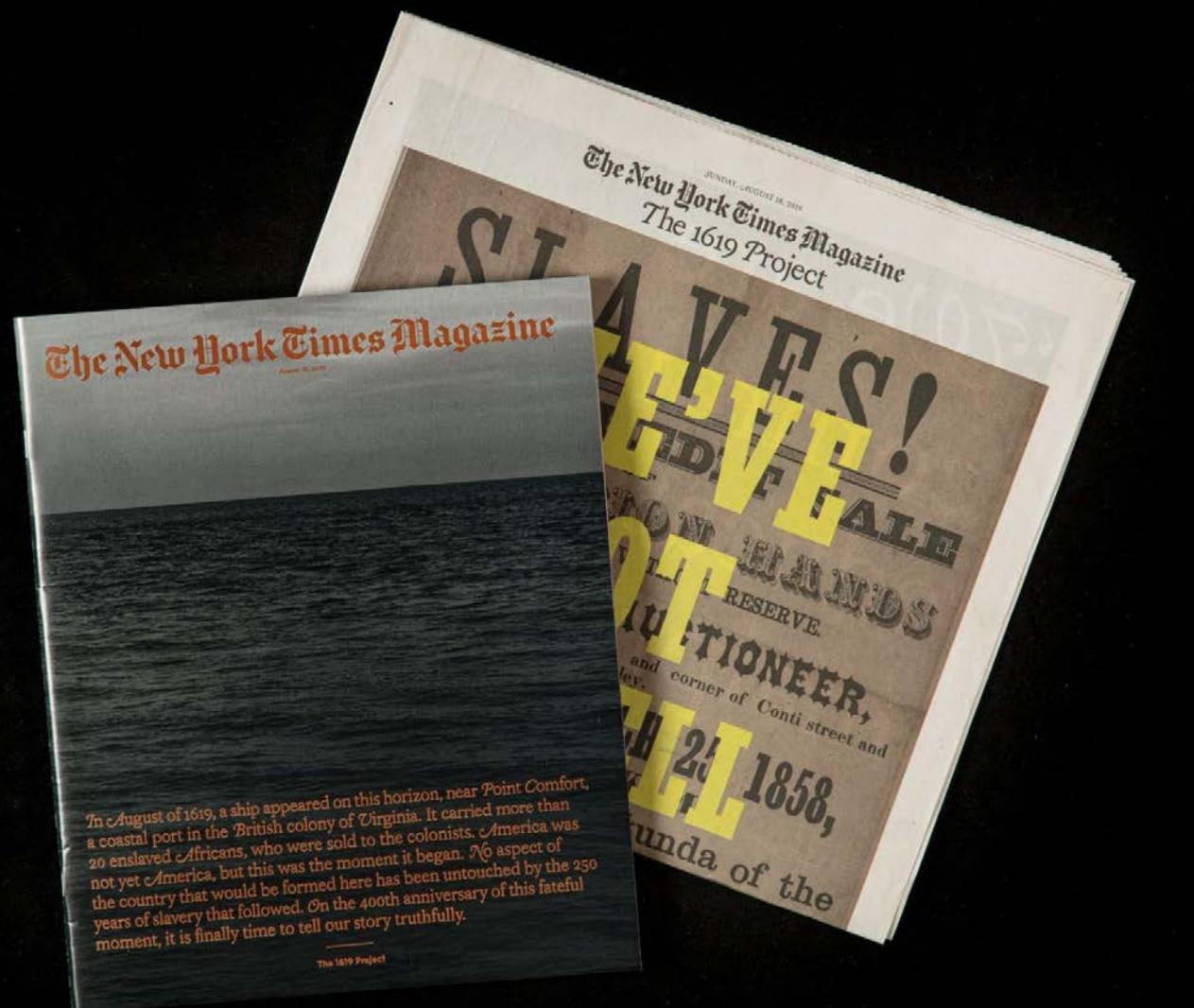
Washington, Harriet A.. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (p. 179). Knopf Doubleday Publishing Group. Kindle Edition.

