



**2024 STAGE IV STAMPEDE
PARTICIPANT PREP PACKET**

Stage IV Stampede Event Itinerary

Tuesday, October 1st at 6:00 PM (Eastern)

Virtual Training Session and Event Kickoff

Join Zoom Meeting

<https://us06web.zoom.us/j/87077963864>

Meeting ID: 870 7796 3864

One tap mobile

+16469313860,,87077963864# US

+19292056099,,87077963864# US (New York)

Tuesday, October 8th

**Holiday Inn Washington Capitol - National Mall, an IHG Hotel
550 C St SW, Washington, DC 20024**

12:00 PM - 1:30 PM - Mandatory Volunteer Training for MBC March Volunteer Marshalls

3:00 PM - 5:00 PM - Advocacy Training – Capitol Ballroom

5:00 PM - 7:00 PM - Advocacy Reception – Congressional Foyer

7:00 PM - Renew and Make New Friendships - Dinner on your own

Wednesday, October 9th

8:30 AM - 8:45 AM - Line up for the MBC March to the Capitol

8:45 AM - MBC March to the U.S. Capitol Lawn

9:15 AM - 9:35 AM - MBC Remembrance – U.S. Capitol Lawn

9:35 AM - Walk to Cannon House Office Building

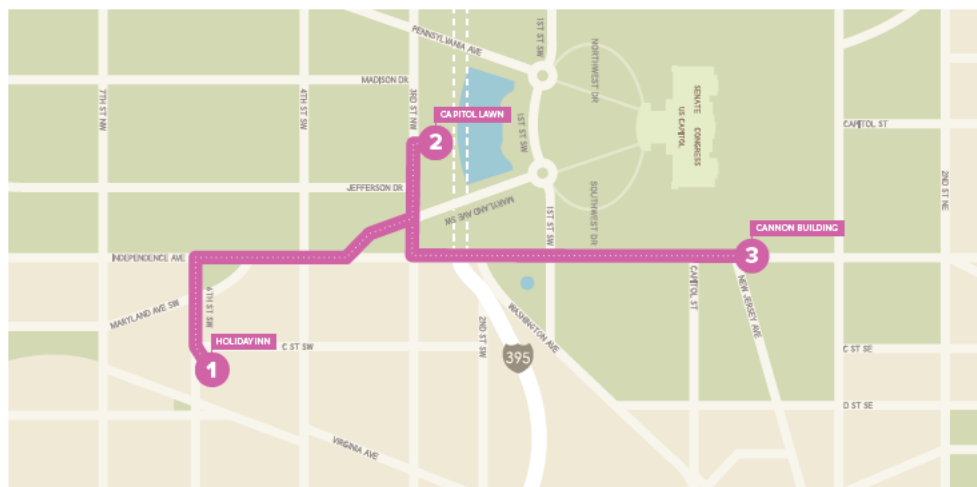
10:00 AM - House Breakfast (Cannon Caucus Room)

10:45 AM - Divide into State Groups

11:00 AM - 3:45 PM - Senate and House Meetings

4:00 PM - Meet at Dirksen Senate Office Building (cafeteria) for Debrief

Map of Capitol Hill



- Wear comfortable shoes. You will be doing a significant amount of walking while on Capitol Hill.
- Business casual attire (or an event branded t-shirt) is considered appropriate for meetings with congressional offices.
- Plan to take photos! There will be many great opportunities during the day.
- Avoid bringing suitcases and prohibited items as you will need to pass through airport-style security to enter federal buildings.
- If you have any questions throughout the day, please call or text Dane Christiansen (METAvivor's Washington representative) at 847-271-0048 or christiansen@hmcw.org.



Thank you to our Sponsors and Partners



Legislative Agenda 118th Congress, 1st Session

The METAvivor Stage IV Stampede is a flagship event honoring National Metastatic Breast Cancer Awareness Day that represents a national grassroots movement to raise awareness of metastatic (stage IV) breast cancer, educate policymakers about the challenges faced by affected individuals, and advocate for advancing medical research and improving care. The Stampede welcomes the participation of anyone who is interested in standing up, speaking out, and using their voice to improve health, wellness, and survivability for the metastatic (stage IV) cancer community.

