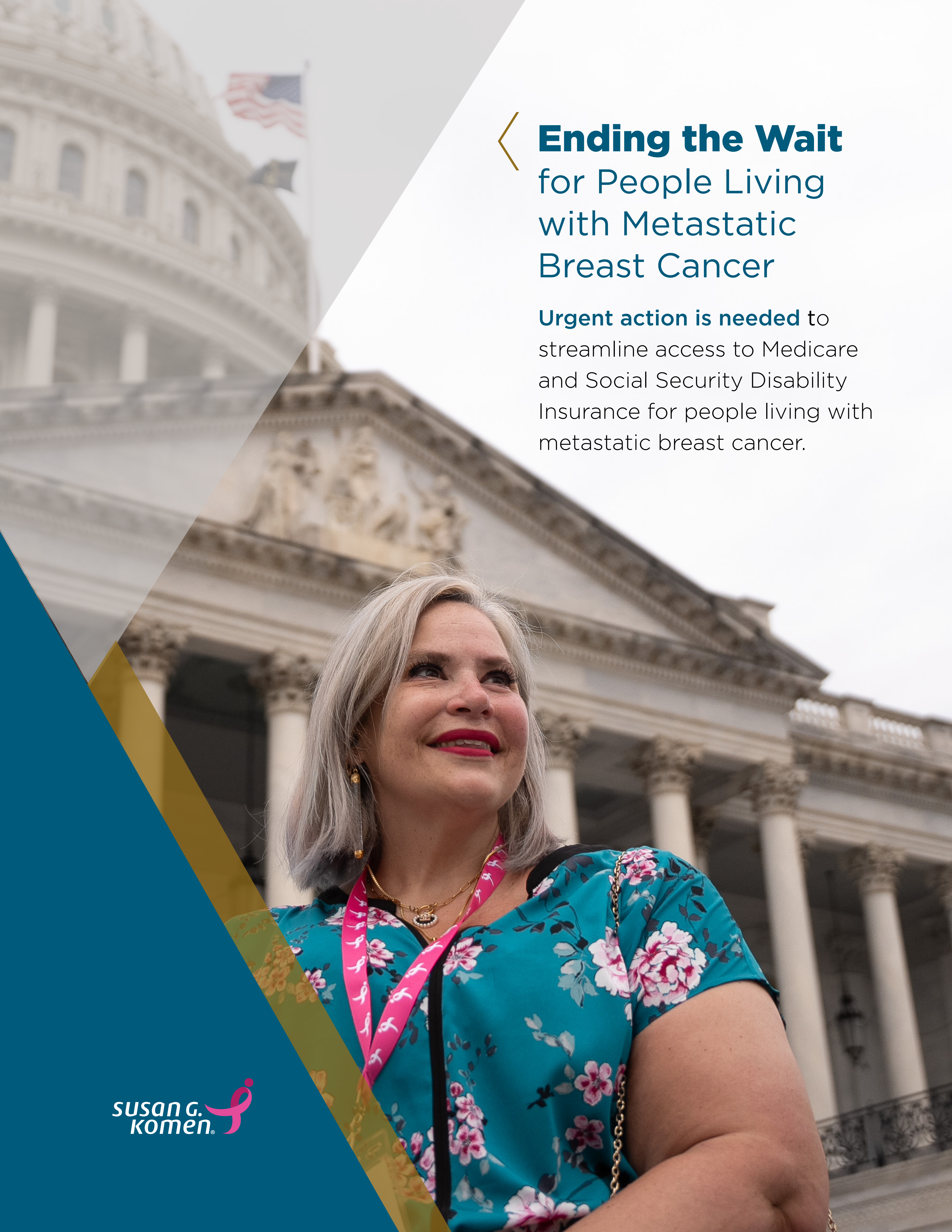


Ending the Wait for People Living with Metastatic Breast Cancer

Urgent action is needed to streamline access to Medicare and Social Security Disability Insurance for people living with metastatic breast cancer.

susan G. komen®

The Clock is Ticking

Now is the time to pass the Metastatic Breast Cancer Access to Care Act.

