GLOBAL ENDOMETRIOSIS MOVEMENT

The Founder's Vision

From Silent Suffering to Collective Action

A MESSAGE FROM THE FOUNDER & CHAIRMAN

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Founder & Chairman, Global Endo Movement (GEM)

Welcome to the Global Endo Movement (GEM).

Today, you are joining something much larger than a website, an organization, or a campaign.

You are joining a global movement dedicated to transforming the future of one of the most neglected diseases in women's health.

For far too long, endometriosis has remained hidden behind silence, misunderstanding, delayed diagnosis, inadequate treatment, and insufficient research. Millions of women and girls have endured years of debilitating pain while being told that their symptoms were "normal." Countless others have faced infertility, repeated surgeries, interrupted education and careers, financial hardship, emotional distress, and diminished quality of life.

190M	7-10	$78-119B
WOMEN & GIRLS AFFECTED WORLDWIDE	YEARS AVERAGE DIAGNOSTIC DELAY	ANNUAL U.S. ECONOMIC BURDEN

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> **This is not merely a medical problem. It is a global public health challenge, a social injustice, and a call to action.**

ENDOMETRIOSIS: NATURE AND NURTURE

Endometriosis is a complex, chronic, systemic inflammatory disease in which, besides pelvic involvement, endometrial-like tissue can migrate to and implant in other organs, including the lungs, liver, and even the brain. These lesions may cause symptoms that recur with hormonal changes. Although extrapelvic endometriosis is uncommon, its clinical presentation can be confusing: chest pain or neurological symptoms may resemble other medical conditions, and patients may experience an agonizing delay before receiving an accurate diagnosis and treatment. Endometriosis is usually benign, but it is associated with an increased risk of certain ovarian cancers, particularly clear cell and endometrioid carcinomas; the absolute increase in cancer risk is low. [8-12]

Current evidence suggests that inherited genetic susceptibility provides a relatively stable biological foundation for endometriosis across populations. In contrast, the acquired molecular profile of endometriotic lesions - including somatic mutations, epigenetic reprogramming, and altered inflammatory and hormonal signaling - is dynamic and may be profoundly shaped by environmental exposures. Consequently, differences in environmental pollution and endocrine-disrupting chemicals among populations may contribute to geographic variation in biology, clinical behavior, disease severity, recurrence, and malignant transformation of endometriosis. It is plausible that greater environmental pollution may contribute to a more biologically active and clinically more severe form of endometriosis. [5-7]

The final statement represents the scientific hypothesis of the Global Endometriosis Movement (GEM), derived from emerging evidence on gene-environment interactions in endometriosis, and is intended to stimulate future research.

Environmental Toxicants and Acquired Molecular Change

A gene-environment framework relevant to endometriosis biology

Inherited susceptibility → **Environmental toxicants** → **Acquired lesion changes** → **Disease behavior & recurrence**

Persistent organo-chlorines

Dioxins/furans, PCBs, and OCPs such as DDT/DDE, HCH/lindane, HCB, dieldrin, heptachlor, nonachlor, and mirex. Stronger epidemiologic signal.

PFAS forever chemicals

PFOA, PFOS, PFNA, PFBS and related persistent compounds. Endometriosis evidence remains mixed/emerging.

Combustion and air pollution

PAHs, tobacco-smoke components, PM2.5/NO2, and combustion mixtures may promote DNA adducts, oxidative stress, and inflammation.

Current-use pesticides

Organophosphates, pyrethroids, glyphosate-related mixtures, and agricultural co-exposures are under study; evidence remains emerging.

Plasticizers and phenols

Phthalates, bisphenols (BPA/BPS/BPF), and benzophenone/UV-filter chemicals. Active evidence, with several positive human associations.

Flame retardants

PBDEs and PBBs. Persistent household-dust and food-chain exposures; evidence is emerging/mixed.

Metals and trace elements

Lead has the most consistent signal; cadmium, mercury, nickel, copper, chromium, zinc and others have mixed findings.

