

TESTIMONY

OF

TANIKA GRAY VALBRUN

PRESIDENT AND FOUNDER, THE WHITE DRESS PROJECT, INC.

REGARDING A HEARING ON

***"INVESTING IN PUBLIC HEALTH:
LEGISLATION TO SUPPORT PATIENTS, WORKERS, AND RESEARCH"***

**BEFORE THE
U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON ENERGY AND COMMERCE
SUBCOMMITTEE ON HEALTH**

Wednesday, June 29, 2022

Testimony of Tanika Gray Valbrun
President and Founder, The White Dress Project, Inc.
Before the Energy and Commerce Subcommittee on Health
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Chairman Pallone, Ranking Member McMorris Rodgers, Subcommittee Chairwoman Eshoo, Subcommittee Ranking Member Guthrie and members of the Committee, my name is Tanika Gray Valbrun, President and Founder of the White Dress Project, Inc.

The mission of the White Dress Project is to raise global awareness about the uterine fibroid epidemic through education, research, community, and advocacy. We are dedicated to this mission, by advocating for research funding, highlighting reproductive health inequities, educating many on fibroids and their treatment options, and empowering a community who will advocate for their best health choices and no longer suffer in silence with this chronic illness.

It is my honor to testify in support of H.R. 2007, the Stephanie Tubbs Jones Uterine Fibroids Research and Education Act of 2021, led by Representatives Yvette D. Clarke, Robin L. Kelly, Bonnie Watson Coleman and David Scott; and co-sponsored by numerous members of this Committee, I stand before today. H.R. 2007 is named in honor of the late Representative Stephanie Tubbs Jones who not only championed women's health issues but suffered from uterine fibroids herself. I am proud to call her son Mervyn Jones, a dear friend and staunch supporter of the White Dress Project.

In addition to my organization, H.R. 2007 has been endorsed by various partners within our coalition including but not limited to: Black Women's Health Imperative, March of Dimes, Society for Women's Health Research, The Fibroid Foundation, CARE About Fibroids, HealthyWomen.

This legislation is a critical first step for improving research into uterine fibroids and ensuring that research dollars and public education funding match the scope of this public health crisis to garner data to improve health outcomes for those living with fibroids.

Specifically, the bill will:

- Establish new research funding through NIH, totaling \$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.

It's important to note, that the critical need to address uterine fibroids is neither a Democratic or Republican issue, but a bipartisan issue that affects all women whether they live in rural

America or urban America. In fact, H.R. 2007 has a Senate companion (S. 2444) introduced by Senators Cory Booker and Shelley Moore Capito.

My Personal Story

Today, as I share my personal story to bring awareness to the importance of H.R. 2007, I speak on behalf of so many individuals across the nation who have battled with uterine fibroids as a chronic condition for years.

My journey with uterine fibroids started around the age of 14 in which I experienced very heavy menstrual bleeding and had to change my pad and underwear at least twice an hour. Additionally, I had extreme bloating, in which I often looked like I was three to four months pregnant, plus frequent urination because the fibroids were sitting on my bladder. I was often nicknamed "Bag Lady," because I was the teenager who always had an extra bag filled with underwear and a complete change of clothes. When it came time to purchase my first car, cloth seats weren't even an option for me; instead I had to go with the upgrade to leather- not to be cool or because I could afford it, but I knew it would be so much easier to get period stains out of leather seats. Rarely would I spend the night at a friend's house, out of sheer fear that I would stain a mattress or couch, or have an accident and stain my clothes. Growing up, I never owned any piece of white clothing.

The trauma that ensued then, still exists with me today, has influenced my thoughts on my body image and instilled fear in participating in very public events. Growing up I was somewhat familiar with fibroids, because my mom had them- lost a set of twins and ultimately had to have a hysterectomy, but I still had no idea when going through my symptoms that it could possibly be the same thing I was experiencing.

At the age of 20, my symptoms became unbearable, and a doctor told me the best thing for me to do was to have a D&C, also known as a dilation and curettage. The D&C is a procedure to remove tissue from inside your uterus. I was terrified but had the procedure done anyway. However, the symptoms did not improve. I had to have multiple blood transfusions due to anemia and my symptoms did not go away. A few years later, I was diagnosed with uterine fibroids and was told by doctors to wait and see what happens.

In 2014, after years of managing life with fibroids, I started The White Dress Project. I was in recovery from my first myomectomy where I had 27 fibroids removed, while looking for answers and support of my own. After my surgery, I looked in my closet and realized I did not own any white clothing.