Every hour. Every minute. Every second. The opportunity to ensure timely access to Medicare and Social Security Disability Insurance for people living with metastatic breast cancer is slipping away.

The Metastatic Breast Cancer Awareness to Care Act would allow mothers, sisters, children, co-workers, neighbors, and friends living with the disease to receive Medicare and Social Security Disability Insurance (SSDI) without being subjected to unnecessary delays.

Metastatic breast cancer (MBC), also called stage 4, has spread beyond the breast and nearby lymph nodes to other parts of the body, most often the bones, lungs, liver or brain. Treatments exist, but there is no cure.

As their cancer progresses, many people cannot continue working, putting their health insurance and financial stability at risk.

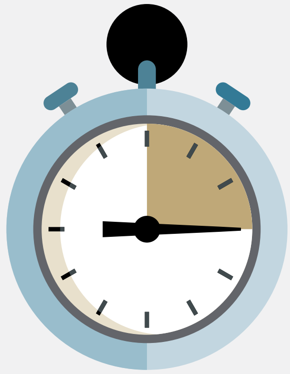
Patients face a staggering wait of five months for government disability insurance and an additional 24 months for Medicare coverage, and many do not live long enough to receive those benefits. About two-thirds of women diagnosed with MBC in the U.S. don't live at least five years after diagnosis.

> "More than anything, she wanted to live out her life with her husband and two children."

U.S. REPRESENTATIVE
JOE MORELLE
Co-signer of the MBC
Access to Care Act

U.S. Rep. Joe Morelle, who represents New York's 25th District, lost his daughter, Lauren, to metastatic breast cancer in 2017. She had triple negative breast cancer – an aggressive form that is often difficult to treat – which quickly spread.

"More than anything, she wanted to live out her life with her husband and two children," says Morelle, a co-signer of the MBC Access to Care Act. "But she died at 31, only 18 months after her diagnosis. She was one of the countless Americans with this disease who did not survive the waiting periods."



For those newly diagnosed with MBC, grappling with symptoms that impair their ability to work is a stark reality for many. Stripped of income and health insurance, they can find themselves reliant on Medicare and Social Security Disability Insurance for vital support. But waiting for it to kick in can postpone care, leading to disease progression that worsens health outcomes and quality of life.

Due to the aggressive nature of the disease, people should not be forced to endure excessive waiting periods to get the care and financial support they urgently need to prolong their lives.

"I hope to be around when I'm 65," says Jennifer Lane Williams, 57, an online sales professional who lives in Maryland. "But if not, I need to be able to access what I paid into. That's all I'm asking for. I've been paying into Social Security since I was 15, and it just seems fair."

Lawmakers can make life easier for the more than 168,000 women and men in the U.S. living with metastatic breast cancer, says Molly Guthrie, vice president of policy and advocacy at Susan G. Komen®.

"Policymakers have an obligation to help these constituents, who face significant administrative and financial barriers to get care they need," Guthrie says. "Legislators can enact laws that remove the unfair burden placed on patients, and already have for individuals with end-stage kidney disease and those with Lou Gehrig's Disease."

Co-sponsoring and passing the federal, bipartisan MBC Access to Care Act (H.R.549/S.663), would waive the waiting periods for SSDI and Medicare, removing financial barriers to care and improving quality of life for patients.

"When we're talking about the MBC community," Guthrie says, "accessing care is literally the difference between life and death, which means policymakers must act."

Most of the estimated 43,000 breast cancer deaths expected in the U.S. this year will be a result of metastasis, but only about 6% of initial cases in women and 9% in men are diagnosed at stage 4. This means most people with metastatic disease were diagnosed and likely treated at earlier stages — and then had a recurrence that spread. Because metastatic cancers often develop resistance to drugs, patients usually must change therapies.

