Congress of the United States

Washington, DC 20515

August 31, 2026

The Honorable Robert F. Kennedy
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Kennedy:

Endometriosis is a chronic, systemic, inflammatory disease affecting millions of Americans and an estimated 200 million people worldwide.[1] Despite its increasing prevalence and substantial health burden, patients continue to face prolonged diagnostic delays, limited access to knowledgeable providers, inconsistent insurance coverage, and barriers to evidence-based care.These barriers contribute to unnecessary suffering, increased healthcare costs, disease progression, and poorer health outcomes.

As scientific knowledge continues to evolve, we respectfully seek information regarding how the Department of Health and Human Services is working to improve diagnosis and access to care for individuals living with endometriosis.

Diagnosis and Access to Care

Despite advances in medical knowledge, studies continue to demonstrate that it takes an estimated 6-12 years to receive an endometriosis diagnosis in the United States.[2] Diagnostic delays have been associated with disease progression, chronic pain, infertility, diminished quality of life, and increased healthcare utilization. Published literature identifies inadequate provider education, normalization of symptoms, inconsistent referral pathways, and limited access to experienced specialists as major contributors to these delays.[1][2] Therefore, we seek to better understand the Department's work to improve diagnosis of endometriosis, and address these delays.

- What steps has HHS taken to reduce diagnostic delays for individuals with endometriosis? Has HHS established measurable goals or benchmarks to improve timely diagnosis?
- Has HHS evaluated the downstream consequences of prolonged diagnostic delay, including disease progression, infertility, repeated surgeries, chronic pain, mental health conditions, organ dysfunction, and preventable healthcare utilization?
- Has HHS assessed the economic impact of delayed diagnosis and inadequate treatment, including healthcare utilization, productivity loss, disability, and workforce participation?
- What initiatives are underway to promote earlier diagnosis through evidence-based imaging, clinical evaluation, and referral pathways?

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[1] Nezhat C, Khoyloo F, Tsuei A, Armani E, Page B, Rduch T, Nezhat C. The Prevalence of Endometriosis in Patients with Unexplained Infertility. J Clin Med. 2024 Jan 13;13(2):444. doi: 10.3390/jcm13020444. PMID: 38256580; PMCID: PMC11326441.

[2] Soliman, A. M., S., C. K., Erica, Z., Jane, C.-H., & and Fuldeore, M. J. (2017). The burden of endometriosis symptoms on health-related quality of life in women in the United States: A cross-sectional study. Journal of Psychosomatic Obstetrics & Gynecology, 38(4), 238-248.
https://doi.org/10.1080/0167482X.2017.1289512

- Has HHS evaluated disparities in diagnosis among adolescents, racial and ethnic minority populations, rural communities, and medically underserved populations?
- What actions has HHS taken to improve recognition of endometriosis in adolescents, given evidence that symptoms can begin in childhood and delayed intervention may contribute to disease progression and long-term disability?

Coding and Reimbursement

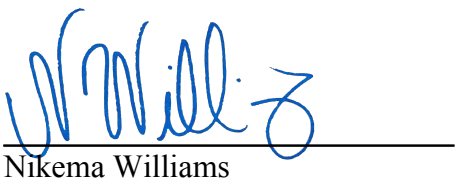
Adequate reimbursement contributes significantly to access to care for patients who may rely on Medicare, Medicaid, and other public insurers for their endometriosis care. Signals from the Centers for Medicare and Medicaid Services (CMS) also contribute to private insurers' coverage and reimbursement decisions. Therefore, to address one major barrier to care, we seek additional information about reimbursement for endometriosis diagnosis and treatment.

- Has HHS evaluated whether existing coding accurately captures the full range of endometriosis presentations, including multi-organ disease and multidisciplinary surgical management?
- Has HHS evaluated whether current ICD-10 and CPT coding adequately reflects the complexity of diagnosing and treating endometriosis?
- What steps has HHS taken to ensure adequate reimbursement for endometriosis diagnostics, including exploratory surgery when clinically appropriate?
- What steps has HHS taken to ensure adequate reimbursement for the treatment of endometriosis, including complex excision surgery?
- Has HHS evaluated whether current reimbursement policies adequately support multidisciplinary care frequently required for bowel, bladder, ureteral, diaphragmatic, and thoracic endometriosis?
- Has HHS evaluated barriers created by prior authorization requirements for advanced imaging, pelvic floor physical therapy, fertility preservation, multidisciplinary surgery, and chronic pain management?
- What actions has HHS taken to improve insurance coverage for evidence-based diagnosis and treatment of endometriosis?
- Will HHS work with CMS and relevant stakeholders to improve coding and reimbursement for evidence-based endometriosis care?

Thank you for your attention to these important questions. We appreciate the Department's commitment to improving the health of Americans and respectfully request information regarding HHS's current activities, future priorities, and measurable plans to improve access to diagnosis, and evidence-based treatment for individuals living with endometriosis.

We look forward to working collaboratively with the Department to improve outcomes for the millions of Americans living with this disease.

Sincerely,



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