The White Dress Project was birthed out of a desire to show up for myself and people suffering with uterine fibroids. To be a source of support, a source of information, and a reminder to people battling fibroids that they are not alone.

Research Findings

In research conducted in partnership with The White Dress Project and Healthy Women, we found that race plays a significant factor in uterine fibroid outcomes and the quality of life among women living with fibroids. They are more common in African Americans (80%) than white, Hispanic or Asian women (70%). For Black women, fibroids typically develop at a younger age, grow larger and cause more severe symptoms than for women of all other races.

Barriers to healthcare play a key role. Research has found that Black women wait an average of 4.5 years for diagnosis while white women wait 3.3 years. Key factors influencing delayed care include misconception and normalization of fibroids symptoms, lack of education, and affordability. As a result of such delays in diagnosis, Black women are more likely to be hospitalized, more likely to have the fibroids surgically removed, seven times more likely to have a myomectomy and 2.5 times more likely to have a hysterectomy compared to white women. Last, we found that research is lacking about how fibroids affect different minority groups, specifically in Latinx and Asian patients.

Location and Lack of Access

Through our research we found that there is a significant gap in studies of the prevalence of fibroids, women in rural areas who seem to be disproportionately impacted by this disease. Typically in rural areas, access to healthcare resources and providers is severely limited. Testing such as ultrasounds, along with MRIs and CT scans, is helpful in differentiating fibroids from other conditions, including ovarian tumors. For fibroid patients in rural areas who desire procedural testing and treatment, access can be difficult because of the requirement for specialized skills or equipment to perform certain procedures.

Also, not all insurance companies cover specialized procedures. The states in which these procedures are not covered by certain companies include Missouri, Louisiana, Kentucky, Mississippi, Arkansas and Tennessee, where the population of Black women who need fibroid treatment tends to be high.

Last, rural areas tend to have fewer specialty trained OB-GYNs who feel comfortable performing certain procedures. Therefore, if the closest OB-GYN has not been trained in certain minimally invasive or highly specialized techniques, those options may not be offered.

There are also high prevalence rates of fibroids in southern regions of the U.S. Studies found that emergency department visits for fibroids were highest among women who were ages 36-45 years (44.5%), in the lowest income quartile (36.1%), privately insured (38.3%) and living in the South (46.2%). One factor that contributes to the rise in emergency department visits is patients lacking established relationships with HCPs to treat symptoms in a trusted environment. This is the result of a lack of knowledge regarding which HCPs specialize in gynecological issues, the lack of insurance coverage and costs associated with seeing an HCP. As a result, patients are more likely to cope with symptoms on their own and delay treatment until they deem their situations to be emergencies.

The Importance of Diversity in Clinical Trials

One last point that I would like to address is the lack of diversity in clinical trials. Genetic studies on fibroids and other conditions in communities of color, particularly Black women, have been limited for a variety of factors leading to a mistrust of the medical community, including the unethical treatment of Black men and women during the Tuskegee Syphilis studies and the cultured process of Henrietta Lacks' cancer cells without approval from her family. H.R. 7845, the NIH Clinical Trial Diversity Act of 2022, introduced by Representatives Robin L. Kelly, Brian Fitzpatrick, Tony Cardenas, G.K. Butterfield, and Yvette L. Clarke will help with taking the necessary steps to increase clinical trial diversity at the National Institutes of Health.

Conclusion

In a 2007 op-ed, Rep. Tubbs Jones once wrote, "Women deserve better." I believe that they still do. It is far past time that uterine fibroids — and women's health — be taken seriously. By passing the Stephanie Tubbs Jones Uterine Fibroids Research and Education Act, Congress would be taking a step toward prioritizing the health care and quality of life for women across the United States.

Fibroid is a public health crisis because of its enormous impact on quality of life and workplace performance, it has exposed and exacerbated the health disparities that gravely impact the Black and Brown communities, and acutely limit our access to effective and less invasive treatment options.

Special thank you to Representative Yvette D. Clarke for her unwavering advocacy on this issue and for serving as a Congressional champion for the White Dress Project. To the Committee, I sincerely thank you for listening to my testimony today and your support of H.R. 2007 to improve the lives of millions of women who are dealing with uterine fibroids.