**“Know from whence you came. If you know whence you came, there are absolutely no limitations to where you can go.” – James Baldwin**



## My Fourth Lesson – We Cannot Forget How We Got Here

# #1619Project

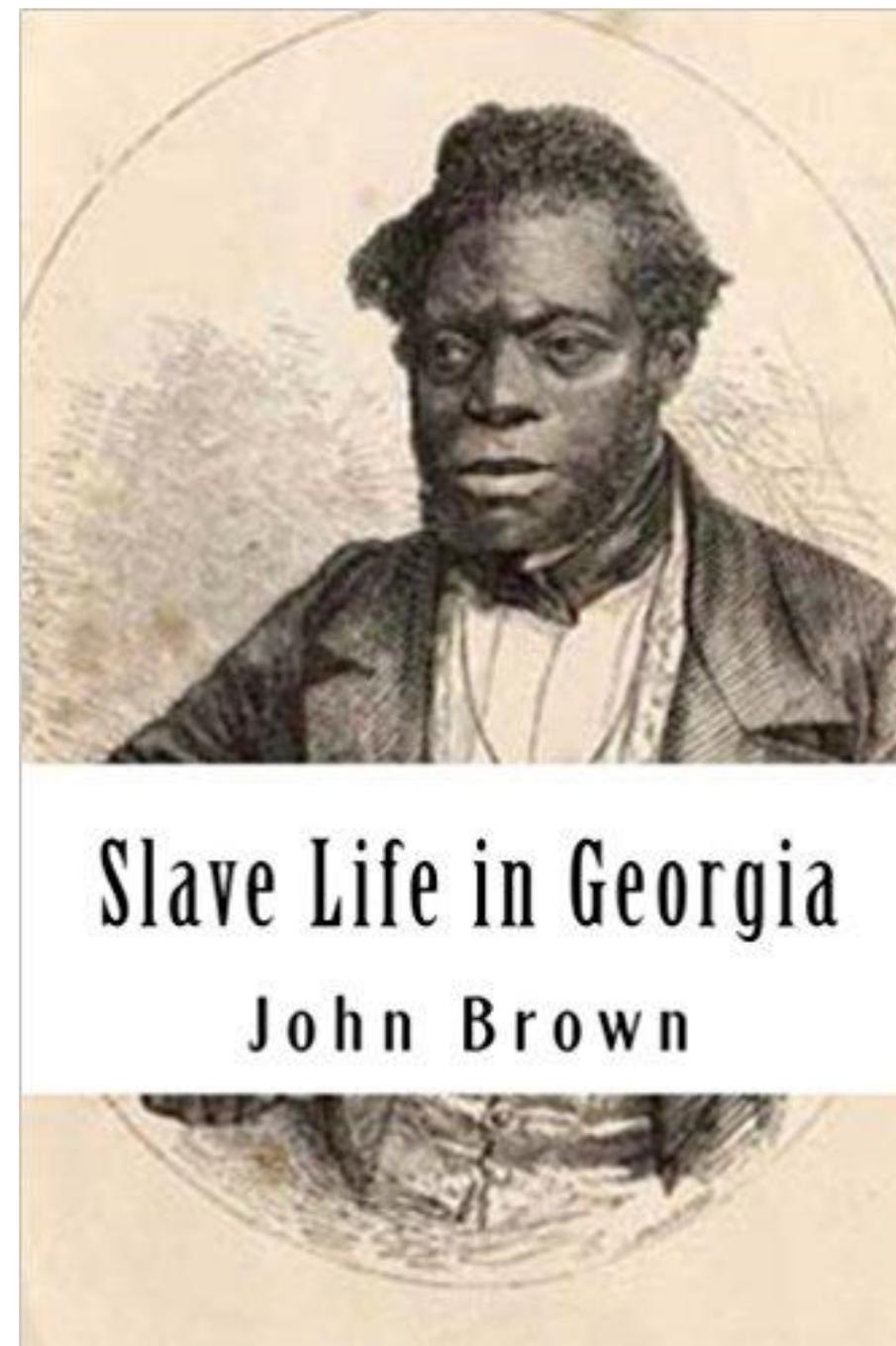


In August of 1619, a ship appeared on this horizon, near Point Comfort, a coastal port in the British colony of Virginia. It