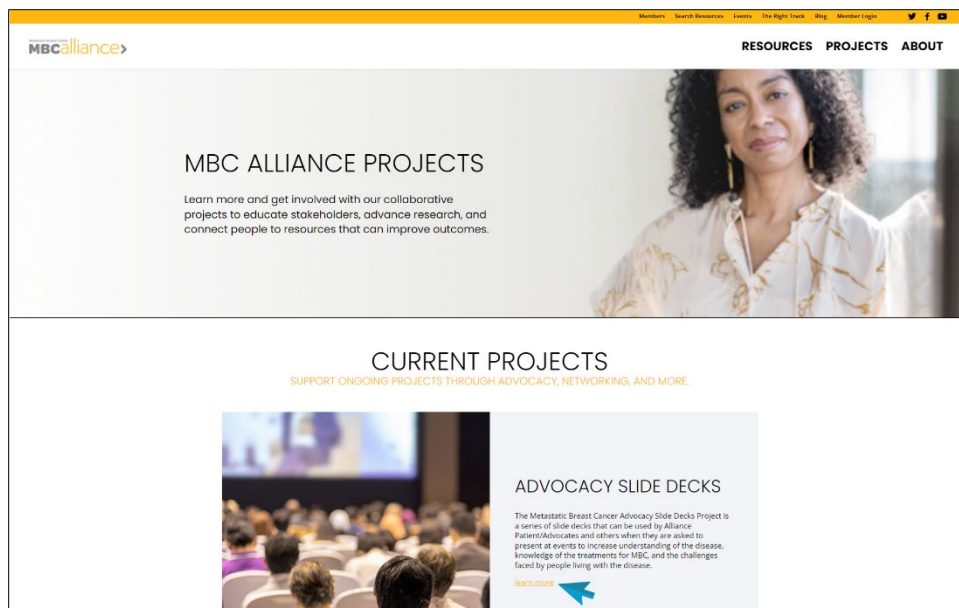
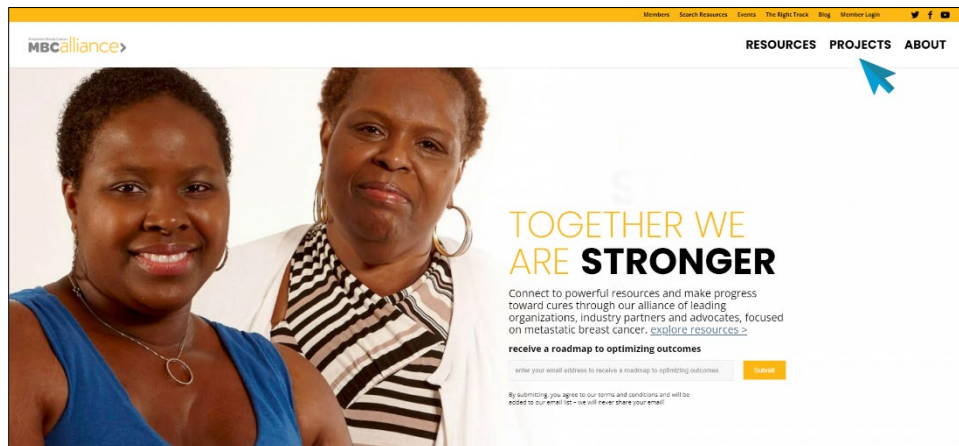


How to Use the Advocacy Slide Decks Video Transcript

Hello, everyone. My name is Caroline Johnson, and I am the founder and executive director of Twisted Pink. We are a nonprofit member of the Metastatic Breast Cancer Alliance. And today, I'm going to be talking to you about how to use the Patient Advocacy Slide Decks that were recently developed.

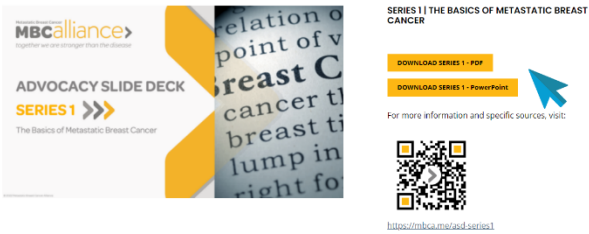
So, I'm going to share my screen and hopefully go to the website and show you. So, you should be able to see the Metastatic Breast Cancer Alliance website. And to access the slide decks, you want to go to **PROJECTS**. So, click on **PROJECTS**, and that's going to take us to the PROJECTS screen and current projects of the Alliance. Advocacy Slide Deck is listed at the top. You want to click on **Learn More**, and then it'll bring you to the four different slide decks.



