
OLR Bill Analysis

sHB 6672 (as amended by House "A")*

AN ACT CONCERNING ENDOMETRIOSIS.

SUMMARY

This bill requires UConn Health Center (UCHC), by January 1, 2024, to develop an endometriosis data and biorepository program to enable and promote research on (1) early detection of endometriosis in adolescents and adults and (2) the development of therapeutic strategies to improve clinical management of the condition. It must do this in collaboration with an independent, nonprofit biomedical research institution in Connecticut that is engaged in endometriosis research with UCHC.

Under the bill, UCHC must annually report on the program's implementation to the Public Health Committee, starting by January 1, 2025.

*House Amendment "A" (1) removes the provision creating a 16-member Endometriosis Data and Biorepository Program Oversight Committee; (2) specifies that the research institution UCHC collaborates with must be nonprofit and independent, and engaged in endometriosis research; and (3) requires UCHC, instead of the eliminated oversight committee, to annually report on the program.

EFFECTIVE DATE: July 1, 2023

ENDOMETRIOSIS DATA AND BIOREPOSITORY PROGRAM

Duties

Under the bill, the endometriosis data and biorepository program must do the following:

1. design a comprehensive longitudinal sample and clinical data collection protocol to characterize endometriosis and cellular functions of those with endometriosis;

2. collect from patients with endometriosis and control patients without the condition and code (a) endometrial tissue specimens; (b) fluids, including blood and urine; and (c) clinical and demographic data and questionnaires on endometriosis symptoms and quality of life;
3. develop standard operating procedures for biological material samples, including for their transportation, coding, processing, and long-term retention and storage;
4. establish data transmission and onboarding operations necessary for institutions in the state to participate in banking with and accessing data from the program;
5. curate biological endometriosis samples from a diverse cross-section of communities in the state to ensure they represent all groups affected by endometriosis, including African American, black, Latino, Latina, Latinx, and Puerto Rican persons; other persons of color; transgender and gender diverse persons; and persons with disabilities;
6. raise awareness on endometriosis in these underrepresented populations and promote research on better diagnostic and therapeutic options, including through communications with health care providers and those impacted by endometriosis on information about the latest therapeutic options for people diagnosed with the condition;
7. create opportunities for collaborative research among institutions in the state focused on the pathogenesis, pathophysiology, progression, prognosis, and prevention of endometriosis and the discovery of noninvasive diagnostic biomarkers, new targeted therapeutics, and improved medical and surgical interventions;
8. serve as a centralized resource for endometriosis information and a conduit to promote endometriosis education and raise its public awareness;

9. facilitate collaboration among researchers and health care providers, educators, students, patients, and others impacted by endometriosis through conferences and continuing medical education programs on best practices for endometriosis diagnosis, care, and treatment;
10. collect information on endometriosis's impact on Connecticut residents, including health and comorbidity, health care costs, and overall quality of life; and
11. apply for and accept grants, gifts, and funds bequeathed to perform its functions.

Under the bill, a “biorepository” is a facility that collects, catalogs, and stores human samples of biological material, including urine, blood, tissue, cells, DNA, RNA, and protein for laboratory research. These samples are coded without individual identifiers and linked with phenotypic data (i.e., non-individually identifiable clinical information on a person's disease history, symptoms, and demographic data, including age, sex, race, and ethnicity).

COMMITTEE ACTION

Public Health Committee

Joint Favorable Substitute

Yea 35 Nay 0 (03/03/2023)

Appropriations Committee

Joint Favorable

Yea 53 Nay 0 (05/01/2023)