IN THE SENATE OF THE UNITED STATES

Ms. HARRIS introduced the following bill; which was read twice and referred to the Committee on ______________________

A BILL

To provide for research and education with respect to uterine fibroids, and for other purposes.

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

SECTION 1. SHORT TITLE.

This Act may be cited as the “Uterine Fibroid Research and Education Act of 2020”.

SEC. 2. FINDINGS.

Congress finds as follows:

(1) It is estimated that between 20 and 30 percent of women of reproductive age have clinically recognized uterine fibroids, and screening studies in-
dicate the prevalence of uterine fibroids in women may be much higher.

(2) In the United States, an estimated 26,000,000 women between the ages of 15 and 50 have uterine fibroids. Uterine fibroids may cause significant morbidity through their presence in the uterus and pelvic cavity, causing significant pelvic pain, iron-deficiency anemia, miscarriages, infertility, and heavy bleeding—one of the most common and bothersome symptoms.

(3) The pain, discomfort, stress, and other physical and emotional symptoms of living with fibroids may significantly interfere with a woman’s quality of life, compromising her ability to function normally or work or care for her family, and may lead to more severe health and wellness issues.

(4) The development of uterine fibroids is a common and significant health problem, affecting women, primarily of reproductive age, across all ages, racial backgrounds, and socioeconomic levels.

(5) Most women will experience uterine fibroids by the age of 50, yet few data exist describing the overall patient experience with fibroids. Women with fibroids or symptoms suggestive of fibroids experience significant distress that reduces quality of life
and many women are likely undiagnosed, underscoring the need for improved awareness and education.

(6) Minority women are more likely to develop uterine fibroids. It is estimated that more than 80 percent of African-American women and about 70 percent of Caucasian women develop fibroids by the time they reach menopause. African-American women have also been shown to have more severe symptoms and develop early-onset uterine fibroids that develop into larger tumors.

(7) The exact number of affected women is unknown, because only 1 out of 4 women who have a uterine fibroid tumor exhibit symptoms severe enough to require treatment.

(8) Current research and available data do not provide adequate information on the rates of prevalence and incidence of fibroids in Asian, Hispanic, and African-American minority women. There is no quantitative data available in regard to the costs associated with treating fibroids, and the methods by which fibroids may be prevented in these women available.

(9) Symptomatic uterine fibroids can cause heavy menstrual bleeding, pain, and reproductive
problems, including infertility. Women with uterine fibroids are much more likely to miscarry during early pregnancy than women without them.

(10) According to the Evidence Report Summary on the Management of Uterine Fibroids, as compiled by the Agency for Healthcare Research and Quality of the Department of Health and Human Services, there is a “remarkable lack of high-quality evidence supporting the effectiveness of most interventions for symptomatic fibroids”.

(11) The presence of symptomatic uterine fibroids is the most common reason for hysterectomies, accounting for approximately one-third of hysterectomies, or 200,000 procedures annually. Twenty-two percent of African-American women and 7 percent of Caucasian women have hysterectomies as a result of uterine fibroids. Lack of patient and provider awareness of less invasive alternatives to hysterectomies lead to an estimated 80,000 to 120,000 unnecessary hysterectomies annually. Uterine fibroids are also the leading cause of hospitalization related to a gynecological disorder.

(12) The personal and societal costs of uterine fibroids in the United States are significant. Uterine fibroid tumors have been estimated to cost the
United States $5,900,000,000 to $34,400,000,000 annually. The annual direct costs, including surgery, hospital admissions, outpatient visits, and medications, were estimated at $4,100,000,000 to $9,400,000,000 annually. Estimated lost work-hour costs ranged from $1,550,000,000 to $17,200,000,000 annually. Obstetric outcomes that were attributed to fibroid tumors resulted in costs of $238,000,000 to $7,760,000,000 annually.

SEC. 3. RESEARCH WITH RESPECT TO UTERINE FIBROIDS.

(a) Research.—The Director of the National Institutes of Health (in this section referred to as the “Director of NIH”) shall expand, intensify, and coordinate programs for the conduct and support of research with respect to uterine fibroids.