Series 1 is the Basics of Metastatic Breast Cancer, and this is where you would download the series. You can either **download it in a PDF or a PowerPoint presentation**. I've downloaded the PowerPoint presentation to my computer. And then each series has a scannable barcode, **QR code, and a link** to each of the sources used in each of the series. You could **click on that link or take a picture with your phone**, and this will give you the link to the sources and information on where we found the information for each of the series. You might want to print this out and use it during your talks or provide it as a source at the end of your presentation for your audience. But this is the page on the Alliance website, as I said, that you'll have access to each of the series.

ADVOCACY SLIDE DECKS PROJECT

The Metastatic Breast Cancer Advocacy Slide Decks Project is a series of slide decks that can be used by Alliance Patient/Advocates and others when they are asked to present at events to increase understanding of the disease, knowledge of the treatments for MBC, and the challenges faced by people living with the disease.




SERIES 1 | THE BASICS OF METASTATIC BREAST CANCER

[DOWNLOAD SERIES 1 - PDF](#)

[DOWNLOAD SERIES 1 - PowerPoint](#)

For more information and specific sources, visit:



<http://mbca.me/adv-series1>

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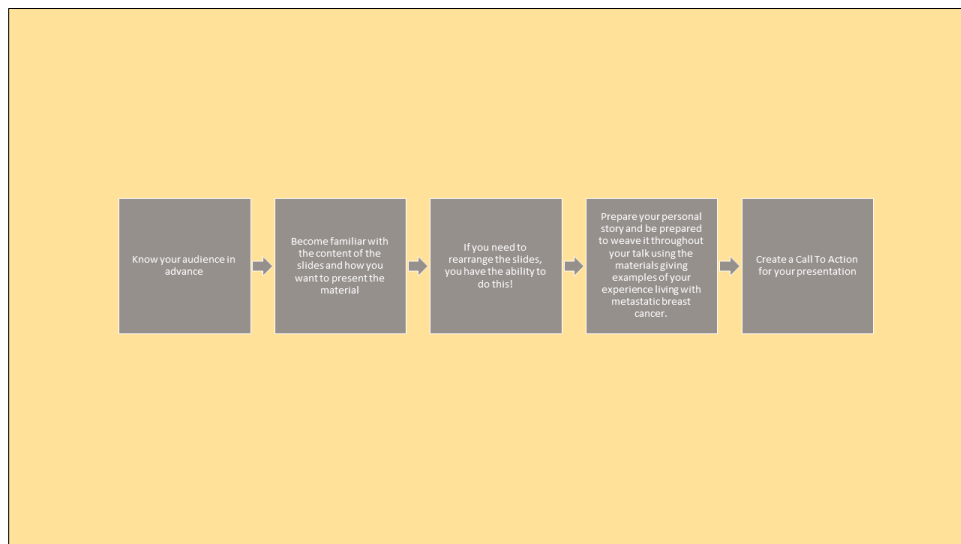
<http://mbca.me/adv-series1>

Series 2 is titled Understanding How Metastatic Breast Cancer Is Treated. Series 3 is Challenges in Metastatic Breast Cancer, Big Issues That Could Change Lives. And then Series 4 is Information for Caregivers. So, we hope that you use the Advocacy Slide Decks as you go out into your communities and speak about metastatic breast cancer and bring awareness and education to members of your community.

And now, I would like to do a new share and share a PowerPoint presentation on some helpful hints to help you prepare for your talk. And as I said, I am a member of the Metastatic Breast Cancer Alliance through the organization Twisted Pink. Our mission is to provide hope and connection to people living with metastatic breast cancer by funding bold breakthroughs in research and awareness of the disease. And I was diagnosed nine years ago with stage 3 estrogen-positive breast cancer, and it's my privilege to present this webinar to you today as a member of the Alliance and an early-stage breast cancer survivor, who advocates more for people living with metastatic disease.



So first, we're going to talk about things to help you get you prepared for your talk. You want to know your audience in advance. You may be giving a talk to other patient advocates. You might be giving a talk to clinicians within a cancer center. They might be nurse navigators, radiologists, oncologists. You might be part of a program that's offering continuing education and giving the patient perspective and using some of these series to talk to those members of your community. So just know your audience in advance, and you will be able to tailor your talk to fit the audience that you will be presenting to.



