

METAvivor

# Basic Advocacy Toolkit

**March 2023**

Welcome to the METAvivor metastatic breast cancer advocacy team!

Thank you for your support of METAvivor and our mission of improving benefits and increasing research funding for metastatic breast cancer (MBC). If you are reading this, you or someone you know, is living with metastatic breast cancer. Did you know that less than 10% of all the money spent on breast cancer research goes to fund research exclusively focused on metastatic breast cancer? Or that 30% of people diagnosed with early-stage breast cancer will unfortunately progress to stage IV? This has to change. Through our advocacy, we can address these disparities, and increase the resources available for metastatic breast cancer research and support.

Our mission is to fund research in order to end death from metastatic breast cancer--or at least make MBC a survivable chronic condition with a good quality of life until a cure is found.

This is where advocacy comes into play. We will do this through a combination of direct engagement with our elected officials and grassroots advocacy to make sure that our voices are heard and that we can advance our priority issues.

***METAvivor's Advocacy has already made a difference.*** Thanks to the active participation of METAvivor advocates and allies we have already seen:

- An increase of federal funding of \$13.9 billion for the National Institutes of Health (NIH) and an increase of federal funding of \$1.69 billion for the National Cancer Institute (NCI);
- An increase of \$80 million in the Defense Department's Peer-reviewed cancer research program and \$30 Million for breast cancer.
- Continued Appropriations Committee Language Recommending an update to the SEER (Surveillance, Epidemiology, and End-Results Registry) to reflect metastatic recurrence and cancer migration across the country.
- METAvivor has also directly funded \$23 million in private grant research since its inception.

But that's just a start! Working together we can increase funding and support even more.

***Building increased advocacy capacity:***

In the past, METAvivor's advocacy work was focused around the Stage IV Stampede held every autumn in Washington DC (and in 2020 and 2021 held virtually). The Stampede will always remain a centerpiece of our advocacy efforts, but we are expanding to build a year-round advocacy program so we can communicate with elected officials and policymakers at critical moments in the legislative process.

You can participate in METAvivor's advocacy program in at least three impactful ways:

1. As an Advocate (volunteers who help by contacting elected officials at different times)
2. A State Captain (a volunteer leader who helps recruit and communicate with Advocates)
3. A Mentor (a volunteer leader who helps train and support Advocates and State Captains).

***Advocacy toolbox:***

METAvivor provides a rich, authoritative Advocacy Toolkit to assist you in your advocacy efforts. This “basic” Advocacy Toolkit is designed to support METAvivor Advocates as they get begin contacting policymakers. It contains background information on METAvivor, a basic advocacy fact sheet, an introduction to METAvivor’s current issue agenda, and a selection of tip-sheets for contacting policymakers. METAvivor will be developing additional tools and trainings to support our advocates over the coming months.

Thank you so much for being a part of METAvivor’s Advocacy Team!

Best Regards,

The METAvivor Advocacy Committee

*P.S. We are just an email, text, or phone call away. If you have any questions about what you see in the toolbox or just need to talk, please contact advocacy mentors Elizabeth “Bess” Harris at [sometimesunshine@msn.com](mailto:sometimesunshine@msn.com) or 1-406-580-7944 or Alpha Lillstrom at [alpha@metavivor.org](mailto:alpha@metavivor.org).*

## METAvivor Fact Sheet

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*Before beginning any advocacy, we thought it would be helpful to share some basic information about METAvivor and metastatic breast cancer so that you have it at your fingertips.*

### About METAvivor

METAvivor is a non-profit charity with the mission to raise awareness, fund research specific to metastatic breast cancer (MBC), and support those affected by MBC. The organization was established by a small group pro-active MBC patients who felt that the lack of research and support dedicated to their disease and to those suffering from it was just plain wrong. Their determination to make a difference has made METAvivor what it is today. In the years since its founding, METAvivor has become internationally recognized for raising awareness and funding research specifically for stage 4 breast cancer. METAvivor has funded \$17.25 million in MBC research since its inception.

### Metastatic breast cancer

Metastatic breast cancer occurs when cancerous cells travel from the breast to a vital organ making the cancer a life-threatening disease. Metastasis refers to the spread of cancer to different parts of the body; breast cancer typically shows up in the bones, liver, lungs, and brain. 73,000 to 86,000 Americans are diagnosed with metastatic breast cancer **each year** and an estimated **300,000** Americans are currently living with metastatic breast cancer. Over time, more and more people are living longer with this condition as a result of new therapies which have improved the quality and length of life.

