

# Closing the Equity Gap: Trailblazing Initiative Holds Cancer Centers Accountable and Empowers Minority Women to Navigate and Advocate for Better Cancer Care

## The Chrysalis Initiative Furthers CTTI's 'Transforming Trials 2030' Vision

### SUMMARY

A community activist motivated by personal experience formed [The Chrysalis Initiative](#) in 2019 to disrupt outcome disparities within breast cancer so all patients receive the care they deserve, regardless of race. Its founder, who sits on CTTI's Steering Committee, furthered CTTI's work by developing evidence-based strategies that reshape the individual and institutional knowledge, attitudes, and behaviors that impact health outcomes for Black women and other women of color (WOC) with breast cancer.

### GOAL(S)

When it comes to Black women and cancer, the data tell a compelling and concerning story. Black women are 40 percent more likely than the rest of the population to face mortality from breast cancer, a phenomenon that is often attributed to social determinants of health such as income or education levels or lack of health insurance. But evidence doesn't back up this assumption. In fact, Black women have a lower cancer incidence rate compared to White women, and racial disparities are most pronounced among Black women of high socioeconomic status. Black women actually seek care and diagnosis at a younger age than their White counterparts, and yet their care is often delayed, incomplete, or otherwise substandard.

These findings force us to consider an uncomfortable truth: that the problem lies primarily with explicit and implicit (conscious and unconscious) bias in the healthcare system, resulting in a kind of structural racism in cancer care institutions – a challenge that isn't helped by the fact that only 2 percent of oncologists are Black. In a systemically inequitable healthcare system, Black women are often dismissed and ignored, and are treated with prejudices that keep them from receiving the proper standard of care. Led by its founder, The Chrysalis Initiative addresses these disparities with innovative interventions, in pursuit of the goal of ensuring all patients receive the care they deserve.

### CHALLENGES

The Chrysalis Initiative had a humble but determined start. It began with just one individual, a 39-year-old Black mother of three who discovered that she had stage 4 metastatic breast cancer. The determination to overcome shock and to fight and survive for her family launched her into vigorous exploration of what she was up against. In making herself fully knowledgeable about her health challenge, she realized how many questions other WOC had about their care. Many of these women also weren't benefiting from a full set of options offered and were then falling short of the self-advocacy they needed. It became clear to her that coaching and navigation could overcome this problem. She needed a process to engage these patients with mentoring, counseling, and resource direction that would equip them with the tools to secure better care. She also needed to align with groups similarly invested in equitable care who could help make her initiative an influential, trusted force in cancer care.

### SOLUTION(S)

The vision for The Chrysalis Initiative could not thrive in a "business as usual" research environment, particularly with its special emphasis on directing WOC to clinical trials. It depended on generating a new paradigm across multiple aspects of the clinical research process, several of which CTTI has outlined in its [Transforming Trials 2030](#) vision and its [commitment to diversity in trials](#). Specifically, The Chrysalis Initiative sought to improve equity through patient-centered, easily accessible research; deeper integration of research in everyday health processes; and furthering research that contributes important knowledge to all patient groups. With its focus on simplifying and communicating criteria for recruitment and steps to enrollment, along with matching its individual patients to trials per their clinical status, Chrysalis was pursuing missing pieces to minority patient participation in research. Noting the alignment of goals, CTTI reached out to The Chrysalis Initiative for perspective on bringing diversity to clinical trials, sparking a fruitful relationship for both parties.

### TAKING ACTION

The founder of The Chrysalis Initiative is advancing CTTI objectives with a program that connects minority communities to resources that will improve their knowledge and ensure standards-adherent care. Chrysalis approached the challenge from several angles:

1) **Patient support** – Patient-centered cancer care requires support systems to address the unique needs of *all* patients. That's why The Chrysalis Initiative invites newly diagnosed patients to participate in one-on-one coaching to help them feel confident and in charge of their cancer journey. Coaching addresses challenges specific to WOC with cancer that are often not understood or that are overlooked entirely by cancer providers. For example, side effects of cancer treatments manifest differently in Black women than in other races and hair loss from chemotherapy often carries a unique emotional burden in these groups. WOC are also less likely to be offered genetic testing. To further close these gaps, patients are invited to use the [BC NAVI app](#), a mobile-phone and desktop platform that provides educational support to patients with breast cancer through training modules, webinars, videos, events, links to helpful websites, and more. The app helps to track patient progress and gather data on problems and successes.

