

106TH CONGRESS
1ST SESSION

S. 1163

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 27, 1999

Mr. BENNETT (for himself, Mrs. MURRAY, Mr. SCHUMER, and Mr. TORRICELLI) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 1999”.

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 debili-
 4 tating pain and fatigue, making it difficult to main-
 5 tain 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 \$75,000,000 for fiscal year 2000, and

1 such sums as may be necessary for each of the fiscal years
 2 2001 and 2002.”.

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, migrant health
 18 center, or homeless health center, or other appropriate
 19 public or nonprofit private entity.

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

23 (1) Delivering or enhancing outpatient, ambula-
 24 tory, and home-based health and support services,
 25 including case management and comprehensive

1 treatment services, for individuals with lupus; and
2 delivering or enhancing support services for their
3 families.

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

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

14 (4) Providing assistance to ensure the con-
15 tinuity of health insurance coverage for individuals
16 with lupus.

17 **SEC. 202. GRANT REQUIREMENTS.**

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

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

23 (2) The grant will be used to supplement and
24 not supplant funds from other sources related to the
25 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 indi-
13 vidual 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 indi-
20 vidual.

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 indi-
2 vidual.

3 (4) With respect to compliance with the agree-
4 ment made under paragraph (3), the applicant may,
5 in the case of individuals subject to a charge for
6 purposes of such paragraph—

7 (A) assess the amount of the charge in the
8 discretion of the applicant, including imposing
9 only a nominal charge for the provision of serv-
10 ices; and

11 (B) take into consideration the medical ex-
12 penses of individuals in assessing the amount of
13 the charge, subject to such paragraph.

14 (5) The limitations established under paragraph
15 (3) regarding the imposition of charges for services
16 applies to the annual aggregate of charges imposed
17 for such services, without regard to whether they are
18 characterized as enrollment fees, premiums,
19 deductibles, cost sharing, copayments, coinsurance,
20 or other charges.

21 (6) The grant will not be expended to make
22 payment for services authorized under section
23 201(a) to the extent that payment has been made,
24 or can reasonably be expected to be made, with re-
25 spect to such services—

1 (A) under any State compensation pro-
 2 gram, under an insurance policy, or under any
 3 Federal or State health benefits program; or

4 (B) by an entity that provides health serv-
 5 ices on a prepaid basis.

6 (7) The applicant will, at each site at which the
 7 applicant provides services under section 201(a),
 8 post a conspicuous notice informing individuals who
 9 receive the services of the policies that apply to the
 10 applicant pursuant to paragraphs (3) through (6).

11 **SEC. 203. TECHNICAL ASSISTANCE.**

12 The Secretary may provide technical assistance to as-
 13 sist entities in complying with the requirements of this
 14 title in order to make such entities eligible to receive
 15 grants under section 201.

16 **SEC. 204. DEFINITIONS.**

17 For purposes of this title:

18 (1) The term “official poverty line” means the
 19 poverty line established by the Director of the Office
 20 of Management and Budget and revised by the Sec-
 21 retary in accordance with section 673(2) of the Om-
 22 nibus Budget Reconciliation Act of 1981.

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

1 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

2 For the purpose of carrying out this title, there are
3 authorized to be appropriated \$40,000,000 for fiscal year
4 2000, and such sums as may be necessary for each of the
5 fiscal years 2001 through 2004.

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