

The Connecticut General Assembly



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ENDOMETRIOSIS WORKING GROUP PRESENTS 2022 POLICY RECOMMENDATIONS

(HARTFORD, CT) – **State Representative Jillian Gilchrest (D-West Hartford)** held a press conference this afternoon to present this year's Endometriosis Working Group Recommendations. She was joined by advocates, researchers, medical providers, and individuals living with endometriosis to discuss the need for increasing awareness of the disease and ensuring individuals have access to quality care.

"Women's health has historically been under researched in this country. Currently, the only way to officially diagnose endometriosis is with surgery and there is no cure," said **Rep. Gilchrest**. "The Endometriosis Working Group Recommendations include partnership with the Department of Public Health to initiate clinical data and tissue collection, to find ways to test for endometriosis and develop treatments. We are fortunate to have researchers right here in Connecticut interested in doing this work."

"Providing important clinical data and a robust biorepository in Connecticut would allow researchers to make substantial progress toward advancing diagnostics, treatments, and cures for patients and their families in the State of Connecticut and the 200 million people globally living with this chronic disorder," says Elise Courtois, Ph.D., Associate Director of Single Cell Biology at The Jackson Laboratory. "I am honored to be involved with this working group to drive progress in enhancing Endometriosis research and therapeutics to serve all communities."

"Endometriosis affects 10% of American women of childbearing age and on average takes 10 years to diagnose. Endometriosis symptoms and delayed diagnosis costs the American healthcare system and workforce productivity an estimated 22 billion dollars a year. I along with my colleagues at UConn Health are honored to be participating in the plan to initiate an Endometriosis data and biorepository program in Connecticut to promote better understanding and study of the disease and hopefully find more targeted therapies and early diagnostic markers," said Dr. Danielle Luciano.

Along with the expansion of data collection and research, the recommendations include requiring all healthcare providers to receive training and continued education on endometriosis that includes information on best practice for identification, treatment and referral of the disease, systemic racism, explicit and implicit bias, microaggressions, racial disparities, anti-blackness, and experiences of transgender and gender diverse people. Additionally, the working group is recommending that school nurses receive the Endo What? School Nurse Training & Toolkit and that the State Department of

Education and local boards of education ensure instruction on human growth and development includes information on common reproductive health concerns.

"We must ensure adolescents and adults have access to safe menstrual products and the menstrual health education they need to fully understand their bodies and how to advocate for their reproductive health when concerns arise. In addition, we must ensure healthcare providers are culturally competent and equipped to effectively address the reproductive health needs of all people who menstruate. We can do this through training on endometriosis that includes information on systemic racism, explicit and implicit bias, microaggressions, racial disparities and experiences of transgender & gender diverse people," said Bria Gadsden, Executive Director of Love Your Menses. "We look forward to continuing to address reproductive health inequities within the state of Connecticut and leading the charge in supporting those who experience endometriosis and other reproductive health conditions."

"Early education about endometriosis could change an individual born with uterus' life for the better. It takes an average of 7-10 years to be diagnosed. That is years of pain and suffering that could be proactively treated," said Diana Falzone, EndoFound ambassador and Executive Producer of Endo TV. "It is vital for parents, adolescents, and physicians to know the symptoms of this chronic, debilitating illness in order to get the best treatment options possible. Without awareness we lack knowledge. Knowledge is power. Everyone deserves to live a happy, pain free life. There is no better time to implement change than now."

"This disease is a true public health crisis in desperate need of increased research funding, better support of those struggling, improved access to care, proper education and training, and an end to the disparities plaguing our community. I am so pleased to support Representative Gilchrest in her forward-looking and timely efforts to make strides on behalf of the endometriosis community," said Heather C. Guidone, BCPA, Program Director of the Center for Endometriosis Care and an endometriosis patient.

"Everyone has now acknowledged the disparities that affect the community, now is the time for both patients and medical professionals to work together. Let's put policies in place that are benefiting the people in which they serve," said Lauren Kornegay, Executive Director of Endo Black, Incorporated.

The Endometriosis Working Group was started by **Rep. Gilchrest** in September 2021 to discuss the shortfalls in endometriosis awareness, research and treatment and develop solutions.

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