117TH CONGRESS
1ST SESSION

S. 2444

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

IN THE SENATE OF THE UNITED STATES

JULY 22, 2021

Mr. BOOKER (for himself and Mrs. CAPITO) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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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 ''Stephanie Tubbs Jones Uterine Fibroid Research and Education Act of 2021''.

SEC. 2. FINDINGS.

Congress finds as follows:

(1) It is estimated that 20 percent to 50 percent of women of reproductive age currently have

uterine fibroids, and up to 77 percent of women will develop fibroids before menopause.

(2) In the United States, an estimated 26,000,000 women between the ages of 15 and 50 have uterine fibroids, and approximately 15,000,000 of these individuals experience symptoms. Uterine fibroids may cause significant morbidity through their presence in the uterus and pelvic cavity, and symptoms can include pelvic pain, severe menstrual bleeding, iron-deficiency anemia, fatigue, bladder or bowel dysfunction, infertility, and pregnancy complications and loss.

(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) Most women will experience uterine fibroids by the age of 50, yet few data exist describing the overall patient experience with fibroids.

(5) Many people with fibroids are likely undiagnosed. Patients wait on average 3.6 years before seeking treatment, and over 40 percent of patients see 2 or more health care providers prior to

receiving a diagnosis, underscoring the need for improved awareness and education.

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

(7) Current research and available data do not provide adequate information on the prevalence and incidence of fibroids in Asian, Hispanic, and Black individuals.

(8) Symptomatic uterine fibroids can cause reproductive problems, including infertility. People with uterine fibroids are much more likely to miscarry during early pregnancy than people without them.

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

(10) Most medical options for managing fibroid symptoms regulate or suppress menstruation and prevent pregnancy. There is a great need for minimally invasive, fertility-friendly therapies, as well as biomarkers, imaging assessments, or risk-based algorithms that can help predict patient response to therapy.

(11) The presence of symptomatic uterine fibroids is the most common reason for hysterectomies, accounting for 39 percent of hysterectomies annually in the United States. Approximately 42 per 1,000 women are hospitalized annually because of uterine fibroids, but Black patients have higher rates of hospitalization, hysterectomies, and myomectomies compared to White women. 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.

(13) At the Federal level, uterine fibroid research remains drastically underfunded as compared to patient disease burden. In 2019, fibroid research received about $17,000,000 in funding from the National Institutes of Health, putting it in the bottom 50 of 292 funded conditions.

SEC. 3. RESEARCH WITH RESPECT TO UTERINE FIBROIDS.

(a) RESEARCH.—The Secretary of Health and Human Services (referred to in this Act as the ''Secretary'') shall expand, intensify, and coordinate programs for the conduct and support of research with respect to uterine fibroids.

(b) ADMINISTRATION AND COORDINATION.—The Secretary shall carry out the conduct and support of research pursuant to subsection (a), in coordination with the appropriate institutes, offices, and centers of the National Institutes of Health and any other relevant Federal agency, as determined by the Secretary and the Director of the National Institutes of Health.

(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 2022 through 2026.

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

(a) RESEARCH.—The Secretary (or the Secretary's designee) shall establish a research database, or expand an existing research database, to collect data on services furnished to individuals diagnosed with uterine fibroids 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 for purposes of assessing the frequency at which such individuals are furnished such services.

(b) REPORT.—

(1) IN GENERAL.—Not later than the date that is 2 years after the date of enactment of this Act, the Secretary shall submit to Congress a report on the amount of Federal and State expenditures with respect to services furnished for the treatment of uterine fibroids 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 Secretary shall coordinate the development and submission of the report required under paragraph (1) with any other relevant Federal agency, as determined by the Secretary.

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

(a) UTERINE FIBROIDS PUBLIC EDUCATION PROGRAM.—The Secretary shall develop and disseminate to the public information regarding uterine fibroids, including information on—

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

(2) the elevated risk for minority individuals 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 2022 through 2026.

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

(a) DISSEMINATION OF INFORMATION.—The Secretary of Health and Human Services shall, in consultation and in accordance with guidelines from relevant medical societies, work with health care-related specialty societies and health systems to promote evidence-based care for individuals with fibroids. Such efforts shall include minority individuals who have an elevated risk 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 Federal 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 2022 through 2026.

SEC. 7. DEFINITION.

In this Act, the term ''minority individuals'' means individuals 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)).

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