### The Issue

Awareness of metastatic breast cancer is not enough. Action is needed to continue to sustain and extend the lives of so many Americans! In the United States, someone dies from breast cancer every 13 minutes. Despite a huge movement to raise awareness and funds for general breast cancer research, this number has not decreased significantly in nearly 40 years. Scientists know that research specifically focused on metastasis is crucial to significantly reduce breast cancer mortality. Metastasis research is challenging for various reasons. However, the biggest obstacle is lack of funding: fewer than 10% of the funds raised for breast cancer research is spent on studies of metastasis.

If you know someone who has died from breast cancer, they died from metastatic breast cancer. Most people don't know and understand the difference between early stage and metastatic breast cancer. And yet, fewer than 10% of breast cancer research funding is dedicated to understanding MBC or finding solutions to significantly extend the lives of those living with the disease. Research focused on MBC is crucial; between twenty and thirty percent of those diagnosed with early-stage breast cancer will metastasize and every day 115 people will die from MBC.

### The Need

Stage 4 MBC needs more...30% more funding for research specific to Metastatic breast cancer.

## The Basics: Introduction to Grassroots Advocacy

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*A grassroots advocate is someone who cares enough about an issue--in our case metastatic breast cancer (MBC)--to speak up about it by contacting their elected officials – members of Congress, state legislators, or their local officials.*

### What is Grassroots Advocacy?

- Grassroots advocacy involves putting a human face on an issue or set of issues so that policymakers can better understand what is at stake.
- The point of grassroots advocacy is to demonstrate to key policymakers that their constituents are eager for them to act on issues impacting people battling metastatic breast cancer.
- The focus of grassroots advocacy is sharing your story, experience, and reasons for being involved.

### Who is a Grassroots Advocate?

- This may be obvious, but the answer is YOU and anyone else who has an interest in metastatic breast cancer. Those could be our friends, family members, colleagues, and social media contacts. All of these people are potential grassroots advocates.

### Why Engage in Grassroots Advocacy?

- *Elected officials listen to their constituents.* This is especially true on less partisan issues like cancer. But elected officials only know what we care about if we tell them!
- *Our stories matter.* Elected officials are bombarded with facts and figures all of the time. Grassroots advocacy allows us to put a human face on our issues and requests. It is harder for policymakers to say “no” when they understand our stories and experiences.
- *Advocacy increases our power.* The more people we get involved, the more power and influence we will have.
- *Advocacy can help with fundraising.* As people get more involved with advocacy and help recruit other advocates these new supporters are more likely to contribute and help fund additional metastatic breast cancer research through METAvivor.

### How do You Engage in Grassroots Advocacy?

- There is no exact right or wrong way to practice grassroots advocacy. You do not have to be an expert on the issue or know an elected official to be an advocate/volunteer for METAvivor.
  - The ***most important thing is to share your story and experience.*** Sharing your own experience is very powerful—both to educate and persuade policy makers to act.
  - If you don’t have a personal story, another option is to share the story of a friend, family member, or neighbor who is willing to have you share their story with a policymaker (and encourage them to join the METAvivor advocacy team too)..
  - You can use personal letters/emails, phone calls, visits, and other things like letters to the editor or local events to help persuade your elected officials to support our issues.

## METAvisor 2024 Federal Issue Agenda

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*METAvisor's issues and agenda will change annually based on current opportunities and past successes. The issues agenda is developed and approved by METAvisor's Board of Directors and the full agenda can be found online at [www.metavivor.org](http://www.metavivor.org). Here is a summary of key issues for the current 118th Congress. Texts of each bill and fact sheets for all of these priority issues may be found on our website.*

### Advance Research

- National Institute of Health: Provide the National Institutes of Health (NIH) with a \$3 billion funding increase for Fiscal Year 2024 specific to the metastatic condition, which would bring total NIH funding up to \$44.7 billion annually).
- Provide a meaningful funding increase for the Department of Defense Peer-Reviewed Cancer Program and ensure continued inclusion of “metastatic cancers” in this program.

### Improve Tracking of Metastatic Cancer

- Encourage timely efforts to assist the National Cancer Institute with fully modernizing the Surveillance, Epidemiology, and End-Results Registry (SEER).
  - SEER was established in 1973 when much less was known about metastatic cancer and longevity after a metastatic cancer diagnosis.
  - SEER's outdated and rigid criteria means that it fails to collect data on metastatic recurrence (when early-stage cancer progresses to metastatic status), instead it's data only reflects those who were diagnosed with MBC *de novo*. As a result, the SEER Registry systematically undercounts the total number of cases of metastatic breast cancer.
  - SEER also fails to record the origin site of 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 root cause which is breast cancer.
- By undercounting the impact of metastatic cancers, metastatic cancer is not receiving the share of research funding to which it is entitled.

