Triple-negative breast cancer nearly killed me. We need to fight back.

The subtype is of extra concern for young and minority women

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I’ve been shot at, struck by lightning, and fled a war-torn country, but my breast cancer journey is still one of the hardest things I have lived through.

At 31, I felt a lump in my breast and knew right away it did not belong there. Yet I was denied the necessary testing for breast cancer because the doctor said I was “too young” and that I should come back when I was in my 40s. After relentlessly calling the doctor for six months, I eventually had a biopsy. I was diagnosed with triple-negative breast cancer, or TNBC, the next day. Had I waited longer, it’s likely that I wouldn’t be alive today.
Instead, I’d be part of the stunning statistics. Breast cancer kills nearly 44,000 people in the U.S. each year, and a staggering 685,000 around the world.

In the U.S., breast cancer disproportionately affects women of color like me. TNBC accounts for up to 20 percent of new breast cancers, and it’s of particular concern for these young and minority women.

TNBC is hard to treat, is often diagnosed at later stages and is more likely to spread to other parts of the body than other types of breast cancer. According to the American Cancer Society, individuals diagnosed with metastatic TNBC have just a 12 percent chance of surviving longer than five years, and there is a higher chance of it recurring compared to other types of breast cancer.

It is relentless. And so must we be to address and overcome TNBC.

One of the most difficult hurdles is that we don’t know much about TNBC. The name of the subtype itself speaks to that. We call it “triple-negative” because it lacks these three known designations of breast cancer: The cancer cells don’t have estrogen or progesterone receptors, and they make too little or none of the HER2 protein. As the cancer cells don’t have these proteins, hormone therapy and drugs that target HER2 are not effective, so chemotherapy is still the main systemic treatment option.

We also don’t know why more young, Black and Hispanic women are diagnosed with TNBC.

Black women are three times as likely as white women to be diagnosed with TNBC and have the lowest survival rate at each stage of diagnosis. Why is this?

Hispanic women are also diagnosed with the triple-negative subtype more often and have a higher risk of mortality from it than non-Hispanic white women. Why?

TNBC is more common in young women, and those diagnosed with breast cancer under the age of 40 are twice as likely to have TNBC as those between the ages of 50 and 64. Why?
We need answers to these questions. Despite this massive threat, there is still a lack of consensus and clear direction in breast cancer screening guidelines for younger people and those at higher risk of TNBC.

The Tigerlily Foundation I founded strongly supports the pending Triple-Negative Breast Cancer Research and Education Act of 2023. Sponsored by Houston Rep. Sheila Jackson Lee, it aims to fund sorely needed research and education on TNBC.

It will go a long way toward saving lives like mine.

Maimah Karmo is founder and CEO of Tigerlily Foundation, which supports women ages 15 to 45 before, during and after breast cancer.