

Connecticut legislature approves historic endometriosis bill

June 8 2023



Elise Courtois, Ph.D. is an endometriosis researcher and is the director of single cell biology at JAX. She has dedicated her career to understanding endometriosis. Credit: The Jackson Laboratory.

Connecticut is poised to become a hub for endometriosis research and innovation following the unanimous passage of House Bill 6672, "An Act Concerning Endometriosis," which creates a first-of-its-kind endometriosis data and biorepository program to bring greater



awareness, action and care options to those suffering from the condition.

Endometriosis is a chronic, debilitating <u>disease</u> that causes pain and infertility, and is the leading cause of hysterectomies among individuals of reproductive age. While it affects 200 million female-born individuals worldwide, including 6.5 million in the United States and one out of 10 female-born people in Connecticut, much about the disease is still unknown.

"I have suffered along with hundreds of thousands of others who have endometriosis for the majority of my life," said Arleigh Cole Doyle, a patient, advocate and member of the Connecticut Endometriosis Working Group, which was established last year to increase awareness of endometriosis and expand access to care. "This debilitating systemic disease is a public health crisis, and the passage of this historic bill gives hope to those who live with it, while providing much-needed resources towards biomedical research for endometriosis."

HB 6672 advances a recommendation spearheaded by State Representative Jillian Gilchrest (D-West Hartford) and the Endometriosis Working Group for the creation of this unique public, multi-institution biorepository program. The goal of this innovative bill is to bring attention to the highly invasive, underdiagnosed and underresearched condition in Connecticut, while driving research breakthroughs for individuals impacted by endometriosis across the state, the nation and beyond.

The program will operate through a partnership between UConn Health and The Jackson Laboratory, an independent, nonprofit biomedical research organization. The biorepository at the core of the program will enable the collection and combination of surgical, clinical and biological information from endometriosis patients statewide. It will foster basic research and clinical collaborations designed to help understand the



disease and catalyze the advancement of new diagnostics, treatments and cures for patients.

"I've heard from hundreds of women across Connecticut who have suffered in silence with endometriosis for far too long. With passage of this legislation we are bringing much needed attention to this disease and these individual's lived experience," said Rep. Gilchrest. "The partnership between UConn Health and JAX will serve as a foundation for successful collaboration statewide and beyond."

Elise Courtois, Ph.D., an endometriosis researcher and director of single cell biology at JAX, has dedicated her career to understanding endometriosis. In partnership with UConn Health's Director for Minimally Invasive Gynecological Surgery Danielle Luciano, M.D., Courtois has studied <u>tissue samples</u> from endometriosis patients one cell at a time to learn more about the condition and possible treatments. Courtois and Luciano are both members of the Connecticut Endometriosis Working Group.

"I am grateful to the Connecticut General Assembly for embarking on this visionary approach, building a government, public and nonprofit partnership to address this disease, and for positioning Connecticut as a leader in the fight against endometriosis," said Courtois. "Without further investigation, endometriosis will persist as a disease requiring invasive diagnostics, lacking a definitive treatment or cure, and continuing to adversely affect the physical and mental health, as well as the economic potential of up to one in 10 female-born individuals."

"Compared to other diseases with similar healthcare and societal burden, endometriosis has been comparatively ignored and remains poorly diagnosed and managed," said Luciano. "This legislative initiative is therefore an unprecedented opportunity to turn the tide towards improved research investment, awareness-building, and clinical impact



in this disease, and will position Connecticut as a trailblazer in endometriosis collaboration and research."

Provided by Jackson Laboratory

Citation: Connecticut legislature approves historic endometriosis bill (2023, June 8) retrieved 10 April 2024 from

https://medicalxpress.com/news/2023-06-connecticut-legislature-historic-endometriosis-bill.html

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.