

**Testimony from Sateria Venable,
Founder and CEO of The Fibroid Foundation
for the
Energy and Commerce Health Subcommittee Hearing:
“Investing in Public Health: Legislation to Support Patients, Workers, and Research”
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Chairwoman Eshoo (D-CA), ranking member Guthrie (R-KY) and members of the subcommittee, I appreciate the opportunity to submit testimony regarding uterine fibroids and the Stephanie Tubbs Jones Uterine Fibroid Research and Education Act of 2021.

In 2007, after decades of suffering from bouts of hemorrhaging where I would lose half the blood in my body and enduring multiple fibroid surgeries, I decided to make a life change and focus all of my energy on advocating for women impacted by uterine fibroids which culminated in the creation of The Fibroid Foundation.

In the summer of 2019, The Fibroid Foundation began a Capitol Hill advocacy effort to help the millions of U.S. women affected by uterine fibroids which culminated in the introduction of the Stephanie Tubbs Jones Fibroid Education and Research Act in the 116th Congress and the reintroduction of H.R. 2007 the identical bill in the 117th Congress. To assist the uterine fibroids community, H.R. 2007 raises community awareness, authorizes funds for research and heightens the awareness of less invasive treatments of uterine fibroids.

Uterine fibroids are probably the most significant health disease of women. Our Medical Advisory Board member, Dr. James Segars, Director, Division of Reproductive Science and Women’s Health Research, Professor of Gynecology and Obstetrics at Johns Hopkins University, authored a 2020 paper which concluded that, *“In the subsets of bodily pain, vitality, and social functioning, fibroids were consistently a larger burden than heart disease, diabetes mellitus, and breast cancer.”*¹

The mission of the Fibroid Foundation, the largest global community of fibroids patients, is to amplify the voice of women living with fibroids. A growing community of over 35,000 with over 20 chapters in the U.S., we create and support initiatives to find a cure for fibroids by advocating for fibroids research. We strive to erase the ‘stigma of silence’ around menstrual health and minimize treatment disparities by creating programs to support the fibroid and menstrual health communities. Our focus is education, innovation of medical technology, research study design and legislation.

Many told me that without a medical background, I would not be able to make a difference. Years later, I’ve attended meetings with thousands of physicians and seen time after time that there are significant voids in treatment philosophy and disease awareness without the presence of the patient voice. I’ve spoken to world renowned gynecologic scholars who did not understand the pervasive nature of menstrual pain.

Uterine fibroids are noncancerous growths of the uterus that often appear during childbearing years. Fibroids range in size from undetectable by the human eye to bulky masses, larger than a melon, that can distort and enlarge the uterus. Fibroid sufferers can have a single fibroid or multiple ones. An estimated 26 million women in the U.S., between the ages of 15 and 50, have uterine fibroids, and approximately more than half of these individuals experience symptoms.

Uterine fibroids may cause significant morbidity, and symptoms can include pelvic pain, severe menstrual bleeding, iron-deficiency anemia, fatigue, bladder or bowel dysfunction, infertility, and pregnancy complications and loss. I, like many women, have been severely anemic for most of my life. A woman's hemoglobin level should be 12. After my third surgery, which resulted in significant bleeding, my hemoglobin level was 5.6. As a result, I worked through years of shortness of breath, as do many women every day. I managed a construction site of 300 while hemorrhaging every day through an entire package of sanitary napkins.

The pain, discomfort, stress, 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. A hysterectomy, which carries significant cardiovascular risks, remains the most common treatment, despite the existence of other minimally invasive options, of which there are few. Oftentimes, particularly in the southeastern U.S., alternatives to hysterectomy are never even offered to patients.

There is an urgent need for minimally invasive, fertility-friendly therapies, as well as biomarkers, imaging assessments, and risk-based algorithms that can help predict patient responses to therapy. I eventually found fibroid specialists to care for me through my work as an advocate. However, most fibroids patients struggle to find care.

I don't want anyone to suffer as I have. I know that collectively we can ease the centuries of suffering and stigmatization experienced by women like me. My third surgery was a myomectomy. During an open myomectomy, your uterus is lifted from your abdomen while the fibroids are cut from your uterus. Afterwards, your uterus is sewn back together and reinserted into your abdomen. The medically documented recovery time for this procedure is 6-8 weeks. That is not nearly enough time to fully recuperate from the procedure, which takes a huge toll on a woman's body.

Some women undergo this procedure multiple times to preserve their fertility because many find that their fibroids have returned. Less than one year after each surgery, I was again faced with debilitating symptoms. The fibroids had returned.

The best form of imaging before a myomectomy is an MRI since each fibroid has its own blood supply. The high cost of an MRI, as well as the high cost of fibroid surgery, create significant barriers to treatment for the vast majority of women who suffer, while ultrasound, the most common imaging used for fibroid diagnosis, does not always identify the number and location of fibroids.

A recent Mayo Clinic study indicated that 80 percent of hysterectomies in incidences of fibroids were not necessary. Meaning, treatment could have been resolved with a less invasive option. Further, providers who specialize in less invasive fibroid procedures require a special fellowship. The vast majority of gynecologists are not trained in Minimally Invasive Gynecologic Surgery (MIGS), which is the specialty most needed to address uterine fibroids.

I had an incredibly difficult time finding a fibroid specialist or gynecologist to help me with alternative treatments for my symptoms, and I lived in the Chicago metropolitan area with a wealth of medical resources. I shudder when I think about the pain and limited choices of a woman living in an area with fewer medical resources.

I firmly believe that the funding and the resources allotted to fibroid research should match the enormity of the community affected. Shockingly, we still do not know what causes uterine fibroids. Every ethnicity is affected, yet, we do not have sufficient data to assess the nuances of the disease.

This health concern is pervasive in our country. I implore you to mark-up and pass H.R. 2007. Congress needs to authorize funding and implement policies to elevate the study of uterine fibroids to a level representative of the 26 million U.S. women affected. Let us end this unnecessary suffering, together. On behalf of all those affected by the suffering of uterine fibroids, thank you for your time and attention.



Sateria Venable

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