METAvivor is a national nonprofit organization dedicated to sustaining hope for those living with metastatic (stage IV) breast cancer. This terminal disease occurs when breast cancer spreads beyond the breast to other organs in the body (most often the bones, lungs, liver, or brain). METAvivor is a volunteer-led, grassroots-driven organization that funds vital research to help improve the longevity and quality of life for affected individuals. METAvivor rallies public attention to the urgent needs of this community, help patients find strength through support and purpose, and makes every dollar count as we work with researchers to advance our scientific understanding of controlling and eliminating cancer that has migrated beyond the breast to other areas of the body from the original site and to extend and improve quality of life for patients.

Each year, almost 600,000 Americans die from **metastatic (stage IV) cancers**. When cancer spreads beyond the original tumor site to other parts of the body and activates it becomes “metastatic” or “stage IV”. Recent scientific breakthroughs in cancer research and improvements in detection and prevention have not benefited the metastatic (stage IV) breast cancer community. Treatment options are extremely limited and metastatic breast cancer is not considered survivable. Presently, science has very few answers to the question of why cancer metastasizes and there are no therapies that permanently arrest metastatic growth. With emerging opportunities, including precision medicine and the “moonshot” initiatives, there is tremendous opportunity to advance science and improve health outcomes for the metastatic (stage IV) breast cancer community through meaningful financial support for critical research activities. METAvivor is committed to being part of the solution, and to give patients both hope and a voice to push for life-altering research advancements.

2024 Legislative and Policy Recommendations

Advance Research

- Federal funding for life-saving research:
 1. Provide the National Institutes of Health (NIH) with at least the Senate-proposed increase of \$1.77billion or \$51.3 billion in funding for Fiscal Year (FY) 2025
 2. Provide the Advanced Research Projects Agency for Health (ARPA-H) with \$2.5 billion for FY 2025
 3. Provide a meaningful increase for the Department of Defense Peer-Reviewed Breast Cancer Research Program, and please continue to include “metastatic cancers” as a condition eligible for study through the Peer-Reviewed Cancer Research Program
- Support Congressional efforts to continue to work with NIH and the Centers for Disease Control and modernize the Surveillance Epidemiology and End-Result (SEER) Registry.
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Improve Care

- Please work with your colleagues to pass the bipartisan ***Metastatic Breast Cancer Access to Care Act (S. 663/H.R. 549)***, which would fast-track access to disability and federal healthcare benefits for individuals with metastatic breast cancer.
- Please work with your colleagues to pass the bipartisan ***Cancer Drug Parity Act (H.R. 6301/S.2039)***, which would prevent manipulating treatment administration to increase patient cost-sharing responsibilities.

-ISSUE BRIEF-

Support Meaningful Funding for Medical Research

This issue is of particular interest to members of the House and Senate Appropriations Committees (as noted on your schedules)

Background

The National Institutes of Health (NIH) is part of the Department of Health and Human Services and forms the cornerstone of this nation's biotechnology industry. NIH supports basic, translational, and clinical research into various diseases and disorders. This federally-funded research often serves as a catalyst for industry working to turn medical breakthroughs and scientific advancements into innovative therapies. On an annual basis, Congress decides how much funding should go to NIH (and all federal priorities), the National Cancer Institute (NCI), and includes recommendations for research areas of support and interest.

Concurrently, we would like Congress to also actively support medical research in this area through the Department of Defense (DoD). The DoD has many cancer research programs due to the impact on military personnel and veterans. In fact, the Congressionally Directed Medical Research Program at DoD recently began to focus on research into controlling and eliminating cancer that has already metastasized. Unlike the National Institutes of Health, which funds broad research initiatives, the DoD only funds projects where Congress has specifically asked for research activities. In order for the DoD research program to move forward, Congress needs to include “metastatic cancers” again this year. Congress also needs to enhance the DoD's line-item Peer-Reviewed Breast Cancer Research Program with additional funding. Right now, “metastatic cancers” is listed in the House DoD Appropriations Bill as eligible for study through the Peer-Reviewed Cancer Research Program, and we need to be included on any final list for FY 2025.

Congress has also responded to the metastatic breast cancer advocacy community by actively encouraging NIH and CDC to modernize the Surveillance, Epidemiology, and End-Results (SEER) Registry to better capture metastatic disease. This project is just starting and NIH and CDC appear enthusiastic to move forward swiftly and effectively. In addition to ensuring additional funding is available to facilitate these activities, Congress needs to continue to weigh in with NIH and CDC to ensure the project is moving forward and accommodating the needs of the community.

