

The Stephanie Tubbs Jones Uterine Fibroid Research and Education Act of 2021

TALKING POINTS FOR CONGRESSIONAL OFFICE MEETINGS

Bill Information

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Bill Overview

- The bill increases research funding for uterine fibroids, improves awareness and training, and seeks to measure cost to government payers.
- The bill also highlights the need for improved patient and provider education surrounding the heightened risk for fibroids faced by women of color.
- Specifically, the bill would:
 - Establish new research funding through NIH at \$150 million over five years;
 - Expand a CMS database on chronic conditions to include information on services provided to individuals with fibroids;
 - Create a public education program through the CDC; and
 - Direct HRSA to develop and disseminate fibroids information to health care providers.

Fibroids

- Uterine fibroids are noncancerous growths of the uterus and are one of the most common gynecological conditions.
- Approximately 26 million individuals in the US from ages 15 to 50 have fibroids.
- About 15 million patients with fibroids experience symptoms that may include severe menstrual bleeding, anemia, fatigue, pain, bladder or bowel dysfunction, impaired fertility, and pregnancy complications and loss.
- Fibroids cost the health care system between \$5.9 billion and \$34.4 billion annually.

Health Disparities

- Black women are twice as likely to develop fibroids than Hispanic women, and up to four times as likely than white women.
- Black women also display earlier age of onset, more and larger tumors, and increased severity of symptoms.
- Hispanic, Asian, and Pacific Islander women are at a slightly higher risk for fibroids than white women.

Diagnosis & Treatment

- Many fibroid symptoms are unrecognized or attributed to other issues. Because of this, many people with fibroids live for years with their symptoms before seeking treatment.
- Diagnosis can be challenging as common symptoms may overlap with other gynecological conditions. Some clinicians may dismiss patient concerns entirely.
- We do not yet fully understand why women of color are disproportionately affected by fibroids, as little research has been done in this area.
- Hysterectomy is the only way to cure fibroids, but it is an invasive surgery that ends fertility and is associated with long-term health risks.
- Other treatments may negatively impact fertility, while those that aim to preserve fertility tend to result in fibroid recurrence.
- Most medical options for managing fibroid symptoms regulate or suppress menstruation and prevent pregnancy.

Research Funding

- In 2019, fibroid research received about \$17 million in NIH funding, putting it in the bottom 50 of 292 funded conditions.
- Fibroid research remains dramatically underfunded as compared to actual patient disease burden.