

116TH CONGRESS
2D SESSION

H. R. 6383

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

IN THE HOUSE OF REPRESENTATIVES

MARCH 24, 2020

Ms. CLARKE of New York (for herself, Ms. KELLY of Illinois, Mrs. WATSON COLEMAN, Mr. DAVID SCOTT of Georgia, Ms. LEE of California, Ms. PLASKETT, Ms. FUDGE, Ms. JOHNSON of Texas, Mr. RUSH, Mr. BROWN of Maryland, Ms. PRESSLEY, Mr. DANNY K. DAVIS of Illinois, Mr. THOMPSON of Mississippi, Mr. CLYBURN, Mr. RICHMOND, Mr. BUTTERFIELD, Mr. BISHOP of Georgia, Mr. CLEAVER, Mr. HASTINGS, Mr. JEFFRIES, Mr. MEEKS, Mr. CARSON of Indiana, Ms. JACKSON LEE, Mr. JOHNSON of Georgia, Mrs. LAWRENCE, Ms. BASS, and Ms. NORTON) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for research and education with respect to uterine fibroids, 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 “Uterine Fibroid Re-
5 search and Education Act of 2020”.

1 **SEC. 2. FINDINGS.**

2 Congress finds as follows:

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

8 (2) In the United States, an estimated
9 26,000,000 women between the ages of 15 and 50
10 have uterine fibroids. Uterine fibroids may cause sig-
11 nificant morbidity through their presence in the
12 uterus and pelvic cavity, causing significant pelvic
13 pain, iron-deficiency anemia, miscarriages, infer-
14 tility, and heavy bleeding—one of the most common
15 and bothersome symptoms.

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

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

1 (5) Most women will experience uterine fibroids
2 by the age of 50, yet few data exist describing the
3 overall patient experience with fibroids. Women with
4 fibroids or symptoms suggestive of fibroids experi-
5 ence significant distress that reduces quality of life
6 and many women are likely undiagnosed, under-
7 scoring the need for improved awareness and edu-
8 cation.

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

17 (7) The exact number of affected women is un-
18 known, because only 1 out of 4 women who have a
19 uterine fibroid tumor exhibit symptoms severe
20 enough to require treatment.

21 (8) Current research and available data do not
22 provide adequate information on the rates of preva-
23 lence and incidence of fibroids in Asian, Hispanic,
24 and African-American minority women. There is no
25 quantitative data available in regard to the costs as-

1 sociated with treating fibroids, and the methods by
2 which fibroids may be prevented in these women
3 available.

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

9 (10) According to the Evidence Report Sum-
10 mary on the Management of Uterine Fibroids, as
11 compiled by the Agency for Healthcare Research and
12 Quality of the Department of Health and Human
13 Services, there is a “remarkable lack of high-quality
14 evidence supporting the effectiveness of most inter-
15 ventions for symptomatic fibroids”.

16 (11) The presence of symptomatic uterine
17 fibroids is the most common reason for
18 hysterectomies, accounting for approximately one-
19 third of hysterectomies, or 200,000 procedures an-
20 nually. Twenty-two percent of African-American
21 women and 7 percent of Caucasian women have
22 hysterectomies as a result of uterine fibroids. Lack
23 of patient and provider awareness of less invasive al-
24 ternatives to hysterectomies lead to an estimated
25 80,000 to 120,000 unnecessary hysterectomies an-

1 nually. Uterine fibroids are also the leading cause of
2 hospitalization related to a gynecological disorder.

3 (12) The personal and societal costs of uterine
4 fibroids in the United States are significant. Uterine
5 fibroid tumors have been estimated to cost the
6 United States \$5,900,000,000 to \$34,400,000,000
7 annually. The annual direct costs, including surgery,
8 hospital admissions, outpatient visits, and medica-
9 tions, were estimated at \$4,100,000,000 to
10 \$9,400,000,000 annually. Estimated lost work-hour
11 costs ranged from \$1,550,000,000 to
12 \$17,200,000,000 annually. Obstetric outcomes that
13 were attributed to fibroid tumors resulted in costs of
14 \$238,000,000 to \$7,760,000,000 annually.

15 **SEC. 3. RESEARCH WITH RESPECT TO UTERINE FIBROIDS.**

16 (a) RESEARCH.—The Director of the National Insti-
17 tutes of Health (in this section referred to as the “Direc-
18 tor of NIH”) shall expand, intensify, and coordinate pro-
19 grams for the conduct and support of research with re-
20 spect to uterine fibroids.

