

Stage IV Stampede
Thursday, October 13th, 2016

EVENT ITINERARY

8:30 AM One-Mile Community March from the Washington Monument to Capitol Hill
Location: Washington Monument, the National Mall
2 15th St. NW, Washington, DC 20024
[Please note, group *departs* at 8:30 AM]

9:00AM – 9:30AM Community Die-in to Represent the 113 Women and Men who Die from Metastatic Breast Cancer Every Day
Location: West Lawn, U.S Capitol

10:00AM – 11:00AM Community Rally and Congressional Briefing
Location: Cannon Caucus Room, Cannon Building
Program:
Welcome Remarks: Dian “CJ” Corneliussen-James, METAvivor
Patient Remarks: Carl “Mac” Holmes, Met Up
Research Investigator Remarks: Yibin Kang, PhD
Concluding Remarks: Beth Fairchild, METAvivor

*After the briefing, we will use the podium and mic to organize advocates into their congressional visit teams (by state), hand out the congressional “leave-behind” folders, and answer any last minute questions about the issues or meeting with congressional staff.

11:15AM – 3:30PM Teams Depart for Congressional Meetings
[House meetings first, lunch, then Senate meetings]
-Lunch is on your own during the break in your congressional meeting schedule, dining options/locations on Capitol Hill are listed in your prep packet.

3:30PM – 3:45PM Optional Debriefing Session
Dirksen Senate Building, Basement Cafeteria



= Cannon House Office Building where the morning briefing will be held

- Wear comfortable shoes. You will be doing a significant amount of walking while on Capitol Hill.
- Business casual attire is considered appropriate for meeting with congressional offices (event t-shirts are also appropriate for congressional meetings).
- Bring a camera. There will be many great photo opportunities during the day. In fact, it is appropriate to ask congressional offices for a picture with the Senator/Congressperson.
- Avoid bringing suitcases and prohibited items as you will need to pass through airport-style security to enter federal buildings. Water, food, perfume, hairspray or similar items are often confiscated and discarded at security checkpoints.
- Dane Christiansen, METAvivor's representative in Washington, will be on Capitol Hill as teams make congressional visits. If you or your team requires any assistance during the day, please call/text him at (847) 271-0048 or e-mail him at christiansen@hmcw.org.

Legislative Agenda 114th Congress, 2nd Session

The Stage IV Stampede The Stage IV Stampede is a flagship event on 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. This patient-driven effort is led by METAvivor Research and Support and partners including the Metastatic Research Society, the Male Breast Cancer Coalition, Living Beyond Breast Cancer, Met UP, Tigerlily Foundation and Young Survivor Coalition. 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.

Metastatic Stage IV Cancer 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.

Congress Can Help

Please provide the National Institutes of Health (NIH) with at least a \$2 billion funding increase for Fiscal Year (FY) 2017 as outlined in the Senate’s FY 2017 Labor-Health and Human Services-Education Appropriations Bill. Moreover, please join the sign on letter to the leadership of the National Cancer Institute’s inquiring on the ongoing research and emerging opportunities for the metastatic stage IV cancer research portfolio by contacting the letter’s sponsors.

Please facilitate access to innovative (and potentially life-saving or life-improving) therapies for individuals facing life-threatening illness by cosponsoring the bipartisan *Trickett Wendler Right to Try Act (H.R. 3012/S. 2912)* by contacting the office of Congressman Matt Salmon (R-AZ-05) in the House or the office of Senator Ron Johnson (R-WI) in the Senate. This legislation relaxes regulatory and legal barriers for experimental drugs to enhance treatment options for patients with serious circumstances.

Please end the waiting period for disability benefits for individuals facing terminal illnesses by cosponsoring the bipartisan *Social Security Disability Fairness Act (H.R. 5347/ S. 2010)* by contacting the office of Congressmen Rodney Davis (R-IL-13) or Ron Kind (D-WI-03) in the House or the office of Senators John Barrasso (R-WY) or Sherrod Brown (D-OH) in the Senate. This commonsense legislation provides a mechanism for individuals facing life-threatening illness to access their benefits almost immediately.