carried more than 20 enslaved Africans, who were sold to the colonists. No aspect of the country that would be formed here has been untouched by the years of slavery that followed. On the 400th anniversary of this fateful moment, it is finally time to tell our story truthfully.

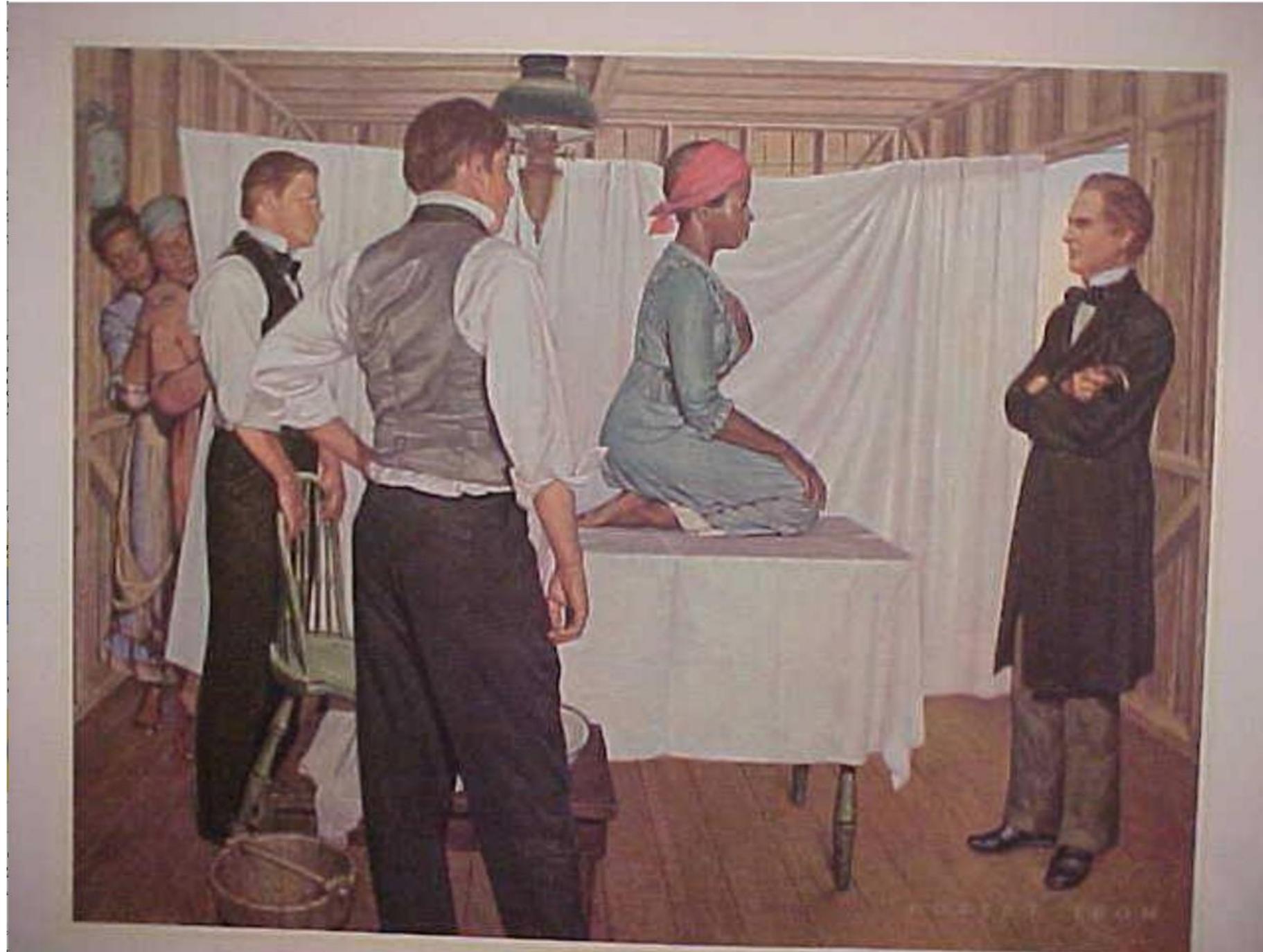
## ***My Fourth Lesson – We Cannot Forget How We Got Here***