21 (b) ADMINISTRATION AND COORDINATION.—The Di-
22 rector of NIH, acting through Director of the Office of
23 Research on Women’s Health, shall carry out research
24 conducted pursuant to subsection (a), in coordination with
25 the appropriate institutes, offices, and centers of the Na-

1 tional Institutes of Health, including the National Insti-
2 tute of Child Health and Human Development, the Na-
3 tional Institute of Environmental Health Sciences, the Of-
4 fice of Women’s Health, the Office of Minority Health,
5 and the National Center on Minority Health and Health
6 Disparities, and any other relevant Federal agency, as de-
7 termined by the Director.

8 (c) AUTHORIZATION OF APPROPRIATIONS.—For the
9 purpose of carrying out this section, there are authorized
10 to be appropriated \$30,000,000 for each of fiscal years
11 2021 through 2025.

12 **SEC. 4. RESEARCH WITH RESPECT TO MEDICAID COV-**
13 **ERAGE OF UTERINE FIBROIDS TREATMENT.**

14 (a) RESEARCH.—The Administrator of the Centers
15 for Medicare & Medicaid Services (referred to in this sec-
16 tion as the “Administrator”) shall expand the Chronic
17 Conditions Data Warehouse research database of such
18 Centers for Medicare & Medicaid Services to collect data
19 on items and services furnished to women diagnosed with
20 uterine fibroids and fibroids-related symptoms under a
21 State plan (or a waiver of such a plan) under the Medicaid
22 program under title XIX of the Social Security Act (42
23 U.S.C. 1396 et seq.) or under a State child health plan
24 (or a waiver of such a plan) under the Children’s Health
25 Insurance Program under title XXI of such Act (42

1 U.S.C. 1397aa et seq.) for the treatment of such fibroids
2 and symptoms for purposes of assessing the frequency at
3 which such women are furnished such items and services.

4 (b) REPORT.—

5 (1) IN GENERAL.—Not later than the date that
6 is one year after the date of the enactment of this
7 Act, the Administrator shall submit to Congress a
8 report on the amount of Federal and State expendi-
9 tures with respect to items and services furnished
10 for the treatment of uterine fibroids and fibroids-re-
11 lated symptoms under State plans (or waivers of
12 such plans) under the Medicaid program under such
13 title XIX and State child health plans (or waivers of
14 such plans) under the Children’s Health Insurance
15 Program under such title XXI.

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

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

22 (i) the Office of Minority Health;

23 (ii) the Center for Medicaid and
24 CHIP Services;

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

3 (iv) any other office or center deter-
4 mined appropriate by the Administrator.

5 (B) Any other relevant Federal agency, as
6 determined by the Administrator.

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

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

13 (a) UTERINE FIBROIDS PUBLIC EDUCATION PRO-
14 GRAM.—The Secretary of Health and Human Services,
15 acting through the Director of the Centers for Disease
16 Control and Prevention, shall develop and disseminate to
17 the public information regarding uterine fibroids, includ-
18 ing information on—

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

22 (2) the elevated risk for minority women to de-
23 velop uterine fibroids; and

24 (3) the availability, as medically appropriate, of
25 the range of treatment options for symptomatic

1 uterine fibroids, including non-hysterectomy treat-
2 ments and procedures.

3 (b) DISSEMINATION OF INFORMATION.—The Sec-
4 retary may disseminate information under subsection (a)
5 directly or through arrangements with intra-agency initia-
6 tives, nonprofit organizations, consumer groups, institu-
7 tions of higher education (as defined in section 101 of the
8 Higher Education Act of 1965 (20 U.S.C. 1001)), or Fed-
9 eral, State, or local public private partnerships.

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

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

16 (a) DISSEMINATION OF INFORMATION.—The Sec-
17 retary of Health and Human Services, acting through the
18 Administrator of the Health Resources and Services Ad-
19 ministration and the Director of the Agency for
20 Healthcare Research and Quality shall, in consultation
21 and in accordance with guidelines from relevant medical
22 societies, develop and disseminate to health care providers
23 information on uterine fibroids for the purpose of ensuring
24 that health care providers remain informed about current
25 information on uterine fibroids. Such information shall in-

1 clude the elevated risk for minority women to develop uter-
2 ine fibroids and the range of available options for the
3 treatment of symptomatic uterine fibroids, including non-
4 hysterectomy drugs and devices approved under the Fed-
5 eral Food, Drug, and Cosmetic Act.

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

10 **SEC. 7. DEFINITION.**

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

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