

[~116H6383]



(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R. _____

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

IN THE HOUSE OF REPRESENTATIVES

Ms. CLARKE of New York introduced the following bill; which was referred
to the Committee on _____

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 “Stephanie Tubbs Jones
5 Uterine Fibroid Research and Education Act of 2021”.

6 **SEC. 2. FINDINGS.**

7 Congress finds as follows:

8 (1) It is estimated that 20 percent to 50 per-
9 cent of women of reproductive age currently have

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

3 (2) In the United States, an estimated
4 26,000,000 women between the ages of 15 and 50
5 have uterine fibroids, and approximately 15,000,000
6 of these individuals experience symptoms. Uterine
7 fibroids may cause significant morbidity through
8 their presence in the uterus and pelvic cavity, and
9 symptoms can include pelvic pain, several menstrual
10 bleeding, iron-deficiency anemia, fatigue, bladder or
11 bowel dysfunction, infertility, and pregnancy com-
12 plications and loss.

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

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

22 (5) Many people with fibroids are likely
23 undiagnosed. Patients wait on average 3.6 years be-
24 fore seeking treatment, and over 40 percent of pa-
25 tients see two or more health care providers prior to

1 receiving a diagnosis, underscoring the need for im-
2 proved awareness and education.

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

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

15 (8) Symptomatic uterine fibroids can cause re-
16 productive problems, including infertility. People
17 with uterine fibroids are much more likely to mis-
18 carry during early pregnancy than people without
19 them.

20 (9) According to the Evidence Report Summary
21 on the Management of Uterine Fibroids, as compiled
22 by the Agency for Healthcare Research and Quality
23 of the Department of Health and Human Services,
24 there is a “remarkable lack of high-quality evidence

1 supporting the effectiveness of most interventions for
2 symptomatic fibroids”.

3 (10) Most medical options for managing fibroid
4 symptoms regulate or suppress menstruation and
5 prevent pregnancy. There is a great need for mini-
6 mally invasive, fertility-friendly therapies, as well as
7 biomarkers, imaging assessments, or risk-based algo-
8 rithms that can help predict patient response to
9 therapy.

10 (11) The presence of symptomatic uterine
11 fibroids is the most common reason for
12 hysterectomies, accounting for 39 percent of
13 hysterectomies annually in the United States. Ap-
14 proximately 42 per 1,000 women are hospitalized
15 annually because of uterine fibroids, but Black pa-
16 tients have higher rates of hospitalization,
17 hysterectomies, and myomectomies compared to
18 white women. Uterine fibroids are also the leading
19 cause of hospitalization related to a gynecological
20 disorder.

21 (12) The personal and societal costs of uterine
22 fibroids in the United States are significant. Uterine
23 fibroid tumors have been estimated to cost the
24 United States \$5,900,000,000 to \$34,400,000,000
25 annually. The annual direct costs, including surgery,

1 hospital admissions, outpatient visits, and medica-
2 tions, were estimated at \$4,100,000,000 to
3 \$9,400,000,000 annually. Estimated lost work-hour
4 costs ranged from \$1,550,000,000 to
5 \$17,200,000,000 annually. Obstetric outcomes that
6 were attributed to fibroid tumors resulted in costs of
7 \$238,000,000 to \$7,760,000,000 annually.

8 (13) At the federal level, uterine fibroid re-
9 search remains drastically underfunded as compared
10 to patient disease burden. In 2019, fibroid research
11 received about \$17,000,000 in funding from the Na-
12 tional Institutes of Health, putting it in the bottom
13 50 of 292 funded conditions.

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

15 (a) RESEARCH.—The Secretary of Health and
16 Human Services (referred to in this Act as the “Sec-
17 retary”) shall expand, intensify, and coordinate programs
18 for the conduct and support of research with respect to
19 uterine fibroids.

20 (b) ADMINISTRATION AND COORDINATION.—The
21 Secretary shall carry out the conduct and support of re-
22 search pursuant to subsection (a), in coordination with the
23 appropriate institutes, offices, and centers of the National
24 Institutes of Health and any other relevant Federal agen-
25 cy, as determined by the Director.

1 (c) AUTHORIZATION OF APPROPRIATIONS.—For the
2 purpose of carrying out this section, there are authorized
3 to be appropriated \$30,000,000 for each of fiscal years
4 2022 through 2026.

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

7 (a) RESEARCH.—The Secretary (or the Secretary’s
8 designee) shall establish a research database, or expand
9 an existing research database, to collect data on services
10 furnished to individuals diagnosed with uterine fibroids
11 under a State plan (or a waiver of such a plan) under
12 the Medicaid program under title XIX of the Social Secu-
13 rity Act (42 U.S.C. 1396 et seq.) or under a State child
14 health plan (or a waiver of such a plan) under the Chil-
15 dren’s Health Insurance Program under title XXI of such
16 Act (42 U.S.C. 1397aa et seq.) for the treatment of such
17 fibroids for purposes of assessing the frequency at which
18 such individuals are furnished such services.

19 (b) REPORT.—

20 (1) IN GENERAL.—Not later than the date that
21 is two years after the date of the enactment of this
22 Act, the Secretary shall submit to Congress a report
23 on the amount of Federal and State expenditures
24 with respect to services furnished for the treatment
25 of uterine fibroids under State plans (or waivers of

1 such plans) under the Medicaid program under such
2 title XIX and State child health plans (or waivers of
3 such plans) under the Children's Health Insurance
4 Program under such title XXI.

5 (2) COORDINATION.—The Secretary shall co-
6 ordinate the development and submission of the re-
7 port required under paragraph (1) with any other
8 relevant Federal agency, as determined by the Sec-
9 retary.

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

12 (a) UTERINE FIBROIDS PUBLIC EDUCATION PRO-
13 GRAM.—The Secretary shall develop and disseminate to
14 the public information regarding uterine fibroids, includ-
15 ing information on—

16 (1) the awareness, incidence, and prevalence of
17 uterine fibroids among individuals, including all mi-
18 nority individuals;

19 (2) the elevated risk for minority individuals to
20 develop uterine fibroids; and

21 (3) the availability, as medically appropriate, of
22 the range of treatment options for symptomatic
23 uterine fibroids, including non-hysterectomy treat-
24 ments and procedures.

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

8 (c) AUTHORIZATION OF APPROPRIATIONS.—For the
9 purpose of carrying out this section, there are authorized
10 to be appropriated such sums as may be necessary for
11 each of fiscal years 2022 through 2026.

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

14 (a) DISSEMINATION OF INFORMATION.—The Sec-
15 retary of Health and Human Services shall, in consulta-
16 tion and in accordance with guidelines from relevant med-
17 ical societies, work with health care-related specialty soci-
18 eties and health systems to promote evidence-based care
19 for individuals with fibroids. Such efforts shall include mi-
20 nority individuals who have an elevated risk to develop
21 uterine fibroids and the range of available options for the
22 treatment of symptomatic uterine fibroids, including non-
23 hysterectomy drugs and devices approved under the Fed-
24 eral Food, Drug, and Cosmetic Act.

1 (b) AUTHORIZATION OF APPROPRIATIONS.—For the
2 purpose of carrying out this section, there are authorized
3 to be appropriated such sums as may be necessary for
4 each of the fiscal years 2022 through 2026.

5 **SEC. 7. DEFINITION.**

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