-ISSUE BRIEF-

Support and Enact the *Metastatic Breast Cancer Access to Care Act* (S.663/H.R. 549) *This issue is of particular interest to members of the House Ways & Means Committee and the Senate Finance Committee*

Background

Under current law, if an individual is found to be disabled for the purposes of Medicare and Social Security Disability Insurance (SSDI), they must wait up to 24 months to enroll in Medicare after waiting 5 months to receive SSDI benefits. During this arbitrary waiting period, individuals with a variety of serious, debilitating, and life-threatening medical conditions face incredible hardships in supporting themselves and their families and maintaining access to appropriate medical care that they desperately need. For many conditions, studies have shown that any disruption in care can lead to disease progression that further impacts health outcomes. Due to the current law, individuals with metastatic breast cancer are hit particularly hard and may never receive the SSDI and Medicare benefits they are eligible to receive as result of these onerous waiting periods. In 2019, Congress fixed a similar barrier for the ALS community.

The vast majority of cancer deaths result from metastatic cancer that has already metastasized, representing that the disease has reached a late-stage. While there have been recent advancements in treatments and care, life expectancy for an individual with metastatic breast cancer still averages about three years. Federal programs that allow patients to by-pass the disability waiting periods require that a condition be fatal within six months in 95% of cases, an impossibly high standard that will be harder to reach as treatment options improve. This creates a situation where patients are harmed and care is jeopardized as a result of medical breakthroughs and improvements in life expectancy.

Senators Chris Murphy (D-CT) and Joni Ernst (R-IA) have re-introduced the ***Metastatic Breast Cancer Access to Care Act***, S. 663, which would simply waive the 5-month waiting period for Social Security Disability Insurance and the 24-month waiting period for Medicare benefits for individuals with a diagnosis of metastatic breast cancer. Congresswoman Kathy Castor (D-FL) and Andrew Garbarino (R-NY) have introduced a companion bill in the House, H.R. 549. Both bills are bipartisan and popular, and just need a little more support to be enacted.

-ISSUE BRIEF-

Support and Enact the *Cancer Drug Parity Act* (H.R. 6301/S. 2309) *This issue is of particular interest to members of the Energy & Commerce Committee and the Senate Health-Education-Labor-and-Pensions Committee*

Background

Insurance coverage is incredibly complex, often opaque, and highly variable. The overall cost of a therapy and a patient's out-of-pocket responsibility are determined by a variety of factors, such as type of administration, utilization of the medical benefit or pharmacy benefit, and site of care. Unfortunately, with a pricing system this complex manipulation is possible and unintended negative consequences are inevitable.

In order to protect patient and physician decision-making and to ensure patients do not face limited options or price gouging, Senators Tina Smith (D-MN) and Jerry Moran (R-KS) have re-introduced the bipartisan *Cancer Drug Party Act* as S. 2039. This House bill, H.R. 6301, is led by Congressman Glenn Grothman (R-WI) and Congresswoman Suzanne Bonamici (D-OR).

S. 2039/H.R. 6301 is "budget neutral" since they deal with private insurance and would not increase federal healthcare spending. Please note, these new protections and the "no-less favorable" cost-sharing requirements called for by the bill apply to FDA-approved therapies. Specifically, *medication approved by FDA that is prescribed based on a finding by the treating physician that the medication is medically necessary for cancer treatment and is clinically appropriate in terms of type, frequency, extent site, and duration*. Private insurance coverage for "experimental" treatment regimens remains a case-by-case exercise.

Sample Meeting Script

Talking Points

- Thank the staff member for meeting with you.
 - Have every member of the group introduce themselves and say why they are an advocate (constituents should lead the discussion though).
 - Explain why you are in DC for the Stage IV Stampede.
 - Explain what metastatic breast cancer is and its impact on a patient (family impact, economic impact) (use this as an opportunity to dispel myths about early detection and therapy development).
 - Talk about where you are from and remind them that you are part of the community their office represents.
- Discuss federal funding and research/patient care programs of interest.
 - The National Cancer Institute at the National Institutes of Health operates a modest and meaningful research portfolio in controlling and eliminating cancer that has already metastasized. While breakthroughs have led to progress with early diagnosis and treatment, this does not help patients that have a cancer that has spread. More research is needed to improve treatment options.
 - Our community supports the largest possible funding increase for NIH and would like to thank the Senate for proposing an increase of \$1.77 billion over FY 2024. Our hope is that this allocation will be reflected in any final FY 2025 funding measures, or that any amount close to the community's request of \$51.3 billion is provided for FY 2025.
 - In this regard, we also support ongoing investment in the Advanced Research Projects Agency for Health (ARPA-H), provided that funding does not compete with or supplant ongoing NIH research.
 - Moreover, the DoD along with Congress has started to prioritize metastatic cancer research through the Congressionally Directed Medical Research Program. Emerging activities hold tremendous promise and the DoD's efforts should continue to be encouraged and supported.
 - For FY 2025, please continue to include "metastatic cancers" within the DoD Peer-Reviewed Cancer Programs eligible conditions list (currently listed in the

