

118TH CONGRESS  
2D SESSION

# H. R. 8565

To advance research, promote awareness, and provide patient support with respect to endometriosis, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 23, 2024

Ms. WILLIAMS of Georgia (for herself, Ms. UNDERWOOD, Mrs. GONZÁLEZ-COLÓN, Ms. ADAMS, and Mrs. SYKES) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To advance research, promote awareness, and provide patient support with respect to endometriosis, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Endometriosis Cov-  
5 erage, Awareness, Research, and Education Act” or the  
6 “Endometriosis CARE Act”.

7 **SEC. 2. FINDINGS.**

8 The Congress finds as follows:

1           (1) Endometriosis is a disease in which tissue  
2           similar to the lining of the uterus grows outside the  
3           uterus. It can cause severe pain in the pelvis and  
4           make it harder to get pregnant. Endometriosis often  
5           causes severe pain in the pelvis, especially during  
6           menstrual periods. Some people also have pain dur-  
7           ing sex or when using the bathroom. Some people  
8           have trouble getting pregnant.

9           (2) It causes a chronic inflammatory reaction  
10          that may result in the formation of scar tissue (ad-  
11          hesions, fibrosis) within the pelvis and other parts of  
12          the body. The cause of endometriosis is unknown.  
13          There is no known way to prevent endometriosis.  
14          There is no cure, but its symptoms can be treated  
15          with medicines or, in some cases, surgery

16 **SEC. 3. ADVANCING ENDOMETRIOSIS DATA COLLECTION,**  
17 **SURVEILLANCE, AND RESEARCH.**

18          (a) IN GENERAL.—The Director of the National In-  
19          stitutes of Health (in this section referred to as the “Di-  
20          rector”) shall conduct or support data collection, surveil-  
21          lance, and research related to endometriosis.

22          (b) USE OF FUNDS.—In carrying out subsection (a),  
23          the Director may—

24                  (1) conduct or support research and related ac-  
25          tivities regarding endometriosis, including research

1 to improve treatment options and develop a cure for  
2 endometriosis;

3 (2) establish or expand an internet clearing-  
4 house to catalog existing endometriosis research,  
5 treatment options, and related information for pa-  
6 tients and health care professionals; or

7 (3) carry out related activities as determined by  
8 the Director.

9 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry  
10 out this section, there is authorized to be appropriated  
11 \$50,000,000 for each of fiscal years 2025 through 2029.

12 **SEC. 4. IDENTIFYING BARRIERS TO ACCESSING TREAT-**  
13 **MENTS FOR ENDOMETRIOSIS SYMPTOMS.**

14 (a) RESEARCH.—The Secretary shall conduct an  
15 analysis of barriers that individuals diagnosed with endo-  
16 metriosis face in accessing treatments for endometriosis  
17 symptoms, including transportation barriers and barriers  
18 caused by health care professional shortages.

19 (b) TOPICS.—In carrying out the analysis under sub-  
20 section (a), the Secretary may—

21 (1) assess data from the Transformed Medicaid  
22 Statistical Information System related to services  
23 furnished to individuals diagnosed with endo-  
24 metriosis for the treatment of endometriosis symp-

1       toms under State Medicaid programs and Children’s  
2       Health Insurance Programs; and

3               (2) assess data related to services furnished to  
4       individuals diagnosed with endometriosis for the  
5       treatment of endometriosis symptoms under group  
6       health plans or group or individual health insurance  
7       coverage offered by a health insurance issuer.

8       (c) DATA COLLECTION.—To carry out the analysis  
9       under subsection (a), the Secretary may require—

10              (1) group health plans or issuers of group or in-  
11       dividual health insurance coverage to provide such  
12       information as may be required to assess barriers  
13       that individuals diagnosed with endometriosis face in  
14       accessing treatments for endometriosis symptoms,  
15       including a lack of insurance coverage or cost-shar-  
16       ing requirements for such treatments; and

17              (2) State Medicaid programs and Children’s  
18       Health Insurance Programs to collect and report  
19       data related to services furnished to individuals diag-  
20       nosed with endometriosis for the treatment of endo-  
21       metriosis symptoms through the Transformed Med-  
22       icaid Statistical Information System, including data  
23       stratified by relevant demographic characteristics.

24       (d) PRIVACY REQUIREMENTS.—In carrying out the  
25       analysis under subsection (a), the Secretary shall ensure

1 that the privacy and confidentiality of individual patients  
2 are protected in a manner consistent with relevant privacy  
3 and confidentiality laws.