Become familiar with the content in advance. So, make sure you download those slides and practice your presentation in advance. Make sure you know, the materials ahead of time and be prepared to fill the questions from your audience in advance that will just help you be prepared and not be caught off-guard.

If you need to rearrange the slides, you have the ability to do this. They are not editable, but you can rearrange them the order of the slides, as well as bring slides in from one series to another. So, you might want to talk about the basics in metastatic breast cancer, but also incorporate information about caregiving, and you have the ability to do that.

Make sure you're prepared to weave your personal story in through your talk. Don't just read from the slides. Make sure that you're talking about your own story, because your story is important as a patient living with metastatic disease.

And then at the end, we think it's important to create a call to action. You want to make sure you allow time for questions, but also create a call to action. And that might be anything from following up with the cancer center that you're speaking at, or maybe getting involved as a patient advocate and inviting your audience to get involved with the organization you're talking on behalf of.



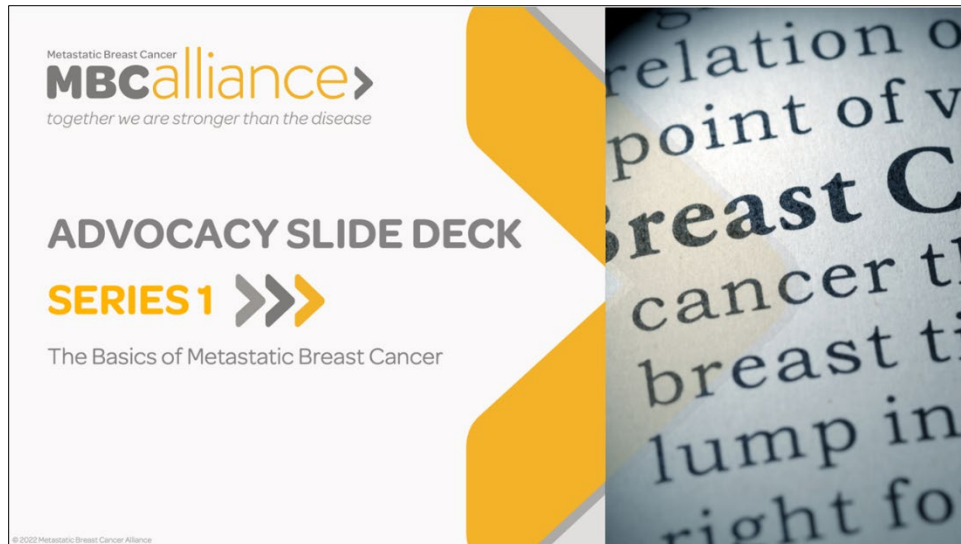
And then next, we just want to talk to you about things to remember during your speech. Make sure you introduce yourself at the beginning. People want to know who you are, what your level of expertise is. And your expertise is obviously going to be a patient, if you're a patient advocate using the Advocacy Slide Deck. If you're a member of the Alliance and working for a nonprofit organization, you want to introduce yourself and talk a little bit about who you work for and why you're using the slide deck series to talk about metastatic breast cancer.

And then speak loudly and slowly enough for your audience to understand you. You want to make sure everybody understands what you're saying during this precious time. And then questions, allow time for questions at the end and make sure that you allow your audience to ask questions of you. If you don't know the answer, don't worry about it. Just make sure that you follow up with that person later and be honest and say, "I really don't know the answer to that question, but I'll find out for you, and we'll talk about it offline another time."