House DOD Bill) the FY 2025 DoD Appropriations Bill and corresponding Committee Report. Please also increase funding for the DOD's Peer-Reviewed Breast Cancer Research Program.

- Finally, Congress is working with NIH and CDC to modernize the SEER registry to ensure it captures metastatic disease. We hope your office will support this important effort and provide the agencies with the resources and guidance they might need. Report language has been included in recent spending measures and new efforts are underway but need to be guided to ensure they are as robust and inclusive as possible.
- Discuss coverage and access bills, and request cosponsorship.
 - Metastatic breast cancer is a life-threatening and debilitating condition and many affected individuals see serious disruptions in care as they wait to qualify for Medicare and disability. Due to the aggressive nature of the disease many do not survive the arbitrary waiting periods or their health declines significantly in the interim.
 - *Metastatic Breast Cancer Access to Care Act*
 - Congresswoman Castor and Congressman Garbarino have re-introduced bipartisan legislation, the *Metastatic Breast Cancer Access to Care Act*, that would address this problem by removing the waiting period for metastatic cancer patients. The Senate bill is led by Senators Chris Murphy and Joni Ernst.
 - Please tell your story if you are personally familiar with this issue.
 - **Already a Cosponsor:** Thank the office for their support. Moreover, make it clear that your expectations is that they work with their colleagues to pass the bills before the end of the current Congress (reach out to leadership, have a mark up, as a supporter please move the process forward!).
 - **House Not a Cosponsor:** Please cosponsor H.R. 549 by contacting the office of Rep Castor or the office of Rep Garbarino.
 - **Senate Not a Cosponsor:** Please cosponsor S. 663 by contacting the office of Senator Chris Murphy or Senator Joni Ernst.
 - Metastatic cancer patients often face barriers related to out-of-pocket cost related to accessing chemotherapy and other innovative medicines.
 - These cost-sharing requirements can impact clinical judgment, create serious hardships for patients, and steer individuals to particular products or forms of administration.
 - *Cancer Drug Parity Act*
 - Senators Tina Smith and Jerry Moran have recently reintroduced legislation, the *Cancer Drug Parity Act*, that would ensure cost-sharing parity for patients and protect access to physician directed treatment options. The House bill is led by Congressman Grothman and Congresswoman Bonamici.
 - Please tell your story if you are personally familiar with this issue.
 - **Current Cosponsor:** Thank the office for their support. Encourage the office to work with their colleagues though to advance the bill or seek the inclusion of core provisions in any end of the year legislative package.
 - **House Not a Cosponsor:** Please cosponsor H.R. 6301 by reaching out to the office of Congressman Glenn Grothman or Suzanne Bonamici.
 - **Senate Not a Cosponsor:** Please cosponsor S. 2039 by reaching out to the office of Senator Tina Smith or Senator Jerry Moran.

- Thank them for their time and exchange contact information so that you can email a thank you note. If they ask a question that you cannot answer, please consider it an opportunity to follow up (and let METAvivor assist with an answer).

***The one thing to remember that is more important than any policy issue or bill number is:
Tell Your Story!***

Capitol Hill Dining Options

SENATE SIDE:

Cups & Co.

Located in the Russell Building Basement

Dirksen Cafeteria

North side of the basement of Dirksen Senate Office Building

Inside Scoop

Located in the Dirksen/Hart Ground Floor Connecting Corridor

Coffee Shop

Located in the Dirksen Basement South

HOUSE SIDE:

Capitol Market

Located in Capitol Building-Rm HB-9

Longworth Cafeteria

Basement of the Longworth House Office Building

Longworth Twelve

Located in Longworth Building-B-223

Rayburn Cafeteria

Basement of the Rayburn House Office Building Rm-2063

Subway

Located in the Rayburn Building-Rm B326