

117TH CONGRESS
2D SESSION

H. R. 7974

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

IN THE HOUSE OF REPRESENTATIVES

JUNE 7, 2022

Ms. UNDERWOOD (for herself, Ms. WILLIAMS of Georgia, Ms. ADAMS, Miss GONZÁLEZ-COLÓN, Mr. LAWSON of Florida, Mrs. HAYES, Mr. ESPAILLAT, Mr. POCAN, Mr. LIEU, and Mr. DAVID SCOTT of Georgia) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 of 2022”
6 or the “Endometriosis CARE Act of 2022”.

1 **SEC. 2. ADVANCING ENDOMETRIOSIS DATA COLLECTION,**
2 **SURVEILLANCE, AND RESEARCH.**

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

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

9 (1) conduct or support research and related ac-
10 tivities regarding endometriosis, including research
11 to improve treatment options and develop a cure for
12 endometriosis;

13 (2) establish or expand an internet clearing-
14 house to catalog existing endometriosis research,
15 treatment options, and related information for pa-
16 tients and health care professionals; or

17 (3) carry out related activities as determined by
18 the Director.

19 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry
20 out this section, there is authorized to be appropriated
21 \$30,000,000 for each of fiscal years 2023 through 2027.

22 **SEC. 3. IDENTIFYING BARRIERS TO ACCESSING TREAT-**
23 **MENTS FOR ENDOMETRIOSIS SYMPTOMS.**

24 (a) RESEARCH.—The Secretary shall conduct an
25 analysis of barriers that individuals diagnosed with endo-
26 metriosis face in accessing treatments for endometriosis

1 symptoms, including transportation barriers and barriers
2 caused by health care professional shortages.

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

5 (1) assess data from the Transformed Medicaid
6 Statistical Information System related to services
7 furnished to individuals diagnosed with endo-
8 metriosis for the treatment of endometriosis symp-
9 toms under State Medicaid programs and Children’s
10 Health Insurance Programs; and

11 (2) assess data related to services furnished to
12 individuals diagnosed with endometriosis for the
13 treatment of endometriosis symptoms under group
14 health plans or group or individual health insurance
15 coverage offered by a health insurance issuer.

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

18 (1) group health plans or issuers of group or in-
19 dividual health insurance coverage to provide such
20 information as may be required to assess barriers
21 that individuals diagnosed with endometriosis face in
22 accessing treatments for endometriosis symptoms,
23 including a lack of insurance coverage or cost-shar-
24 ing requirements for such treatments; and

1 (2) State Medicaid programs and Children’s
2 Health Insurance Programs to collect and report
3 data related to services furnished to individuals diag-
4 nosed with endometriosis for the treatment of endo-
5 metriosis symptoms through the Transformed Med-
6 icaid Statistical Information System, including data
7 stratified by relevant demographic characteristics.

8 (d) PRIVACY REQUIREMENTS.—In carrying out the
9 analysis under subsection (a), the Secretary shall ensure
10 that the privacy and confidentiality of individual patients
11 are protected in a manner consistent with relevant privacy
12 and confidentiality laws.

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

18 **SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION**

19 **WITH RESPECT TO ENDOMETRIOSIS.**

20 (a) ENDOMETRIOSIS PUBLIC EDUCATION PRO-
21 GRAM.—The Secretary shall develop and disseminate to
22 the public information regarding endometriosis, including
23 information on—

24 (1) the awareness, incidence, and prevalence of
25 endometriosis, with a particular focus on individuals

1 from racial and ethnic minority groups and other
2 underserved groups;

3 (2) culturally and linguistically appropriate sup-
4 port that is available to address the mental health
5 impacts of endometriosis; and

6 (3) the availability, as medically appropriate, of
7 the range of treatment options for symptoms of
8 endometriosis.

9 (b) DISSEMINATION OF INFORMATION.—The Sec-
10 retary may disseminate information under subsection (a)
11 directly or through arrangements with intra-agency initia-
12 tives, nonprofit organizations, consumer groups, institu-
13 tions of higher education, or Federal, State, or local public
14 private partnerships.

15 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry
16 out this section, there is authorized to be appropriated
17 \$2,000,000 for each of fiscal years 2023 through 2027.

18 **SEC. 5. INFORMATION TO HEALTH CARE PROVIDERS WITH**
19 **RESPECT TO ENDOMETRIOSIS.**

20 (a) DISSEMINATION OF INFORMATION.—The Sec-
21 retary shall, in consultation with relevant health care pro-
22 fessional societies and associations, disseminate informa-
23 tion to health care professionals, health care-related orga-
24 nizations, and health systems to promote evidence-based

1 care for individuals with endometriosis, including informa-
2 tion related to—

3 (1) detecting and diagnosing endometriosis;

4 (2) providing care for individuals with endo-
5 metriosis;

6 (3) communicating with patients about endo-
7 metriosis; and

8 (4) related topics.

9 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
10 out this section, there is authorized to be appropriated
11 \$2,000,000 for each of fiscal years 2023 through 2027.

12 **SEC. 6. ENDOMETRIOSIS DISPARITIES STUDY THROUGH**
13 **NATIONAL ACADEMIES.**

14 (a) IN GENERAL.—The Secretary shall seek to enter
15 an agreement, not later than 90 days after the date of
16 enactment of this Act, with the National Academies of
17 Sciences, Engineering, and Medicine (referred to in this
18 section as the “National Academies”) under which the Na-
19 tional Academies agree to conduct a study on endo-
20 metriosis disparities.

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

23 (1) assess endometriosis prevalence, detection,
24 treatment, and outcome disparities by race, eth-
25 nicity, geography, primary language, sexual orienta-

1 tion, gender identity, disability status, and insurance
2 status, and related topics as determined by the Sec-
3 retary; and

4 (2) make recommendations to the Congress,
5 Federal agencies, health care professionals, and
6 other relevant stakeholders based on the National
7 Academies' findings pursuant to paragraph (1).

8 (c) REPORT.—The agreement under subsection (a)
9 shall direct the National Academies to complete the study
10 under this section, and transmit to the Congress and make
11 publicly available a report on the results of the study, not
12 later than 24 months after the date of enactment of this
13 Act.

14 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
15 out this section, there is authorized to be appropriated
16 \$500,000.

17 **SEC. 7. DEFINITIONS.**

18 In this Act:

19 (1) The term “institution of higher education”
20 has the meaning given to such term in section 101
21 of the Higher Education Act of 1965 (20 U.S.C.
22 1001).

23 (2) The term “racial and ethnic minority
24 group” has the meaning given such term in section

1 1707(g) of the Public Health Service Act (42 U.S.C.
2 300u-6(g)).

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

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