



METAVIVOR

Metastatic Breast Cancer | Research | Advocacy | Support

June 11, 2026

The Honorable Robert Aderholt
Chairman

House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

The Honorable Rosa DeLauro
Ranking Member

House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

The Honorable Shelley Moore Capito
Chair

Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

The Honorable Tammy Baldwin
Ranking Member

Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Dear Chairs and Ranking Members:

On behalf of METAvivor, the only U.S. organization solely dedicated to funding metastatic breast cancer (MBC) research and supporting those living with stage IV breast cancer, we write to express our concerns with the proposed rescission of fiscal year 2027 funding for the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund) included in the Fiscal Year 2027 Labor, Health and Human Services, Education, and Related Agencies appropriations proposal.

Specifically, we are concerned by the provision stating:

"Amounts made available for fiscal year 2027 to the Patient Centered Outcomes Research Trust Fund, authorized by the Patient Protection and Affordable Care Act of 2010 (Public Law 111-148, title VI, sec. 6301(e)(1)(A)), are hereby permanently rescinded."

We respectfully urge Congress to reject this proposal and preserve the current funding structure that supports the Patient-Centered Outcomes Research Institute (PCORI).

For the metastatic breast cancer community, PCORI's work fills a critical gap in the research landscape. While much of the nation's cancer research enterprise focuses on discovering new therapies and cures, patients living with metastatic disease also need evidence to help them navigate the complex realities of treatment, symptom management, and quality of life.. PCORI's patient-centered comparative clinical effectiveness research provides exactly this type of evidence-based research that helps patients, caregivers, and clinicians understand what works best, for whom, and under what circumstances.

Metastatic breast cancer remains incurable, and more than 170,000 - 200,000 Americans are currently living with the disease.¹ Additionally, approximately 30% of individuals initially diagnosed with early-stage breast cancer will eventually develop metastatic (Stage IV) breast cancer.²

Patients with metastatic breast cancer undergo continuous treatment for the remainder of their lives while managing significant physical, emotional, and financial burdens. For our community research that reduces treatment toxicity, sustains quality of life, and supports informed decision-making can be just as important as the development of new therapies.

PCORI has demonstrated the value of patient-centered research by supporting studies that help patients, providers, and healthcare systems make more informed healthcare decisions. This work is particularly important for the metastatic breast cancer community, where patients often face complex treatment decisions while balancing effectiveness, side effects, and quality of life. Striking the balance between living as long as possible and quality of life is a primary consideration for metastatic breast cancer patients and their families. For example, PCORI is supporting a study examining whether older adults with metastatic breast cancer can achieve similar outcomes when starting targeted therapies at lower doses compared to standard dosing.³ This ongoing research seeks to determine whether patients can remain on treatment longer while potentially experiencing fewer side effects, a question that matters deeply to patients balancing treatment effectiveness with quality of life. The study is funded through November 2029 and represents the type of long-term, patient-centered research that depends on stable and predictable support. Preserving PCORI's funding structure is essential to ensuring

¹ Susan G. Komen. Metastatic Breast Cancer.

<https://www.komen.org/breast-cancer/facts-statistics/what-is-breast-cancer/metastatic-breast-cancer/>. Updated March 14, 2026. Accessed June 8, 2026.

² National Breast Cancer Foundation. Stage 4 Breast Cancer Overview.

<https://www.nationalbreastcancer.org/breast-cancer-stage-4/>. Updated April 6, 2026. Accessed June 8, 2026.

³ Galow, Julie. Does Starting at Lower Doses of Targeted Therapy and Increasing as Tolerated Help People With Metastatic Breast Cancer Stay on Treatment Longer?

<https://www.pcori.org/research-results/2023/does-starting-lower-doses-targeted-therapy-and-increasing-to-lerated-help-people-metastatic-breast-cancer-stay-treatment-longer>. Updated October 23, 2025. Accessed June 8, 2026.

that ongoing studies like this can continue generating evidence that will be used to improve care and outcomes for patients living with metastatic breast cancer.

PCORI has also funded innovative research focused on improving symptom management for patients living with metastatic cancer. Symptoms such as fatigue, nausea, depression, pain, and difficulty performing everyday activities often go underreported between clinical visits, leading to missed opportunities for intervention. Through the PRO-TECT trial, a large-scale, five-year patient-centered comparative effectiveness study involving nearly 1,200 participants across 52 clinics, researchers evaluated whether weekly electronic symptom monitoring could improve outcomes compared to standard care.⁴ Studies such as PRO-TECT recognize that patients are more than their disease and that improving how symptoms are identified and managed can lead to better quality of life, more personalized care, and potentially improved clinical outcomes.

What makes PCORI uniquely valuable is that patients are not merely subjects of research, they are partners in it. Individuals living with metastatic breast cancer, caregivers, clinicians, and advocates help shape research priorities, study design, and dissemination efforts. This engagement ensures that the evidence generated reflects the questions that matter most to patients and produces findings that can be readily incorporated into clinical practice.

As an organization committed to improving and extending the lives of people living with metastatic breast cancer, METAvivor recognizes the essential role PCORI plays in generating evidence that empowers patients and improves care delivery. PCORI's work complements biomedical research investments by helping ensure that patients and clinicians have the information needed to make informed treatment decisions, manage symptoms effectively, and achieve outcomes that matter to those living with serious illness.

Importantly, PCORI's success has been made possible through the stable, dedicated funding provided by the Patient-Centered Outcomes Research Trust Fund. Congress reaffirmed the value of this model through the Institute's bipartisan reauthorization in 2019. Rescinding fiscal year 2027 funding would jeopardize ongoing research, undermine future patient-centered studies, and weaken a nationally recognized source of evidence that directly benefits patients and families facing some of the most difficult healthcare decisions imaginable.

For the metastatic breast cancer community and countless other patient populations, PCORI represents a vital investment in research that improves lives today while informing the healthcare decisions of tomorrow.

We respectfully urge Congress to reject the proposed rescission of fiscal year 2027 funding for the Patient-Centered Outcomes Research Trust Fund and preserve PCORI's current funding structure so that it can continue generating the patient-centered evidence that patients, caregivers, clinicians, and policymakers rely upon.

⁴ Basch, Ethan. Comparing the Effectiveness of Electronic Symptom Monitoring versus Usual Care in Improving Survival among Patients with Metastatic Cancer -- The PRO-TECT Trial. <https://www.pcori.org/sites/default/files/PCORI-Basch488-English-Abstract.pdf>. November 2023. Accessed June 8, 2026.

Thank you for your consideration and your continued commitment to advancing research that improves the lives of patients across the nation. Thank you for your consideration. For questions, please contact michelle@federalgrp.com or taylor@federalgrp.com.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kelly Shanahan', with a stylized flourish at the end.

Kelly Shanahan, M.D.
President
METAvivor

A handwritten signature in black ink, appearing to read 'Alpha Lillstrom Cheng', with a stylized flourish at the end.

Alpha Lillstrom Cheng
Vice President and Advocacy Committee Co-chair
METAvivor