



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 humans,  
4 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, sex,  
11 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 endometriosis.

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

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

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

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

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

45 (5) Create opportunities for collaborative research among institutions  
46 in the state focused on the pathogenesis, pathophysiology, progression,  
47 prognosis and prevention of endometriosis and the discovery of  
48 noninvasive diagnostic biomarkers, novel targeted therapeutics and

49 improved medical and surgical interventions;

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

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

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

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

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

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

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

- 78 (2) Two appointed by the speaker of the House of Representatives;
- 79 (3) Two appointed by the president pro tempore of the Senate;
- 80 (4) One appointed by the majority leader of the House of  
81 Representatives;
- 82 (5) One appointed by the majority leader of the Senate;
- 83 (6) One appointed by the minority leader of the House of  
84 Representatives;
- 85 (7) One appointed by the minority leader of the Senate;
- 86 (8) The Commissioner of Public Health, or the commissioner's  
87 designee;
- 88 (9) The executive director of the Office of Health Strategy, or the  
89 executive director's designee;
- 90 (10) The Healthcare Advocate, or the Healthcare Advocate's  
91 designee; and
- 92 (11) The executive director of the Commission on Women, Children,  
93 Seniors, Equity and Opportunity, or the executive director's designee.
- 94 (c) Any member of the committee appointed under subdivisions (1)  
95 to (7), inclusive, of subsection (b) of this section may be a member of the  
96 General Assembly.
- 97 (d) Any vacancy shall be filled by the appointing authority.
- 98 (e) The Commissioner of Public Health, or the commissioner's  
99 designee, and a member of the General Assembly selected jointly by the  
100 speaker of the House of Representatives and the president pro tempore  
101 of the Senate from among the members serving pursuant to subdivision  
102 (1) of subsection (b) of this section shall be cochairpersons of the  
103 committee. Such cochairpersons shall schedule the first meeting of the

104 committee, which shall be held not later September 1, 2023.

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

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

**APP**      *Joint Favorable*