



METAVIVOR

Metastatic Breast Cancer
Research, Support & Advocacy

Metastatic Breast Cancer Access to Care Act (H.R. 2048)

REQUEST

METAvivor urges members of Congress to co-sponsor and support the bipartisan Metastatic Breast Cancer Access to Care Act (H.R. 2048).

WHY WE'RE HERE

Metastatic breast cancer (MBC) is stage IV breast cancer where the tumors have spread beyond 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 MBC, and 2,800 men will be diagnosed with breast cancer in 2025.
- 42,170 women and 510 men will die from MBC this year.
- About 1 in 4 patients with early-stage breast cancer will develop MBC
- Only 32% of people diagnosed with MBC live longer than 5 years.

BACKGROUND

The Metastatic Breast Cancer Access to Care Act would eliminate arbitrary waiting periods for Social Security Disability Insurance (SSDI) benefits and Medicare coverage for those with metastatic breast cancer.

Under current law, there is a five month waiting period between when a person with MBC applies for Social Security Disability benefits and when they begin receiving those payments.

Also, that person must then wait an additional 24 months after disability benefits begin before they are able to receive Medicare insurance coverage.

This delay creates obvious hardships for people with metastatic breast cancer as they struggle to navigate care and pay medical expenses.

Because Stage IV MBC patients live, on average, 18–36 months after diagnosis, this delay also means many people with MBC may not live long enough to receive benefits from the system they have paid into and for which they are fully eligible. Only 32% of women and 19% of men survive 5 years post-diagnosis.

Nearly 30,000 Americans die annually waiting for Social Security Disability Insurance and Medicare benefits.

We urge you to support the *Metastatic Breast Cancer Access to Care Act (H.R. 2048)* to ensure that Americans living with MBC can access the disability and Medicare benefits they have earned without delays that too often surpass their lives.

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Cancer Drug Parity Act of 2025 (H.R. 4101)

REQUEST

METAvivor urges members of Congress to co-sponsor and support the bipartisan Cancer Drug Parity Act (H.R.4101).

Oral Parity is especially important as oral chemotherapy is becoming a common standard of care for cancer patients and many of these oral chemotherapy drugs do not have IV/injectable equivalents.

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BACKGROUND

Oral oncology drugs offer patients a more convenient, less invasive alternative to IV chemotherapy, but they often carry much higher out-of-pocket costs due to insurance coverage differences. IV treatments are usually covered under a plan's medical

benefit, while oral drugs fall under the prescription benefit. This creates a cost disparity.

To address this, 43 states and D.C. have enacted "oral parity" laws, but patients in federally regulated plans remain unprotected.

The Cancer Drug Parity Act would provide equal coverage for all cancer patients—regardless of how their treatments are administered—ensuring that medication cost is not a factor in physician and patient decisions.

Specifically, the bill will:

- Expand oral parity protections to privately insured patients whose health care is regulated at the federal level.
- Prevent insurers from covering oral and self-administered medicines at different cost-sharing rates than IV chemotherapy.
- Implement these requirements for health plans that already cover both oral and IV chemotherapy treatments.

No patient should face higher costs simply because their life-saving cancer treatment comes in a pill instead of an IV.

By passing the Cancer Drug Parity Act, Congress can ensure fairness in coverage, protect patients from financial hardship, and allow treatment decisions to be guided by medical need, not insurance rules. Act now to give cancer patients the access to care they deserve.

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Increasing Research Funding for Metastatic Breast Cancer

REQUEST

METAvivor urges Congress to:

- Provide the **National Institute of Health (NIH) with at least \$51 billion in funding for Fiscal Year (FY) 2026.**
- Fund **Advanced Research Projects Agency for Health (ARPA-H) with \$1.5 billion for FY 2026.**
- Restore **\$150 million in funding for the Department of Defense Peer-Reviewed Breast Cancer Research Program** within the Congressionally Directed Medical Research Programs, and continue to include “metastatic cancers” as a condition eligible for study through the Program.

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- Only 32% of people diagnosed with MBC live longer than 5 years.

MEETING AN URGENT NEED

Every 12 to 13 minutes someone in the United States dies from breast cancer.

Almost all breast cancer deaths are from Stage IV or metastatic breast cancer. Science has very few answers to the reason why cancer metastasizes, and we don't yet have an effective treatment to permanently arrest metastatic growth.

