



# CARE ABOUT FIBROIDS

## CAPITOL HILL BRIEFING

Monday, April 8, 2019

CARE About Fibroids, in partnership with The White Dress Project, held a policy briefing and discussion with lawmakers, policy experts, patients, and advocates on uterine fibroids and their impact on women in the U.S.

The event was held on Monday, April 8 on Capitol Hill in Washington, D.C. and was moderated by Jenny Rosenberg, Executive Director of CARE About Fibroids, who presented findings from the organization's recent white paper entitled, Uterine Fibroids: A briefing on the condition of, and its impact on, women in the U.S. Featured guest speakers included Adrianna Hopkins from ABC7 News, Dori Salcido, a former U.S. Department of Health and Human Services Assistant Secretary; Dr. Serina Floyd, a faculty member at George Washington University and Georgetown who serves as the medical director for Planned Parenthood of Washington, DC; Tanika Gray Valbrun, Founder of The White Dress Project; and Dr. Evan Myers, Principal Investigator of COMPARE - UF at the Duke University School of Medicine.

"I would guarantee you of all the women in here, more than half have fibroids." Adrianna Hopkins is one of them. The ABC7 News - WJLA anchor suffered from symptomatic uterine fibroids, going to her doctor and having ten of the muscular growths removed after noticing a lump on her stomach. Since her fibroids were found, she took it upon herself to learn more about the condition and has become a vocal advocate for women who experience it.



Speaking on a CARE About Fibroids educational panel just feet from the U.S. Capitol, Ms. Hopkins shared her personal story of living with uterine fibroids, with a room full of policy experts, patients, and advocates. Women in the audience nodded knowingly and sympathetically throughout the discussion and offered their own stories, underscoring the shared — if mostly unacknowledged — experience of living with uterine fibroids.

## What are Uterine Fibroids?

Uterine fibroids are a common gynecological condition among women and the primary reason for hysterectomy for women in the U.S. The cause of fibroids is unknown, and they are not consistent in terms of size or growth rate. Fibroids, also called leiomyomata or myomas, are mostly noncancerous with lifetime incidence around 80 percent among Black women and 70 percent among white women. However, not all fibroids are symptomatic: about 50 percent of Black women and 25 percent of white women experience difficult health consequences when they have symptomatic uterine fibroids.

During a lifetime, Black women are 3 times more likely to develop fibroids than white women.

Black women require more hospitalizations and surgeries than other racial groups and face higher medical costs for their fibroid treatment.

It is unknown why fibroids are more common among Black women, nor why Black women experience more frequent and more severe symptomatic fibroids than others. While some women are more likely than others to have uterine fibroids, the greatest known risk factor is simply being a woman of reproductive age with a uterus.

Fibroid symptoms include heavy or long-lasting menstrual periods, pelvic or lower abdominal pain or pressure, frequent urination, difficulty emptying the bladder, constipation, pain during intercourse, and backache or leg pain. In severe cases, they can lead to kidney problems, anemia, urinary tract infections, difficulty in pregnancy and childbirth, and, though rare, infertility.

But what counts as a heavy period? It's a question that advocates say gets left out of the conversation, leading many women to believe that their fibroid symptoms are normal. "We need to have conversations around what are normal periods," said Tanika Gray Valbrun, Founder of the White Dress Project. "Sometimes, there are women who don't even recognize what a normal period is." Panelist Dr. Serina Floyd added that she had a patient who had a volleyball-sized uterus due to a large number of fibroids. Her patient didn't know that the heavy periods she was experiencing as a result were not normal.

A renewed focus on education, starting with sexual education in schools, is key for greater understanding. "I don't remember anyone talking about women's health," said Ms. Hopkins. "We need to start knowing these things at period age... not when you're about to have a baby or trying to have a baby, because then it could be too late."

According to Executive Director Jenny Rosenberg, the CARE About Fibroids white paper discusses what's normal and what might be a cause for concern. A normal period lasts two to seven days, and women typically lose 2-3 tablespoons of blood during one. Women should see a doctor if their period lasts longer than a week, they bleed through one or more pads or tampons every 2-3 hours, they pass menstrual clots larger than a quarter, or they feel lightheaded, dizzy, out of breath, or tired.



## Suffering in Silence

Tanika Gray Valbrun leads [White Dress Project](#), an organization that promotes advocacy and research surrounding uterine fibroids. The white dress is a “symbol of hope” that women with fibroids can look to, Ms. Gray Valbrun said. “When I have fibroids, no, I don’t feel comfortable wearing white. It’s not something I ever had in my closet. But I wanted to use it as a symbol of hope.” “I knew when I started to have really heavy periods at 15 that this could potentially be what was happening to me. But all through college, I just dealt with it. I would always know to carry a backpack full of pads, always had an extra pair of underwear, always had

an extra pair of leggings, never wore any white,” said Ms. Gray Valbrun. “There are so many women suffering with this condition in silence. Everybody has fibroids. But why is no one talking about it? So, I wanted to make it my mission to make sure that we did have the conversation.”

There are so many women suffering from fibroids in silence.



