

Calendar No. 608

103D CONGRESS
2D SESSION

S. 1629

[Report No. 103-364]

A BILL

To amend the Public Health Service Act to provide for expanding and intensifying activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases with respect to lupus, and for other purposes.

SEPTEMBER 13 (legislative day, SEPTEMBER 12), 1994
Reported with an amendment

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To amend the Public Health Service Act to provide for expanding and intensifying activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases with respect to lupus, and for other purposes.

IN THE SENATE OF THE UNITED STATES

NOVEMBER 5 (legislative day, NOVEMBER 2), 1993

Ms. MOSELEY-BRAUN (for herself, Ms. MIKULSKI, Mr. KENNEDY, Mr. LEVIN, Mrs. MURRAY, Mr. REID, Mr. SHELBY, Mr. SIMON, Mr. INOUE, and Mr. JOHNSTON) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

SEPTEMBER 13 (legislative day, SEPTEMBER 12), 1994

Reported by Mr. KENNEDY, with an amendment

[Strike out all after the enacting clause and insert the part printed in italic]

A BILL

To amend the Public Health Service Act to provide for expanding and intensifying activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases with respect to lupus, 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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Lupus Research
3 Amendments of 1993”.

4 **SEC. 2. FINDINGS.**

5 The Congress finds that—

6 (1) lupus is a serious, complex, inflammatory,
7 autoimmune disease of particular concern to women;

8 (2) lupus affects women 9 times more often
9 than men;

10 (3) there are 3 main types of lupus: systemic
11 lupus, a serious form of the disease that affects
12 many parts of the body; discoid lupus, a form of the
13 disease that affects mainly the skin; and drug-in-
14 duced lupus caused by certain medications;

15 (4) lupus can be fatal if not detected and
16 treated early;

17 (5) the disease can simultaneously affect var-
18 ious areas of the body, such as the skin, joints, kid-
19 neys, and brain, and can be difficult to diagnose be-
20 cause the symptoms of lupus are similar to those of
21 many other diseases;

22 (6) lupus disproportionately affects African-
23 American women, as the prevalence of the disease
24 among such women is 3 times the prevalence among
25 white women, and an estimated 1 in 250 African-

1 American women between the ages of 15 and 65 de-
2 velops the disease;

3 (7) it has been estimated that over 500,000
4 Americans have been diagnosed with the disease,
5 and that many more have undiagnosed cases;

6 (8) current treatments for the disease can be
7 effective, but may lead to damaging side effects; and

8 (9) many victims of the disease suffer debilitat-
9 ing pain and fatigue, making it difficult to maintain
10 employment and lead normal lives.

11 **SEC. 3. EXPANSION AND INTENSIFICATION OF ACTIVITIES**

12 **REGARDING LUPUS.**

13 Subpart 4 of part C of title IV of the Public Health
14 Service Act (42 U.S.C. 285d et seq.) is amended by insert-
15 ing after section 441 the following new section:

16 “LUPUS

17 “SEC. 441A. (a) IN GENERAL.—The Director of the
18 Institute shall expand and intensify research and related
19 activities of the Institute with respect to lupus.

20 “(b) COORDINATION WITH OTHER INSTITUTES.—

21 The Director of the Institute shall coordinate the activities
22 of the Director under subsection (a) with similar activities
23 conducted by the other national research institutes and
24 agencies of the National Institutes of Health to the extent
25 that such Institutes and agencies have responsibilities that
26 are related to lupus.

1 “(c) PROGRAMS FOR LUPUS.—In carrying out sub-
2 section (a), the Director of the Institute shall conduct or
3 support research to expand the understanding of the
4 causes of, and to find a cure for, lupus. Activities under
5 such subsection shall include research to determine the
6 reasons underlying the elevated prevalence of the disease
7 among African-American and other women. Activities
8 under such subsection shall provide for an expansion and
9 intensification of the conduct and support of—

10 “(1) basic research concerning the etiology and
11 causes of lupus;

12 “(2) epidemiological studies to address the fre-
13 quency and natural history of the disease and the
14 differences among the sexes and among racial and
15 ethnic groups with respect to the disease;

16 “(3) the development of improved screening
17 techniques;

18 “(4) clinical research for the development and
19 evaluation of new treatments, including new biologi-
20 cal agents; and

21 “(5) information and education programs for
22 health care professionals and the public.

23 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
24 purpose of carrying out this section, there are authorized
25 to be appropriated \$20,000,000 for fiscal year 1994, and

1 such sums as may be necessary for each of the fiscal years
2 1994 through 1996. The authorization of appropriations
3 established in the preceding sentence is in addition to any
4 other authorization of appropriations that is available for
5 such purpose.”.

6 **SECTION 1. SHORT TITLE.**

7 *This Act may be cited as the “Lupus Research Amend-*
8 *ments of 1994”.*

9 **SEC. 2. EXPANSION AND INTENSIFICATION OF ACTIVITIES**

10 **REGARDING LUPUS.**

11 *Subpart 4 of part C of title IV of the Public Health*
12 *Service Act (42 U.S.C. 285d et seq.) is amended by insert-*
13 *ing after section 441 the following new section:*

14 *“LUPUS*

15 *“SEC. 441A. (a) IN GENERAL.—The Director of the In-*
16 *stitute shall conduct lupus research and related activities.*

17 *“(b) COORDINATION WITH OTHER INSTITUTES.—The*
18 *Director of the Institute shall coordinate the activities of*
19 *the Director under subsection (a) with similar activities*
20 *conducted by the other national research institutes and*
21 *agencies of the National Institutes of Health to the extent*
22 *that such Institutes and agencies have responsibilities that*
23 *are related to lupus.*

24 *“(c) PROGRAMS FOR LUPUS.—In carrying out sub-*
25 *section (a), the Director of the Institute shall conduct or*
26 *support research to expand the understanding of the causes*

1 *of, and to find a cure for, lupus. Activities under such sub-*
2 *section shall provide for the conduct and support of—*

3 “(1) *research to determine the reasons for the ele-*
4 *vated prevalence of the disease in women, including*
5 *African American women;*

6 “(2) *basic research concerning the etiology and*
7 *causes of lupus;*

8 “(3) *epidemiological studies to address the fre-*
9 *quency and natural history of the disease and the dif-*
10 *ferences among the sexes and among racial and ethnic*
11 *groups with respect to the disease;*

12 “(4) *the development of improved diagnostic*
13 *techniques;*

14 “(5) *clinical research for the development and*
15 *evaluation of new treatments, including new biologi-*
16 *cal agents;*

17 “(6) *information and education programs for*
18 *health care professionals and the public; and*

19 “(7) *other relevant activities.”.*