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(Original Signature of Member)

119TH CONGRESS
1ST SESSION

H. R. _____

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

IN THE HOUSE OF REPRESENTATIVES

Ms. WILLIAMS of Georgia introduced the following bill; which was referred to
the Committee on _____

A BILL

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

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. ENDOMETRIOSIS COVERAGE, AWARENESS, RE-**
17 **SEARCH, AND EDUCATION.**

18 Part F of title IV of the Public Health Service Act
19 (42 U.S.C. 287d et seq.) is amended by adding at the end
20 the following:

21 **“SEC. 486C. ENDOMETRIOSIS COVERAGE, AWARENESS, RE-**
22 **SEARCH, AND EDUCATION.**

23 “(a) ADVANCING ENDOMETRIOSIS DATA COLLEC-
24 TION, SURVEILLANCE, AND RESEARCH.—

1 “(1) IN GENERAL.—The Director of NIH shall
2 conduct or support data collection, surveillance, and
3 research related to endometriosis.

4 “(2) USE OF FUNDS.—In carrying out sub-
5 section (a), the Director may—

6 “(A) conduct or support research and re-
7 lated activities regarding endometriosis, includ-
8 ing research to improve treatment options and
9 develop a cure for endometriosis;

10 “(B) establish or expand an internet clear-
11 inghouse to catalog existing endometriosis re-
12 search, treatment options, and related informa-
13 tion for patients and health care professionals;
14 or

15 “(C) carry out related activities as deter-
16 mined by the Director.

17 “(3) AUTHORIZATION OF APPROPRIATIONS.—
18 To carry out this subsection, there is authorized to
19 be appropriated \$50,000,000 for each of fiscal years
20 2026 through 2030.

21 “(b) IDENTIFYING BARRIERS TO ACCESSING TREAT-
22 MENTS FOR ENDOMETRIOSIS SYMPTOMS.—

23 “(1) RESEARCH.—The Secretary shall conduct
24 an analysis of barriers that individuals diagnosed
25 with endometriosis face in accessing treatments for

1 endometriosis symptoms, including transportation
2 barriers and barriers caused by health care profes-
3 sional shortages.

4 “(2) TOPICS.—In carrying out the analysis
5 under paragraph (1), the Secretary may—

6 “(A) assess data from the Transformed
7 Medicaid Statistical Information System related
8 to services furnished to individuals diagnosed
9 with endometriosis for the treatment of endo-
10 metriosis symptoms under State Medicaid pro-
11 grams under title XIX of the Social Security
12 Act and Children’s Health Insurance Programs
13 under title XXI of such Act; and

14 “(B) assess data related to services fur-
15 nished to individuals diagnosed with endo-
16 metriosis for the treatment of endometriosis
17 symptoms under group health plans or group or
18 individual health insurance coverage offered by
19 a health insurance issuer (as those terms are
20 defined in section 2791).

21 “(3) DATA COLLECTION.—To carry out the
22 analysis under paragraph (1), the Secretary may re-
23 quire—

24 “(A) group health plans or issuers of
25 group or individual health insurance coverage to

1 provide such information as may be required to
2 assess barriers that individuals diagnosed with
3 endometriosis face in accessing treatments for
4 endometriosis symptoms, including a lack of in-
5 surance coverage or cost-sharing requirements
6 for such treatments; and

7 “(B) State Medicaid programs and Chil-
8 dren’s Health Insurance Programs to collect
9 and report data related to services furnished to
10 individuals diagnosed with endometriosis for the
11 treatment of endometriosis symptoms through
12 the Transformed Medicaid Statistical Informa-
13 tion System, including data stratified by rel-
14 evant demographic characteristics.

15 “(4) PRIVACY REQUIREMENTS.—In carrying
16 out the analysis under paragraph (1), the Secretary
17 shall ensure that the privacy and confidentiality of
18 individual patients are protected in a manner con-
19 sistent with relevant privacy and confidentiality
20 laws.

21 “(5) REPORT.—Not later than two years after
22 the date of enactment of this section, the Secretary
23 shall submit to the Congress, and make publicly
24 available on the website of the Department of

1 Health and Human Services, a report on the anal-
2 ysis carried out under this subsection.

3 “(c) EDUCATION AND DISSEMINATION OF INFORMA-
4 TION WITH RESPECT TO ENDOMETRIOSIS.—

5 “(1) ENDOMETRIOSIS PUBLIC EDUCATION PRO-
6 GRAM.—The Secretary shall develop, and dissemi-
7 nate to the public, information regarding endo-
8 metriosis, including information on—

9 “(A) the awareness, incidence, and preva-
10 lence of endometriosis, with a particular focus
11 on individuals from racial and ethnic minority
12 groups (as defined in section 1707(g)) and
13 other underserved groups;

14 “(B) culturally and linguistically appro-
15 priate support that is available to address the
16 mental health impacts of endometriosis; and

17 “(C) the availability, as medically appro-
18 priate, of the range of treatment options for
19 symptoms of endometriosis.

20 “(2) DISSEMINATION OF INFORMATION.—The
21 Secretary may disseminate information under para-
22 graph (1) directly or through arrangements with
23 intra-agency initiatives, nonprofit organizations, con-
24 sumer groups, institutions of higher education (as
25 defined in section 101 of the Higher Education Act

1 of 1965), or Federal, State, or local public private
2 partnerships.

3 “(3) AUTHORIZATION OF APPROPRIATIONS.—

4 To carry out this subsection, there is authorized to
5 be appropriated \$2,000,000 for each of fiscal years
6 2026 through 2030.

7 “(d) INFORMATION TO HEALTH CARE PROVIDERS
8 WITH RESPECT TO ENDOMETRIOSIS.—

9 “(1) DISSEMINATION OF INFORMATION.—The
10 Secretary shall, in consultation with relevant health
11 care professional societies and associations, dissemi-
12 nate information to health care professionals, health
13 care-related organizations, and health systems to
14 promote evidence-based care for individuals with
15 endometriosis, including information related to—

16 “(A) detecting and diagnosing endo-
17 metriosis;

18 “(B) providing care for individuals with
19 endometriosis;

20 “(C) communicating with patients about
21 endometriosis; and

22 “(D) related topics.

23 “(2) AUTHORIZATION OF APPROPRIATIONS.—

24 To carry out this section, there is authorized to be

1 appropriated \$2,000,000 for each of fiscal years
2 2026 through 2030.

3 “(e) ENDOMETRIOSIS DISPARITIES STUDY THROUGH
4 NATIONAL ACADEMIES.—

5 “(1) IN GENERAL.—The Secretary shall seek to
6 enter an agreement, not later than 90 days after the
7 date of enactment of this section, with the National
8 Academies of Sciences, Engineering, and Medicine
9 (referred to in this section as the ‘National Acad-
10 emies’) under which the National Academies agree
11 to conduct a study on endometriosis disparities.

12 “(2) STUDY REQUIREMENTS.—The agreement
13 under paragraph (1) shall direct the National Acad-
14 emies to—

15 “(A) assess endometriosis prevalence, de-
16 tection, treatment, and outcome disparities by
17 race, ethnicity, geography, primary language,
18 sexual orientation, gender identity, disability
19 status, and insurance status, and related topics
20 as determined by the Secretary; and

21 “(B) make recommendations to the Con-
22 gress, Federal agencies, health care profes-
23 sionals, and other relevant stakeholders based
24 on the National Academies’ findings pursuant
25 to subparagraph (A).

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

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