-ISSUE BRIEF-

Support Meaningful Funding for Medical Research

This issue is of particular interest to members of the Appropriations Committee

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.

Recent years of near-level funding coupled with inflation have caused NIH to lose a significant amount of purchasing power. The pay line for funding NIH grants has dropped to about 15% (meaning only 1 in 7 research projects are funded) while the average age of an investigator having their first NIH grant funded has increased to 42. Securing a funding increase of \$2 billion (as recommended by the Senate) will facilitate growth in NIH research portfolios and allow new research projects to be supported. NIH currently funds a research portfolio in this area, but the primary way to ensure our slice of the pie grows larger is to ensure the pie overall grows larger through additional funding.

Concurrently, we would like Congress to send a letter to the National Cancer Institute (NCI) inquiring on the current size, scope, and direction of the metastatic stage IV cancer research portfolio. The more members that sign this letter, the more powerful the inquiry will be (and your representatives will only join if you ask them to). Such action also sends a clear message to NCI that they should increase their research activities in this area moving forward and provides the community with an entry point to discuss expanding research with policymakers and NCI researchers.

Talking Points

- The National Cancer Institute at the National Institutes of Health operates a modest research portfolio in metastatic stage IV cancer. 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 Congress for the \$2 billion increase provided for NIH in last year's omnibus appropriations bill. We are supportive of the Senate's allocation of an additional \$2 billion for FY 2017 as well as specific funding for precision medicine and the cancer moonshot initiative.
- House Offices: Congressional champions are currently leading a letter to NCI inquiring on the size, scope, and direction of the metastatic stage IV cancer portfolio as well as how new opportunities may benefit the community. We hope your office will join this important sign on letter during the October congressional recess.
- Senate Offices: The House is currently advancing a bipartisan sign on letter inquiring on the size, scope, and direction of the metastatic stage IV cancer portfolio which will help guide emerging opportunities like the Moonshot Initiative. We hope the Senate will lead a similar letter and would like to know if your office is interested in taking a leadership role on this during the October recess.

-ISSUE BRIEF-

Cosponsor the Trickett Wendler Right to Try Act (H.R. 3012/S. 2912)

This issue is of particular interest to members of the Energy & Commerce Committee and the Health, Education, Labor, and Pensions (HELP) Committee

Background

Each year 250,000 Americans are diagnosed with breast cancer; 6-10% of the breast cancer diagnoses are considered metastatic stage IV. An additional 30% of breast cancer diagnoses will eventually progress to stage IV metastatic cancer. We do not currently have an effective treatment to arrest metastatic growth and a diagnosis of stage IV breast cancer is not considered survivable – in fact, 41,000 people, women and men, die of it each year.

Prevention and early detection is the focus of much of the breast cancer research conducted in recent decades. While those are laudable goals, those who have been diagnosed with metastatic breast cancer are left with minimal life-saving options. Allowing seriously affected patients access to innovative treatment options will help advance science and potentially save lives.

The *Right to Try Act* (H.R. 3012/S. 2912) would bar the federal government from prohibiting or restricting the production, manufacture, distribution, prescribing, dispensing, possession or use of an experimental drug, biological product or device that is both intended to treat a patient who has been diagnosed with a terminal illness and is authorized by, and in accordance with, state law. This legislative effort is being led by Congressman Matt Salmon (R-AZ-5th) in the House and Senator Ron Johnson (R-WI) in the Senate. Supporting this bill is important to distinguish our community from other cancer communities focused on prevention and treatment. It is important for lawmakers to understand the severity of the disease and the timeliness of the effort.

In order for this important bill to move through the legislative process and become law, additional Senators and Representatives need to support the measure by cosponsoring. The more support a bill has, the more likely it is to be given valuable time on the legislative calendars of the House or Senate moving into the end of the year.

