

116TH CONGRESS
1ST SESSION

H. R. 1824

To amend the Public Health Service Act to provide for the establishment of a mesothelioma patient registry, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 18, 2019

Mr. KATKO (for himself and Mr. KENNEDY) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the establishment of a mesothelioma patient registry, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Mary Jo Lawyer Spano
5 Mesothelioma Patient Registry Act of 2019”.

6 **SEC. 2. PATIENT REGISTRY FOR MESOTHELIOMA DATA**
7 **COLLECTION AND RESEARCH.**

8 Title III of the Public Health Service Act is amended
9 by inserting after section 399V–6 of such Act (42 U.S.C.
10 280g–17) the following:

1 **“SEC. 399V-7. PATIENT REGISTRY FOR MESOTHELIOMA**
2 **DATA COLLECTION AND RESEARCH.**

3 “(a) IN GENERAL.—The Secretary, acting through
4 the Administrator of the Agency for Toxic Substances and
5 Disease Registry, shall develop a patient registry to collect
6 data on mesothelioma, including information with respect
7 to the incidence and prevalence of the disease in the
8 United States.

9 “(b) USES.—The Secretary shall use the registry
10 under subsection (a)—

11 “(1) to enhance and expand infrastructure and
12 activities for tracking the epidemiology of mesothe-
13 lioma patients;

14 “(2) to collect, consolidate, and report on health
15 information on patients who have been diagnosed
16 with mesothelioma, including with respect to—

17 “(A) treatment outcomes, including patient
18 longevity; and

19 “(B) the number of patients receiving
20 treatment for mesothelioma disaggregated by
21 hospital;

22 “(3) to better describe the incidence and preva-
23 lence of mesothelioma in the United States;

24 “(4) to facilitate further research on mesothe-
25 lioma;

1 “(5) to examine factors, such as environmental
2 and occupational factors, that may be associated
3 with mesothelioma;

4 “(6) to better outline key demographic factors
5 (such as age, race or ethnicity, gender, and family
6 history) associated with mesothelioma; and

7 “(7) to make the information in such registry,
8 other than individually identifiable information,
9 available to the public to facilitate and enhance re-
10 search on, and prevention and treatment of, meso-
11 thelioma.

12 “(c) CONTENT.—In carrying out this section, the
13 Secretary—

14 “(1) shall provide for the collection and storage
15 of information on the incidence and prevalence of
16 mesothelioma in the United States;

17 “(2) when scientifically possible, shall provide
18 for the collection and storage of other available in-
19 formation on mesothelioma, such as information con-
20 cerning—

21 “(A) demographics and other information
22 associated or possibly associated with mesothe-
23 lioma, such as age, race, ethnicity, sex, geo-
24 graphic location, and family history;

1 “(B) risk factors associated or possibly as-
2 sociated with mesothelioma, including genetic
3 and environmental risk factors; and

4 “(C) diagnosis and progression markers;
5 and

6 “(3) may provide for the collection and storage
7 of information relevant to analysis on mesothelioma,
8 such as information concerning—

9 “(A) the epidemiology of the disease;

10 “(B) the natural history of the disease;

11 “(C) the prevention of the disease;

12 “(D) the detection, management, and
13 treatment approaches for the disease; and

14 “(E) the development of outcomes meas-
15 ures.

16 “(d) CONSULTATION.—In carrying out this section,
17 the Secretary shall consult with individuals with appro-
18 priate expertise, including non-Federal mesothelioma ex-
19 perts including—

20 “(1) epidemiologists with experience in disease
21 surveillance or registries;

22 “(2) representatives of national voluntary asso-
23 ciations that focus on mesothelioma or have dem-
24 onstrated experience in research, care, or patient
25 service for mesothelioma;

1 “(3) health information technology experts or
2 other information management specialists;

3 “(4) clinicians with expertise in mesothelioma;
4 and

5 “(5) research scientists with experience con-
6 ducting translational research or utilizing surveil-
7 lance systems for scientific research purposes.

8 “(e) COORDINATION WITH OTHER FEDERAL AGEN-
9 CIES.—The Secretary shall make information in and anal-
10 ysis derived from the registry under this section available,
11 as appropriate, to Federal departments and agencies, such
12 as the National Institutes of Health, the Food and Drug
13 Administration, the Centers for Medicare & Medicaid
14 Services, the Agency for Healthcare Research and Quality,
15 the Department of Veterans Affairs, and the Department
16 of Defense.

17 “(f) PUBLIC ACCESS.—Subject to subsection (g), the
18 Secretary shall make information in, and analysis derived
19 from, the registry under this section available, as appro-
20 priate, to the public, including researchers.

21 “(g) PRIVACY.—The Secretary shall ensure that pri-
22 vacy and security protections applicable to the registry
23 under this section are at least as stringent as the privacy
24 and security protections under HIPAA privacy and secu-
25 rity law (as defined in section 3009).

1 “(h) REPORTS TO CONGRESS.—

2 “(1) INITIAL REPORT.—Not later than 18
3 months after the date of enactment of the Mary Jo
4 Lawyer Spano Mesothelioma Patient Registry Act of
5 2019, the Secretary shall submit to the Congress a
6 report that—

7 “(A) shall outline—

8 “(i) the findings in the mesothelioma
9 patient registry under subsection (a);

10 “(ii) future plans for expansion or re-
11 vision of such registry; and

12 “(iii) the scope of such registry; and

13 “(B) may include a description of the ac-
14 tivities undertaken by the Secretary to establish
15 partnerships with research and patient advocacy
16 communities to expand such registry.

17 “(2) SUBSEQUENT REPORT.—Not later than 4
18 years after the date of enactment of the Mary Jo
19 Lawyer Spano Mesothelioma Patient Registry Act of
20 2019, the Secretary shall submit a report to the
21 Congress concerning the implementation of this sec-
22 tion. Such report should include information on—

23 “(A) the development and maintenance of
24 the mesothelioma patient registry under sub-
25 section (a);

1 “(B) the type of information collected and
2 stored in the registry;

3 “(C) the use and availability of such infor-
4 mation, including guidelines for such use; and

5 “(D) the use and coordination of databases
6 that collect or maintain information on meso-
7 thelioma.”.

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