

Photo:  Fibroid Foundation panelists.jpg

Caption: Fibroid Summit panelists Dr. Julia DiTosto, Dr. Gloria Bowles-Johnson, Sateria Venable, founder of the Fibroid Foundation, Dr. Erika Moore, and Dr. Bhuchitra Singh, during the 2026 Fibroid Summit. (Courtesy Photo/Imagine Photography DC)

Photo 2:  Fibroid Summit Gloria Dixon.jpg

Caption 2: Seattle-based philanthropist Gloria Dixon listens intently to panelists during Fibroid Summit '26.(Courtesy Photo/Imagine Photography DC)

Photo 3:  Fibroid Summit Khaleelah Harris.jpg

Caption 3:Khaleelah Harris, executive director of The Beauty of Our Wellness, asks panelists about alleviating the economic burdens of the fibroid experience. (Courtesy Photo/Imagine Photography DC)

HED: Fibroid Foundation Hosts Fifth Annual Summit

SubHED: Experts, Patients Talk Disparities in Health Care, Research, Cultural Competency

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The Fibroid Foundation gathered for the fifth year on March 7 to share new research, provide resources, offer warnings and risks, encourage advocacy and foster hope for the future.

Fibroids are the most common gynecological tumors affecting millions of people around the world. However, advocates note that few funds are given for researchers to focus on fibroids.

“We know that the dollars that are given for research are very different than dollars that are given for male health,” said Dr. Gloria Bowles-Johnson during her keynote, adding that women are the number one consumers of health care. “Society has to look at the purpose of women and [decide] that women's health is just as important as male health.”

While treatment of the benign tumors has evolved, Bowles-Johnson, of MedStar Georgetown University Hospital, argued more research and advocacy are needed to improve women’s health outcomes.

“When we look at fibroids, we need more money for research,” she said. “We need more voices of women going up on the Hill and speaking, as you know, advocates.”

Growing Pains: Fibroid Research that Resonates

The biology of fibroids is still a mystery. Up to 70-80% of women will develop uterine fibroids by age 50, but researchers still don’t know why they grow.

New research using lab-grown fibroids seeks to answer those questions.

Dr. Erika Moore, an assistant professor at the University of Maryland, and her team built a model of healthy uterine tissue to replicate how fibroid cells grow and test ways to block their growth and development.

The innovative research was inspired by her personal experience, as Moore, a biomedical engineer, and her three sisters all have fibroids, each with different symptoms.

“We have not been doing this [fibroid research] work for that long,” she said, “but I’ve been suffering for a long time.”

Moore is not alone. Fibroid symptoms can include heavy menstrual bleeding; pelvic pressure or discomfort; reproductive dysfunction, including infertility and miscarriages; urinary and bowel symptoms; pregnancy complications; and anemia.

Reoccurring fibroids can complicate treatment.

“In 2017, I had 40 fibroids removed, and then this past July, I had 110 fibroids removed,” said one Fibroid Summit attendee, who spoke to The Informer on the condition of anonymity. “I had an ultrasound last month, and I have fibroids again.”

Shocked and devastated by the news, the 44-year-old came to the summit looking for information.

“I wanted to see if there were any preventative measures that I could take,” said the Syracuse native, who has experienced painful periods since she was 11.

For Dr. Bhuchitra Singh, director of Clinical Research at the Howard W. and Georgeanna Seegars Jones Laboratory, said raising awareness about what fibroid patients face is critical.

“The quality-of-life scores of individuals with fibroids is actually similar, or worse, to patients with heart disease, diabetes and breast cancer,” Singh said. “That’s why we need earlier care for these individuals.”

The Cultural Conundrum: Black Women and Fibroids

Black women are diagnosed with fibroids at three times the rate of white women and often experience more severe symptoms at a younger age.

Research on the effect of hair dyes and relaxers reveals additional risks.

Singh and his team shared results from a review of multiple studies on the effect of hair relaxers and dyes on a range of gynecological conditions (from cancers to fibroids, endometriosis, PCOS, early start of menstrual cycles) and the impact to Black women, specifically.

“There seems to be a higher use of no lye relaxers in the last decades, amongst Black and African American women,” Singh said. “Most of the time we use [hair products] on our scalp, and the scalp offers actually a wonderful way to get something to your bloodstream.”

Hair care and grooming for Black women can be ritual, with products and techniques passed down from mother (or other female relative) to daughter, along with the chemicals contained in those products.

“Hair care should not come at the cost of having an endocrine disease,” he said. “It’s just not worth it.”

While the research showed an increased risk associated with hair care products, Singh said more research is needed.

Higher than the risk of hair care products, Singh revealed, was stress. Further, other risks, such as starting a menstrual cycle younger than age 10, obesity or high BMI, are challenges that [disproportionately affect Black women](#).

As health equity advocates work toward raising more awareness about the disease, the prevalence of symptomatic fibroids among Black women contributes to over normalizing symptoms and pain.