### Improve Care

- The Metastatic Breast Cancer Access to Care Act (S.663/H.R.549): This 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 unjustly means because of their reduced lifespan (currently averaging 33 months after diagnosis) that many people with MBC are unable to collect the benefits that they paid into the system.
- The Cancer Drug Parity Act: This legislation ([S.2039/H.R.6301](#)) would require various agencies and health insurers to pay for the medications doctors prescribe because they are the best fit for their patients—even if those medications are more costly than alternatives. It would also require insurers to cover oral medicines and intravenous or injected medications equally and prevent

insurers from 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.

## Tips for Calling Your Legislator

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*Making a phone call to your legislator is quick, easy, and may be done at a moment's notice--making it a useful method for legislative contact. For these same reasons, it is critical that the phone call be effective. You do not need to be an expert on the issue ~~in order~~ to be persuasive; you just need to give your personal perspective. Follow these steps for an effective call to your legislator:*

1. **Prepare:** Before you make the call, **think through** what you are going to say. Your phone call will likely be very brief, so keep your message simple and to-the-point. Take a moment to make some notes about what you want to say. You will find that your call is easier and goes more smoothly than if you were to call "off the cuff". Know your request (for example, "Please cosponsor the Metastatic Breast Cancer Access to Care Act (S.663/H.R.549)" so you can state it clearly.
2. **Story:** After identifying (and possibly writing down) your request, think about a key point or **personal story** that supports your position.
3. **Call:** Make the **call**. It is most likely that you will talk to one of the legislator's **staff**. Make sure you get the staff person's full name and treat them with respect. If you leave a message, be sure to include your full name, town you live in and your email address so they can contact you for follow-up.
4. **Constituent:** Begin by stating that you are a **constituent**. Legislators are most responsive to the people who can keep them in office—their constituents.
5. **Familiarity.** Ask whether the staff person has any family or friends who have been impacted by metastatic breast cancer.
6. **Persuade:** Get to the point. Following your plan, state the reason for the call. Ask the staff member to state the legislator's position on the issue and try to **persuade** them using the points you developed or sharing your personal story.
7. **Thank:** If they agree to support your issue, **thank them**. Regardless of their position, thank the staff member or legislator for their time. Let them know that you will be tracking the issue.
8. **Recruit:** Recruit a like-minded friend, family member, or colleague to make a call as well. Share your notes with them so they don't have to do "homework" before placing the call. Particularly with phone calls, quantity is critical. Legislators pay attention to issues when they believe that many of their constituents care about that issue.
9. **Report** your call. When you are part of a grassroots effort, your participation is most helpful when the people mobilizing the effort know about it. Let them know that you made the call, and report anything of import that the legislator said.

10. **Call Back:** If you haven't received a response, call again a week later. Quantity is as important, if not more important, than quality in grassroots advocacy, because a high number of calls indicates to a legislator that many people in their district care about an issue. As you monitor the issue, **call back** to ask for specific support or action as appropriate to the process. METAvivor will provide guidance and suggestions for when additional calls will be helpful.

## **Tips for E-mailing Your Legislator**

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*E-mail has in many ways replaced other forms of communication with policy makers, such as phone calls or letters. This technological tool is fast, cheap, and efficient. METAvivor will soon have an advocacy platform that makes it easy to email your legislator. Here are some things to keep in mind when communicating.*

1. **In the subject line of the message, state that you are a constituent** (For example—*Subject: Message from a constituent on xyz issue*). Most legislators have their staff sort and respond to their e-mail, and this strategy will increase the likelihood that your letter is read.
2. **Make an actionable ask** such as “Please cosponsor the Metastatic Breast Cancer Access to Care Act ([S.663/H.R.549](#))” so that your lawmaker knows exactly what you would like them to do.
3. **State your request concisely.** E-mail is less formal and much more brief than traditional written communication. Craft your message accordingly—keep it tight and short—but be sure to use proper grammar and punctuation.
4. **Provide personal examples and local context.** Use similar principles as those in letter-writing, but in a tighter format. If you are using a template email provided by a group, be sure to customize it and include personal examples in the message. Many emails which say the same thing aren't given as much weight as customized correspondence.
5. **Persuade a like-minded friend, family member, or colleague to send an e-mail as well.** Again, quantity is critical. Legislators pay attention to issues when they believe that many of their constituents care about that issue. One e-mail is not convincing or compelling.
6. **Report your e-mail.** If the e-mail is initiated by METAvivor please report back that you sent your e-mail. Some groups can monitor responses electronically without your having to report, but most want you to let them know. If you persuaded a friend, let them know that that friend will be reporting as well. Make sure that your friend follows through, and encourage your friend to join the METAvivor Advocacy Team.
7. **Follow up.** Again, because the impact of e-mail varies widely from legislator to legislator, be sure that you are using other methods to communicate with your legislator. Follow your e-mail with a phone call or visit.
8. **Communicate more than once.** As with all other forms of communication with your legislator, view your e-mail as part of an ongoing relationship. Ask for the name of the lawmaker's staff



