



METAVIVOR

Metastatic Breast Cancer | Research | Advocacy | Support

Metastatic Breast Cancer Access to Care Act (H.R. 2048/S. 3442)

REQUEST

METAvivor urges members of Congress to co-sponsor and support the bipartisan Metastatic Breast Cancer Access to Care Act (H.R. 2048/S.3442).

The House has already demonstrated overwhelming bipartisan support for this legislation, with a majority of the House cosponsoring the bill, including two-thirds of the Ways and Means Committee. We are asking the Ways and Means Committee to move H.R. 2048 forward so that this bipartisan legislation can advance in the House.

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. It is a terminal diagnosis. While treatable, it is not curable. People with MBC face unique challenges in accessing timely, affordable, and effective treatment.

- An estimated 170,000 women in the U.S. are currently living with MBC, and 2,670 men will be diagnosed with breast cancer in 2026.
- 42,140 women and 530 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.

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

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.

That person must then wait another 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 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-MBC diagnosis.

We urge you to support the *Metastatic Breast Cancer Access to Care Act (H.R. 2048/S.3442)* to ensure that Americans living with MBC can access the disability and Medicare benefits they have earned before they die.

METAvivor is a volunteer-driven, non-profit organization that funds vital research to help improve the longevity and quality of life for MBC patients. As passionately committed patients ourselves, we rally public attention to the urgent needs of the MBC community, help patients find strength through support and purpose, and make every dollar count as we work with and fund researchers seeking to extend and improve the quality of care for MBC patients.



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Cancer Drug Parity Act of 2025 (H.R. 4101/S. 5004)

REQUEST

METAvivor urges members of Congress to co-sponsor and support the bipartisan Cancer Drug Parity Act (H.R.4101/S. 5004).

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

WHY WE'RE HERE

Metastatic breast cancer (MBC) is stage IV breast cancer that has spread beyond the breast to other parts of the body. It is a treatable terminal diagnosis, but 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 2,670 men will be diagnosed with breast cancer in 2026.
- 42,140 women and 530 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

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 the treatment is administered—ensuring that medication cost is not a factor in physician and patient treatment 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 treatments.
- 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 through 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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Fully Fund Cancer Surveillance: Support NPCR and SEER

REQUEST

METAvivor urges Congress to support America's cancer registries by providing \$63.4 million for the CDC's National Program of Cancer Registries (NPCR) to fund state and regional cancer registries nationwide and by including report language directing that funding for the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program be maintained or increased as necessary to continue nationwide cancer surveillance.

BACKGROUND

About NPCR: Established by Congress in 1992, the NPCR is a CDC public health program that provides funding and technical support to cancer registries in 46 states, D.C., and U.S. jurisdictions. NPCR collects critical data on cancer diagnoses, types, and treatments across the United States.

About SEER: Established in 1973, the SEER Cancer Program 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).

WHY WE'RE HERE

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- An estimated 168,000 women in the U.S. are currently living with MBC.

- This year 2,670 men will be diagnosed with breast cancer.
- 42,140 women and 530 men will die from MBC this year.
- Only 32% of people diagnosed with MBC live longer than 5 years.
- Just 13% of breast cancer research dollars go toward MBC research.

NPCR and SEER work together to collect cancer data covering nearly 100% of the U.S. population, providing critical information to researchers, clinicians, policymakers, and public health professionals.

WHY CONGRESS MUST ACT NOW

America's cancer surveillance infrastructure is at risk. Over the past 15 months, SEER registries have experienced approximately 20% reductions in funding, including initial reductions associated with contracts entering a new cycle on May 1, 2026.

These are not traditional research grants. They are operational contracts that support the nation's cancer surveillance infrastructure. Continued funding reductions could limit registries' ability to collect and maintain the high-quality cancer data Americans have relied on for decades.

Congress has an opportunity to modernize cancer data collection with additional investments so that registries can better capture the full trajectory of metastatic cancers, including recurrence, progression to metastatic disease, and cause-specific mortality.

We need Congress to act now to properly fund the SEER and NPCR programs because lives truly depend on it.

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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) 2027.**
- Fund **Advanced Research Projects Agency for Health (ARPA-H) with \$1.5 billion for FY 2027.**
- 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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- 168,000 women in the U.S. are currently living with MBC, and 2,670 men will be diagnosed with breast cancer in 2026.
- This year, 42,140 women and 530 men will die from MBC.
- 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 (metastatic) breast cancer. Science has yet to discover the reason cancer metastasizes, and we don't have effective treatments 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 that over **316,000 Americans were diagnosed with breast cancer**. Only about 6% of diagnoses are Stage 4 MBC *at the time of diagnosis*.

An estimated 30% of all people 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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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. Our goal is 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 IV cancer research. Since its founding, METAvivor has become internationally recognized for raising awareness and directly, exclusively funding MBC research. Today, while more people have taken up the cry for increased focus on and funding for stage IV 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 regularly 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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