Local biologic stressors

Iron overload and reactive oxygen species from retrograde bleeding can create a local oxidative/inflammatory microenvironment.

Scientific framing: these exposures are best described as associated or biologically plausible contributors, not proven single causes. They may influence somatic mutation patterns, epigenetic reprogramming, oxidative stress, inflammatory signaling, and hormone-responsive lesion biology.

Selected references for each exposure family are provided on the following page.

Environmental Toxicants: Scientific References

These references support the exposure families shown in the diagram. The evidence is strongest for some persistent organochlorines and more mixed or emerging for PFAS, flame retardants, air pollution, current-use pesticides, and several plasticizer/phenol compounds. Associations do not prove causation.

Broad reviews and evidence synthesis

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Organochlorines, dioxins/furans, PCBs, OCPs, PBDE/PBB

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PFAS

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Phthalates, bisphenols, benzophenones/UV filters

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Environmental Toxicants: Scientific References (continued)

Metals, air pollution, current-use pesticides, and local iron/ROS stress

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THE GLOBAL BURDEN OF ENDOMETRIOSIS

Endometriosis affects approximately 190 million women and girls worldwide — nearly one in every ten women of reproductive age. It is one of the leading causes of chronic pelvic pain and infertility, yet women still wait years for a diagnosis. The disease carries a staggering economic burden, costing an estimated US$78–119 billion annually in the United States and approximately €30 billion across the European Union through healthcare costs, lost productivity, absenteeism, and reduced quality of life.

To place this in perspective, the estimated U.S. economic burden of endometriosis substantially exceeds the annual U.S. medical care costs reported for breast cancer and ovarian cancer. Yet despite this immense burden, a 2022 NIH analysis found that federal research investment in endometriosis amounted to only about US$2 per affected patient per year, compared with approximately US$159 per patient for HIV/AIDS. This profound mismatch between disease burden and research investment reflects why endometriosis remains one of the most under-recognized, underfunded, and inadequately treated diseases in women's health.

The numbers speak for themselves.