(b) Administration and Coordination.—The Director of NIH, acting through Director of the Office of Research on Women’s Health, shall carry out research conducted pursuant to subsection (a), in coordination with the appropriate institutes, offices, and centers of the National Institutes of Health, including the National Institute of Child Health and Human Development, the National Institute of Environmental Health Sciences, the Office of Women’s Health, the Office of Minority Health, and the National Center on Minority Health and Health
Disparities, and any other relevant Federal agency, as determined by the Director.

(c) Authorization of Appropriations.—For the purpose of carrying out this section, there are authorized to be appropriated $30,000,000 for each of fiscal years 2021 through 2025.

SEC. 4. RESEARCH WITH RESPECT TO MEDICAID COVERAGE OF UTERINE FIBROIDS TREATMENT.

(a) Research.—The Administrator of the Centers for Medicare & Medicaid Services (referred to in this section as the “Administrator”) shall expand the Chronic Conditions Data Warehouse research database of such Centers for Medicare & Medicaid Services to collect data on items and services furnished to women diagnosed with uterine fibroids and fibroids-related symptoms under a State plan (or a waiver of such a plan) under the Medicaid program under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) or under a State child health plan (or a waiver of such a plan) under the Children’s Health Insurance Program under title XXI of such Act (42 U.S.C. 1397aa et seq.) for the treatment of such fibroids and symptoms for purposes of assessing the frequency at which such women are furnished such items and services.

(b) Report.—
(1) IN GENERAL.—Not later than the date that is one year after the date of the enactment of this Act, the Administrator shall submit to Congress a report on the amount of Federal and State expenditures with respect to items and services furnished for the treatment of uterine fibroids and fibroids-related symptoms under State plans (or waivers of such plans) under the Medicaid program under such title XIX and State child health plans (or waivers of such plans) under the Children’s Health Insurance Program under such title XXI.

(2) COORDINATION.—The Administrator shall coordinate the development and submission of the report required under paragraph (1) with each of the following:

(A) Within the Centers for Medicare & Medicaid Services—

(i) the Office of Minority Health;

(ii) the Center for Medicaid and CHIP Services;

(iii) the Office of Enterprise Data and Analytics; and

(iv) any other office or center determined appropriate by the Administrator.
(B) Any other relevant Federal agency, as determined by the Administrator.

(c) Authorization of Appropriations.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2021 through 2025.

SEC. 5. EDUCATION AND DISSEMINATION OF INFORMATION WITH RESPECT TO UTERINE FIBROIDS.

(a) Uterine Fibroids Public Education Program.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall develop and disseminate to the public information regarding uterine fibroids, including information on—

   (1) the awareness, incidence, and prevalence of uterine fibroids among women, including all minority women;

   (2) the elevated risk for minority women to develop uterine fibroids; and

   (3) the availability, as medically appropriate, of the range of treatment options for symptomatic uterine fibroids, including non-hysterectomy treatments and procedures.

(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 (as defined in section 101 of the Higher Education Act of 1965 (20 U.S.C. 1001)), or Federal, State, or local public private partnerships.

(c) Authorization of Appropriations.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2021 through 2025.

SEC. 6. INFORMATION TO HEALTH CARE PROVIDERS WITH RESPECT TO UTERINE FIBROIDS.

(a) Dissemination of Information.—The Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration and the Director of the Agency for Healthcare Research and Quality shall, in consultation and in accordance with guidelines from relevant medical societies, develop and disseminate to health care providers information on uterine fibroids for the purpose of ensuring that health care providers remain informed about current information on uterine fibroids. Such information shall include the elevated risk for minority women to develop uterine fibroids and the range of available options for the treatment of symptomatic uterine fibroids, including non-hysterectomy drugs and devices approved under the Fed-
eral Food, Drug, and Cosmetic Act (21 U.S.C. 301 et seq.).

(b) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2021 through 2025.

SEC. 7. DEFINITION.

In this Act, the term “minority women” means women who are members of a racial and ethnic minority group, as defined in section 1707(g) of the Public Health Service Act (42 U.S.C. 300u–6(g)).