



General Assembly

Amendment

January Session, 2023

LCO No. 7311



Offered by:

REP. MCCARTHY VAHEY, 133 rd Dist.	REP. GILCHREST, 18 th Dist.
SEN. ANWAR, 3 rd Dist.	REP. KENNEDY, 119 th Dist.
REP. KLARIDES-DITRIA, 105 th Dist.	REP. KAVROS DEGRAW, 17 th Dist.
SEN. SOMERS, 18 th Dist.	REP. BERGER-GIRVALO, 111 th Dist.

To: Subst. House Bill No. 6672

File No. 59

Cal. No. 63

"AN ACT CONCERNING ENDOMETRIOSIS."

1 Strike everything after the enacting clause and substitute the
2 following in lieu thereof:

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

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

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

13 race and ethnicity.

14 (b) Not later than January 1, 2024, The University of Connecticut
15 Health Center, in collaboration with an independent, nonprofit
16 biomedical research institution in the state engaged in endometriosis
17 research with said health center, shall establish an endometriosis data
18 and biorepository program in the state to enable and promote research
19 regarding (1) early detection of endometriosis in adolescents and adults,
20 and (2) the development of therapeutic strategies to improve clinical
21 management of endometriosis.

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

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

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

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

43 (4) Raise awareness regarding endometriosis in such under-

44 represented populations and promote research of better diagnostic and
45 therapeutic options, including through communications with health
46 care providers and persons impacted by endometriosis concerning
47 information about the latest therapeutic options for persons diagnosed
48 with endometriosis;

49 (5) Create opportunities for collaborative research among institutions
50 in the state focused on the pathogenesis, pathophysiology, progression,
51 prognosis and prevention of endometriosis and the discovery of
52 noninvasive diagnostic biomarkers, novel targeted therapeutics and
53 improved medical and surgical interventions;

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

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

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

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

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

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