

Endometriosis Advocacy Toolkit



Society for
Women's Health
Research



What is endometriosis?

Endometriosis is a common chronic disease in which tissue that resembles the lining of the uterus (the endometrium) grows outside the uterus where it doesn't belong, leading to lesions, pelvic pain, and other symptoms.

It affects an **estimated 6.5 million women** between ages 15 to 44 in the United States, although statistics are likely underestimated because many women experience missed or delayed diagnoses. It takes, on average, **6.7 years** for women to receive an accurate endometriosis diagnosis.

Despite its prevalence, the exact cause of endometriosis is still unknown, and research into endometriosis has been underfunded and underprioritized. In 2022, \$27 million (0.082%) of the National Institutes of Health (NIH) research **budget** supported endometriosis, averaging \$2 per patient. For comparison, NIH spent \$31.30 per diabetes patient and \$130.07 per Crohn's disease patient; these diseases have similar prevalence among U.S. women, affecting about 10% of the population.

The Department of Defense's (DoD) Congressionally Directed Medical Research Programs (CDMRP), which fosters novel approaches to biomedical research, has not maintained consistent endometriosis funding. Within CDMRP, the Peer Reviewed Medical Research Program (PRMRP) has funded endometriosis research in previous years, but endometriosis was not included as a research topic area in fiscal year 2024.

Beyond insufficient research funding, endometriosis care faces other challenges. Most primary care clinicians (family medicine, pediatrics, internal medicine) and even OB/GYNs do not receive adequate training in recognizing endometriosis symptoms and treating the disease. There is a need for comprehensive, evidence-based guidelines for symptom identification and diagnosis, care coordination, treatment selection, and post-treatment follow-up.

“Endometriosis is much more than a gynecologic condition; it is a systemic disease and constitutes a **public health crisis.”**

- Miguel Luna Russo, MD, FACOG, Director of the Endometriosis, OB/GYN, & Women's Health Institute at the Cleveland Clinic

What is the Endometriosis CARE ACT?

The Endometriosis Coverage, Awareness, Research, and Education (CARE) Act seeks to advance endometriosis research, expand access to treatment, and improve public awareness of endometriosis. Specifically, the legislation directs the NIH to:

- Invest **\$50 million per year** in endometriosis research through the NIH;
- Commission a **national study** on the disparities in endometriosis prevalence, detection, treatments and outcomes by race, ethnicity, geography and insurance status;
- Establish a **national campaign** to promote public awareness of endometriosis;
- **Identify barriers** to accessing treatments for endometriosis symptoms, such as health care coverage, transportation, and health care professional shortages.



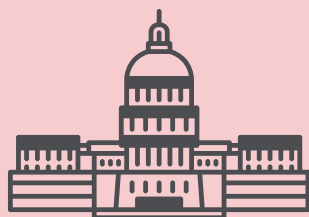
Take Action - Contact Your Elected Officials

If you would like to **see the Endometriosis CARE Act signed into law**, the advocacy tools and resources below show you how. They can help you connect with your members of Congress to encourage them to support passage of the bill.

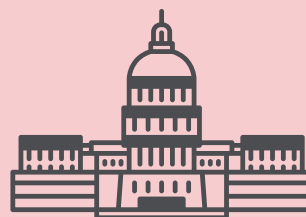
Remember these practical tips:

- Share with your elected officials what this legislation means to you and how it will affect health outcomes for girls and women living with endometriosis nationwide.
- **To make your communication especially impactful, personalize your message!** Whether you or a loved one has received an endometriosis diagnosis, work in women's health, or you simply recognize the value of funding research, your outreach can create a lasting impression among policymakers and their staff.

[Find Your Representative](#)



[Find Your Senators](#)



Sample Communications to Congress

If you'd like guidance on what to say, feel free to use all or part of these sample communications!

Sample Emails

Dear Representative _____,

As a constituent, I am writing to express support for the Endometriosis CARE Act and ask that you consider co-sponsoring this important legislation. This bill would make a difference in the lives of the more than 6.5 million girls and women living with endometriosis in the United States and the girls and women who have yet to be diagnosed by providing dedicated research funding for endometriosis research at the National Institutes of Health, providing funding for a public education and awareness campaign, and identifying barriers to accessing treatments for endometriosis symptoms.

[Insert a personal anecdote or connection to endometriosis here.]

Given the burden of endometriosis, I encourage you to work with your colleagues to support this bill's passage and prioritize our nation's focus on this public health crisis. To become a cosponsor of the legislation, please contact Iyanla Kollock, at iyanla.kollock@mail.house.gov.

Your support is greatly appreciated.
Sincerely,
[Your Name]

Dear Senator _____,

As a constituent, I am writing to express support for the bipartisan Endometriosis CARE Act, co-sponsored by Reps. Williams (GA-05), Underwood (IL-14), Adams (NC-12) and González-Colón (PR-At Large), and to ask that you consider championing a companion bill in the Senate.

This bill would provide dedicated NIH research funding for endometriosis, provide funding for a public education and awareness campaign, and identify barriers to accessing treatments for endometriosis symptoms. It could improve outcomes for the more than 6.5 million girls and women living with endometriosis in the United States and the women who have yet to be diagnosed.

[Insert a personal anecdote or connection to endometriosis here.]

Please work with your colleagues to prioritize our nation's focus on this public health crisis. If you are interested in serving as a lead sponsor on the Senate companion bill, please contact Iyanla Kollock, Legislative Assistant for Rep. Williams, at iyanla.kollock@mail.house.gov. Thank you for your support.

Sincerely,
[Your Name]

Sample Post for X (Twitter)

#Endometriosis affects 6.5 million girls and women in the United States. @[Congressperson], please work with your colleagues to pass the Endometriosis CARE Act!