The biggest obstacle is lack of funding: from 2014 to 2020, only 13% of all breast cancer research dollars were devoted to MBC research.

In 2025, it is estimated there will be over **316,000 Americans diagnosed with breast cancer**. Only about 6% of these diagnoses are Stage 4 MBC *at the time of diagnosis*.

An estimated 30% of all people diagnosed with early-stage breast cancer will eventually go on to develop metastatic breast cancer.

Scientists know that research specifically focused on metastasis is crucial to significantly reduce the breast cancer mortality rate.

Investing in metastatic breast cancer research is the **ONLY PATH** to saving lives. With dedicated funding, we can unlock the science of metastasis, develop effective treatments, and give patients more time with their families.

We urge Congress to increase federal research funding for metastatic breast cancer now, because every 12 minutes, another life is lost, and we cannot afford to wait.

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Strengthening Federal Cancer Surveillance: Modernizing the SEER Cancer Database

REQUEST METAvivor urges members of Congress to support modernization of the SEER Database.

BACKGROUND

About SEER: Established in 1973, the Surveillance, Epidemiology and End Results (SEER) Cancer Database provides information on cancer statistics in an effort to reduce the cancer burden among the U.S. population. SEER is supported by the Surveillance Research Program (SRP) in NCI's Division of Cancer Control and Population Sciences (DCCPS).

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- This year, 42,170 women and 510 men will die from MBC.
- Only 32% of people diagnosed with MBC live longer than 5 years.
- Just 13% of breast cancer research dollars go toward MBC research.

WHY MODERNIZE SEER?

The SEER database **systematically undercounts the number of people with metastatic breast cancer (MBC)** by failing to collect data on metastatic recurrence—which is when early-stage breast cancer progresses to stage IV because it has spread to other parts of the body. Instead, SEER data only reflects the 6% of people whose first breast cancer diagnosis was Stage IV MBC.

SEER fails to record the accurate type of cancer when recording metastatic cancer mortalities. For example, breast cancer that has spread to the brain, causing death, will be counted as a brain cancer mortality, ignoring breast cancer as the root cause.

SEER's failure to capture the full impact of MBC **negatively affects the allocation of vital research dollars**, and the 2–3-year lag between cancer diagnosis and the public release of data makes it **difficult to analyze contemporary trends or evaluate the impact of newer treatments and policies.**

MBC patients deserve to be fully represented in our federal health data systems. As Congress evaluates investments in public health infrastructure and cancer data modernization, upgrading the SEER database to capture the full trajectory of breast cancer, including MBC recurrences and cause-specific mortality, is a vital step forward. This is not just a data issue; it is a life and death issue for hundreds of thousands living with metastatic breast cancer in the United States.

We need Congress to act now to modernize the SEER database because lives truly depend on it.

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About METAvivor

Funding Research That Can End MBC

Fueled by our coast-to-coast grassroots community, we're proud to be the country's only nonprofit that exclusively funds metastatic breast cancer research through a peer-and-patient-advocate review process. We strive to sustain hope and make every dollar count as we work with and fund researchers who are seeking to extend and improve quality of life for MBC patients. We seek to render this disease a truly survivable condition.

Our Story

METAvivor was established in 2009 by a small group of metastatic breast cancer patients who were determined to make a difference. At the time, no organization was dedicated to funding research for the disease, and no patient groups were speaking out about the lack of stage 4 cancer research. Since its founding, METAvivor has become internationally recognized for raising awareness and funds explicitly for MBC research. Today, while more people have taken up the cry for increased focus on and funding for stage 4 research, we

remain the sole US organization dedicated to awarding annual grants to fund MBC research.

Our Mission

We focus exclusively on stage IV metastatic breast cancer to improve the lives of people living with MBC by funding research, advancing federal policies through advocacy, and facilitating a community of peer-to-peer support.

Our Leadership

As a volunteer-driven organization, our work is fueled by patients and others with a deep connection to MBC, working in partnership with a small staff of professionals. We are inspired by those who continue to step up to this challenge, even as we lose colleagues and friends to the disease.

OUR VISION

...until no one dies of MBC

Our vision is to advance research and policy until no one dies of metastatic breast cancer.

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