Session 3

Pharma and Patient Advocacy
Collaboration: Strengthening
Best Practices
Maimah Karmo

The Advocate Perspective: The Truth About Diversity and Clinical Trials

black-women-speak.org
The Advocate Perspective: Diversity and Clinical Trials – From Admiring to Action

Maimah Karmo
CEO/President, Tigerlily Foundation

December 5, 2022

Tigerlily Foundation
We Must Move from Admiring the Problem to Ignite Action for Inclusive Clinical Trials

**Barriers**

- Distrust
- Logistics
- Access
- Fear
- Financial
- Employment issues
- Mental health
- Sexual health
- Co-morbidity issues
- Interests of people of childbearing age
- HCP is unaware of trials

- Stigma
- Patients diagnosed too late to qualify
- Rigid inclusion/exclusion criteria
- Health literacy
- Culturally / linguistically sensitive patient education about clinical trials
- Address patient concerns
- Patients’ rights and risks
- Implicit/Explicit bias

**Opportunities**

- Build trusted partnerships with People before they are patients
- Embedded CBO, FBO engagement and trusted BIPOC providers
- Authentic patient engagement with all clinical trial stakeholders
- Community input for all phases of drug development
- Provide opportunities for learning more about clinical Trials, where the trials are located and the hope that they bring to people and communities
- Educate HCPs on clinical trials and their benefits
- Build Centers of Excellence at Community and Local Health Centers for diagnosis, biomarker testing and treatment
- Policy commitments and accountability
Partnering to Address Barriers

Partner with all Stakeholders, including Sponsors, Sites, Systems & Contract Research Organizations (CROs)

Sponsor Engagements

Let us Lead. Engage patient every step of the way as leader/driver within the clinical trial ecosystem for BIPOC patients to support inclusive clinical trials (and research in general)

The Patient is the Customer. Design around our needs and deliver a memorable consumer experience (Think Nordstrom, Amazon, Walmart, Uber)

CRO/Site Engagements

Accelerate inclusive best site practices and drive convenings of clinical trial site leaders in BIPOC communities, health systems and cancer centers working with CROs, sponsors, CBOS/FBOs, Oncology Nurse Organizations and other stakeholders

Stand up sites for sustainability and success

Deliberately address Barriers to clinical trials and SDOH with BIPOC patients. Implement solutions to address structural barriers in specific geo-targeted geo locations – 20 cities

Policy Change

Advocate for policy change – invest, pilot test, replicate on state and national level.
Tigerlily’s Evolving Mission

To educate and empower women to be advocates for their health

To partner with communities, Sponsors and healthcare entities to reduce barriers and create a more inclusive clinical research ecosystem

To lead and build a pragmatic advocacy framework that includes women in all communities to represent breast cancer and clinical trial participation

December 5, 2022, SABCS
Tigerlily Foundation is working with stakeholders to engage patients at every intersection throughout the clinical trial journey.
Tigerlily Foundation’s Roar for Inclusive Clinical Trials

TLF Action for inclusive clinical trials by the numbers

28 Initiatives in Action

12 Initiatives in Active Planning

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TLF's Roar for Inclusive Clinical Trials

Goal:
To dismantle barriers by driving transparency, brokering authentic partnerships, exposing and replicating best practices in the clinical trial ecosystem.

To foster trust and increase access to clinical trials for those individuals most in need ---to ensure the representation of BIPOC communities in clinical trials.

Our Strategy has four major themes or pillars:

- People - Multiply
- Capacity Building
- Multi-stakeholder Best Practices
- Policy
TLF Actions by Strategic Theme - “The Roar”

- Training Black patients/advocates in 20 cities on Clinical Trials
  - Healthcare is self care
- Trusted Angel engagement and navigation with BIPOC patients and caregivers with focus on 21 High risk metro areas/regions
- 5 Pilot Cities with ANGEL Leads

The People

- Community + Events: 44
- People: 29k
- Community Partners: 82
- Through Social Media: 151k
- Video Impressions: 5M+
TLF Actions by Strategic Theme- “The Roar”

Capacity Building
TLF Actions by Strategic Theme- “The Roar”

The Multi-Stakeholder Best Practices
The Policy

• Worked with FDA on diversity plan inputs
• Working with sponsors on diversity plans
• Engage with NCI Cancer Center Outreach Leaders and nationalize alignment with FDA guidance
• The Diverse Act-Letter writing campaign with BIPOC patients supporting clinical trial and health equity initiatives
• Federal and State Level Policy Partnerships
“Alone we can do so little; together we can do so much.”

- Helen Keller

We must move past the past and create a present that leads to a better future.

– Maimah Karmo
GET IN TOUCH WITH US

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