

Closing the Gaps in Endometriosis Research & Care



6.5 million women of reproductive age in the US have endometriosis.

Endometriosis is a chronic, gynecologic disease that occurs when tissue resembling the lining of the uterus (the endometrium) grows where it does not belong – typically within the pelvic cavity (ovaries, fallopian tubes, bowel, or outer surface of the uterus). These **implants** may thicken and bleed during the menstrual cycle, causing swelling and severe pain.



Common Symptoms

- ▶ Pelvic pain and pain between periods
- ▶ Lower back pain
- ▶ Pain during sex
- ▶ Infertility

Up to 50% of women with endometriosis experience fertility issues.

Diagnosis and Treatment

Laparoscopic surgery is the traditional tool used to definitively diagnose endometriosis. Because it is invasive and costly, providers will typically use medical history, assessment of symptoms, and an ultrasound

6.7 years — Average time it takes to receive an accurate diagnosis

or MRI to diagnose the disease instead. Women often experience misdiagnoses with other chronic conditions, or their symptoms being overlooked due to societal stigma and biases surrounding menstrual issues and pain.

There is no cure for endometriosis.

Most treatment options outside of surgery can only help to manage symptoms – alleviating pain or reducing bleeding – instead of treat the disease itself. Even with surgery, up to **67% of women** experience a relapse in symptoms and pain within 5 years.

Impact on Women's Health

Little is understood about the underlying biology, causes, and progression of endometriosis, which incurs significant physical, emotional, and financial burdens on the lives of millions. Women report higher rates of chronic stress, anxiety, depression, decreased quality of life, and loss of productivity at work and home.

Women with endometriosis are also at higher risk for co-morbid conditions, such as:

- ▶ Asthma
- ▶ Autoimmune disease
- ▶ Cancer
- ▶ Cardiovascular disease

Nearly **95%** of women with endometriosis report having at least one other chronic condition.

Endometriosis By the Numbers

\$78B-119B Annual costs in the US

\$12,119 Direct costs (treatment, surgery, and prescription costs) per patient

\$16,000 Indirect costs (days of work lost, reduced quality of work) per patient

Policy Opportunities

Given its prevalence, impacts, and financial burden, endometriosis deserves greater prioritization across federal research and public health agencies to improve outcomes for all women.



Dedicated Federal Funding for Research. In 2022, only **\$27 million (0.082%)** of the National Institutes of Health research spending supported endometriosis studies, and the Department of Defense's Congressionally Directed Medical Research Programs have not funded an endometriosis project since 2018. Robust, dedicated funding for endometriosis at these and other federal agencies is essential for advancing our knowledge of this disease.



Improved Education to Reduce Diagnosis Delays. Beyond not knowing the cause of endometriosis, the United States lacks sufficient research and education that explores symptoms and treatment outcomes. Understanding the influences and impacts of race/ethnicity are also critical to eliminating disparities experienced by a diversity of women.



Access to Timely, Appropriate Care. According to experts at the Endometriosis Foundation of America, there is a shortage of endocrinologists and OB-GYNs trained in advanced gynecological surgeries (e.g., laparoscopy to diagnose and treat endometriosis). Policy measures to grow the physician workforce and identify ways to raise awareness among other health professionals are key to addressing these issues.

References

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