



Substitute House Bill No. 6672

Public Act No. 23-67

AN ACT CONCERNING ENDOMETRIOSIS.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (*Effective July 1, 2023*) (a) As used in this section:

(1) "Biorepository" means a facility that, for laboratory research, collects, catalogs and stores samples of biological material from humans, including, but not limited to, urine, blood, tissue, cells, DNA (deoxyribonucleic acid), RNA (ribonucleic acid) and protein, that is coded without individual identifiers and linked with phenotypic data; and

(2) "Phenotypic data" means clinical information about a person, coded without individual identifiers, that includes disease history, symptoms and demographic data including, but not limited to, age, sex, race and ethnicity.

(b) Not later than January 1, 2024, The University of Connecticut Health Center, in collaboration with an independent, nonprofit biomedical research institution in the state engaged in endometriosis research with said health center, shall establish an endometriosis data and biorepository program in the state to enable and promote research regarding (1) early detection of endometriosis in adolescents and adults,

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and (2) the development of therapeutic strategies to improve clinical management of endometriosis.

(c) The endometriosis data and biorepository program established pursuant to subsection (b) of this section shall:

(1) (A) Design a comprehensive longitudinal sample and clinical data collection protocol to characterize endometriosis and cellular functions of individuals with endometriosis, and (B) collect from patients with endometriosis and control patients without endometriosis and code (i) endometrial tissue specimens, (ii) fluids, including, but not limited to, blood and urine, and (iii) clinical and demographic data and questionnaires regarding symptoms of endometriosis and quality of life;

(2) (A) Develop standard operating procedures concerning samples of biological material, including, but not limited to, transportation, coding, processing, long-term retention and storage of such samples, and (B) establish data transmission and onboarding operations necessary for institutions in the state to participate in banking with and accessing data from the data and biorepository program;

(3) Curate biological samples of endometriosis from a diverse cross-section of communities in the state to ensure representation of all groups affected by endometriosis, including such under-represented populations as African American and black persons, Latino, Latina and Latinx persons, Puerto Rican persons, other persons of color, transgender and gender diverse persons, and persons with disabilities;

(4) Raise awareness regarding endometriosis in such under-represented populations and promote research of better diagnostic and therapeutic options, including through communications with health care providers and persons impacted by endometriosis concerning information about the latest therapeutic options for persons diagnosed with endometriosis;

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(5) 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, novel targeted therapeutics and improved medical and surgical interventions;

(6) Serve as a centralized resource for endometriosis information and a conduit to promote education and raise public awareness regarding endometriosis;

(7) Facilitate collaboration among researchers and health care providers, educators, students, patients and other individuals impacted by endometriosis through conferences and continuing medical education programs regarding best practices for the diagnosis, care and treatment of endometriosis;

(8) Collect information on the impact of endometriosis on residents of the state, including, but not limited to, its impact on health and comorbidity, health care costs and overall quality of life; and

(9) Apply for and accept grants, gifts and bequests of funds for the purpose of performing its functions pursuant to subdivisions (1) to (8), inclusive, of this subsection.

(d) Not later than January 1, 2025, and annually thereafter, The University of Connecticut Health Center shall report, in accordance with the provisions of section 11-4a of the general statutes, to the joint standing committee of the General Assembly having cognizance of matters relating to public health, regarding the implementation of the endometriosis data and biorepository program established pursuant to subsection (b) of this section.