



Endometriosis CARE Act

To advance scientific research, circulate educational information, and identify and dismantle barriers to accessing treatment necessary to improve millions of American lives.

The Endometriosis Care Act invests \$50 million annually for five years for endometriosis research through the National Institutes of Health. This bill commissions essential surveillance, healthcare expansions, and a public awareness campaign of the debilitating condition affecting patients, their loved ones, and healthcare professionals.

Endorsing Organizations: Friends of the National Institute of Nursing Research, Birthing the, Magic Collaborative, Black Mamas Matter Alliance, Black Women's Health Imperative, Cookie La, Doula, Dr. Shalon's Maternal Action Project (DSMAP), Endo Black, Endometriosis Foundation of America, In Our Own Voice: National Black Women's Reproductive Justice Agenda, Jacobs, Institute of Women's Health, Milken Institute School of Public Health, Melinated Moms, Mothering Justice, National Health Law Program, National Medical Fellowships, NETWORK Lobby for, Catholic Social Justice, PA Education Association, Reproductive Freedom for All, The Endometriosis Summit, Urban Baby Beginnings, Wayne State University Office of Women's Health, Yeye's Gift Doula Services, Society for Public Health Education

Why Does This Matter?

Endometriosis occurs when tissue similar to tissue found within the uterine lining grows outside of the uterus^[1]. This abnormal tissue growth can cause a multitude of menstruation-related health issues, immense pain, infertility, and/or cancer^{[2][3]}. More than 6.5 million women in the United States alone have endometriosis^{[1][3]}, affecting any girl or woman who has menstrual periods as young as 15 years old^[1], typically common amongst the ages of 20 through 40^[2].

Limited medical options exist for the treatment of endometriosis, and many patients—particularly women in marginalized communities and teenagers—are misdiagnosed or not diagnosed at all^{[4][5]}. On average, there is a 7- to 10-year gap between the start of symptoms and a confirmed diagnosis^[6].

By the Numbers:

- **1 in 9 women** of reproductive age has endometriosis in the United States.^[3]
- **67% of women** experience a relapse in symptoms and pain within five years of surgery.^[4]
- The direct cost of endometriosis in the US averages **\$12,118 per patient per year**.^[3]
- The National Institutes of Health has **\$2 per person per year** allotted for endometriosis in the research budget in comparison to **diabetes (\$31.30)** and **Crohn's Disease (\$130.07)**—all diseases that have a similar prevalence in women in the United States.^[4]

[1]<https://womenshealth.gov/a-z-topics/endometriosis>

[2]<https://my.clevelandclinic.org/health/diseases/10857-endometriosis>

[3]<https://pmc.ncbi.nlm.nih.gov/articles/PMC9127440/>

[4]<https://swhr.org/rewriting-endometriosis-education-for-providers-and-policymakers/>

[5]<https://endometriosis.net/statistics>

[6]<https://pmc.ncbi.nlm.nih.gov/articles/PMC11625652/>

