

Advocate for yourself! HHS must be allowed to function

Background:

METAvivor is deeply concerned about the unintended consequences of the recent directive halting external communications from the Department of Health and Human Services (HHS) as well as the stoppage of internal scientific meetings, including critical scientific review groups which are an essential step for awarding research funding.

The cancellation of meetings to review vital research proposals is extremely troubling. Prolonged delays will hinder the launch of promising studies and disrupt the crucial exchange of discoveries and insights among scientists and researchers. Furthermore, a stable funding environment is essential to both young and seasoned researchers pursuing research careers and a crucial element for fostering groundbreaking discoveries.

We urge everyone impacted by this directive to contact their Members of Congress and express the urgent need to allow science to progress without hindrance. To reach your Senators and Representatives, call the United States Capitol switchboard at (202) 224-3121. To email your lawmakers use the following links to find their websites, then send them a message using the template below: for Representatives use <https://www.house.gov/representatives/find-your-representative>, for Senators use <https://www.senate.gov/senators/senators-contact.htm>.

Advocacy Opportunities:

1. **Share your story!** METAvivor is collecting stories to share with lawmakers so they can really understand the impact of this policy on their constituents. Please email METAvivor's Advocacy Committee advocacy@metavivor.org a few sentences to answer one of these questions:
 - How has having access to a clinical trial extended your life? OR
 - What lines of therapy have you had access to that have been approved by the FDA since your initial MBC diagnosis? How much time were you able to spend on each of those lines of therapy?
2. **Tell your lawmakers how dangerous this communications and funding freeze is.** We need your help making sure your legislator understands the impact of the White House's block on communications between researchers as well as the indefinite stoppage of federal grant money. They need to know how this will interrupt your care or block your ability to advise scientists who are focused on MBC research. (*TEMPLATE ON PAGE 2*)
3. **If you are on social media, write a post tagging your legislator and use METAvivor's Advocacy handle: "until no one dies of MBC".** *TEMPLATE message:* "Interrupting Research is a Death Sentence to those with metastatic breast cancer. [[@Representative/Senator handle](#)] #METAvivor until no one dies of MBC"

TEMPLATE EMAIL:

Subject line: Continuity of care is key for patients with metastatic breast cancer. White House directives are life-threatening.

Dear Representative/Senator _____,

I am a patient with metastatic breast cancer (MBC). 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).

Thank you for your previous support for funding of the National Institutes of Health and the life-changing research performed there, as well as your support for including metastatic cancers in the Department of Defense's CDMRP research projects.

On behalf of myself and the tens of thousands of patients with MBC, I'm asking you to speak up and challenge the White House's indefinite prohibition on external communications between the Department of Health and Human Services and outside groups. Prolonged delays of meetings to review vital research proposals will hinder the launch of promising studies and disrupt the crucial exchange of discoveries and insights among scientists and researchers. Furthermore, the stoppage of payment of previously awarded federal grants is dangerously disruptive and could result in the termination of promising and life-extending research. Patients with MBC have an average life expectancy of 2-5 years—we cannot afford to wait.

[Tell your lawmaker how this will interrupt your care or block your ability to advise scientists who are focused on MBC research. If you are located in a geographic region where you have limited access to oncologists as well as clinical trials—include how far you have to drive to get care, how often you make the trip, and how far you'd have to travel to get to a provider who offers clinical trial care.]

I'd be happy to talk to you anytime if you have questions about what it is like to live with MBC and fight for my life every day.

Thank you ahead of time for standing up for your constituents,

[Name]

Patient with metastatic breast cancer or loved one/caretaker of someone with metastatic breast cancer

[mailing address]

[phone number]

Thank you. Speaking up is crucial. Together we can make a difference.