117TH CONGRESS
2D 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. UNDERWOOD 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 purposes.

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

SECTION 1. SHORT TITLE.

This Act may be cited as the “Endometriosis Cov-
erage, Awareness, Research, and Education Act of 2022” or the “Endometriosis CARE Act of 2022”.

(Original Signature of Member)
SEC. 2. ADVANCING ENDOMETRIOSIS DATA COLLECTION, SURVEILLANCE, AND RESEARCH.

(a) IN GENERAL.—The Director of the National Institutes of Health (in this section referred to as the “Director”) shall conduct or support data collection, surveillance, and research related to endometriosis.

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

(1) conduct or support research and related activities regarding endometriosis, including research to improve treatment options and develop a cure for endometriosis;

(2) establish or expand an internet clearinghouse to catalog existing endometriosis research, treatment options, and related information for patients and health care professionals; or

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

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

SEC. 3. IDENTIFYING BARRIERS TO ACCESSING TREATMENTS FOR ENDOMETRIOSIS SYMPTOMS.

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

(b) TOPICS.—In carrying out the analysis under subsection (a), the Secretary may—

(1) assess data from the Transformed Medicaid Statistical Information System related to services furnished to individuals diagnosed with endometriosis for the treatment of endometriosis symptoms under State Medicaid programs and Children’s Health Insurance Programs; and

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

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

(1) group health plans or issuers of group or individual health insurance coverage to provide such information as may be required to assess barriers that individuals diagnosed with endometriosis face in accessing treatments for endometriosis symptoms, including a lack of insurance coverage or cost-sharing requirements for such treatments; and
(2) State Medicaid programs and Children’s Health Insurance Programs to collect and report data related to services furnished to individuals diagnosed with endometriosis for the treatment of endometriosis symptoms through the Transformed Medicaid Statistical Information System, including data stratified by relevant demographic characteristics.

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

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

SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION WITH RESPECT TO ENDOMETRIOSIS.

(a) ENDOMETRIOSIS PUBLIC EDUCATION PROGRAM.—The Secretary shall develop and disseminate to the public information regarding endometriosis, including information on—

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

(2) culturally and linguistically appropriate support that is available to address the mental health impacts of endometriosis; and

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

(b) Dissemination of Information.—The Secretary may disseminate information under subsection (a) directly or through arrangements with intra-agency initiatives, nonprofit organizations, consumer groups, institutions of higher education, or Federal, State, or local public private partnerships.

(c) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $2,000,000 for each of fiscal years 2023 through 2027.

SEC. 5. INFORMATION TO HEALTH CARE PROVIDERS WITH RESPECT TO ENDOMETRIOSIS.

(a) Dissemination of Information.—The Secretary shall, in consultation with relevant health care professional societies and associations, disseminate information to health care professionals, health care-related organizations, and health systems to promote evidence-based
care for individuals with endometriosis, including information related to—

(1) detecting and diagnosing endometriosis;
(2) providing care for individuals with endometriosis;
(3) communicating with patients about endometriosis; and
(4) related topics.

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

SEC. 6. ENDOMETRIOSIS DISPARITIES STUDY THROUGH NATIONAL ACADEMIES.

(a) IN GENERAL.—The Secretary shall seek to enter an agreement, not later than 90 days after the date of enactment of this Act, with the National Academies of Sciences, Engineering, and Medicine (referred to in this section as the “National Academies”) under which the National Academies agree to conduct a study on endometriosis disparities.

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

(1) assess endometriosis prevalence, detection, treatment, and outcome disparities by race, ethnicity, geography, primary language, sexual orienta-
tion, gender identity, disability status, and insurance status, and related topics as determined by the Secre-
tary; and

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

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

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

SEC. 7. DEFINITIONS.

In this Act:

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

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

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