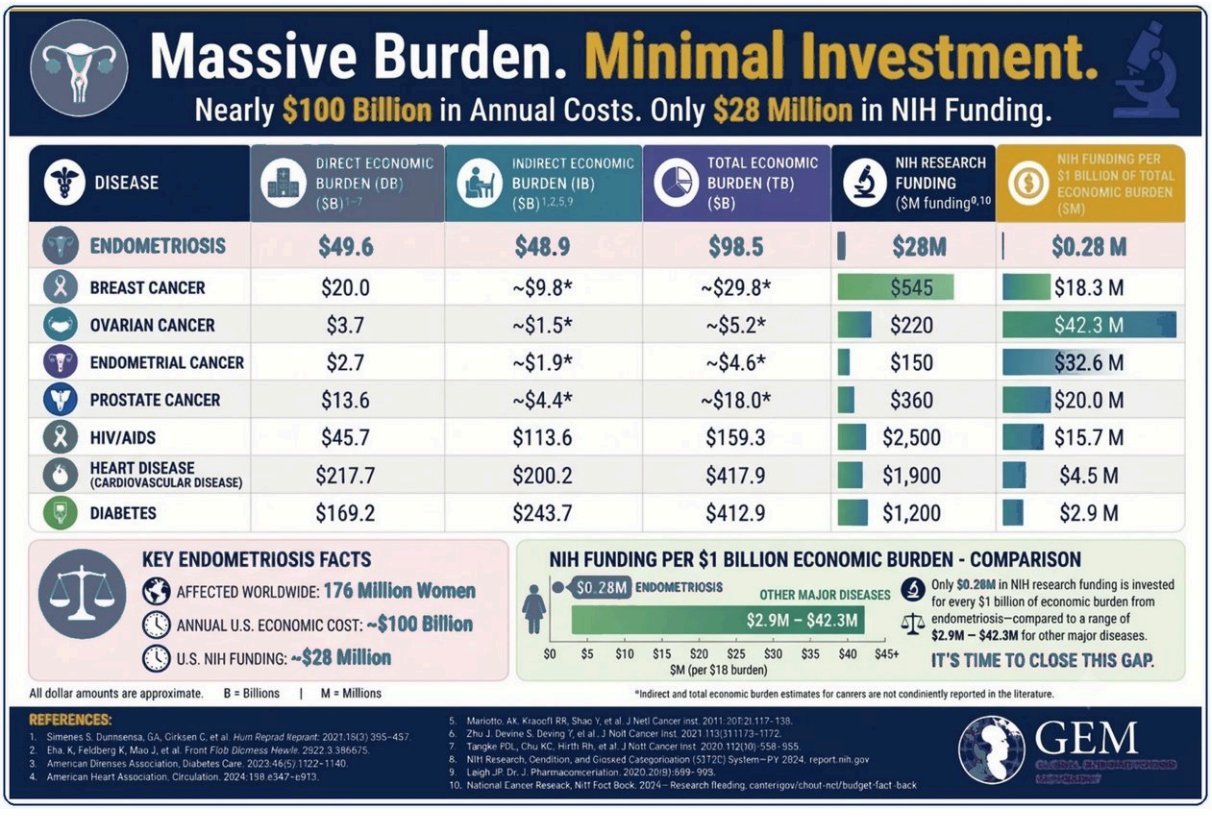


FIGURE 1. *Economic burden of endometriosis versus NIH research funding, compared with other major diseases.*

THE DIAGNOSIS GAP

Medicine has achieved extraordinary advances in science and technology. Yet for millions living with endometriosis, those advances have not translated into timely diagnosis, equitable access to expert care, or consistently high standards of treatment.