A list of X (Twitter) handles for members of Congress can be found [here](#).

What is the DoD Peer Reviewed Medical Research Program?

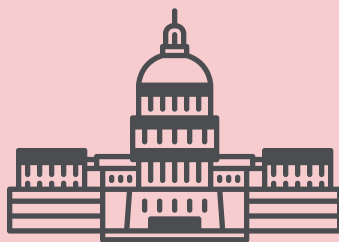
The Peer Reviewed Medical Research Program (PRMRP) supports research “with an underlying goal of enhancing the health, care, and well-being of military Service members, Veterans, retirees, and their family members.” The program is funded through congressional appropriations, and the topic areas funded are determined by the Senate through the Defense Appropriations Act. Endometriosis was **included as a topic area** in fiscal years 2020-2023 but was not selected as a topic area in fiscal year 2024.

Take Action

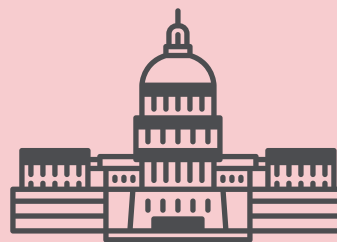
Encourage your Senators to include endometriosis as a PRMRP topic area in fiscal year 2025. The more Senators that submit the request, the more likely it is to be included in final appropriations legislation!

Share with your elected officials why endometriosis research funding is important to you and how more knowledge on this topic will affect health outcomes for women living with endometriosis nationwide. **Make your communication especially impactful and personalize your message!** Whether you or a loved one has received an endometriosis diagnosis, work in women’s health, or you simply recognize the value of funding research, your outreach can create a lasting impression among policymakers and their staff.

Find Your Representative



Find Your Senators



Sample Communications

Sample Email

Dear Senator _____,

As a constituent, I would like to ask you to request that endometriosis be included as a topic area in the fiscal year 2025 Defense Appropriations Act. Endometriosis affects an estimated 6.5 million women in the United States, and notably, it can be a disqualifying condition for military service.

Despite its prevalence and burden on girls and women across the United States, the exact cause of endometriosis is unknown and treatments that exist are targeted toward managing the symptoms of endometriosis. The PRMRP is an important pathway for improving the knowledge base about endometriosis and examining its impact on women in the military.

[Insert personal story here, if applicable.]

Please include endometriosis as a topic area in the fiscal year 2025 Defense Appropriations Act. I appreciate your time and consideration.

Sincerely,
[Your Name]

Sample Post for X (Twitter)

Did you know #endometriosis can be a disqualifying condition for military service and affects more than 6.5 million girls and women across the US? @[Senator], please include endometriosis as a #PRMRP topic area in the FY25 Defense Appropriations Act!

A list of X (Twitter) handles for members of Congress can be found [here](#).

Partner Organizations

SWHR is proud to work alongside partners and endometriosis champions throughout the year to raise awareness and advocate for endometriosis at the federal level. Learn more about these groups by visiting their respective websites.



Endo What?

A social impact movement and films aimed to dramatically improve awareness, education, and policy about endometriosis and women's health equity.



Endo Black

Endo Black, Inc. is a Black-women-led nonprofit organization advocating for and educating Black women living with and impacted by endometriosis. Our philosophy is to engage, educate, and encourage endo sisters.



Endometriosis Foundation of America

The Endometriosis Foundation of America (EndoFound) strives to increase disease recognition, provide advocacy, facilitate expert surgical training, and fund landmark endometriosis research.



The Endo Co

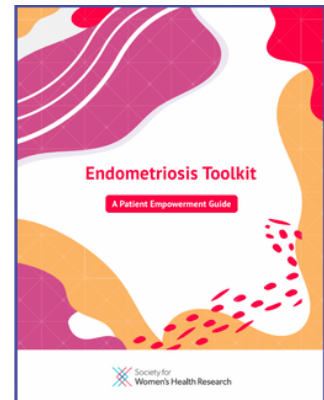
The Endo Co aims to raise awareness, promote reliable education, and increase research funding for endometriosis.

SWHR Endometriosis Resources

The Society for Women's Health Research has multiple endometriosis resources, all available for free at [swhr.org](https://www.swhr.org).

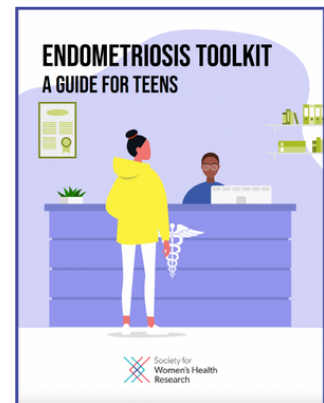
Endometriosis Toolkit: A Patient Empowerment Guide

This toolkit provides easy-to-understand information on menstrual health, guidance on endometriosis diagnosis and treatment, and tips for interacting with your health care provider. The toolkit aims to facilitate productive conversations between patients and providers so individuals can get the endometriosis care they need.



Endometriosis Toolkit: A Guide for Teens

This toolkit, available in English and Spanish, was created to empower teenagers who have menstrual health questions or are living with endometriosis to better understand their health and navigate their care.



Recommended Webinars

- [Elevating Endometriosis to a Public Health Crisis](#)
- [Journey to Wellness with Endometriosis](#)
- [Precision in Practice for Endometriosis Care](#)



Recommended Blog Posts

- [Illuminating the Endometriosis Experience to Improve Care](#)
- [Rewriting Endometriosis Education for Providers and Policymakers](#)
- [SWHR Commits to Caring for Women: Advancing Research this Endometriosis Awareness Month](#)