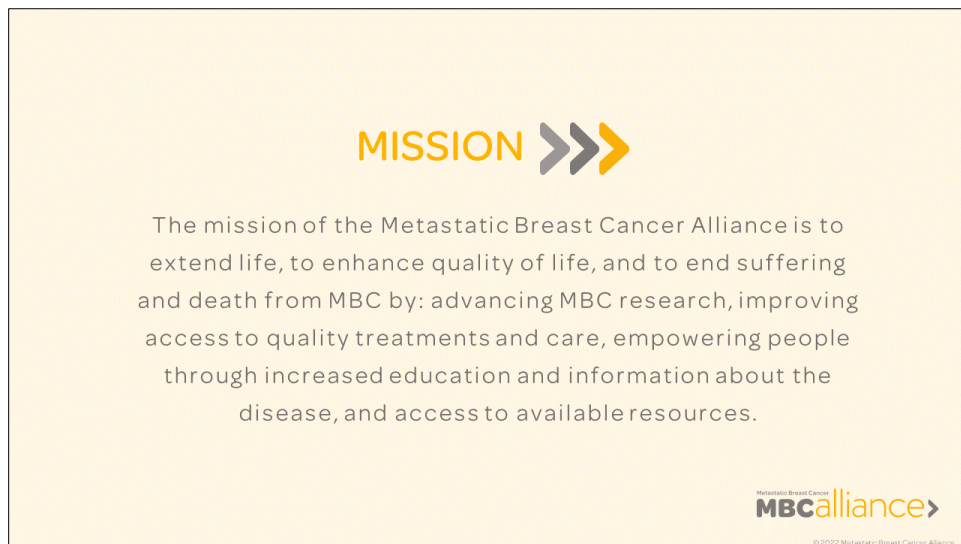
Make sure you're confident. Make sure that your audience knows that you are the patient expert and your experience working within the metastatic breast cancer setting matters. And incorporate your story throughout your speech. Make sure you don't read from the slides, but you incorporate your story throughout.

And so now, I want to give a mock presentation using the Advocacy Slide Deck with Series 1, The Basics of Metastatic Breast Cancer. So, I'm going to go ahead and do this. And again, I'll share my picture here. Again, my name is Caroline Johnson. I am an early-stage 3 estrogen-positive breast cancer survivor. I was diagnosed at age 39 years old, a month before my 40th birthday, with stage 3 breast cancer. And I found a lump myself and went to my physician who ordered a diagnostic mammogram and an ultrasound. And I ultimately, that same day, would have a test, a biopsy on the lump that I found in my left breast. And over the next weekend, it was a holiday weekend, Memorial Day weekend, the following Tuesday, learned that I did indeed have breast cancer.

And so that started my journey, and since that time, I've been making it my personal mission to advocate for other patients. I learned a lot about... I think being a stage 3 patient, I often felt like I was sitting on a fence between early-stage breast cancer and metastatic disease. And so, I made it my mission to learn as much as I could about metastatic breast cancer and what I learned was shocking. And, some of the facts that I learned are in this slide deck, and I'd like to share those with you today.

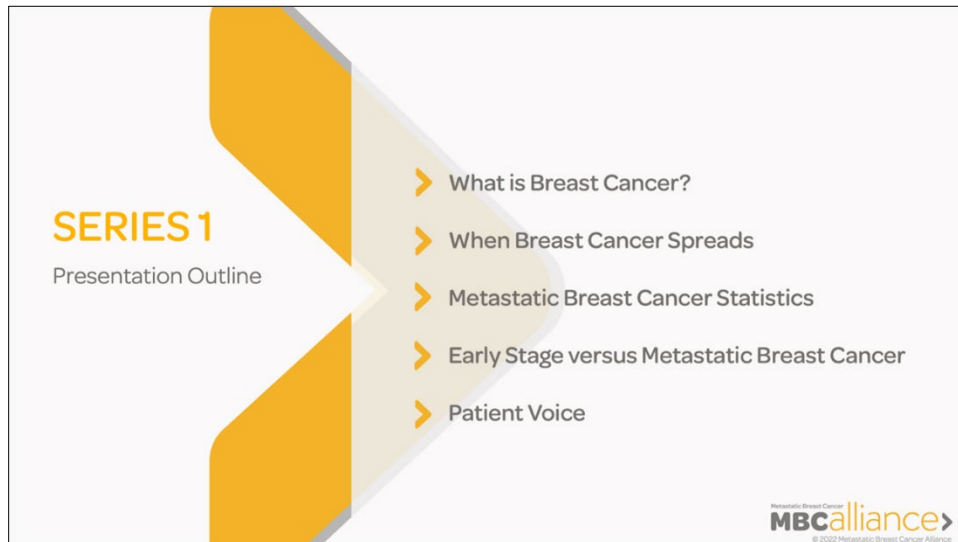


I'm going to be talking about the basics of metastatic breast cancer on behalf of Metastatic Breast Cancer Alliance, whose mission is to unify the efforts of its members to improve the lives of and outcomes for those living with metastatic breast cancer and their families through increasing awareness and education about the disease, ultimately to cure breast cancer. They have a focus on metastases that has the potential to extend life, enhance quality of life, and ultimately cure breast cancer.

