

105TH CONGRESS
2D SESSION

S. 2101

To amend the Public Health Service Act to provide for research and services with respect to lupus.

IN THE SENATE OF THE UNITED STATES

MAY 20, 1998

Mr. BENNETT (for himself, Ms. MOSELEY-BRAUN, and Mr. SHELBY) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To amend the Public Health Service Act to provide for research and services with respect to lupus.

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 “Lupus Research and
5 Care Amendments of 1998”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds that—

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

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

3 (3) there are 3 main types of lupus: systemic
4 lupus, a serious form of the disease that affects
5 many parts of the body; discoid lupus, a form of the
6 disease that affects mainly the skin; and drug-in-
7 duced lupus caused by certain medications;

8 (4) lupus can be fatal if not detected and treat-
9 ed early;

10 (5) the disease can simultaneously affect var-
11 ious areas of the body, such as the skin, joints, kid-
12 neys, and brain, and can be difficult to diagnose be-
13 cause the symptoms of lupus are similar to those of
14 many other diseases;

15 (6) lupus disproportionately affects African-
16 American women, as the prevalence of the disease
17 among such women is 3 times the prevalence among
18 white women, and an estimated 1 in 250 African-
19 American women between the ages of 15 and 65 de-
20 velops the disease;

21 (7) it has been estimated that between
22 1,400,000 and 2,000,000 Americans have been diag-
23 nosed with the disease, and that many more have
24 undiagnosed cases;

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

3 (9) many victims of the disease suffer debilitat-
4 ing pain and fatigue, making it difficult to maintain
5 employment and lead normal lives; and

6 (10) in fiscal year 1996, the amount allocated
7 by the National Institutes of Health for research on
8 lupus was \$33,000,000, less than 1/2 of 1 percent of
9 the budget for such Institutes.

10 **TITLE I—RESEARCH ON LUPUS**

11 **SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVI-** 12 **TIES.**

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:

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 conducting and supporting
6 the following:

7 “(1) Research to determine the reasons under-
8 lying the elevated prevalence of lupus in women, in-
9 cluding African-American women.

10 “(2) Basic research concerning the etiology and
11 causes of the disease.

12 “(3) 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 “(4) The development of improved screening
17 techniques.

18 “(5) Clinical research for the development and
19 evaluation of new treatments, including new biologi-
20 cal agents.

21 “(6) 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 \$45,000,000 for fiscal year 1999, and

1 such sums as may be necessary for each of the fiscal years
2 2000 and 2001.”.

3 **TITLE II—DELIVERY OF**
4 **SERVICES REGARDING LUPUS**

5 **SEC. 201. ESTABLISHMENT OF PROGRAM OF GRANTS.**

6 (a) IN GENERAL.—The Secretary of Health and
7 Human Services shall in accordance with this title make
8 grants to provide for projects for the establishment, oper-
9 ation, and coordination of effective and cost-efficient sys-
10 tems for the delivery of essential services to individuals
11 with lupus and their families.

12 (b) RECIPIENTS OF GRANTS.—A grant under sub-
13 section (a) may be made to an entity only if the entity
14 is a public or nonprofit private entity, which may include
15 a State or local government; a public or nonprofit private
16 hospital, community-based organization, hospice, ambula-
17 tory care facility, community health center, or other ap-
18 propriate public or nonprofit private entity.

19 (c) CERTAIN ACTIVITIES.—Activities that the Sec-
20 retary may authorize for projects under subsection (a) in-
21 clude the following:

22 (1) Delivering or enhancing outpatient, ambula-
23 tory, and home-based health and support services,
24 including case management and comprehensive
25 treatment services, for individuals with lupus; and

1 delivering or enhancing support services for their
2 families.

3 (2) Delivering or enhancing inpatient care man-
4 agement services that prevent unnecessary hos-
5 pitalization or that expedite discharge, as medically
6 appropriate, from inpatient facilities of individuals
7 with lupus.

8 (3) Improving the quality, availability, and or-
9 ganization of health care and support services (in-
10 cluding transportation services, attendant care,
11 homemaker services, and day or respite care) for in-
12 dividuals with lupus and their families.

13 (4) Providing assistance to ensure the continu-
14 ity of health insurance coverage for individuals with
15 lupus.

16 **SEC. 202. GRANT REQUIREMENTS.**

17 A grant may be made under section 201 only if the
18 applicant involved makes the following agreements:

19 (1) Not more than 5 percent of the grant will
20 be used for administration, accounting, reporting,
21 and program oversight functions.

22 (2) The grant will be used to supplement and
23 not supplant funds from other sources related to the
24 treatment of lupus.

1 (3) With respect to the imposition of charges
2 for the provision of services under the grant:

3 (A) In the case of an individual with an in-
4 come less than or equal to 100 percent of the
5 official poverty line, the applicant will not im-
6 pose a charge.

7 (B) In the case of an individual with an in-
8 come greater than 100 percent of the official
9 poverty line and not exceeding 200 percent of
10 such poverty line, the applicant will not impose
11 charges for any calendar year exceeding 5 per-
12 cent of the annual gross income of the individ-
13 ual involved.

14 (C) In the case of an individual with an in-
15 come greater than 200 percent of the official
16 poverty line and not exceeding 300 percent of
17 such poverty line, the applicant will not impose
18 charges for any calendar year exceeding 7 per-
19 cent of the annual gross income of the individ-
20 ual.

21 (D) In the case of an individual with an in-
22 come greater than 300 percent of the official
23 poverty line, the applicant will not impose
24 charges for any calendar year exceeding 10 per-

1 cent of the annual gross income of the individ-
2 ual.

3 **SEC. 203. TECHNICAL ASSISTANCE.**

4 The Secretary may provide technical assistance to as-
5 sist entities in complying with the requirements of this
6 title in order to make such entities eligible to receive
7 grants under section 201.

8 **SEC. 204. DEFINITIONS.**

9 For purposes of this title:

10 (1) The term “official poverty line” means the
11 poverty line established by the Director of the Office
12 of Management and Budget and revised by the Sec-
13 retary in accordance with section 673(2) of the Om-
14 nibus Budget Reconciliation Act of 1981.

15 (2) The term “Secretary” means the Secretary
16 of Health and Human Services.

17 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

18 For the purpose of carrying out this title, there are
19 authorized to be appropriated \$40,000,000 for fiscal year
20 1999, and such sums as may be necessary for each of the
21 fiscal years 2000 through 2003.

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