METAVIVOR
Metastatic Breast Cancer
Research, Support & Advocacy

Stampede Hill Day Meeting Talking Points

1. Introduction (METAvivor Advocate)
"Hi, my name is [Name], and I'm a [metastatic breast cancer patient / family member of someone living with MBC] from [City/State]."

"I'm here today with METAvivor, an organization dedicated to supporting and advocating for the MBC community. I want to share why urgent policy changes are needed to improve access to treatment for those of us living with this disease."

2. Why We're Here (Advocate Talking Points)
"Metastatic breast cancer is stage IV breast cancer that has spread from the breast to other parts of the body. While treatable, it is not curable. People with MBC face unique challenges in accessing timely, affordable, and effective treatment."

- An estimated 168,000 women in the U.S. are currently living with metastatic breast cancer. (Source: Metastatic Breast Cancer Explained: Symptoms, Diagnosis & More)
- This year, 42,170 women will die from metastatic breast cancer, that is 115 women per day. (Sources: Stop the Clock! - National Breast Cancer Coalition)
- This year, approximately 2,800 men will be diagnosed with breast cancer and approximately 510 men will die from the disease. (Sources: American Cancer Society and National Breast Cancer Coalition (Stop The Clock).
- Approximately 85% of those diagnosed with MBC previously had an early-stage breast cancer diagnosis. (Source: Metastatic Breast Cancer Explained: Symptoms, Diagnosis & More)
- Nearly 30% of women initially diagnosed with early-stage breast cancer will ultimately develop metastatic disease, although most early-stage patients do not progress to MBC. (Source: Metastatic Breast Cancer Explained: Symptoms, Diagnosis & More)

"We're here today to talk about four key federal policy issues that directly impact the lives of people with MBC across the country:"

- **The Metastatic Breast Cancer Access to Care Act (H.R.2048, seeking reintroduction in the Senate):**
  "This bipartisan bill would waive the 5-month waiting period for Social Security Disability Insurance (SSDI) and the 24-month waiting period for Medicare for people

with MBC. Time is not on our side, people with MBC need immediate access to treatment and coverage when they are diagnosed."

- **The Cancer Drug Parity Act (H.R.4101, seeking reintroduction in the Senate):** "This bill would require that out-of-pocket cost for oral cancer medications be the same as intravenous treatments. Many people with MBC rely on oral therapies to manage their disease, but without parity of pricing, the out-of-pocket costs for oral medicines can be unmanageable, even with insurance."

- **Concerns with the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry Database:**
  The SEER cancer registry is a national cancer database that tracks cancer diagnoses and deaths across the U.S. It's meant to help researchers, policymakers, and public health officials understand the burden of cancer which then guides funding and care decisions.

  But SEER has some serious gaps when it comes to metastatic breast cancer. First, it only counts patients who are diagnosed with Stage IV MBC right at the start—what we call de novo metastatic breast cancer. It does not track people whose early-stage breast cancer later spreads to other parts of the body, which is actually the vast majority of MBC cases. Only about 6 to 10 percent of MBC patients are de novo, so most MBC patients are completely missing from the data.

  Additionally, the SEER collects and publishes cancer incidence and survival data from population-based registries covering 45.9% of the U.S population, meaning more than half of Americans aren't represented in the data. Broadening this cancer surveillance system to include additional registries covering more of the population would greatly enhance the quality of data and enhance the research that it informs.

  Without accurate, complete data, it's much harder to track outcomes, understand where gaps in care exist, or allocate research dollars effectively. Modernizing SEER to capture all MBC cases and their outcomes would be a critical step toward better research, better policies, and ultimately, better care for patients."

- **Increasing Federal Research Funding for Metastatic Breast Cancer:**

  "Metastatic breast cancer research is severely underfunded, even though almost all breast cancer deaths are due to Stage IV disease. Right now, only about 13 percent of all breast cancer research dollars go toward metastatic breast cancer, and we still don't fully understand why some cancers spread or how to stop them.

Investing in research is the only way to develop effective treatments, improve survival, and give patients more time with their families. Through increasing funding for the National Institutes of Health, the Department of Defense Peer-Reviewed Breast Cancer Research Program, and ARPA-H, it will allow more research focused specifically on metastatic breast cancer. This research can improve both the length and quality of life for patients and accelerate life-saving advancements for the MBC community."

3. Personal Story (Advocate)

"I'd like to share a bit about my own experience."

[Advocate(s) briefly shares a personal story related to one of the above issues—delayed access to SSDI benefits or Medicare, high oral drug costs, struggles with data access, or the need for increased funding for MBC research.]

4. Policy Asks (State Champion)

"We're asking for your office's support in addressing these issues:"

- **FOR THE HOUSE:Cosponsor the Metastatic Breast Cancer Access to Care Act (H.R. 2048)** to eliminate harmful delays in access to Medicare and SSDI.
- **FOR THE HOUSE: Cosponsor the Cancer Drug Parity Act of 2025 (H.R. 4101)** to ensure affordable access to oral cancer treatments.
- **FOR THE SENATE: Supporting the reintroduction of the Metastatic Breast Cancer Access to Care Act in the Senate** to eliminate harmful delays in access to Medicare and SSDI.
- **FOR THE SENATE: Supporting the reintroduction of the Cancer Drug Parity Act in the Senate** to ensure affordable access to oral cancer treatments.
- **Supporting the modernization of cancer surveillance systems like SEER** to ensure that all MBC cases are counted and to help guide funding for research and treatments for MBC**.**.
- **Increase funding for metastatic breast cancer research by:**
    - Funding the National Institutes of Health (NIH) at at least $51 billion
    - Funding the Advanced Research Projects Agency for Health (ARPA-H) at $1.5 billion
    - Restoring at $150 million in funding for the Department of Defense Peer-Reviewed Breast Cancer Research Program, and continuing to include "metastatic cancers" as a condition eligible for study through the Peer-Reviewed Cancer Research Program

CLOSING:

“ Thank you for taking the time to meet with us today. These changes are essential for our survival. In the United States, a woman dies from metastatic breast cancer every 13 minutes. That means that while we have been speaking today, two women lost their lives. We cannot afford to wait. Every day of inaction costs lives, and every step Congress takes toward change brings hope to families like mine. This is why it is so urgent for Congress to act now because not addressing these issues means more lives cut short.”