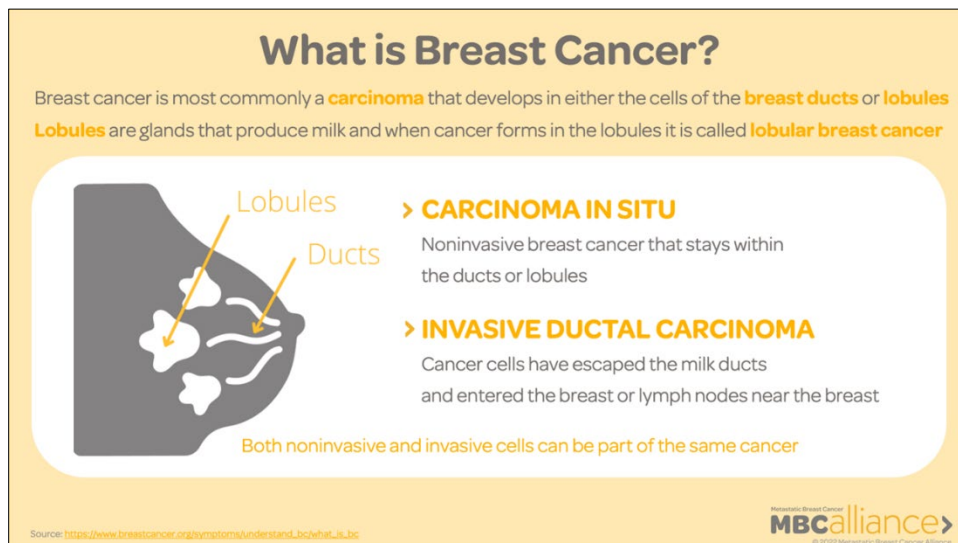


I'm happy to be a part of the Metastatic Breast Cancer Alliance. I've served on many different committees. And today, I'm here to talk to you about the basics of metastatic breast cancer. So, we'll go through what breast cancer is, when it spreads, what it's called. We'll talk about statistics of metastatic breast cancer. We'll look at

the differences between early-stage breast cancer and metastatic breast cancer. And we'll hear some quotes from patients, and you'll get to meet some patients at the end of our presentation.




What is breast cancer? Breast cancer is most commonly a carcinoma that develops in either the cells of the breast or lobules. You can see here on this slide that breast cancer that remains in the ducts or lobules is called carcinoma in situ, and that's noninvasive breast cancer that stays within those areas. Invasive ductal carcinoma is when cancer cells have spread beyond those areas of the lobules and ducts and entered the breast or lymph nodes near the breast. And both non-invasive and invasive cancer cells can be part of the same cancer. So, you can have cancer cells in the ducts and also cancer cells within the breast or lymph nodes.




My personal story with breast cancer is that my breast cancer was invasive ductal carcinoma and stage 3. That meant that it was estrogen-positive, and it had already traveled through the lymph nodes. I had 18 lymph nodes removed during my lymph node biopsy at the time of my lumpectomy. And my lumpectomy actually did not have a clear margin. So, we decided to go ahead and do a mastectomy on the left breast. And that started my journey before chemo and radiation. I'll talk a little bit more about that later.

Women and men can receive a diagnosis of breast cancer



1 in 8 women
Will develop invasive breast cancer in their lifetime

1 in 833 men
Approximately 1% of all breast cancer cases occur in men



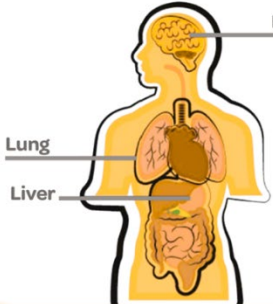
Source: <https://www.cancer.org/cancer/05m/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2019-2020.pdf>

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But women and men can receive a breast cancer diagnosis. It's obviously more common in women. One in eight women will develop invasive breast cancer in a lifetime, and approximately 1% of all breast cancer occurs in men.

