

## Endometriosis Stakeholders Bring Their Fight to DC



Image © Michelle Pedone for EndoWhat?

The American College of Obstetricians & Gynecologists (ACOG) is the “premier professional membership organization dedicated to the improvement of women's health” (ACOG.org). The organization isn't doing nearly enough, however, to promote early diagnosis and proper treatment of endometriosis, say advocates. As a result, some activists have begun pushing back against the institutional failures surrounding the disease, even bringing their fight to a protest at ACOG's Washington, DC headquarters in early April.

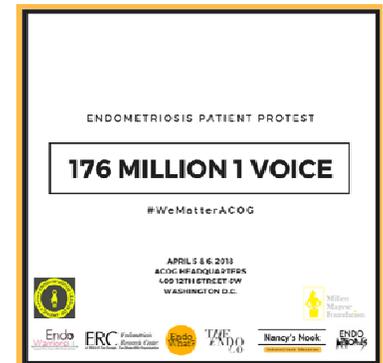
Endometriosis is often dismissed as simply ‘painful periods’ and remains particularly under-served at the non-specialist tier, with significant knowledge deficits contributing directly to the consequential diagnostic delays, sub-optimal treatments and poor outcomes so inherent to the condition. “Too many individuals with this disease see far too many physicians before they are correctly diagnosed and effectively treated,” said Ken Sinervo, MD, MSc, FRCSC, ACGE, the Medical Director of the Center for Endometriosis Care (CEC) and a renowned endometriosis expert. “Despite its vast prevalence and impact, endometriosis is often

still mistakenly normalized as just “bad cramps” - particularly in teen or adolescent years when symptoms may first present. Unfortunately, as doctors we are trained early on that there is no difference in how endometriosis is treated - but in reality, there is an excess of evidence to the contrary. Unfortunately, such myths and misinformation continue to be perpetuated at the institutional level. This is harmful, and can result in long diagnostic delays, poor information systems and continued ineffective care and support of those suffering,” said Dr. Sinervo.



The protest organizers point to one of the biggest problems with the current standards - the significant lack of gynecologists who actually specialize in treating the disease. “Of the 50,000+ ob/gyns represented among ACOG membership, only an estimated 125-150 are true endometriosis specialists - and their interests are not at all represented; therefore, endometriosis patients are not represented,” noted protest co-organizer Heather Guidone of the CEC. “To that end, a most critical challenge persists: a lack of factual disease education, awareness and training. The dedicated, multidisciplinary treatment of endometriosis in tertiary referral centers remains neither acknowledged nor recognized by bodies of influence like ACOG, and the non-specialist majority continues to shape and inform the guidelines for the minority of true specialists who are highly capable of diagnosing and treating even the most complex of manifestations with great success,” she said.

Protest co-organizer Casey Berna, a noted social worker specializing in infertility and endometriosis and the eminent reproductive advocate who authored the ACOG Petition signed by more than 8,000 physician and lay supporters, agrees. “Endometriosis patients, advocates and experts have been going to ACOG for decades, telling them again and again that there is a big problem with the way in which endometriosis is approached,” she said, pointing out the palliative hormonal measures and non-excisional surgery so commonly offered, yet which both carry extremely poor outcomes. Berna also noted that the definitive treatment ACOG promotes is hysterectomy, when “by its very definition, endometriosis is a disease outside the uterus. Even after hysterectomy, many patients are still in pain and suffering.”



The CEC's Jeff Arrington, MD, FACOG, ACGE, a recognized expert on endometriosis, concurs. “The main problem with the ACOG Practice Bulletin [on the disease] is summed up by their stated main outcome measurement, ‘percentage of patients with suspected endometriosis receiving oral contraceptive therapy for pain management before more advanced therapies.’ The recommendations focus on treatment of symptoms - palliation - and not treatment of the disease,” said Dr. Arrington. “It uses studies of pharmaceuticals that don't treat endometriosis compared to surgical studies that do not fully remove the disease - we then act surprised that two therapies that leave disease behind have similar outcomes. This ignores studies from multiple specialties including gynecology, colorectal surgery, urology and others that support the full excision approach. It applies a double standard for included discussion. Excisional studies are excluded as they are single center, non-controlled studies, yet discussions on pharmaceuticals are included while citing the exact same study protocols,” he pointed out. “Last but not least is the inclusion of the phrase, ‘hysterectomy, with bilateral salpingo-oophorectomy is often considered definitive treatment for endometriosis.’ There is not one study to support the statement that hysterectomy magically treats a disease that, by very definition, occurs outside the uterus. This one statement has resulted in misguided gynecologists convincing patients that this was their last ‘magic bullet’ - the current “Standard of Care” as established by ACOG is not limited by the availability of better treatment, but by the training of those providing care.”