Talking Points

- Metastatic stage IV cancer is currently classified as a terminal illness with a low survivability rate and extremely limited treatment options.
- The *Right to Try Act* (H.R. 3012/S. 2912) would allow many patients to access innovative therapies that may ultimately save their lives, extend their lives, or advance science so that other patients benefit from increased knowledge about the impact of treatments in development. This bipartisan bill is crafted as to not disrupt the innovation process.
- **[House Only]** Please co-sponsor this important bill by contacting Jenell Biggs in Congressman Matt Salmon's office at Jenell.Biggs@mail.house.gov.
- **[Senate Only]** Please support this important bill by contacting Sean Riley in Senator Ron Johnson's office at Sean_Riley@ronjohnson.senate.gov.

-ISSUE BRIEF-

Cosponsor the Social Security Disability Fairness Act (H.R. 5347/S. 2010)

This issue is of particular interest to members of the Ways & Means Committee and the Senate Finance Committee

Background

Once again, it is important for lawmakers to understand the severity of the disease and the challenges facing the metastatic stage IV cancer community. Such an effort will distinguish us from other communities focused on early diagnosis and screening. This issue can contrast the needs of those communities with the significant and timely requests of our community. Fast-tracking disability benefits is an important issue for communities dealing with life-threatening illness.

The *Social Security Disability Fairness Act* (H.R. 5347/S. 2010) provides a mechanism for individuals facing life-threatening illness to access their benefits almost immediately, rather than being subject to a waiting period. This effort is being led by Congressmen Rodney Davis (R-IL-13) and Ron Kind (D-WI-03) in the House and Senators John Barrasso (R-WY) and Sherrod Brown (D-OH) in the Senate.

In order for this important bill to move through the legislative process and become law, additional Senators and Representatives need to support the measure by cosponsoring. The more support a bill has, the more likely it is to be given valuable time on the legislative calendars of the House or Senate. Your Representatives and Senators will only cosponsor the bill if their constituent (you) asks them to.

Talking Points

- Individuals with metastatic breast cancer suffer from a terminal illness and significant disability.
- Under the Social Security Act, a person who qualifies for disability benefits is subject to a waiting period before receiving those benefits. This delay can be months or years, which is unacceptable to individuals and families relying on benefits to deal with a serious and life-threatening illness.
- The bipartisan *Social Security Disability Fairness Act* (H.R. 5347/S. 2010) would provide a mechanism for individuals facing terminal illness to access their rightful disability benefits almost immediately.
- **[House Only]** Please support this important bill by contacting Miles Chiotti in Congressman Davis's office at Miles.Chiotti@mail.house.gov or by contacting Elizabeth Stower in Congressman Kind's office at Elizabeth.Stower@mail.house.gov.
- **[Senate Only]** Please support this important bill by contacting Jay Eberle in Senator Barrasso's office at Jay_Eberle@barrasso.senate.gov or by contacting Abigail Duggan in Senator Brown's office at Abigail_Duggan@brown.senate.gov.

General Talking Points

- Introduce yourself to the staffer and let the group introduced themselves too.
- The constituents should talk about their home and local connections to the community.
- The group should use their stories to explain what metastatic stage IV cancer is and how individuals are impacted.
- The three legislative issues and associated “asks” should be put forward by the group.
- Thank them for their time and provide the staffer with the leave-behind folder.
- Exchange contact information and take their business card so you can follow up with a thank you note next week (HMCW will provide a draft note for you and subsequent instructions).

Capitol Hill Dining Options

SENATE SIDE:

Hart Senate Chef

Located in the ground floor corridor connecting the Dirksen Senate Office Building with the Hart Senate Office Building 8:00 am - 6:30 pm, M-F

Dirksen Buffet

South side of the basement of the Dirksen Senate Office Building
11:30 am - 2:30 pm, M-F

Dirksen Cafeteria

North side of the basement of Dirksen Senate Office Building
11:00 am - 2:30 pm, M-F

Russell Carryout

Northwest corner of the basement of Russell Senate Office Building
7:30 am - 5:00 pm, M-F

HOUSE SIDE:

Cannon Carryout Basement of the Cannon House Office Building

7:30 am to 4:00 pm, M-F

Longworth Cafeteria

Basement of the Longworth House Office Building
7:30 am to 2:30 pm, M-F

Rayburn Cafeteria

Basement of the Rayburn House Office Building
7:30 am to 2:30 pm, M-F