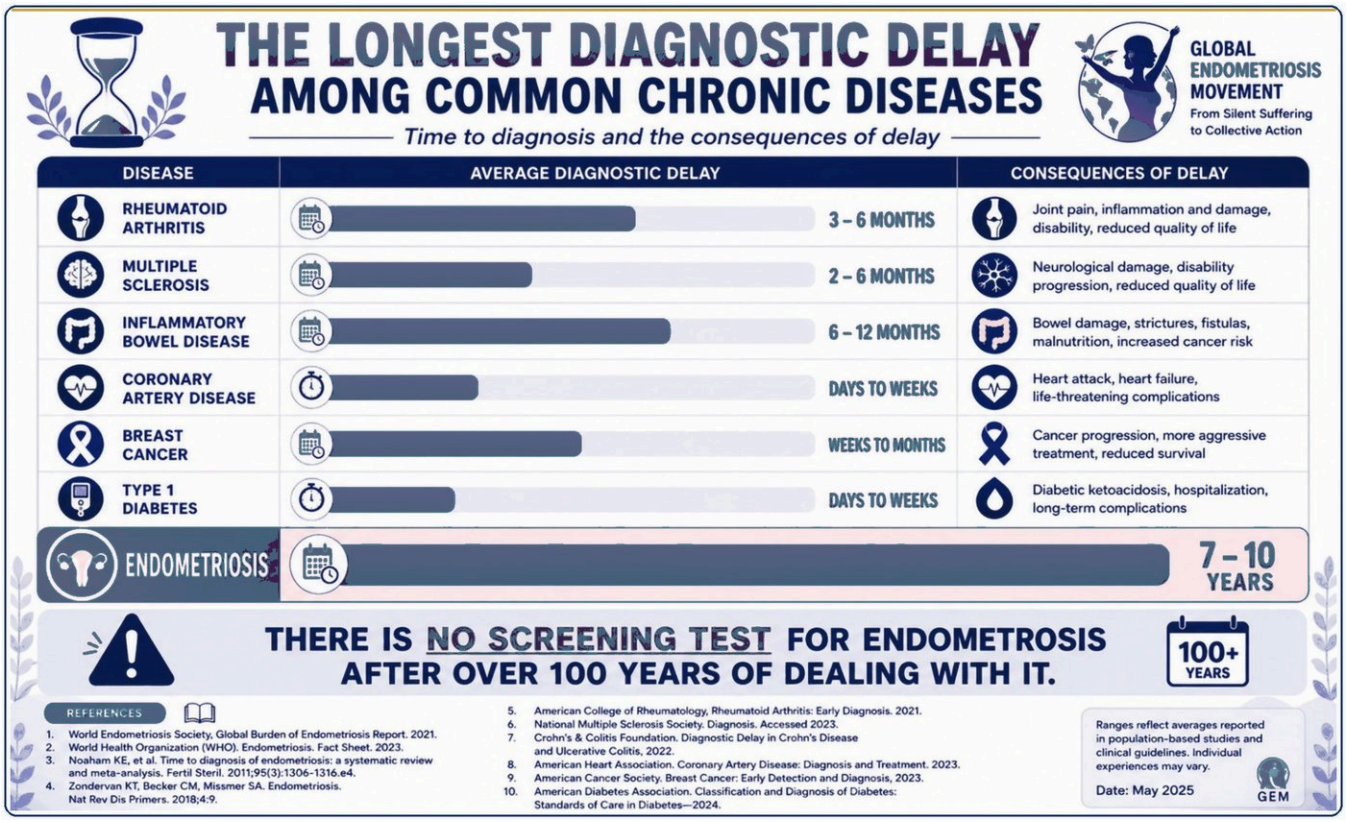


FIGURE 2. *Diagnostic delay in endometriosis compared with other chronic diseases, and its consequences.*

KEY FACTS

✓ Every year of delayed diagnosis allows disease progression, increasing the risk of chronic pain, infertility, organ involvement, repeated operations, reduced quality of life, and escalating healthcare costs. Earlier diagnosis is not merely desirable — it is essential to preventing lifelong consequences.

✓ More than a century after endometriosis was first described, there is still no reliable, widely accepted non-invasive diagnostic test, leaving millions of women dependent upon clinical suspicion and, in many cases, surgical confirmation.

THE HUMAN TOLL

This disconnect demands more than awareness — it demands leadership, collaboration, innovation, accountability, and meaningful reform to prevent:

Psychological Impact on Affected Women

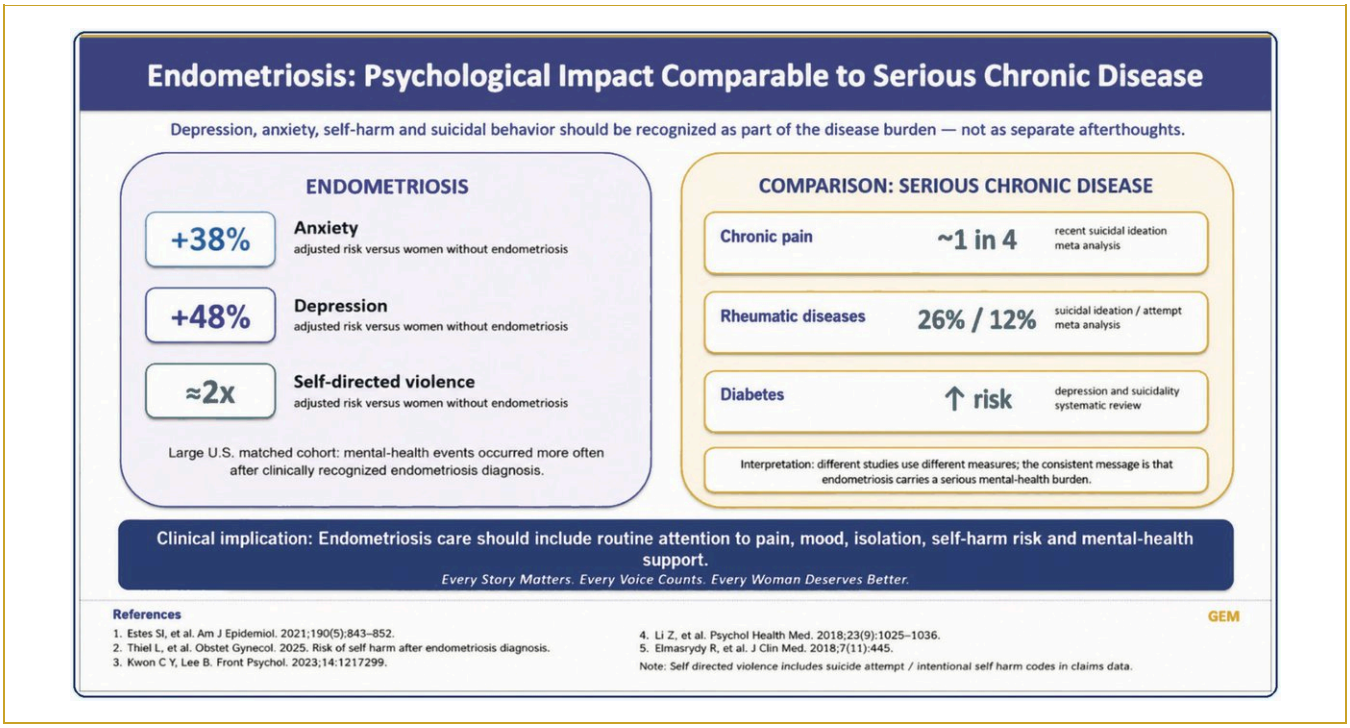


FIGURE 3. *Endometriosis is associated with significantly higher rates of depression, anxiety, and suicidal ideation.*

Impact on Work Productivity

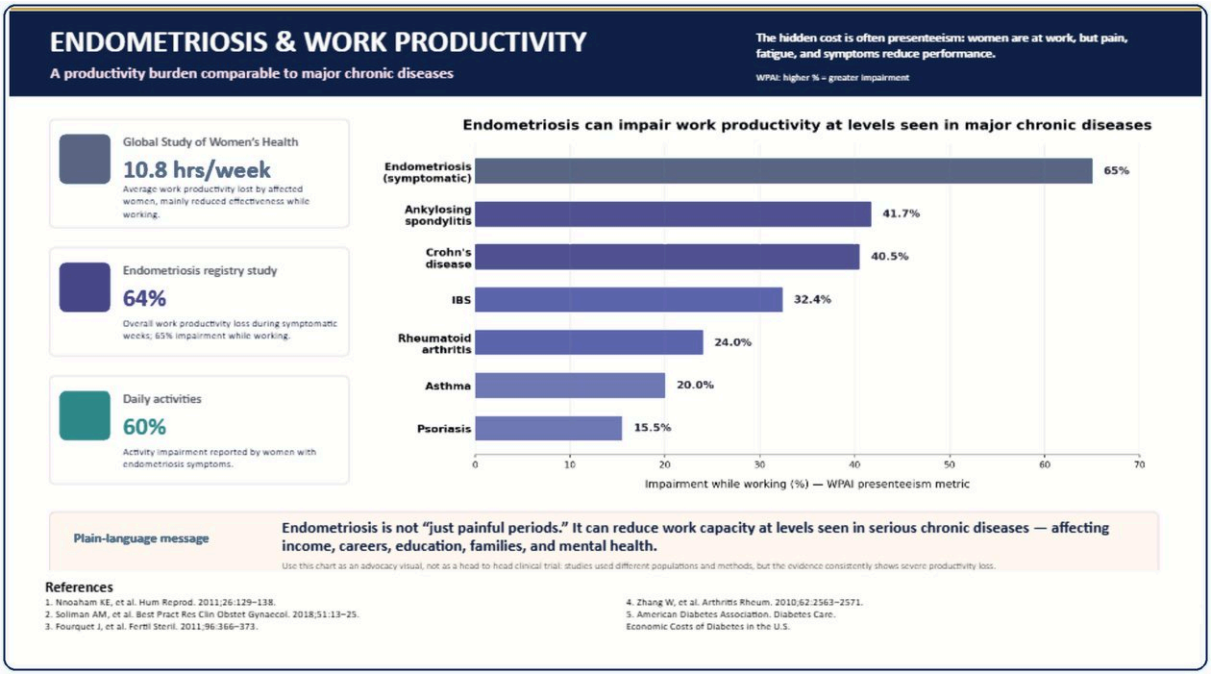


FIGURE 4. *Work impairment caused by endometriosis compared with other major chronic diseases.*