who handles healthcare issues. Keep in touch with that staffer and remain tuned into your legislator and his or her position on the issue. METAvivor will provide guidance and suggestions for when additional contact will be helpful.

9. **Follow-up with a thank you email** to the legislative staff for their time and restate in the email the purpose of your call once more as a reminder. For example: “Mr. Smith, Thank you for your time and attention today and allowing me to discuss MBC and METAvivor’s Advocacy goals with you. Please relay our conversation to Senator X, and let him know that his constituent(s) ~~has~~ called and asked for him/her to cosponsor House Bill XYZ or Senate Bill XYZ. A favorable response from Senator \_\_\_\_\_ would be greatly appreciated!”  
Sincerely,

First and Last name

Constituent from House [State, District XX] or Senate [State]

Phone number

Email address

## Tips for Meeting Your Legislator

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*A face-to-face meeting with your legislator can be a powerful opportunity to advance your agenda. The meeting may also position you as a reliable expert on your issue and an important ally for your legislator or their staff. Follow these steps for a successful visit:*

1. **Plan your meeting.** Decide whether you are going alone, or with a group of fellow constituents. If you go as a group, decide who is going to lead the meeting, and what each person is going to contribute to the discussion. This will help eliminate awkward silences or repetitive messages and will ensure that you hit all the key points you want to cover. You will likely have only 15 or 20 minutes for your meeting, so plan accordingly. ZOOM meetings may be a second-best method of gaining an audience with your legislator or their staff person and allow a group of Advocates to join the meeting. ZOOM may be highly effective when an in-person meeting is difficult to schedule or traveling to Washington DC outside of the Stampede in the fall is not feasible.
2. **Know your audience.** Do a little research about your legislator. Find out if they are generally interested in healthcare issues, have a personal connection to breast cancer, or are a member of the [House Cancer Caucus](#) or the [Senate Cancer Coalition](#). Find out his or her positions on the issues you are focusing on. Check congress.gov to see if they have already cosponsored the bills you are going to talk to them about. METAvivor will help with this.
3. **If there are multiple issues that are important to you, select one that you will discuss or focus on for that meeting.** While it is certainly appropriate to mention multiple issues, it is often most effective to focus attention on your top priority.
4. **Define your message.** Focus your comments on your priority issue. Plan on sharing your personal story or experience which will help make you an even more credible and compelling voice. Then, rather than trying to say everything you know or think about that issue, plan two or three observations that get at the heart of your position.

5. **Meet in your home district if possible.** Meetings in the home district are often less hurried than meetings at the Capitol, and they provide the “home turf” advantage. This applies to scheduling ZOOM calls as well. Find out when your legislator is in his or her home district, and schedule your appointment then, or if your workplace illustrates your position, invite them to visit you. If this is not possible, travel to the Capitol as an alternative.
6. **State the reason for your visit.** Be clear about why you are there, why they should be interested (remember to mention again that you are a constituent, and use local examples), and what you want them to do.
7. **State your case.** Again, keep it concise, focused, and personalized. Your story matters most!
8. **Invite comments and questions.** Engage your legislator or their staff member in dialogue. Do not worry if they ask you something you don’t know the answer to—simply tell them you don’t know, but that you’ll find out for them.
9. **State only what you know.** Do not overstate your case, fudge the facts, or guess.
10. **Ask for a commitment.** If you don’t ask your legislator or their staff member for action, you won’t see any. If they decline, encourage them to think about it, and let them know you will keep in touch.
11. **Have a leave-behind.** Provide your legislator with brief, written information for further reflection. Make sure it contains the local angle for your district, if possible. Write your name, town, and email address on the paper so that they can be reminded who they talked to.
12. **Report on your visit.** As soon as possible after your visit (in the hallway is ideal), jot down notes that record the tone, what was said, and what questions were asked in the meeting. Not only will this help in reporting on your visit, but it will help you build a record of your relationship with your legislator that can inform future dialogue. Let your group know that you made the visit, and report what you covered and what the legislator said. If possible, provide them with a copy of your leave-behind materials as well. METAvivor will send you a post-visit questionnaire on which to report the results of your meeting.
13. **Follow up.** Send a thank-you note to your legislator or the staff member with whom you met. Let them know that you appreciate their time. If you promised to get them additional information, provide it or let them know how and when they can expect to receive it.

