Modernizing Endometriosis:
An Ancient Disease Still Waiting for Advanced Solutions

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Introduction: Endometriosis Affects Women and the Economy

Endometriosis is a chronic, estrogen-dependent inflammatory disease in which tissue normally lining the uterus grows outside the uterine cavity. It can cause pelvic pain, heavy or painful periods, gastrointestinal symptoms, and infertility, among other symptoms.[1] Endometriosis is often framed as a women's health issue or a niche condition affecting a subset of reproductive-aged women. This view ignores a longstanding failure of medical, research, and policy systems to recognize, diagnose, and treat a serious condition that has been documented for millennia.[2,3]

In his book, *The Doctor Will See You Now*, endometriosis specialist Tamer Seckin, MD, notes that symptoms consistent with endometriosis were described more than 4,000 years ago in ancient medical texts, long before the disease was formally named in the 1920s.[2] Yet, endometriosis still remains misunderstood, underdiagnosed, and underfunded in modern healthcare.

Today, approximately 190 million women globally (nearly 1 in 10) are living with endometriosis.[1] In the United States, the condition is estimated to cost the economy over $100 billion annually in lost productivity, workforce attrition, absenteeism, and healthcare expenditures.[4] These figures underscore that endometriosis is not only a global public health issue, but a significant societal and economic one.

While its cause remains unknown, endometriosis behaves in ways that are similar to cancer. It is driven by hormones, immune system dysfunction, and inflammation.[1,5] Endometriosis lesions can attach to surrounding organs, create their own blood supply, avoid immune defenses, and recur after surgical removal.[1,5] This behavior helps explain the disease's persistence, progression, and resistance to treatment. Reframing endometriosis as an invasive, inflammatory disease rather than a localized gynecologic complication is essential to fully understanding its impact.

Beyond Pelvic Pain: A Systemic Disease with a Significant Impact

Endometriosis is most commonly associated with pelvic pain and painful menstruation (dysmenorrhea), but its impact extends far beyond menstrual symptoms. Many individuals experience fatigue, brain fog, gastrointestinal symptoms, painful intercourse (dyspareunia), fertility challenges, nerve pain, and mental health strain, often concurrently.[1,6]

The burden of endometriosis is not solely physical. Patient-reported data show significant disruption to daily life and relationships. In a Healogix consumer survey fielded in March 2026 among women ages 18-45, 75% of respondents with confirmed endometriosis report altering their routines (work, school, social activities) because of their menstrual or pelvic pain.[6]

Normalizing menstrual pain and gaps in provider education both add to the burden patients face. In the same Healogix study, two-thirds of respondents have assumed their "pain was normal because others said it was" and, 62% with confirmed or suspected endometriosis have had their menstrual or pelvic pain dismissed by a healthcare provider.[6]

These findings highlight a stark contrast to cancer care where early diagnosis, defined care pathways, and major research investment have expanded treatment options and standardized care. Applying the same urgency to endometriosis would increase clinical attention, reduce diagnostic delays, and address limitations in the current treatment landscape.

The Diagnostic Gap: Why Endometriosis Takes Years to Identify

A major challenge in endometriosis care is diagnostic delay. Multiple studies indicate diagnosis can take 7 to 12 years from the onset of symptoms.[1] During this time, disease progression, chronic pain, fertility challenges, and psychological distress can worsen.[2]

Historically, laparoscopic surgery has been considered the "gold standard" and mandatory for clinical diagnosis. While it allows for biopsy, pathological confirmation, and assessment of disease extent, relying on surgery has led to extensive delays in diagnosis and inequitable access to care.[1,2,7]

In March 2026, the American College of Obstetricians and Gynecologists (ACOG) updated guidance to allow clinical diagnosis without surgery. Endometriosis can now be diagnosed based on patient history, physical examination, symptom patterns, and non-invasive imaging.[8]

This shift towards symptom-based diagnosis has meaningful implications. It can lead to earlier identification, reduce time to treatment, reduce cumulative disease burden, and validate patient experiences sooner in their journey. Most importantly, it removes invasive surgery as a barrier to receiving appropriate care.

Encouraging Progress: Advances in Non-Invasive Diagnosis

Innovation is accelerating across non-invasive diagnostics. Several companies have tools in late-stage development or available for early clinical use, including Hera Biotech (tissue-based molecular assays), Ziwig (saliva-based microRNA diagnostics), DotLab, Temple Therapeutics, and Kephera Diagnostics (blood-based diagnostic tests), NextGen Jane, Endometrics, and Proteomics International (menstrual- or blood-based biomarker platforms), and Diamens (RNA-sequencing–test).

Although many tools are still undergoing clinical validation, they signal progress toward a shorter diagnostic timelines and earlier clinical intervention. These advances mark an encouraging shift in how endometriosis may be identified and managed in the near future.

Treatment Landscape: Current Gaps and Real-World Challenges

Drug treatments for endometriosis have typically focused on symptom relief, and there are currently no disease-modifying treatments. Available options primarily aim to suppress estrogen and manage pain, rather than prevent new lesion growth or recurrence.[1] Treatment uptake is limited due to variable efficacy, side-effect burden, inconsistent clinical guidance, and restricted access to specialized care.[1]

Commonly used pharmaceutical treatments include hormonal contraceptives that prevent ovulation and menstruation; progestins, which reduce lesion activity but cause tolerability issues; GnRH agonists and antagonists, which carry safety concerns and limits on long-term use; and NSAIDs for pain management.[1]

Historically, women have undergone laser ablation surgery to remove lesions using high-energy heat. This approach is associated with tissue damage, inflammation, and high rates of recurrence.[2] The only intervention with proposed disease-modifying potential is specialized deep-excision surgery, which removes lesions using a "cold cut" technique. However, few surgeons are trained in this approach, and access is limited to a small number of multidisciplinary centers, reinforcing the unmet need for disease-modifying therapies.[2]

Policy Momentum: From Advocacy and Awareness to Action

After decades of inadequate research and investment, policy momentum is growing. The Endometriosis CARE Act, reintroduced in Congress in December 2025, calls for $50 million annually in dedicated NIH funding for five years, a national study on diagnostic and treatment disparities, and expanded public and provider education.[9]

This legislation responds directly to longstanding inequities in research prioritization. According to the Society for Women's Health Research (SWHR), endometriosis has historically received less than 0.1% of total NIH research funding, despite prevalence comparable to conditions such as diabetes and Crohn's disease.[10] Policy progress is increasingly driven by patient voices, clinician advocates, and real-world data that quantify the disease's social and economic burden.

In the Healogix survey, 81% of respondents with confirmed or suspected endometriosis agree "other people don't understand how disruptive my menstrual or pelvic pain can be".[6] Amplifying the patient voice is essential to shaping policy, research priorities, and care models that meaningfully address unmet needs.

Call to Action: Aligning Science and Policy with Patient Experience

Despite being identified thousands of years ago, endometriosis still lacks the clinical and policy urgency it deserves. Progress depends on earlier diagnosis, coordinated care, sustained research investment, and patient-centered advocacy. As real-world evidence continues to emerge from medical and market research alike, the imperative is to better align science, clinical practice, and policy to drive measurable change. We now know endometriosis is common, serious, and costly; what remains is for healthcare and policy systems to act with the urgency this disease has demanded for centuries.

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