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> ***No woman or girl should suffer in silence from a disease that modern medicine has both the knowledge and the responsibility to diagnose earlier, treat better, research more aggressively, and manage more effectively.***

The Global Endometriosis Movement (GEM) was founded on a bold and transformative vision: to serve as a powerful advocate for change in the understanding, diagnosis, treatment, and research of this complex and often misunderstood disease.

Our mission is to unite patients, healthcare professionals, researchers, educators, policymakers, philanthropic organizations, and communities across every nation to transform the global landscape of endometriosis through science, education, advocacy, and collective action.

THE FIVE PILLARS OF SYSTEMIC CHANGE

1

Professional Recognition

Recognition and standardization of endometriosis as an independent subspecialty within Obstetrics and Gynecology, supported by standardized education, competency-based training, accredited fellowship programs, and official subspecialty board certification.

2

Centers of Excellence

Development of **specialized Endometriosis Treatment and Research Centers** capable of delivering comprehensive multidisciplinary care while advancing scientific discovery, innovation, and translational research.

3

Patient-Centered Surgical Documentation

We believe that every woman undergoing endometriosis surgery should have the right and the opportunity, through informed consent, to choose a complete surgical record of her operation. Such a record should include standardized operative reporting, comprehensive disease mapping, pathology correlation, and complete unedited video recording preserved as a permanent part of her medical record.

This proposal is not intended to monitor or penalize surgeons. Rather, it reflects GEM's commitment to surgical excellence, transparency, continuity of care, education, clinical research, and continuous quality improvement. Most importantly, it empowers women by preserving an objective, lasting record of their disease and surgical management, ensuring that essential information remains available to guide their future healthcare whenever needed.

We recognize that this proposal extends beyond current practice in many healthcare systems. However, it reflects a reasonable, patient-centered approach to reducing inadequate surgical treatment and to supporting timely referral to highly qualified centers, helping to avoid repeated surgeries that increase suffering and make subsequent procedures more complex.

Many advances that are now fundamental to modern medicine began as bold ideas that constructively challenged existing practice. GEM hopes this initiative will foster open, collaborative dialogue among patients, clinicians, professional societies, healthcare institutions, and policymakers, ultimately contributing to higher standards of care for women living with endometriosis.

