

CDC Advisory Committee for Breast Cancer in Young Women

Mental Health Workgroup



**THE MISSING PINK
BREAST CANCER ALLIANCE**
CONNECTING CHANGE AGENTS FOR COMMUNITIES OF COLOR

Tigerlily
Foundation
Beauty. Strength. Transformation.

Members

- Chair: Maimah Karmo, Tigerlily Foundation
- Co-Chair: TBD
- Members: Dr. Anne Blaes, Dr. Joan Blakey, Jasmine Souers,

Agenda

- **Discussion: Issues Identified**
- **Recommendations**
- **Next Steps**

Discussion: Issues Identified/Gaps

•Overlooked needs

- Perception of being a “warrior” can be shaming and isolating
- Shame around loss of life as we know it, body image, stolen dreams, fertility, letting others down
- Fear of recurrence can be debilitating and long-term
- Having to “suffer through” and be thankful
- Anger around cancer and issues like stolen fertility and future as it was planned
- For advocates – it becomes their entire life and there is extreme amounts of pressure to go nonstop – not healthy and people should not be shamed or feel isolated if they just want to live

•Children

- Fear of parent’s re-diagnosis, particularly a single parent
- Anxiety about life that shapes the child’s life
- All they hear about is cancer/death
- Feel guilty and don’t want to make it about them, or be a further burden by sharing their feelings
- They feel like their feelings are less significant than what their parents are going through
- There is an opportunity to provide therapeutic support and a space to be authentic and vulnerable and coach both – together or separately
- Need to provide age-appropriate support – to child, and/or with family, caregivers and peers

Discussion: Issues Identified/Gaps

- BIPOC populations – stress of reliving trauma around our healthcare and racism and demands on this community, with so much focus on reliving trauma around being Black/Brown, in addition to the everyday pressures of living in our bodies and how the world sees us
- LGBTQAI populations – navigating stigma

- What does “whole person healing” look like?
- Needs more focus on identity, grief, abandonment, relationships, etc.
- With breast cancer, especially metastatic, TNBC and BIPOC populations – the added trauma and long-term stressors – forever a patient at risk/fear/stress/vigilance
- Handling the weight of cancer and how it disrupts life
- Menopause, PMS, lack of choice around certain issues – losing self

- Opportunities
 - What does the current mental health space look like for patients, caregivers, children
 - What can the future look like

Recommendations

- **Conduct a gap analysis cross matrixed with identified needs/services (member, community and open source)**
- **What is currently available**
- **Identifying mental health experts in the field that can support this work**
- **Potential solutions**
 - **Educational content**
 - **Listening sessions/tour**
 - **Campaign on Candid Conversations / Vulnerability (OpEds, Media, Video, Social Media)**
 - **Insurance**
 - **Policy**

Next Steps

- **Build committee**
- **Firm goals and objectives/charter**
- **Develop project plan and timeline**
- **Schedule next meeting/set up cadence**