When Breast Cancer Spreads

Metastatic breast cancer (MBC) is breast cancer that has spread beyond the breast to other parts of the body. Breast cancer most commonly spreads to the bone, brain, liver or lungs




Brain

Lung

Liver

No matter what organ is affected by breast cancer cells it is still called **metastatic breast cancer** and treated with breast cancer treatments



Bones

Source: <https://www.cancer.gov/types/metastatic-cancer/how-cancer-spreads>

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When breast cancer spreads, it is called metastatic breast cancer. It most commonly spreads to the brain, bone, liver or lungs, and you can see that in this diagram here, that metastatic breast cancer, because it starts in the breast, if it goes to the bone, it's still considered breast cancer. It's just called metastatic breast cancer to the bone, and the same with traveling to other organs.

MORE ON MBC

- Also referred to as Stage IV breast cancer
- Metastasis, or spread, can occur regardless of the size or stage of the primary tumor
- Breast cancer cells spread through the lymphatic system or bloodstream to distant parts of the body, where they may lie dormant for months or years

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And metastatic breast cancer is also considered stage 4. There is no cure for metastatic breast cancer, and regardless of the size or stage of the primary tumor, metastases can occur at any time. So, for instance, I was diagnosed with stage 3 breast cancer nine years ago. If I were to have a recurrence, I would be considered stage 4, and it would be called metastatic breast cancer. Breast cancer cells spread throughout the lymphatic system or bloodstream to distant parts of the body, where they may lie dormant for months or years.

MBC Statistics

The exact percentage of metastatic recurrences among those treated for early-stage breast cancer is unknown, but estimates range between **20-30%**¹

De novo MBC means that the cancer was metastatic upon first diagnosis. In the US, this accounts for **6%** of people living with MBC²

It is estimated that there were **168,000** US women living with MBC in 2020³

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Sources:
 1. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC371134/>
 2. <https://www.cancer.net/cancer-types/breast-cancer-metastatic-statistics>
 3. <https://onlinelibrary.wiley.com/doi/10.1002/ajoc.12017>

Roughly 20 to 30% of breast cancer patients will experience a metastatic recurrence, and only 6% of people living with metastatic breast cancer are diagnosed de novo, and that means at initial diagnosis. And it's estimated that there are 168,000 people in the US living with metastatic breast cancer. We believe this number is higher though, because of the way the metastatic breast cancer patients are counted.

Early Stage versus Metastatic Breast Cancer

	Early-Stage Breast Cancer	Metastatic Breast Cancer
Location of disease	Confined to breast ducts and lobes and adjacent lymph nodes	Most common to bones, brain, liver, lungs
Number of cases	All cases counted	Counted only if De Novo
Stage of disease ¹	0, I, II, III	IV
Threat to life	Only if untreated	Incurable but treatable
Treatment goal	Curative	Control disease and maintain quality of life
Treatment length	Limited	For rest of patient's life
5-Year survival rate ²	Local 99%; Regional 86% ³	28% women and 22% men
Research dollars ⁴	93% of all breast cancer research dollars	7% of all breast cancer research dollars

Source: Metastatic Breast Cancer Network (www.mbcn.org)

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In this chart, we'll show you the difference between early-stage breast cancer and metastatic disease. Obviously, I talked at the beginning a little bit about how early-stage breast cancer remains in the breast ducts or lobules and can also be in the adjacent lymph nodes, as it was in my case, and metastatic breast cancer travels beyond those locations to other areas of the body, most commonly the brain, bone, liver and lungs. And in early-stage disease, all cases are counted, and early-stage disease is considered stage 0, 1, 2 or 3. The threat to life is only if untreated, it will progress to stage 4. However, we know that even with treatment, metastatic breast cancer can and does happen in early-stage disease in 20 to 30% of patients.


The treatment goal for early-stage breast cancer is curative. The goal is to cure the disease and have it remain in remission for the rest of your life. But with metastatic breast cancer, which is considered stage 4, it's not curable. It's treatable, but not curable. And the goal is to control the disease and maintain a high quality of life.

As far as the number of cases for metastatic breast cancer, you're only counted if you are diagnosed from the beginning de novo. Treatment length for early-stage disease is limited to chemotherapy, radiation, the standard of care and sometimes taking medication for a limited time after any type of standard of care therapy, but for a metastatic patient, they will be in treatment for the rest of their life.

And according to the five-year survival rates, early-stage breast cancer has a 99% five-year survival rate for local disease, and for regional disease an 86% survival rate. With metastatic breast cancer, the five-year survival rate in women is 28%, and in men, 22%.