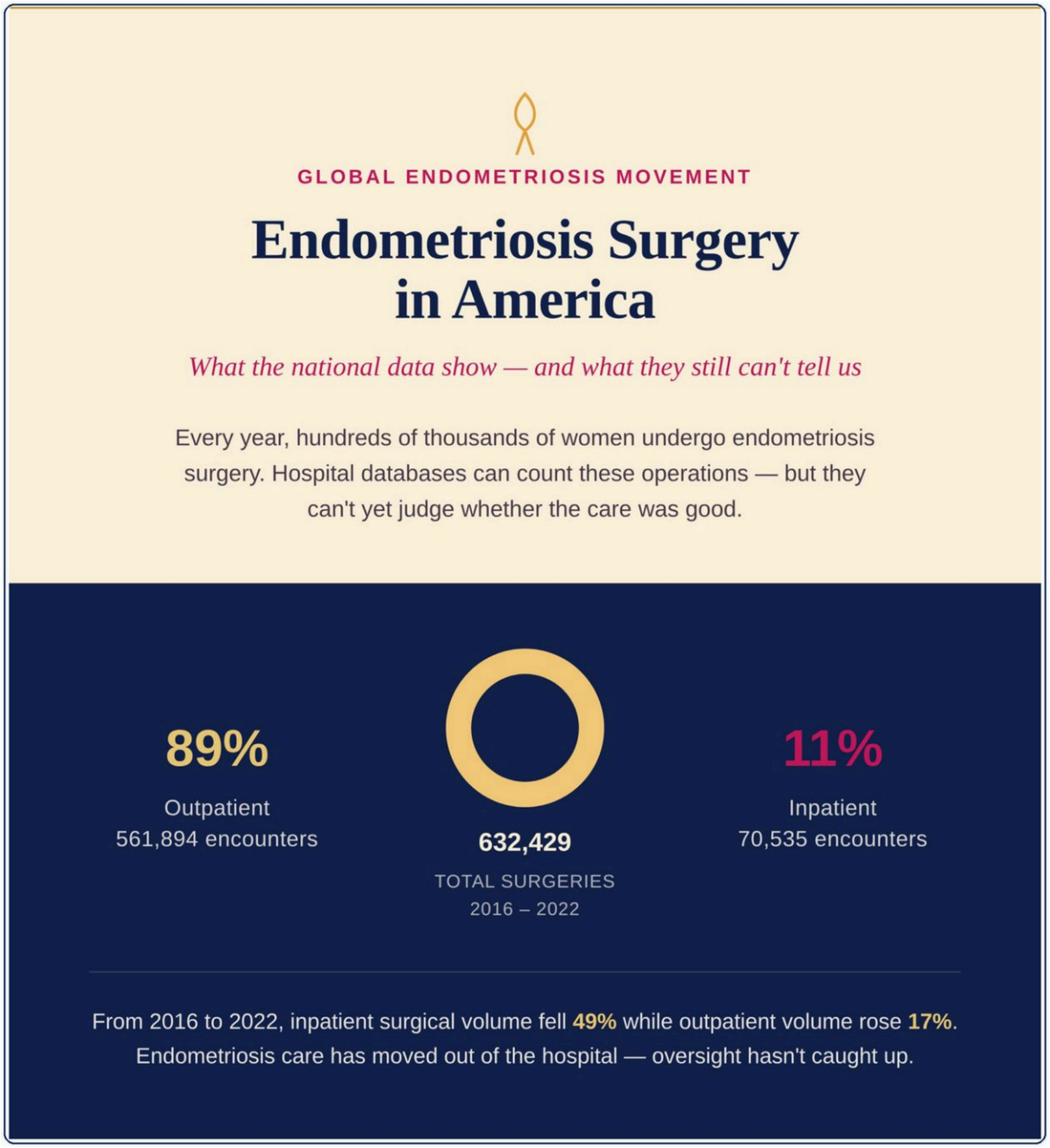

GLOBAL ENDOMETRIOSIS MOVEMENT
Endometriosis Surgery in America
What the national data show — and what they still can't tell us
Every year, hundreds of thousands of women undergo endometriosis surgery. Hospital databases can count these operations — but they can't yet judge whether the care was good.
89%
Outpatient
561,894 encounters
632,429
TOTAL SURGERIES
2016 – 2022
11%
Inpatient
70,535 encounters
From 2016 to 2022, inpatient surgical volume fell 49% while outpatient volume rose 17%.
Endometriosis care has moved out of the hospital — oversight hasn't caught up.



FIGURE 5. *Endometriosis surgery trends in the United States: rising outpatient rates, falling inpatient rates, and persistent data gaps.*

GLOBAL ENDOMETRIOSIS MOVEMENT

Too Many Women Need More Than One Endometriosis Surgery

Repeat surgery is common — and it carries a high personal and economic cost

Endometriosis is a chronic, complex disease. For many women, one operation is not the end of treatment — it's the beginning of a cycle.

~18–20%

WITHIN 5 YEARS

Nearly 1 in 5 women need another operation within 5 years.