Women talking about fibroids — friend to friend, mother to daughter, provider to patient — is a critical step to understanding and addressing the condition. “This is a conversation that we need to, as sisters and friends, share with each other. Ten years into fibroids, my mother said, ‘oh, I have those,’” said Dori Salcido, currently CEO of Salcido Strategies, her government affairs consulting firm, going on to say that mothers need to recognize the importance of sharing their health history with their daughters. “It’s important for us not to just share with each other here, but beyond.”

## Being Your Own Best Advocate

Conversations about fibroids and how they affect women are a first step, and awareness is crucial for any public policy response. It is also crucial for women to be their own advocates regarding their fibroids. “If I had this knowledge and if this was something people talked about when I went through my situation, I wouldn’t have felt so alone,” said Ms. Hopkins. “I’m big on patient advocacy and advocating for yourself, and if you don’t know something, you can’t do something.”

Awareness is crucial for any public policy response

Many women, particularly underserved women of color, have had bad experiences with “providers who were condescending or dismissive or downright disrespectful when they were trying to seek care,” leaving them alienated from the healthcare system, said Dr. Serina Floyd. The panelists agreed this can leave women feeling discouraged about seeking care or that it is a made-up condition.

Ms. Gray Valbrun encouraged women with fibroids or who may have fibroids to not accept lack-luster care, emphasizing the importance of being “your own best health advocate.” “It is so important that if you don’t trust your doctor, or you aren’t getting what you need from your doctor, that you go to another doctor,” said Ms. Gray Valbrun. “Women really have to get out of the mindset that there’s something wrong with seeking a second opinion.”

Prioritizing mental health while coping with fibroids is also very important. Dr. Serina Floyd said that the most common thing she hears from fibroids patients is, “I’m exhausted”—meaning both physically and mentally. Starting to talk about fibroids, how they affect women’s lives, and what can be done about them is a valuable component of a woman having peace of mind and understanding what’s happening with her body

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## Treatments

There are a number of medical and surgical interventions for symptomatic fibroids, and treatments are becoming more advanced and less disruptive. While the only sure way to be rid of fibroids permanently is to have a hysterectomy, other surgical and nonsurgical options are available. Several medications can halt the growth of and even shrink fibroids, though there is no pharmaceutical solution that gets rid of them entirely. Among the more invasive options that can actually remove fibroids, clinicians can use uterine artery embolization to cut off blood flow to fibroids, causing them to shrink and die. Such a procedure typically results in a brief hospital stay and a brief recovery period. A myomectomy, or the surgical removal of fibroids from the uterus, is a more aggressive intervention that requires a recovery period of several weeks.

Acessa Health has developed a treatment, which is a minimally-invasive laparoscopic procedure for fibroids. Event attendee Kim Rodriguez, ACESSA's President & CEO, explained that the procedure involves applying heat to fibroids through small needle arrays. While not damaging the surrounding tissue, the procedure shrinks fibroids and may cause them to be completely reabsorbed by the body. "We can target each fibroid individually, and there's no cutting and no suturing," said Ms. Rodriguez. "As a result, patients are on an outpatient basis and back to normal activity in about 3-5 days."

Many of the women who are at the highest risk for developing symptomatic uterine fibroids are also those who are least likely to have access to good care.

"There are a lot of women of color who do not have the same access to good doctors and good health care," Ms. Hopkins reminded the audience. "You can Google your life away [looking for answers]."

Ms. Salcido expressed hope that the conversations about fibroids facilitated by CARE About Fibroids and the White Dress Project would educate women about finding access to care. "Having means should not be a requirement for actually understanding your options," she said. However, surgical options may be out of reach for women with limited means, said Dr. Serina Floyd, and alternative treatments are important.

Although infertility is rare as a result of fibroids, it does happen and women at risk should consider how to mitigate that possibility. Ms. Gray Valbrun encouraged young women with fibroids or who are at risk to consider freezing their eggs if there is even a small possibility that they will want children in the future.

## What's Next?

“The stories from Tanika (Gray Valbrun), and Dr. Floyd’s experience with her patients, testify to the reason why CARE About Fibroids exists, why we need to get more people involved in this movement, and why we need to keep moving forward until we can help all women and make this conversation more of the norm than the exception,” said Ms. Rosenberg.

One recurring issue the panel raised is that there is insufficient research being performed on uterine fibroids. Dr. Evan Myers of Duke University, working on a Patient-Centered Outcomes Research Institute (PCORI) grant, helped found a registry focused on uterine fibroids called COMPARE-UF. The registry uses survey data from women with uterine fibroids and tracks their decision-making as they pursue treatment. Currently, they are working to design what the registry will look like going forward and how to make it easy. The vision is to have a registry that anyone can enroll in. “Everything except the ultrasound report,” Dr. Myers said, “it’s your story. Your quality of life is your quality of life.” Such research and tracking will help clinicians, policymakers, and women experiencing fibroids to better understand and treat the condition.

Awareness, screening, and accessible treatment (particularly non-invasive treatments) will help to prevent women today and future generations from suffering in silence. CARE About Fibroids stands ready, alongside the White Dress Project and other advocates, to make the case. “This is something that needs to be talked about — that needs to be dealt with on the legislative level,” concluded Ms. Gray