Protest Co-organizer Shannon Cohn, a lawyer and famed filmmaker behind the critically acclaimed *Endo What?* Documentary, attributes her own good outcomes to the fact that her doctors didn't follow ACOG's treatment guidelines. "We represent hundreds of thousands of individuals who are tired of this status quo," she said. "It is because of the lack of proper endometriosis education and training among healthcare providers in the U.S. that patients are still being regularly told their symptoms are in their heads or somehow normal, or that pregnancy and hysterectomy are cures, or that hormonal therapies will treat this disease effectively," said Cohn. "Time and time again for decades, ACOG executives have been presented with the grave reproductive injustices endured by patients at the hands of their members, but have continuously failed to act. The very organization charged with protecting women's health is in fact complicit in their systemic mistreatment. Their continued inaction is inexplicable - except for the increasingly obvious fact that their own institutional self-interest and the profitability of their members take precedence over the lives of more than 6 million American girls and women living with endometriosis."



Dr. Andrea Vidali, a world renowned endometriosis expert and reproductive surgeon, wrote on the petition: "It is evident that ACOG is out of touch with what is happening out there. There is a clear disconnect between the needs of patients and the medical community. Let me remind you that one of the basic rules of medicine is 'listen to your patients.'" Those sentiments are echoed by Michelle E. Marvel, Founder & Executive Director of the Endometriosis Research Center. "The lack of quality education and training in endometriosis has been a historic problem we have been trying to address for decades," said Marvel. "Despite repeated attempts to work with the various institutions responsible, patients continue to be misdiagnosed and dismissed. When they do finally obtain care, often it is grounded in antiquated notions of the disease, leaving individuals suffering and healthcare costs soaring. Imagine how many lives could be changed by early diagnosis and correct treatments - that starts with the organizations responsible for keeping endometriosis undermined across the country for millions of affected individuals. We have been silenced for far too long."

ACOG's guidelines on endometriosis care and treatment were last updated in 2010 and reaffirmed in 2016. On April 5 & 6, the organization again convened to review their guidelines. The protest organizers, who have been communicating with ACOG in earnest for some time, but particularly over the past year, to try to solve some of the issues, contributed requested research on multidisciplinary care and suggested evidence-based revisions to the current bulletin to be reviewed at the meetings. The group went one step further than simply contributing more evidence of need for a change, however; they also stood outside ACOG headquarters during the meetings to bring attention to their fight, while a robust "#WeMatterACOG" online protest was coordinated simultaneously with countless supporters.



Image © Wendy Bingham, DPT

The outcome of the guidelines review will not be clear for several months, and ACOG states that 'over 85 physicians will have had the opportunity to review and approve them when the process is complete.' However, the organizers again point to the dearth of endometriosis specialists and advocates involved in the review process. "We have not seen any evidence that actual endometriosis experts are represented at the table at any point in the process," Cohn, Berna and Guidone stated, going on to note that "we are also concerned about the continued influence of powerful industry donors who may sway the guidelines." The organizers plan to continue to put pressure on the organization to make positive

changes and will be organizing additional calls to action throughout the review process.

"The endometriosis patient community will continue to call upon ACOG to fulfill their mission of being a leader in women's health by replacing harmful, archaic, paternalistic approaches to endometriosis care with new policies guided by patient advocates and expert multidisciplinary providers," said Berna. "ACOG should be accurately educating their providers, and it should not take so long to diagnose patients and refer them to a specialist who is equipped to properly manage this challenging disease."

The "We Matter ACOG" movement is a cross-collaborative effort – the first of its kind - between *EndoWhat?*, the Endometriosis Coalition, the Latina Endometriosis League of America, EndoWarriors, the Endometriosis Research Center, Endometropolis, Nancy's Nook for Endometriosis Education and the Millen Magese Foundation. It has received support from the Chronic Disease Coalition and The Suffering the Silence Community, Inc., as well as many endometriosis practitioners and individuals affected by the disease from around the United States and beyond. For more information:



<https://www.wematteracog.com>

<https://www.causes.com/actions/1789268-sign-the-petition-to-we-are-petitioning-the-american-congress-of-obstetricians-and-gynecologists-acog>