And looking at research dollars, most of the research dollars go to early-stage breast cancer research. 93% of all breast cancer research dollars goes to early-stage, and then only 7% of breast cancer research dollars are looking at the already metastatic breast cancer research. And so, part of what the Alliance is doing is to create awareness and education about some of these statistics and hopefully change the level of interest for researchers to really focus on metastatic breast cancer.

Patient Voice: Getting the diagnosis




My de novo MBC diagnosis was a complete shock. Asymptomatic and feeling great. Being a nurse of 40 years was no help at the beginning of the journey. I have to advocate everyday for myself or someone else. But life continues and I fight to have a good quality of life.

Stephanie
MBC diagnosis in 2015



I was diagnosed with stage 11b HER2+ breast cancer in January 2010. I was panicked. I didn't do any reading, research, or see an oncologist. I just wanted the cancer out of me ... A routine x-ray 4. 5 years later found the lung metastasis. After a year on H+P, I progressed. That's when I began to research, question my oncologist, find resources for second opinions.

Lori
MBC diagnosis in 2014



After my early stage diagnosis, I still had hope for a normal life on the other side of treatment. When I was diagnosed metastatic, fear and grief became constant companions. I grieve for the life I thought I'd have, for my family, and for cancer friends who have died. And even though I've been fortunate enough to live a pretty normal life for nearly six years, I fear the day that cancer takes that from me.

Kristen
MBC diagnosis in 2015

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Here we have the voice of the patient, which is so very important when talking about metastatic breast cancer. Obviously, each person is different and has a different experience with their diagnosis. You look at Stephanie, who Stephanie is actually a patient advocate with the Metastatic Breast Cancer Alliance and one person that was implemental in helping to develop the series that you see here and will be able to use yourself if you so wish.

Stephanie was diagnosed de novo, which means her cancer was stage 4 from the beginning, and it came as a complete shock to her. She had asymptomatic symptoms and was feeling great at the time. She was a nurse for 40 years, and the fact that she was a nurse, she felt like that was really no help at the beginning of her journey with metastatic breast cancer. She has to advocate every day for herself or someone else, but life continues, and she fights on to create a good quality of life. I have the pleasure of knowing Stephanie and many other metastatic breast cancer patients, and it's just my honor to help them advocate for better research funding for this disease, because I know that I have that 20 to 30% chance of recurrence myself, and I want to do more for metastatic breast cancer.

And then you see Lori's experience. She was diagnosed with stage 2B HER2-positive breast cancer in January of 2010. She was panicked, didn't do any reading or research at the time. She just wanted the cancer to get out of her body, which I certainly can relate to that. She had a routine X-ray four and a half years later and found lung metastases. And she's been on hormone therapy and progressed, and that's when she began to research and question her oncology team and find sources for second opinions. And Lori was diagnosed in 2014.

And then you have this other lovely lady here, Kristen, who... And I need to move my bar there down. Kristen was diagnosed with metastatic breast cancer in... Well, she first had early-stage breast cancer, and she had hope, at that time, for a normal life on the other side of treatment and was diagnosed metastatic. She had fear and grief from the diagnosis, and she grieved for a life that she thought she had with her family. She's had friends die of cancer. And even though she's been fortunate enough to live a pretty normal life for nearly six years, she fears the day that cancer will take that from her. And Kristen was diagnosed in 2015.

So now, it's my pleasure to take any questions from the audience. And I'm trying to progress through the slides, and it's not letting me. There we go. So, here's the question screen. And then this barcode down here will... If you want to take a picture of that, use your phone to take a photograph of the QR code, it'll take you to the source links for this presentation, and I'm happy to answer any questions. Thank you so much.

So that's it, and I hope that you have been able to use this presentation as a means to encourage you to get out there and start giving your own talks about metastatic breast cancer. You are a patient advocate, and other members of the Alliance are welcome to use the slides as well. You don't have to be a patient advocate to use these slides, but we encourage everyone to use them as you give talks about metastatic breast cancer.

If you have any questions, you can contact the Alliance directly, and they'll be happy to answer questions for you. And just remember that you can tailor these slides in any order that you wish. Download all four series, and you can incorporate the different slides from each series into your PowerPoint presentation together. You just can't edit each individual slide.

We thank you so much. We hope that you start recording your own talks out in the community and email those to the Alliance as well. And good luck with all of your sharing and educating about metastatic breast cancer.

Thank you.



THANK YOU >>>
Questions?

For more information and specific sources, visit:
<https://mbca.me/asd-series1>

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together we are stronger than the disease

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