“At the expiration of that time, [Dr. Thomas Hamilton] set to work to ascertain how deep my black skin went. This he did by applying blisters to my hands, legs and feet, which bear the scars to this day. He continued until he drew up the dark skin from between the upper and the under one.

He used to blister me at intervals of about two weeks. He also tried other experiments upon me, which I cannot dwell upon. Altogether, and from first to last, I was in his hands, under treatment, for about nine months, at the end of which period I had become so weak, that I was no longer able to work in the fields.”

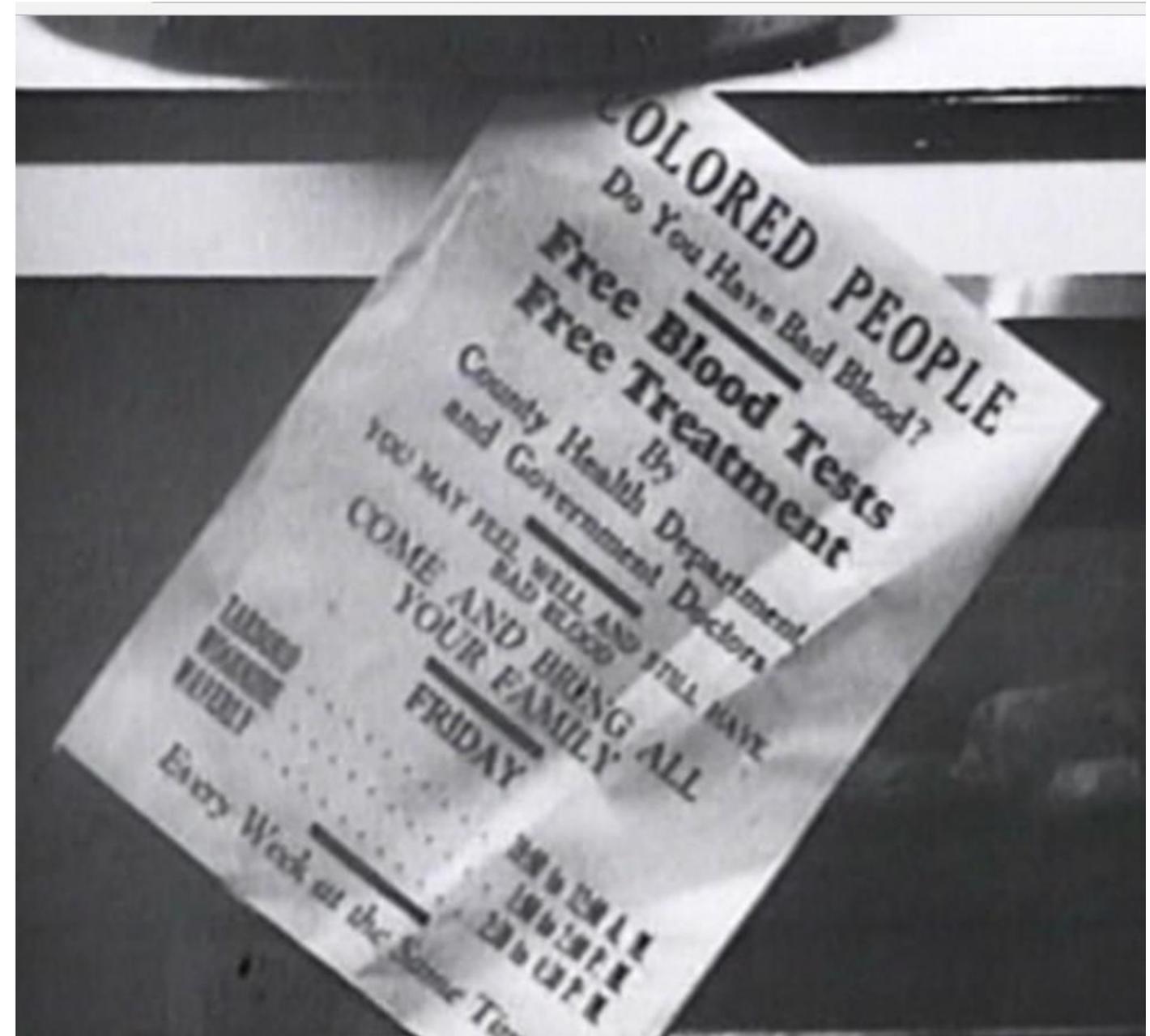


***My Fourth Lesson – We Cannot Forget How We Got Here***





# The Tuskegee Syphilis Study (1932-1972)



# *The Tuskegee Syphilis Study (1932-1972)*

[Peter Buxtun] learned of the study and immediately risked his job by writing his superiors to ask that it be stopped. A handful of PHS physicians responded by holding meetings, at which they lectured Buxtun on the scientific merits of their work and decided to continue the study.

In 1972, Buxtun, exasperated by seven years of PHS inaction, told a journalist friend about the study. On July 25 of that year, Jean Heller broke the story for the Associated Press.

The news media, physicians, politicians, and ordinary citizenry, black and white, expressed horrified anger and demanded an explanation from the government and some sort of assurance that such cruelty would never again be sanctioned by the PHS.

Washington, Harriet A.. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (p. 168). Knopf Doubleday Publishing Group. Kindle Edition.

## ***Syphilis Victims in U.S. Study Went Untreated for 40 Years***

By **JEAN HELLER**

The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the

# *The Moral Imperative Of Health Equity*

“Still, it is a mistake to attribute African Americans’ medical reluctance to simple fear generated by the Tuskegee Syphilis Study, because this study is not an aberration that single-handedly transformed African American perceptions of the health-care system. The study is part of a pattern of experimental abuse, and many African Americans understand it as such, because a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians.”

Washington, Harriet A.. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (p. 179). Knopf Doubleday Publishing Group. Kindle Edition.