2) **Connecting patients with relevant trials** – Black patients account for [just 5 percent of clinical trial participants](#) in the United States, while African Americans account for more than 12 percent of the country's general population. This disproportion leaves blind spots in research results and drives potential distrust of the resulting healthcare among these communities. Ensuring research contributes knowledge to the full diversity of patient groups means bringing more Black and other disparate groups into the research fold. Although the traditional narrative is that Black participants inherently distrust research, opportunities to participate are also not presented equitably to Black and other underrepresented patients.

The Chrysalis Initiative counters this by serving as a trusted voice to meaningfully connect research opportunities with patients who may benefit. It is not about simply steering Black patients to trials to increase diversity generally, but rather investing time to ensure matches are specific to the patient's cancer profile and history, thus increasing the odds of treatment success. The organization also focuses on communicating the tremendous opportunity research can offer Black and other disparate groups of patients. "Research participation shouldn't be considered a last resort, but rather as a VIP opportunity to access innovative therapies that are not yet on market," said Chrysalis' founder. "When Black women participate in research, we not only unlock potential opportunities for success in our own treatment but also for millions of other Black women seeking insights on new treatments who need to see themselves reflected in the research. We deserve to be represented."

**3) Accountability at cancer care centers** – To better integrate research into the everyday health processes of Black and other underserved cancer communities, cancer care centers must acknowledge the need for change. The Chrysalis Initiative founder stresses that most cancer centers are well intentioned, but simply aren't aware of the bias that creeps into their practices. So how can providers ensure their cancer care delivery system is equitable, not only by intention, but in demonstrated impact? To answer this challenge, the Initiative designed an [Equity Assessment, Tools and Improvement Plan](#), which provides an evidence-based system-wide audit that brings about intervention and training for cancer centers and other organizations. When Chrysalis reports on how a care group performed in its assessment, it uses indisputable data to illustrate inequity. For example, the report may note significantly higher percentages of White women being referred for additional radiologic imaging than Black women with a similar clinical profile. Through post-assessment training and discussion, the process probes these kinds of disparities and invites the organization to consider its practices, working collaboratively and cooperatively with provider and administrative staff.

"Most organizations are surprised at the results of the assessment, but welcome our advice for how to improve," said Chrysalis' founder. "Once persistent patterns of treatment and diagnosis are highlighted in no uncertain terms and with data, they are often grateful for the knowledge and eager to hear our guidance on how to remedy any inequity."

## **IMPACT**

Three years later, The Chrysalis Initiative has blossomed into a highly respected nonprofit with 20 equity associates and 180 coaches. Its founder has testified to the FDA in order to connect more women with resources for screenings, treatment, and support. She has been featured in *People Magazine*, the *Philadelphia Inquirer*, the *Philadelphia Tribune*; participated in national campaigns for Anthropologie, Novartis, Pfizer and Cancer and Careers; and was invited to speak as a guest on *CBS News* and *Good Morning America*. The Initiative's Equity Assessment Tool has been deployed in more than a dozen hospital/health systems and demand is growing from more organizations.

## **ADVICE**

The founder of The Chrysalis Initiative is thrilled with how her nonprofit has developed, but knows there is still a great distance to travel toward equitable care. Given that 100 percent of participating hospital systems that took the Equity Assessment so far have found areas for improvement, she believes the tool should be standard for health systems in America.

"We are at an important turning point for health equity today, where there is finally an open acknowledgement of the systemic bias that pervades our healthcare interactions and a willingness to change," she said. "The interest and support is exploding, and we want to put it into action to fully meet this moment — and thereby make evidence-based accountability for equitable care and research part of the healthcare mainstream."

## **ORGANIZATION**

The Chrysalis Initiative

## **CONTACT**

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## **ORGANIZATION TYPE**

Patient

## **IMPLEMENTATION DATE**

2019

## **TOPIC**

Clinical Trials Transformation

## **RELATED CTTI PROJECT**

[Transforming Trials 2030](#)

## **CTTI RESOURCES**

[Transforming Trials 2030 Vision](#)