For those newly diagnosed with MBC, grappling with symptoms that impair their ability to work is a stark reality for many. Stripped of income and health insurance, they can find themselves reliant on Medicare and SSDI for vital support. But waiting for it to kick in can postpone care, leading to disease progression that worsens health outcomes and quality of life.

> New therapies can have high price tags, and no one should have to face financial ruin to get care they desperately need.

JENNIFER LANE WILLIAMS
Living with Metastatic
Breast Cancer

> "I want to be there. I want to be able to hold my grandchildren. I want to help raise them. Those are the things I think about."
>
> **JENNIFER LANE WILLIAMS**
> Living with Metastatic Breast Cancer

Jennifer Lane Williams first found out about her breast cancer in 2017. It was stage 3, hormone receptor-positive breast cancer. She got a mastectomy, chemotherapy, radiation therapy and hormone therapy.

In 2019, scans detected a recurrence in the same area. It was stage 1, triple negative. Doctors removed the tissue, and she received chemotherapy and proton therapy.

However, in November 2022, an annual PET scan revealed the cancer had spread to her lung. Follow-up tests revealed stage 4 triple negative breast cancer. She was prescribed an oral chemo pill, which worked only briefly. In February 2023, she started taking another chemotherapy. It stopped working in September. Since then, she has had only a partial response to therapy.

She worries about paying for future medical care and living expenses if she needed Medicare and government disability and couldn't get it right away.

"It terrifies me," she says. "What would happen if I were to lose my job?"

Although her son, who is 26, doesn't have children, she hopes to be a grandmother one day.

"I want to be there. I want to be able to hold my grandchildren. I want to help raise them," Williams says. "Those are the things I think about."

Co-sponsoring and passing the federal, bipartisan MBC Access to Care Act (H.R.549/S.663), would waive the waiting periods for SSDI and Medicare, removing financial barriers to care and improving quality of life for patients.

Katie Strobel wouldn't gain anything from passage of the MBC Access to Care Act because she doesn't qualify for SSDI or Medicare.

But she advocates for it anyway so that patients can get what they need — and earned.

Her husband is a military physician, and the family is covered by TRICARE, the uniform services health care program. She hasn't paid into Social Security and therefore there is no money for her to take out.

"The biggest disappointment when it comes to these laws is, we're not fighting to discover the treatments," says Strobel, who lives in North Carolina and is the mother of three children, 8, 6 and 2. "We just need to get them to everyone."

She learned she had metastatic disease in November 2022 when she was 28. She first felt a lump in her right breast in March of that year. She eventually was diagnosed with stage 4 inflammatory breast cancer, which was HER2-positive. It spread to her brain. She had a double mastectomy, lymph nodes removed, and radiation to her chest and later her brain. She's had several rounds of chemo.

"I was diagnosed with cancer on a Monday, seven days later I had my first chemotherapy treatment, that's how fast we had to move. And unfortunately, my cancer is still moving very rapidly," she says. "Sometimes, if you're not able to get treatments when you should, it's too late, the cancer has gotten ahead of us. If we can get women diagnosed earlier and they get their treatments when they need them, mortality is going to go down. We're going to be able to live longer."

"For nearly a decade, we've kicked this bill to the next Congress," Guthrie says. "Every year we wait, about 40,000-plus women and men die of this disease. Even if we can't save all of them, we can remove these barriers to help as many as possible."

Lawmakers can act now to give them as much time as possible.

"We've gotten more treatments out there. But clearly, not everyone is able to get them," Guthrie says. "We have to demand change; we have to demand action."

Strobel, alongside Williams, travel often to the nation's capital to urge legislators to pass the bill. Strobel's message:

"We're here, we want to live, we want to fight, please just help us. We need lawmakers, and we need these laws to be the lifeline to get back to our normal life."

It's time.

“The biggest disappointment when it comes to these laws is, we’re not fighting to discover the treatments. **We just need to get them to everyone.”**

KATIE STROBEL
Living with Metastatic Breast Cancer

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