“They’ll be told, ‘that’s just part of being a woman, particularly in your own family— very common in African Americans,’” Bowles-Johnson said. “That’s not abnormal, that’s just the way it actually is,” leading to a delay in women seeking care.

Despite disparities, the obstetrician-gynecologist said there’s hope.

“We know that when we can recognize fibroids earlier, an intervention can dramatically improve a woman’s quality of life and reproductive outcomes,” she said.

The Cost of Care, Importance of Advocacy

The Summit ’26 provided a safe space for attendees to share their difficult fibroid stories and ask questions, as panelists shared recommendations for medical, holistic and financial care.

“I always say you need a medical team and a holistic team,” said Sateria Venable, founder of the Fibroid Foundation. “Because if you’re hemorrhaging out, you need medical intervention. But if you have the luxury of time, you can look at some holistic remedies.”

Holistic treatments include: Reiki, acupuncture, the use of Chinese herbs (with the help of a licensed herbalist), strengthening the pelvic floor, stress management and nutrition.

While some patients decide to seek help outside of medicine, others are unable to afford the high costs of medical care.

“There is an estimated economic burden of about \$42.2 billion annually,” Singh shared.

Another critical part of advocacy is understanding the insurance system and how to code claims and file appeals, an often complicated and frustrating process.

“What matters with fibroid treatment, at least in my experience, is what insurance approves or denies,” Moore said, “it’s a whole separate aspect that needs to be brought into our advocacy.”

Khaleelah I.L. Harris, 30, executive director of [The Beauty of Our Wellness](#), helps uninsured and underinsured Black women pay for fibroid surgery through a wellness fund. After her own experience with insurance bills after fibroid surgery, Harris co-founded the D.C. based non-profit to help those facing similar challenges.

“No one else was offering money,” she told The Informer. “Everyone else was offering awareness.”

The Evolution of Treatment

While physicians are critical for fibroid research and advocacy, lay people like Venable serve as subject matter experts and use their voices to advocate for federal funding.

In 2019, Venable, who contributes to grant research, was instrumental in introducing the Fibroid Bill in the U.S. Congress.

Seven years later, she’s continuing that work, particularly as Fibroid Foundation nears a planned Congressional briefing in May, during National Menstrual Health Awareness Month.

“It’s vital that lived experience is paired with research and science,” said Venable, who launched the Fibroid Foundation in 2013.

Diagnosed with fibroids at 26, Venable looked for alternatives to a recommended hysterectomy.

“After my third or fourth fibroid surgery, I was shocked at the lack of information available,” she recalled. “I wondered, ‘what are other women going through.’”

Some women, like Shontelle Dixon, suffered for years.

“Fibroids changed my life in many ways I never expected,” said Dixon, who shared her painful and debilitating patient experience from the stage. “They tested my body, my faith and my resilience, but they also gave me something else— a voice. Because when women share their stories we don’t just heal ourselves. We help create a future where fewer women have to experience the same pain.”

Dr. Bowles-Johnson explained that hysterectomies were considered the default treatment for fibroids for years.

“Treatment today is becoming more personalized,” said Bowles-Johnson, who has treated thousands of women with uterine fibroids, including Venable, over the past 30 years.

She added that there's "more thinking about fertility sparing," and using minimally invasive techniques as surgical options.

More innovative treatments may impact future health outcomes, according to Dr. Julia DiTosto's dissertation work recently completed at the University of Pennsylvania exploring the connection between gynecologic health and heart disease, [the leading cause of death for both men and women in the U.S.](#)

DiTosto's studies found that a fibroid diagnosis was associated with a significantly higher risk of heart disease, and the rate of heart disease risk varied, based on the type of surgical intervention.

While troubling, DiTosto cautions more data is needed to validate her findings.

"We think our data should inform conversations and future research but not dictate decisions," she repeated.

Sharing Our Stories

Sponsored by [Always®](#) and [Hologic](#), 75-80 people attended the summit in person, and many attendees left with a new or renewed sense of purpose.

Philanthropist Gloria Dixon, travelled from Seattle, Washington to attend the fifth annual event.

Dixon, 55, had a fibroid removed in October and now has leiomyosarcoma, a very rare cancer.

"It's emotional, being in a room with women who understand unique health concerns which aren't unique," Dixon told The Informer, adding that she was so inspired she might start a Fibroid Foundation chapter in the Pacific northwest. "I'm truly blessed to be here—so many women don't have it and need it."

For Dipsu Shrestha, a 22-year-old public health student at the University of Maryland who learned about the summit a few days prior on Instagram, the stories heard at the convening were all too familiar, as her mother and aunts suffer from fibroids.

She is excited to use her newfound knowledge to share with her loved ones and others.

"This was so amazing," Shrestha said. "I want to go back [to Nepal] and learn how to advocate for this for my own community."