4 (e) REPORT.—Not later than two years after the date  
5 of enactment of this Act, the Secretary shall submit to  
6 the Congress and make publicly available on the website  
7 of the Department of Health and Human Services a report  
8 on the analysis carried out under this section.

9 **SEC. 5. EDUCATION AND DISSEMINATION OF INFORMATION**  
10 **WITH RESPECT TO ENDOMETRIOSIS.**

11 (a) ENDOMETRIOSIS PUBLIC EDUCATION PRO-  
12 GRAM.—The Secretary shall develop and disseminate to  
13 the public information regarding endometriosis, including  
14 information on—

15 (1) the awareness, incidence, and prevalence of  
16 endometriosis, with a particular focus on individuals  
17 from racial and ethnic minority groups and other  
18 underserved groups;

19 (2) culturally and linguistically appropriate sup-  
20 port that is available to address the mental health  
21 impacts of endometriosis; and

22 (3) the availability, as medically appropriate, of  
23 the range of treatment options for symptoms of  
24 endometriosis.

1 (b) DISSEMINATION OF INFORMATION.—The Sec-  
2 retary may disseminate information under subsection (a)  
3 directly or through arrangements with intra-agency initia-  
4 tives, nonprofit organizations, consumer groups, institu-  
5 tions of higher education, or Federal, State, or local public  
6 private partnerships.

7 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry  
8 out this section, there is authorized to be appropriated  
9 \$2,000,000 for each of fiscal years 2025 through 2029.

10 **SEC. 6. INFORMATION TO HEALTH CARE PROVIDERS WITH**  
11 **RESPECT TO ENDOMETRIOSIS.**

12 (a) DISSEMINATION OF INFORMATION.—The Sec-  
13 retary shall, in consultation with relevant health care pro-  
14 fessional societies and associations, disseminate informa-  
15 tion to health care professionals, health care-related orga-  
16 nizations, and health systems to promote evidence-based  
17 care for individuals with endometriosis, including informa-  
18 tion related to—

- 19 (1) detecting and diagnosing endometriosis;  
20 (2) providing care for individuals with endo-  
21 metriosis;  
22 (3) communicating with patients about endo-  
23 metriosis; and  
24 (4) related topics.

1 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry  
2 out this section, there is authorized to be appropriated  
3 \$2,000,000 for each of fiscal years 2025 through 2029.

4 **SEC. 7. ENDOMETRIOSIS DISPARITIES STUDY THROUGH**  
5 **NATIONAL ACADEMIES.**

6 (a) IN GENERAL.—The Secretary shall seek to enter  
7 an agreement, not later than 90 days after the date of  
8 enactment of this Act, with the National Academies of  
9 Sciences, Engineering, and Medicine (referred to in this  
10 section as the “National Academies”) under which the Na-  
11 tional Academies agree to conduct a study on endo-  
12 metriosis disparities.

13 (b) STUDY REQUIREMENTS.—The agreement under  
14 subsection (a) shall direct the National Academies to—

15 (1) assess endometriosis prevalence, detection,  
16 treatment, and outcome disparities by race, eth-  
17 nicity, geography, primary language, sexual orienta-  
18 tion, gender identity, disability status, and insurance  
19 status, and related topics as determined by the Sec-  
20 retary; and

21 (2) make recommendations to the Congress,  
22 Federal agencies, health care professionals, and  
23 other relevant stakeholders based on the National  
24 Academies’ findings pursuant to paragraph (1).

1       (c) REPORT.—The agreement under subsection (a)  
2 shall direct the National Academies to complete the study  
3 under this section, and transmit to the Congress and make  
4 publicly available a report on the results of the study, not  
5 later than 24 months after the date of enactment of this  
6 Act.

7       (d) AUTHORIZATION OF APPROPRIATIONS.—To carry  
8 out this section, there is authorized to be appropriated  
9 \$500,000.

10 **SEC. 8. DEFINITIONS.**

11       In this Act:

12           (1) The term “institution of higher education”  
13 has the meaning given to such term in section 101  
14 of the Higher Education Act of 1965 (20 U.S.C.  
15 1001).

16           (2) The term “racial and ethnic minority  
17 group” has the meaning given such term in section  
18 1707(g) of the Public Health Service Act (42 U.S.C.  
19 300u–6(g)).

20           (3) The term “Secretary” means the Secretary  
21 of Health and Human Services.

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