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## **OLR Bill Analysis**

### **sHB 6672**

#### ***AN ACT CONCERNING ENDOMETRIOSIS.***

#### **SUMMARY**

This bill requires UConn Health Center, by January 1, 2024, and in collaboration with a research laboratory, 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.

The bill also establishes a 16-member Endometriosis Data and Biorepository Program Oversight Committee within the Legislative Department to do the following:

1. oversee the program's governance and operation;
2. develop processes and guidelines for scientific review of the program's research projects and data-sharing processes; and
3. ensure the integrity of, and facilitate access to and distribution of, the program's data and biorepository specimens.

Under the bill, the oversight committee must annually report on the program to the Public Health Committee, starting by January 1, 2025.

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 bequested to perform its functions.

### ***Definitions***

Under the bill, “biorepository” means 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.

“Phenotypic data” means non-individually identifiable clinical information on a person’s disease history and symptoms and his or her demographic data, including age, sex, race, and ethnicity.

## **ENDOMETRIOSIS DATA AND BIOREPOSITORY PROGRAM OVERSIGHT COMMITTEE**

### ***Membership***

Under the bill, committee members include the following individuals:

1. the chairpersons and ranking members of the Public Health Committee, or their designees;
2. two members each appointed by the House speaker and Senate

- president pro tempore;
3. one member each appointed by the House and Senate majority and minority leaders;
  4. the Department of Public Health (DPH) commissioner, or her designee;
  5. the Office of Health Strategy executive director, or her designee;
  6. the healthcare advocate, or his designee; and
  7. the Commission on Women, Children, Seniors, Equity and Opportunity executive director, or his designee.

Under the bill, appointed members may be legislators, and appointing authorities must fill any vacancies. Committee members are not compensated but may be reimbursed for necessary expenses incurred in performing their duties.

### ***Leadership and Meetings***

Under the bill, the committee co-chairpersons are (1) the DPH commissioner, or her designee, and (2) a legislator jointly selected by the House speaker and Senate president pro tempore from among the committee members.

The co-chairpersons must schedule the first meeting, which must be held by September 1, 2023.

### **COMMITTEE ACTION**

Public Health Committee

Joint Favorable Substitute  
Yea 35 Nay 0 (03/03/2023)