

METAvivor

Basic Advocacy Toolkit

April 2021

Dear metastatic breast cancer Advocate,

Thank you for your support of METAvivor and our mission of improving benefits, increasing research funding for metastatic breast cancer. If you are reading this, you or someone you know, is living with metastatic breast cancer. Did you know that only 2% of all the money dedicated to breast cancer research goes to fund metastatic breast cancer? Or that 30% of people diagnosed with breast cancer will unfortunately experience a metastasis? This has to change and through our advocacy we can alter these dynamics and increase the resources available for metastatic breast cancer research and support.

Our goal is to fund research to end death from metastatic breast cancer or at least make it 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 \$1.25 billion for the National Institutes of Health (NIH) and an increase of federal funding of \$119.41 million for the National Cancer Institute (NCI);
- An increase of \$5 million in the Defense Dept. Peer-reviewed cancer research program;
- 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 **\$17.25** 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 held virtually). The Stampede will always remain a centerpiece of our advocacy efforts, but we are now building a year-round advocacy program to 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 important ways: as an Advocate (volunteers who help by contacting elected officials at different times), State Captain (a volunteer leader who helps recruit and communicate with Advocates), or 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 Toolbox 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 also be developing additional tools and trainings to support our advocates over the coming months.

Thank you so much for your participation in METAvivor’s Advocacy Program.

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 or 1-406-580-7944 or Dan Cramer at dan@grassrootssolutions.com or 1-651-270-5173.

METAvivor Fact Sheet

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 research since its inception.

Metastatic breast cancer

Metastatic breast cancer occurs when cancerous cells travel to a vital organ and that is what threatens life. Metastasis refers to the spread of cancer to different parts of the body, typically 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, we find more and more people are living longer with this condition as some therapies have improved the quality and length of life.

The Issue

Awareness of Metastatic breast cancer is not enough. Action is needed to continue to make a difference in the lives of so many Americans! In the United States, someone dies from breast cancer every 14 minutes. This number has not decreased significantly in nearly 40 years despite a huge movement to raise awareness and funds for breast cancer research. 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: only an estimated 2% 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 that, and even fewer people understand that. And yet, only 2% of breast cancer research funding is dedicated to understanding MBC or finding solutions to significantly extend the lives of those living with the disease. Every day 110 people will die from MBC. Between twenty and thirty percent of those diagnosed with early-stage breast cancer will metastasize.

The Need

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

The Basics: Introduction to Grassroots Advocacy

A grassroots advocate is someone who cares enough about an issue, in our case Metastatic breast cancer 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 issues surrounding people battling Metastatic breast cancer have support from their constituents.
- 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. The ***most important thing is to share your story and experience.*** You may say to yourself, I do not have a personal story but your friend, family member or neighbor may have a story and you are an advocate/volunteer to share their story for METAvivor..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.

METAvivor 2021 Federal Issue Agenda

METAvivor's issues and agenda will change annually based on current opportunities and past successes. The issues agenda is developed and approved by METAvivor's Board of Directors and the full agenda can be found online at www.metavivor.org. Here is a summary of key issues for the current 117th Congressional Legislative Session. 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 with a \$3 billion funding increase for Fiscal Year 2022 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 systematically undercounts the impact of metastatic breast cancer. SEER fails to reflect metastatic recurrence, thereby significantly undercounting cases of MBC. 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 impact of 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:** 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 ensures that many people with MBC are unable to collect the benefits that they paid into the system because of their reduced lifespan, currently averaging 33 months after diagnosis.
- **The Cancer Drug Parity Act:** This legislation would prevent various agencies and health insurers from refusing to pay for more costly medications that doctors prescribe because they are best for their patients. It would also 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

Making a phone call to your legislator is quick, easy, and may be done at a moment's notice, making it an attractive 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 think about it—you might even want to make some notes--and you will find that your call goes more smoothly than if you were to call “off the cuff”. Know your request (for example support the Metastatic breast cancer Access to Care Act) 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**. Be prepared to talk to one of the legislator’s **staff** or to leave a **message** instead. Make sure you get the staff person’s full name and treat them with respect.
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. Try to get 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 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. 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:** Call more than once. 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

E-mail has changed the way that we communicate and in many ways has replaced other forms of communication, 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. **State your request concisely.** View your message as different from an electronic letter. Again, e-mail is less formal and much more brief than traditional written communication. Craft your message accordingly—keep it tight and short.
3. **Provide personal examples and local context.** Use similar principles as those in letter-writing, but in a tighter format. If you are sending a generic e-mail written by a group of which you are a part, insert personal examples in the message.
4. **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.
5. **Report your e-mail.** If the e-mail is initiated by an organization, ask if they want you to report 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.
6. **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.
7. **Communicate more than once.** As with all other forms of communicating with your legislator, view your e-mail as part of an ongoing relationship. Keep in touch and 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.
8. **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, ~~expressed~~, and advocated for House Bill XYZ or Senate Bill XYZ. A favorable response from Senator Paul would be greatly appreciated!”

~~When signing the email~~

Sincerely,

First and Last name

Constituent from House District XX or Senate District YY

Phone number

Tips for Meeting Your Legislator

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.
2. **Know your audience.** Do a little research about your legislator if you don't know much about him or her. Find out his or her positions on the issues you are focusing on. 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 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.
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

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 with your issue. For example, if Covid is having a big impact on your community use that as a jumping off point to discuss our issues.
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, use common vocabulary, and let 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 (METAvivor) are involved in work that addresses the issue, include that in your letter as it can help attract other supporters.
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.