Attachment: The White Dress Project, Inc. and Healthy Women, "Hotmapping Report- Uterine Fibroids" (2022).



healthy
women

*Hotmapping Report
Uterine Fibroids*

May 2022

HealthyWomen and the White Dress project conducted a hotmapping initiative to determine areas in the United States where the rates of uterine fibroids are most prevalent and health disparities are most common. The goal of this initiative is to understand barriers to care and determine how increasing awareness and improving education can help address disproportionate rates of and access to care in the U.S. The data gathered from the hotmapping initiative will be used to inform educational directives and content.

Background

Between 20%-70% percent of women develop uterine fibroids throughout their reproductive years, with the most common occurrence among women between the ages of 30-40. Studies show the incidence of fibroids are [three times](#) greater in Black women than in white women and that African American women experience differences in treatment and health outcomes. The research we conducted found that lack of healthcare access and other barriers that inhibit access to quality, safe care and providers were prominent in rural areas and southern parts of the United States. Cost of care, insurance coverage, location, access to HCPs and specialists, and lack of awareness were also some of the main barriers for women living with fibroids, which reiterates the need to address healthcare barriers, close the gaps in health disparities and health inequities, and provide education and awareness to improve health outcomes.

We used peer-reviewed research articles and interviewed fibroids expert [Shawana Moore, DNP](#), a member of our [Women's Health Advisory Board \(WHAC\)](#), to conduct our research and examine these barriers from different angles.

Race

In our research, we found that race plays a significant factor in uterine fibroid outcomes and the quality of life among women living with fibroids. They are [more common](#) in African Americans (80%) than white, Hispanic or Asian women (70%). For Black women, fibroids typically develop at a younger age, grow larger and cause more severe symptoms than for women of all other races. Barriers to healthcare play a key role: [Research](#) has found that Black women wait an average of 4.5 years for diagnosis while white women wait [3.3 years](#). Key factors influencing delayed care include misconception and normalization of fibroids symptoms, lack of education, and affordability. As a result of such delays in diagnosis, [Black women](#) are more likely to be hospitalized, more likely to have the fibroids surgically removed, seven times more likely to have a myomectomy and 2.5 times more likely to have a hysterectomy compared to white women. Last, we found that research is lacking about how fibroids affect different minority groups, specifically in Latinx and Asian patients.

Location

Although there is a significant gap in studies of the prevalence of fibroids, women in rural areas seem to be disproportionately impacted by this disease. Typically in rural areas, access to healthcare resources and providers is severely limited. Testing such as ultrasounds, along with MRIs and CT scans, is helpful in differentiating fibroids from other conditions, including ovarian

tumors. For [fibroid](#) patients in [rural areas](#) who desire procedural testing and treatment, access can be difficult because of the requirement for specialized skills or equipment to perform certain procedures.

Also, not all insurance companies cover specialized procedures. The states in which these procedures are not covered by certain companies include Missouri, Louisiana, Kentucky, Mississippi, Arkansas and Tennessee, where the population of Black women who need fibroid treatment tends to be high.

Last, rural areas tend to have fewer specialty trained OB-GYNs who feel comfortable performing certain procedures. Therefore, if the closest OB-GYN has not been trained in certain minimally invasive or highly [specialized techniques](#), those options may not be offered.

There are also high prevalence rates of fibroids in southern regions of the U.S. Studies found that emergency department visits for fibroids were highest among women who were ages 36-45 years (44.5%), in the lowest income quartile (36.1%), privately insured (38.3%) and living in the South (46.2%). One factor that contributes to the rise in [emergency department visits](#) is patients lacking established relationships with HCPs to treat symptoms in a trusted environment. This is the result of a lack of knowledge regarding which HCPs specialize in gynecological issues, the lack of insurance coverage and costs associated with seeing an HCP. As a result, patients are more likely to cope with symptoms on their own and delay treatment until they deem their situations to be emergencies.

Cost

The economic burden associated with uterine fibroids has significantly affected women. [Studies](#) found the overall economic burden of fibroids is estimated at \$3.5 to \$10.3 billion each year. Direct costs (such as surgery, hospital admissions, outpatient visits, medications) for one year after a woman was diagnosed with uterine fibroids averaged \$9,000. Indirect costs (lost work as the result of absenteeism and short-term disability) for the same time frames were at least \$2,400 and could be as high as \$15,500. Both indirect and direct costs could be as high as \$25,000 per year for a patient.

