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State of Minnesota

HOUSE OF REPRESENTATIVES

NINETY-FOURTH SESSION

H. F. No. 2556

03/20/2025 Authored by Frazier; Virnig; Pursell; Hanson, J., and Clardy
The bill was read for the first time and referred to the Committee on Higher Education Finance and Policy

A bill for an act

relating to health; establishing an endometriosis data and biorepository program administered by the University of Minnesota; requiring a report; appropriating money; amending Minnesota Statutes 2024, section 13.3806, by adding a subdivision; proposing coding for new law in Minnesota Statutes, chapter 137.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

Section 1. Minnesota Statutes 2024, section 13.3806, is amended by adding a subdivision to read:

Subd. 23. **Endometriosis data and biorepository program.** Data on individuals in the endometriosis data and biorepository program administered by the University of Minnesota is classified under section 137.48, subdivision 3.

Sec. 2. **[137.48] ENDOMETRIOSIS DATA AND BIOREPOSITORY PROGRAM.**

Subdivision 1. **Definitions.** For purposes of this section, the following terms have the meanings given:

(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 that is coded without individual identifiers and that includes disease history, symptoms, and demographic data including but not limited to age, sex, race, and ethnicity.

Subd. 2. **Program established.** (a) The Board of Regents of the University of Minnesota is requested to 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; and

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

(b) The program may be established and operated in collaboration with other entities engaged in endometriosis research.

Subd. 3. **Program duties; data classified.** (a) The endometriosis data and biorepository program shall:

(1) design a comprehensive longitudinal sample and clinical data collection protocol to characterize endometriosis and cellular functions of individuals with endometriosis;

(2) 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;

(3) develop standard operating procedures concerning samples of biological material, including but not limited to transportation, coding, processing, long-term retention, and storage of samples;

(4) 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;

(5) 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 representation of the state's underrepresented communities, as defined in section 148E.010, subdivision 20;

(6) raise awareness of endometriosis in underrepresented populations and promote research of improved diagnostic and therapeutic treatment options by communicating with health care providers and persons impacted by endometriosis information on the latest therapeutic treatment options for endometriosis;

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

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

(9) 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;

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

(11) apply for and accept grants, gifts, and bequests of money for the purpose of performing the program's functions pursuant to this subdivision.

(b) Data on individuals, as defined by section 13.02, subdivision 5, collected, created, or maintained by the endometriosis data and biorepository program is classified as private data on individuals, as defined by section 13.02, subdivision 12.

Subd. 4. **Report required.** Beginning January 15, 2026, and each even-numbered year thereafter, the Board of Regents of the University of Minnesota must report to the chairs and ranking minority members of the legislative committees with primary jurisdiction over health policy and finance on the work accomplished regarding the implementation, accomplishments, and future goals of the endometriosis data and biorepository program established by this section.

Sec. 3. **APPROPRIATIONS; ENDOMETRIOSIS DATA AND BIOREPOSITORY PROGRAM.**

$..... in fiscal year 2026 and $..... in fiscal year 2027 are appropriated from the general fund to the Board of Regents of the University of Minnesota for the endometriosis data and biorepository program under section 2.