# Collaborating to Accelerate Access to Innovations

Nikia Blakey

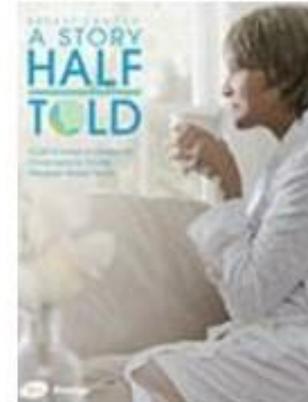
Angela (Jersi) Baker

Sheila McGlown

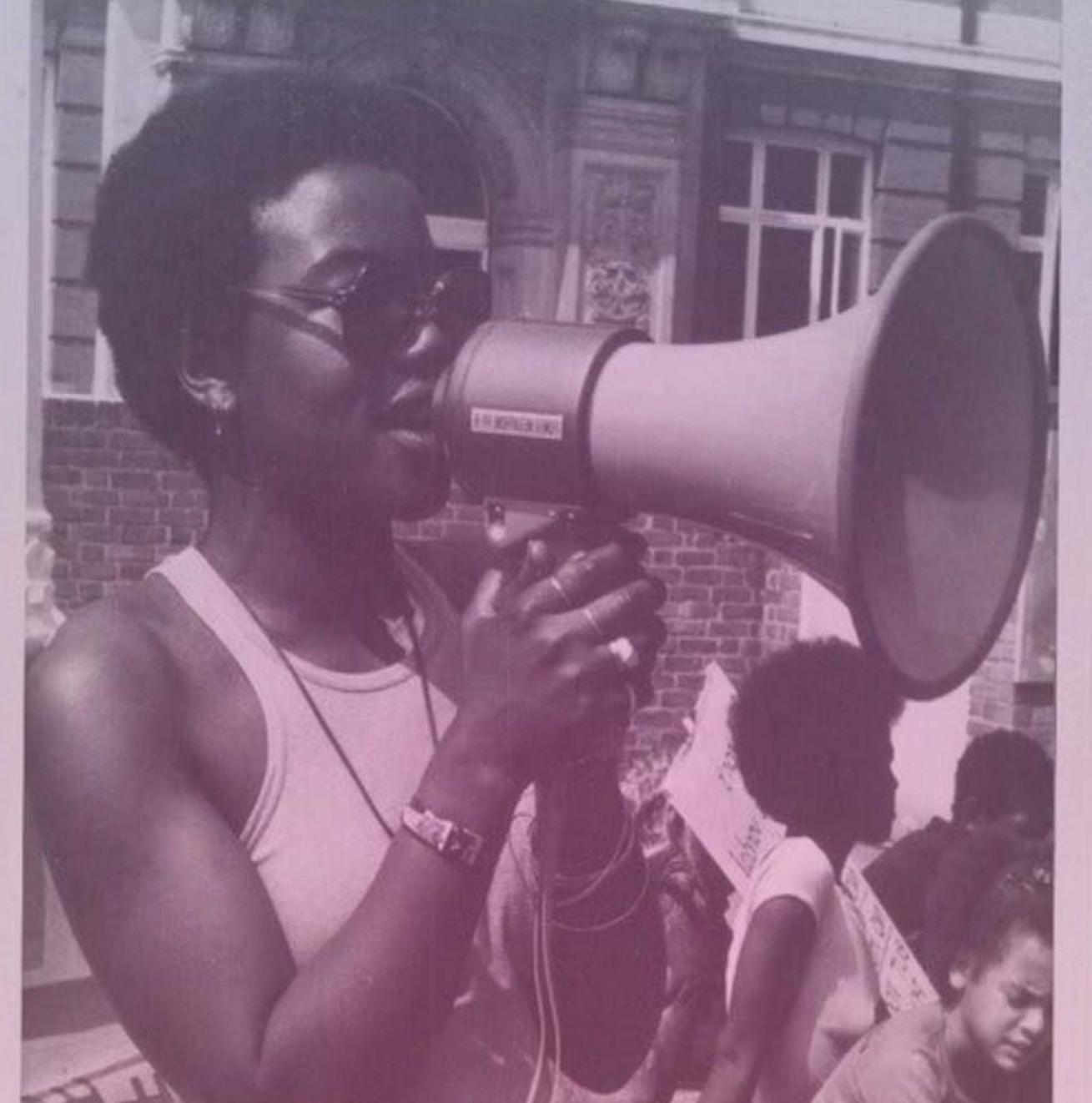
# Breast Cancer: A Story Half Told

*Breast Cancer: A Story Half Told is an initiative by Pfizer in partnership with advocates, patients and healthcare professionals that aims to elevate public understanding of metastatic breast cancer, dispel misperceptions, combat stigma and expand the breast cancer conversation to be more inclusive of metastatic breast cancer.*

