**2022 (VIRTUAL) STAGE IV STAMPEDE**

**PREP PACKET**

Training Webinar Schedule

State Captains Meeting, Option 1:

Thursday, September 22, 2022, at 7:00 pm ET/ 6:00 pm CT/ 5:00 pm MT /4:00 pm PT

Meeting ID: 889 6085 5991

Passcode: 750397

Join Link:

<https://us06web.zoom.us/j/88960855991?pwd=RkR3eVlSZUtZdUtwVHhTWHJzUFRaUT09>

State Captains Meeting, Option 2:

Saturday, September 24, 2022, at 1:00 pm ET/ 12:00 pm CT/ 11:00 am MT /10:00 am PT

Meeting ID: 848 2959 9929

Passcode: 397157

Join Link:

<https://us06web.zoom.us/j/84829599929?pwd=NFhDOGRxSTkzT1JEdzdsckt6cUpMUT09>

Community Stampede Kickoff Event:

Full Advocate Webinar/Kickoff event

Friday, September 30, 2022, at 3:00 pm ET/ 2:00 pm CT/ 1:00 pm MT /12:00 pm PT

Meeting ID: 868 5431 2841

Passcode: 710045

Join Link:

<https://us06web.zoom.us/j/86854312841?pwd=c3M1TVNxbkJOWERXS1BnbHRGdmFXdz09>

Event Background

Capitol Hill is still closed to visitors for public health and security reasons, however, Congress is still conducting regular business and working on annual legislation and policy priorities. In fact, congressional offices and staff have been uniquely accessible with the switch to online meetings. Congress is considering a number of timely funding recommendations and coverage and access bills, and it is time to make our collective voices heard with the [**7th Annual Stage IV Stampede!**](https://donate.metavivor.org/event/stage-iv-stampede/e416664)

During October, your Senators and Representatives are deciding how much annual funding to provide towards medical research priorities, including research efforts focused on controlling and eliminating cancer that has already disseminated (metastatic cancer). They will be making these decisions so they can finalize Fiscal Year (FY) 2023 appropriations bills and pressing legislative matters during the “Lame Duck” session after the November elections and before the end of the year. The urgency and importance of legislation that improves healthcare coverage and access to innovative therapies for the community must be prioritized by Congress. Most importantly though, elected officials need to hear and understand your story.

Similar to last year, we will be working together through state-based teams, led by a local or regional coordinating captain. The Health and Medicine Counsel will be facilitating a key virtual visit for your state team while your local captain will be coordinating additional meetings. For additional information on the legislative issues and talking points, please see the background materials below.

**Legislative Agenda**

**117th Congress, 2nd Session**

**The 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 cancer, educate policymakers about the challenges faced by affected individuals, and advocate for advancing medical research and improving care. The Stampede welcomes anyone who is interested in standing up, speaking out, and using their voice to improve health, wellness, and survivability for the stage IV metastatic cancer community.

**METAvivor** is a national nonprofit organization dedicated to sustaining hope for those living with stage IV metastatic 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. Passionately committed patients ourselves, we rally public attention to the urgent needs of this community, help patients find strength through support and purpose, and make every dollar count as we work with researchers to advance our scientific understanding of controlling and eliminating cancer that has disseminated 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 cancer**. Metastatic cancer can develop from any cancer. It becomes metastatic cancer when it spreads to other parts of the body and activates. Recent scientific breakthroughs in cancer research and improvements in detection and prevention have not benefited the metastatic stage IV cancer community. Treatment options are extremely limited and the condition for most cancers 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 cancer community through meaningful financial support for critical research activities.

**2022 Legislative and Policy Recommendations**

Advance Research

* Please provide the National Institutes of Health with at least $47.6 billion in funding for Fiscal Year (FY) 2023 (as proposed by the House).
* Please provide the Advanced Research Projects Agency for Health (ARPA-H) with $2.75 billion for FY 2023 (as proposed by the House).
* Please support establishing a $5 million program at the Centers for Disease Control and Prevention to modernize the Surveillance, Epidemiology, and End-Results Registry.
* Please provide $150 million for the Department of Defense Peer-Reviewed Breast Cancer Research Program (as proposed by the House), and please continue to include “metastatic cancers” as a condition eligible for study through the Peer-Reviewed Cancer Research Program (as proposed by the Senate).

Improve Care

* Please work with you colleagues to pass the bipartisan ***Metastatic Breast Cancer Access to Care Act* (S.1312/H.R.3183)**, which would fast-track 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. 4385/S.3080)**, which would prevent manipulating treatment administration to increase patient cost-sharing responsibilities.

**FY 2023 Conference Appropriations Letter**

September 12, 2022

The Honorable Patrick Leahy The Honorable Richard Shelby

Chair Vice Chair

Committee on Appropriations Committee on Appropriations

U.S. Senate U.S. Senate

The Honorable Rosa DeLauro The Honorable Kay Granger

Chair Ranking Member

Committee on Appropriations Committee on Appropriations

U.S. House of Representatives U.S. House of Representatives

Dear Chairman Leahy, Chairwoman DeLauro, Vice Chair Shelby, and Ranking Member Granger:

Thank you for your ongoing support for medical research and patient care programs. On behalf of METAVivor and the local metastatic breast cancer community, please continue to advance critical funding increases for federal medical research programs that facilitate efforts to control and eliminate cancer that has already disseminated within any final Fiscal Year (FY) 2023 spending measures.

METAvivor is a national nonprofit organization dedicated to sustaining hope for those living with stage IV metastatic 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. Passionately committed patients ourselves, we rally public attention to the urgent needs of this community, help patients find strength through support and purpose, and make every dollar count as we work with researchers to advance our scientific understanding of controlling and eliminating cancer that has disseminated to other areas of the body from the original site and to extend and improve quality of life for patients.