Overall, women suffering from the symptoms of fibroids spent \$2,200 to \$16,000 more per year than healthy women of the same age. These costs can contribute to a decrease in accurate diagnoses and timely treatment, as well as an increase in [emergency room](#) visits, which are among the costliest types of care for fibroids, with the average charge at more than \$6,000 per visit.

Education

Lack of [education](#) and awareness about uterine fibroids and treatment options also appeared to be a barrier for women with this condition. [Studies](#) show only 49% of women who had symptoms suggestive of fibroids but not a clinical diagnosis had heard of uterine fibroids. Also, after the onset of their symptoms, 60% of these women tried to manage symptoms themselves

and 50% waited to see if the symptoms went away. This is the result of the normalization of fibroids symptoms because of the lack of education about the condition. Many women attribute this tolerance of symptoms to witnessing other family members live with fibroids symptoms as a normal part of their lives, causing them to believe the same for themselves.

In terms of treatment options, studies suggest that [Black women](#) are offered a hysterectomy as a first treatment option and one in five Black women believe hysterectomy is the only solution for fibroid symptoms. They are also two to three times more likely to undergo the procedure than white women. For women who are not educated about the many treatment options, this may seem like the only option.

Healthcare providers who treat most women with fibroids play an important role in advising and guiding women as they decide on the best treatment for their fibroids. Therefore, it is important for providers to educate patients about all of the available options and allow them to make decisions that are the best fit for their lives.

[Research](#) shows that provider beliefs and unconscious biases about Black women are linked to racial disparities in health and healthcare, and can affect the care and recommendations provided by HCPs. In some cases, providers downplay pain levels and are less likely to recommend certain treatments and medications as a result of biases, despite the patient communicating high pain levels. Lack of training in cultural competency and sensitivity plays a key role in this. When caring for patients with diverse beliefs, attitudes, values and behaviors, differences between HCPs and patients can affect communication, which can ultimately impact both clinicians' and patients' decisions about treatment, as well as trust between the patient and provider. It is important for HCPs to be [trained](#) to recognize their own biases and learn strategies to prevent them from influencing the care they deliver to ensure that they are administering quality and equal treatment.

Recommendations

These findings have allowed us to pinpoint the barriers and issues that plague women living with fibroids. Based on this research, we recommend creating the following deliverables to close the gaps in disparities and promote a more equitable system of health, information and access nationwide.

Grand Rounds Webinars

Education is important not only for women, but for providers as well. Many of our findings highlight a lack of access to HCPs trained in fibroids management and treatment, resulting in misinformation spreading among women. We will offer webinars that focus on strengthening patient-provider relationships and communication with patients, including how to address uterine fibroids, cultural competency tips for better communication with diverse patient populations and how to present women with the best options for their care.

Webinars for Rural Populations

From our findings, rural areas and populations face some of the greatest challenges with affordability of and accessibility to fibroids care. We will provide a two-part webinar series to respond to this issue.

In the first segment of our two-part webinar series, we will talk to patients and experts about the effects of fibroids on women in rural areas, pinpointing cost issues, accessibility to and availability of providers for patients in primary care deserts, patient-provider remote communication via televisits, and how to improve overall outcomes for women in these regions. In the second segment, we will talk to experts about risk factors, strategies to optimize treatment adherence and symptom management, options for preventive care, and best practices to better educate women in rural areas.

Infographics

We will create a series of at least two infographics to provide a creative and easily distributable tool to educate women about uterine fibroids. The first infographic will reiterate the conversation among patients and providers in rural areas during our webinar series regarding financial tips, access to healthcare facilities, picking suitable providers and tips for what patients can do from their homes when coping with fibroid symptoms.

The second infographic will focus on distinguishing between normal versus heavy bleeding as a fibroid symptom, while being conscious of race, ethnicity and religious affiliations. This will help educate women about abnormal bleeding signs to look for to determine when it is time to reach out to an HCP. It will also reiterate the importance of cultural sensitivity and competency in conversations that providers have with patients regarding these symptoms.

Promotional and Partnership Plan

We will provide closed captioning for our webinars and translations for our infographics to ensure the program is inclusive of the women most affected by fibroids and to further promote the findings of our research. These pieces will live on both organizations' respective websites and social media platforms, and will be heavily promoted throughout the life of the grant, with a special focus during Fibroids Awareness Month in July. We will also work with organizations, including the Rural Health Association, and consult with fibroids experts on our Women's Health Advisory Board to bring further insight, attention and awareness to our content.

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