- Empowers people with MBC to be **storytellers**, capturing their lives through photography,
- The initiative included diverse patients including **Khadijah Carter, an African American** female from New York, and **Esther Garza, a Hispanic** woman from Texas
- Resources also include statistics on **ethnic disparities and public perceptions**
- Since the initiative launch in 2014, the social media reach and website metrics (i.e. page views, visits) represent almost **29.7 million impressions**
  - In 2017, the program will launch its **first male MBC patient** to include men in the conversation



*"Additionally, most people believed breast cancer death rates are the same across various ethnic groups.<sup>9</sup> The reality is that while death rates are decreasing across ethnicities, five-year survival is much lower in certain ethnic groups than in the Caucasian population. African-American women with breast cancer are on average 40 percent more likely to die of the disease than white women with breast cancer. For Hispanic women, breast cancer is the leading cause of cancer death."*



# 1 Word. 1 Goal. 1 Voice.

Zora Asberry | Shyrea Thompson

## YOU

- 1 min: YOUR 1 word that describes the *culture of engaging metastatic young women of color in scientific conferences*

- 4 mins at table to each discuss YOUR 1 word.

## TABLE

- 3 mins - word that represents the entire TABLE.

## EVERYONE

- What can we do to shift this culture?
- Is the solution at this table?
- Do we need to invite someone else to this table?

## YOU

- 1 min: YOUR 1 word that describes the *culture of engaging metastatic young women of color in scientific conferences*
- 4 mins at your table to each discuss YOUR 1 word.

## TABLE

- 3 mins to pick the word that represents the entire TABLE.

## EVERYONE

- What can we do to shift this culture?
- Is the solution at this table?
- Do we need to invite someone else to this table?



Dr. Lori Wilson  
Howard University

**Fireside Keynote**  
**Coming to the Table Together: From Provider to Patient to MBC**  
**Advocate**



Don't Forget:  
Grab your mobile  
device of choice and  
return ready for the  
tweet-up!

**Break**

# We Are Ending Clinical Trial Disparities

Zora Asberry

Ms. Ricki Fairley

Dr. Virginia Kaklamani

Dr. Tatiana Prowell

Ms. Tiah Tomlin

**#TweetUpMBC**



**Tigerlily**  
Foundation

*Beauty. Strength. Transformation.*

Together we will end breast cancer disparities among young women of color in our lifetime.

Help amplify our message.

Follow **@TigerlilyCares** and share using:

**#ListenUpMBC**



## 3 ways to share your voice using #ListenUpMBC

- Take A Pic!: Share a photo of your group using #ListenUpMBC and your message
- Video/Boomerang / GIF: Share a quick video or loop of your group using #ListenUpMBC and your message
- Ah Ha Moment: Post, Share or Tweet your group's favorite thought, quote or moment from today using #ListenUpMBC

**#TweetUpMBC**

Zora Asberry | Shyrea Thompson



BLOG RESOURCES UPCOMING EVENTS ABOUT US CONTACT US SHOP SUPPORT

## OUR GUIDE TO BEING AN ACCOMPLICE

At For the Breast of Us, we exist to build community among and elevate the narratives of women of color affected by breast cancer. We exist so that we can thrive without accomplices. While an ally is someone who stands by your side, an accomplice actively participates in the perpetuation of the system that oppresses you.

We invite those who do not identify as women of color to be a #BreastCancerBaddie accomplice in our fight against breast cancer among women of color (WOC) and the health disparities they create.

Ready to Mobilize? Check Out the Accomplice Guide:  
[breastofus.com/our-accomplice-guide](https://breastofus.com/our-accomplice-guide)

# Mobilizing to End Young Women's MBC Disparities Together

Maimah S. Karmo  
Shonte Drakeford  
Christine Hodgdon  
Julia Maues  
Jasmine Soeurs  
Marissa Thomas



**Tigerlily**  
Foundation

*Beauty. Strength. Transformation.*

*#ListenUpMBC*

@tigerlilycares

ANGELS@TigerlilyFoundation.org

*Thank You!*