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~28–30%

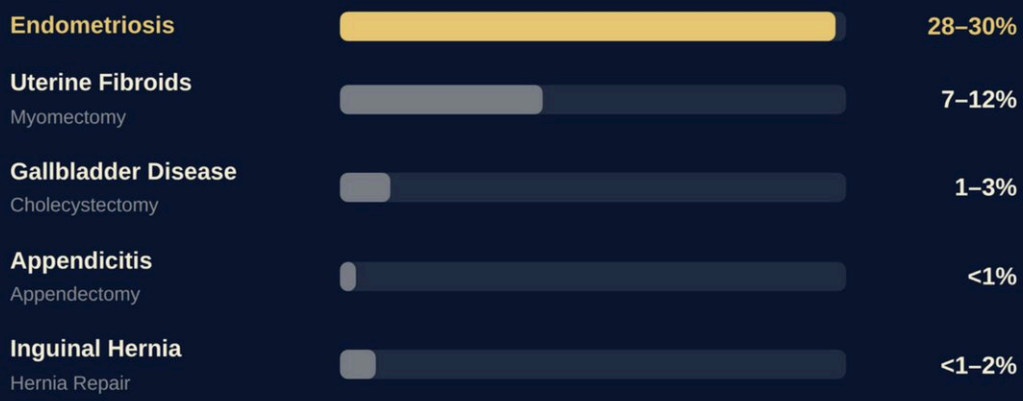
WITHIN 10 YEARS

Almost 1 in 3 women need another operation within 10 years.

Cumulative incidence of repeat surgery after conservative endometriosis surgery (uterus and ovaries preserved), based on a high-quality study of 1,092 women followed for up to 10 years.

HOW ENDOMETRIOSIS COMPARES

One of the highest reoperation rates among common surgeries — measured at 10 years.



Endometriosis has one of the highest reoperation rates among common surgeries.



FIGURE 6. *The prevalence and impact of repeat endometriosis surgery: personal cost, economic cost, and reoperation risk.*

4	**Research** Expand funding for research into better treatments and the development of reliable, noninvasive diagnostic tests.
5	**Education** Expand patient and physician education to support earlier recognition and timely referral for specialized treatment.

These goals are undeniably ambitious. Yet history teaches that meaningful progress in medicine is rarely achieved by individuals working in isolation; it arises when people unite around a common purpose, guided by science, compassion, integrity, and determination. That is precisely why GEM exists.

A PERSONAL MESSAGE

As Founder and Chairman of the Global Endo Movement (GEM), I have had the privilege of dedicating more than four decades to the care of women living with endometriosis. During this journey — as a clinician, surgeon, educator, researcher, and humanitarian — I have witnessed both their extraordinary resilience and the profound consequences of delayed diagnosis, inadequate treatment, and systemic neglect.

I have performed thousands of complex endometriosis surgeries, trained surgeons across several continents, helped establish fellowship programs and treatment centers, and worked alongside colleagues devoted to advancing minimally invasive gynecologic surgery. Yet the most enduring lessons have not come from lecture halls or operating rooms, but from the women themselves — the tearful eyes resting on my shoulder, and the joyful, grateful faces when they finally experienced relief after appropriate treatment.

These women have been my greatest teachers. Their stories have revealed the true human cost of this disease. Their courage, perseverance, and determination inspired the creation of GEM.

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> ***This movement belongs to them, and now, it belongs to all of us.***

Whether you are a woman living with endometriosis, a family member, a healthcare professional, a scientist, an educator, a policymaker, or someone who simply believes women deserve better healthcare, I strongly urge you to register on this site and be a part of this global movement. Your voice matters. Every member strengthens our community. Every story strengthens our understanding. Every partnership strengthens our mission.

✓ IMPROVE RESEARCH	✓ IMPROVE EDUCATION	✓ IMPROVE SURGICAL CARE	✓ INFLUENCE PUBLIC POLICY

History remembers those who refuse to accept that suffering is inevitable.

Together, let us build a future where every woman and girl with endometriosis is heard, diagnosed early, treated with excellence, and given the opportunity to live with dignity, hope, and health.

Together, We Will Transform Silent Suffering into Collective Action.

With gratitude,

Adel Shervin, MD, FACOG, FACS, ACGE

Founder & Chairman, Global Endo Movement (GEM)



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