## **Ten Tips for “Printable” Letters to the Editor**

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*An underused resource in grassroots advocacy is the local media. Letters to the editor can be powerful vehicles for influencing or inspiring public debate, making the case for your issue, or responding to related events. In addition, elected officials always read the opinion pages of their local paper; because it gives them an idea of what their constituents think. The trick is to write a letter that the editors find compelling enough to print. Use these tips to write a letter that is more likely to get printed:*

1. **Capitalize on the hot stories.** Find ways to tie stories in the news to MBC. For example, March is Women's History month, Mother's Day is in May, October is Breast Cancer Awareness month, and October 13<sup>th</sup> is MBC Awareness Day so you can use those as a jumping off point to discuss our issues. Anytime you are a month or two from a primary or general election is also good time to write a letter to the editor about a legislative issue.
2. **Keep it brief.** Most Letters to the Editor should be under 250 words. Edit your letter aggressively. Many newspapers impose hard limits on number of words. Your letter will NOT be printed if it goes over the allowed number of words. Check the rules before submitting your letter.
3. **Be clear.** This may seem obvious, but a surprising number of letters that do not get published just plain don't make sense. Avoid jargon and acronyms, use common vocabulary, and ask a few friends or colleagues review the letter for you before you send it.
4. **Make it personal.** Ground your letter in your personal story and/or experience. Tie the change you are advocating for to what you or your loved one has experienced.
5. **Use word cues to underscore your point.** For instance, preface your major conclusion with "The important thing is,..." If you have research that makes your case, preface the facts with "Research proves that..."
6. **Do not overlook neighborhood weeklies and smaller papers.** Often these publications have more room for letters, and community papers have very large readerships.
7. **Include a call to action or solution.** If you are illustrating a need or making a case for a specific action, include a line about what people may do to help.
8. **Do not be afraid to toot your own horn.** If you or your organization (METAvisor) are involved in work that addresses the issue, including that in your letter can help attract other supporters. (And increase exposure for METAvisor itself.)
9. **Be passionate, but not poisonous.** There is a difference between "fire in the belly" and righteous indignation. Avoid sarcasm, and if you are angry, cool off a bit before sending a final version.

## **Basic Legislative Process**

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Before a bill can be introduced, a lawmaker must agree to "sponsor" that legislation. Once it is introduced, it will be assigned a number. *H.R.* means House of Representatives and *S.* is for Senate). Often a bill is introduced in both the House and the Senate, if the bill language is the same in both they will be called "companion bills". A big part of advocacy is to ask other lawmakers to join bills as "cosponsors". The more cosponsors a bill obtains, the more likely it will be considered by a

committee, be the subject of a hearing, or even be brought up for a vote. Every two years there's a new Congress, and if a bill isn't brought to a vote within those two years, the bill dies and you have to start all over again. This is why you will recognize the names of some of the bills we are advocating for (but the bill numbers have changed).

You can find your representative [here](#) and your senator [here](#), plus links to sites with their email addresses. Contact them and ask that they sign onto the bills as sponsors.

## **Nuts and Bolts of Lobbying the Staff of a Member of Congress**

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### **Long-game**

- Build and sustain a trusted relationship with the legislator and staff
- Persistence with hard-to-reach Members

### **Meeting Pointers**

- Identify yourself, where you live, and other family connections in the district. Write this information and the date on the leave-behind document.
- Emphasize difference between MBC and early-stage breast cancer
  - Only \_\_% of breast cancer research funding is focused on MBC—the breast cancer that kills.
  - The SEER Registry undercounts MBC patients by at least 30% (those who had early-stage breast cancer, then progressed).
- Briefly explain two or three legislative issues
- Share an example of how one of those issues impacts your access to treatment or financial well-being.
- Invite staff and Member of Congress to keep in touch and use you as a resource.
- Reiterate “The Ask”
- Hand them the leave-behind documents as you leave
- Use social media to thank Member of Congress for meeting that day (ideally attach photos). Tag Members of Congress and use #[META]vivor Advocacy][StageIVneedsMore]
- Email a thank-you note a few days later, and attach relevant one-pagers

### **Resources Available**

- META]vivor Website
- META]vivor Advocacy Toolkit

### **Don'ts**

- Don't forget to ask for them to cosponsor legislation
- Don't be afraid to say, “I don't know” then tell them that you will get back to them with the answer
- Don't bring campaign donations to the official office