METAvivor encourages your ongoing support for the following funding levels in any final FY 2023 appropriations bills:

* Please provide the National Institutes of Health (NIH) with as close to $47.6 billion as possible, consistent with the increase proposed by the House.
* Please provide the Department of Defense (DoD) Peer-Reviewed Cancer Research Program with as close to $130 million as possible and please continue to include “metastatic cancers” on the eligible conditions list, consistent with the Senate and House proposals.
* Please provide the DoD Peer-Reviewed Breast Cancer Program with as close to $150 million as possible, consistent with the House proposal.
* Please provide $5 million in line-item funding at the Centers for Disease Control and Prevention to support grants to states that are interested in advancing innovative approaches to modernize the Surveillance, Epidemiology and End Results (SEER) by capturing data on metastatic disease and cancer progression. Please also support committee recommendations in the Senate proposal asking NCI for an FY 24 budget justification estimate to modernize SEER effectively.

Thank you again for your support and for your consideration of this request. Please consider METAvivor a resource if you have any questions or if you need anything as the FY 2023 appropriations process moves forward.

Sincerely,

Text, letter

Description automatically generated

Sonya Negley

Executive Director

**-ISSUE BRIEF-**

**Support Meaningful Funding for Medical Research**

*This issue is of particular interest to members of the House and Senate Appropriations Committees*

**Background**

The National Institutes of Health (NIH) 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) and the National Cancer Institute (NCI), and includes recommendations for research areas of support and interest.

Due to community outreach, there has been a tremendous expansion of interest in metastatic cancer research. In this regard, Congress has asked NIH to modernize the Surveillance, Epidemiology, and End Results (SEER) Registry. Congress is also considering a vast expansion of the cancer moonshot, including advancement of the new Advanced Research Projects Agency for Health (ARPA-H). At this time, the community is requesting $5 million in dedicated funding to support a state-based pilot program on SEER modernization. The community is also requesting additional investment in ARPA-H while ensuring any funding does not compete with or otherwise supplant ongoing NIH research activities.

Concurrently, we would like Congress to 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 projects into controlling and eliminating cancer that has already disseminated. 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 Peer-Reviewed Breast Cancer Research Program with additional funding.

**Talking Points**

* 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 disseminated. While breakthroughs have led to progress with early diagnosis and treatment, this does not help patients that have a progressive cancer and more research is needed to improve treatment options.
* Our community would like to thank the House for proposing a $2.5 billion funding increase for NIH for FY 2023. Our hope is that this allocation will be reflected in any final FY 2023 funding measure. .
* 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 2022, please continue to include “metastatic cancers” within the DoD Peer-Reviewed Cancer Programs Eligible For Study List Through the FY 2022 DoD Appropriations Bill and corresponding Committee Report. Please also increase funding for the DOD’s Peer-Reviewed Breast Cancer Research Program.

**-ISSUE BRIEF-**

**Support and Enact the *Metastatic Breast Cancer Access to Care Act* (S.1312/H.R. 3182)** *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. Congress just fixed a similar barrier for the ALS community.

The vast majority of cancer deaths result from metastatic cancer that has already disseminated, 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 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 only be harder to reach as treatment options improve. This creates a situation where patients are penalized 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 introduced a bipartisan bill, S. 1312, 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 John Katko (R-NY) have introduced a companion bill in the House, H.R. 3182. Both bills are bipartisan and popular, and just need a little more support to be enacted.

**Talking Points**

* Metastatic breast cancer is a life-threatening and debilitating condition and many affected individuals see serious disruptions in care as they wait to quality 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.
* Congresswoman Castor and Congressman Katko have introduced bipartisan legislation that would address this problem by removing the waiting period for metastatic cancer patients.
* Please tell your story if you are personally familiar with this issue.
* **House Cosponsor**: Thank the office for their support.
* **House Not a Cosponsor**: Please cosponsor H.R. 3182 by contacting the office of Rep Castor or the office of Rep Katko.
* **Senate**: Please cosponsor S. 1312 by contacting the office of Senator Chris Murphy or Senator Joni Ernst.

**-ISSUE BRIEF-**

**Support and Enact the *Cancer Drug Parity Act* (**H.R. 4385/S. 3080**)**

*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 gauging, Congressmen Brian Higgins (D-NY) and Brett Guthrie (R-KY) introduced the bipartisan *Cancer Drug Party Act* as H.R. 4385. The legislation had nearly 140 cosponsors in the last Congress and seeks to ensure that health plans covering chemotherapy facilitate access to all available treatment regiments. Further, the legislation works to protect patient cost-sharing by eliminating systemic variability in out-of-pocket costs. A Senate companion bill, led by Senator Tina Smith (D-MN) and Jerry Moran (R-KS) was also introduced as S. 3080.

These bills are budget neutral (no cost to tax payers) since they deal with private insurance and are therefore popular. 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 regiments remains a case-by-case exercise.

**Talking Points**

* 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.
* Congressman Higgins and Guthrie are leading the *Cancer Drug Parity Act* (H.R. 4385) that would ensure cost-sharing parity for patients and protect access to physician directed treatment options. The Senate companion bill will be introduced by Senators Smith and Moran soon.
* Please tell your story if you are personally familiar with this issue.
* **Current Cosponsor**: Thank the office for their support.
* **House Not a Cosponsor**: Please cosponsor H.R. 4385 by contacting the office of Congressman Higgins for Congressman Guthrie.
* **Senate Not a Cosponsor**: Please cosponsor S. 3080 by reaching out to the office of Senator Tina Smith or Senator Jerry Moran.

**When reaching to congressional outreach, the one thing to remember that is more important than any policy issue or bill number is: Tell Your Story!**