



General Assembly

Substitute Bill No. 6672

January Session, 2023



AN ACT CONCERNING ENDOMETRIOSIS.

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

- 1 Section 1. (NEW) (*Effective July 1, 2023*) (a) As used in this section:
- 2 (1) "Biorepository" means a facility that, for laboratory research,
3 collects, catalogs and stores samples of biological material from
4 humans, including, but not limited to, urine, blood, tissue, cells, DNA
5 (deoxyribonucleic acid), RNA (ribonucleic acid) and protein, that is
6 coded without individual identifiers and linked with phenotypic data;
7 and
- 8 (2) "Phenotypic data" means clinical information about a person,
9 coded without individual identifiers, that includes disease history,
10 symptoms and demographic data including, but not limited to, age,
11 sex, race and ethnicity.
- 12 (b) Not later than January 1, 2024, The University of Connecticut
13 Health Center, in collaboration with a research laboratory in the state,
14 shall establish an endometriosis data and biorepository program in the
15 state to enable and promote research regarding (1) early detection of
16 endometriosis in adolescents and adults, and (2) the development of
17 therapeutic strategies to improve clinical management of
18 endometriosis.

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

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

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

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

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

47 (5) Create opportunities for collaborative research among
48 institutions in the state focused on the pathogenesis, pathophysiology,
49 progression, prognosis and prevention of endometriosis and the

50 discovery of noninvasive diagnostic biomarkers, novel targeted
51 therapeutics and improved medical and surgical interventions;

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

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

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

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

66 Sec. 2. (NEW) (*Effective July 1, 2023*) (a) There is established an
67 Endometriosis Data and Biorepository Program Oversight Committee
68 to (1) oversee the governance and operation of the endometriosis data
69 and biorepository program established pursuant to section 1 of this act,
70 (2) develop processes and guidelines for scientific review of research
71 projects and data-sharing processes within such program, (3) ensure
72 the integrity of data and biorepository specimens within such
73 program, and (4) facilitate access to and distribution of data and
74 biorepository specimens within such program. The committee shall be
75 within the Legislative Department.

76 (b) The committee shall consist of the following members:

77 (1) The chairpersons and ranking members of the joint standing
78 committee of the General Assembly having cognizance of matters
79 relating to public health, or their designees;

80 (2) Two appointed by the speaker of the House of Representatives;

81 (3) Two appointed by the president pro tempore of the Senate;

82 (4) One appointed by the majority leader of the House of
83 Representatives;

84 (5) One appointed by the majority leader of the Senate;

85 (6) One appointed by the minority leader of the House of
86 Representatives;

87 (7) One appointed by the minority leader of the Senate;

88 (8) The Commissioner of Public Health, or the commissioner's
89 designee;

90 (9) The executive director of the Office of Health Strategy, or the
91 executive director's designee;

92 (10) The Healthcare Advocate, or the Healthcare Advocate's
93 designee; and

94 (11) The executive director of the Commission on Women, Children,
95 Seniors, Equity and Opportunity, or the executive director's designee.

96 (c) Any member of the committee appointed under subdivisions (1)
97 to (7), inclusive, of subsection (b) of this section may be a member of
98 the General Assembly.

99 (d) Any vacancy shall be filled by the appointing authority.

100 (e) The Commissioner of Public Health, or the commissioner's
101 designee, and a member of the General Assembly selected jointly by
102 the speaker of the House of Representatives and the president pro
103 tempore of the Senate from among the members serving pursuant to
104 subdivision (1) of subsection (b) of this section shall be cochairpersons
105 of the committee. Such cochairpersons shall schedule the first meeting

106 of the committee, which shall be held not later September 1, 2023.

107 (f) Members of the committee shall serve without compensation,
108 except for necessary expenses incurred in the performance of their
109 duties.

110 (g) Not later than January 1, 2025, and annually thereafter, the
111 committee shall report, in accordance with section 11-4a of the general
112 statutes, to the joint standing committee of the General Assembly
113 having cognizance of matters relating to public health regarding the
114 endometriosis data and biorepository program.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>July 1, 2023</i>	New section
Sec. 2	<i>July 1, 2023</i>	New section

PH *Joint Favorable Subst.*