

Legislative Priorities 119th Congress, 1st Session

METAvisor is a national nonprofit organization focusing exclusively on stage IV metastatic breast cancer (MBC), 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. Metastatic breast cancer is a terminal disease that occurs when breast cancer spreads beyond the breast to other organs in the body (most often the bones, lungs, liver or brain). METAvisor's legislative agenda may change annually based on current opportunities and past successes. The agenda is developed and approved by METAvisor's Board of Directors. Below is a summary of key issues for the current 119th Congressional Legislative Session.

PROTECT AND ADVANCE METASTATIC BREAST CANCER RESEARCH

- **National Institute of Health:** Provide the National Institutes of Health (NIH) with at least \$51.93 billion in funding for Fiscal Year (FY) 2026.
- **ARPA-H:** Provide the Advanced Research Projects Agency for Health (ARPA-H) with \$1.5 billion for FY 2026.
- **Congressionally Directed Medical Research Programs:** Restore \$150 million in funding for the Department of Defense Peer-Reviewed Breast Cancer Research Program and continue to include "metastatic cancers" as a condition eligible for study through the Peer-Reviewed Cancer Research Program.

IMPROVE TRACKING OF METASTATIC CANCER

- **Encourage critical evaluation and public reporting on the data quality and insufficient accuracy of the Surveillance, Epidemiology, and End-Results Registry (SEER) .**
- **Advocate for efforts at the National Cancer Institute to fully modernize SEER.** SEER was established in 1973 when much less was known about metastatic cancer and longevity after a metastatic cancer diagnosis. Due to its current outdated structure, SEER systematically undercounts the impact of metastatic breast cancer. SEER entries are triggered by the first cancer diagnosis that a patient experiences, and fails to reflect metastatic recurrence—thereby significantly undercounting cases of MBC. SEER also fails to record the origin site of a metastatic 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 the connection to breast cancer as the underlying cancer. By undercounting the occurrence of metastatic cancers and their original cancer types which have progressed to the metastatic stage, metastatic cancer is not able to receive the share of research funding to which it is entitled.

IMPROVE PATIENT CARE

- **Protect Medicaid and Medicare**
 - Advocate against cuts or harmful changes to Medicaid and Medicare, ensuring continued access to vital healthcare services for individuals with metastatic breast cancer. Medicare and Medicaid are fundamentally important avenues to breast cancer diagnosis and treatment.

- 8.2% of females enrolled in Medicare fee-for-service (FFS) had claims with a diagnosis of breast cancer in 2022, and the prevalence rate increased over time during 2017–2022.
- The Breast and Cervical Cancer Treatment program (BCCTP), offers access to health care for thousands of underserved women by authorizing enhanced matching funds to states to provide Medicaid coverage to uninsured or underinsured women diagnosed with breast or cervical cancer through a federal screening program. In 2021 the program served over 41,000 enrollees.
- **Metastatic Breast Cancer Access to Care Act. (H.R.2048)** This bipartisan legislation would fast-track disability and federal healthcare benefits for individuals with metastatic breast cancer. Under current law, a person with metastatic breast cancer must wait five months after applying for Social Security Disability benefits to begin receiving those payments. Also, that person must wait an additional 24 months after disability benefits begin before receiving Medicare insurance coverage. This delay creates obvious hardships for people with metastatic breast cancer as they struggle to pay medical expenses. This delay also means that many people with MBC are unable to collect the benefits from the system that they paid into because of their reduced lifespan which is currently an average of 33 months after diagnosis.
- **Cancer Drug Parity Act**
This bipartisan legislation would address the disparity in access to and coverage of oral cancer treatments versus equivalent intravenous treatments. The bill would prevent various agencies and health insurers from:
 - Manipulating where treatment is provided or which treatment is prescribed in order to increase patient cost-sharing responsibilities (e.g. in an hospital-based infusion clinic versus at home);
 - Refusing to pay for more costly medications even when prescribers have identified the treatment as the best intervention their patients; and
 - Charging different co-pays for identical treatments in different locations, such as home versus a doctor's office, or a doctor's office versus a hospital.

AMPLIFY THE VOICE OF METASTATIC BREAST CANCER PATIENTS AMONG KEY POLICY MAKERS

- Meet with the Bipartisan House Cancer Caucus to discuss the unique challenges metastatic breast cancer patients face and how their concerns and needs align with the Caucus' key priorities for the 119th Congress, which include expanding critical research funding, accelerating treatment pathways, and supporting survivors and families.
- Seek opportunities for METAvivor Voice advocates to share their experience with policy makers.
- Deepen METAvivor's engagement with partners in the cancer and patient advocacy communities to present the strongest possible voice for patients and their families.