106TH CONGRESS
2D SESSION

H. R. 762

AN ACT

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

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

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Lupus Research and Care Amendments of 2000''.

SEC. 2. FINDINGS.

The Congress finds that—

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

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

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

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

(5) the disease can simultaneously affect various areas of the body, such as the skin, joints, kidneys, and brain, and can be difficult to diagnose because the symptoms of lupus are similar to those of many other diseases;

(6) lupus disproportionately affects African-American women, as the prevalence of the disease among such women is three times the prevalence among white women, and an estimated 1 in 250 Af-

rican-American women between the ages of 15 and 65 develops the disease;

(7) it has been estimated that between 1,400,000 and 2,000,000 Americans have been diagnosed with the disease, and that many more have undiagnosed cases;

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

(9) many victims of the disease suffer debilitating pain and fatigue, making it difficult to maintain employment and lead normal lives; and

(10) in fiscal year 1996, the amount allocated by the National Institutes of Health for research on lupus was $33,000,000, which is less than one-half of 1 percent of the budget for such Institutes.

TITLE I—RESEARCH ON LUPUS

SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVITIES.

Subpart 4 of part C of title IV of the Public Health Service Act (42 U.S.C. 285d et seq.) is amended by inserting after section 441 the following section:

''LUPUS

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

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

''(c) PROGRAMS FOR LUPUS.—In carrying out subsection (a), the Director of the Institute shall conduct or support research to expand the understanding of the causes of, and to find a cure for, lupus. Activities under such subsection shall include conducting and supporting the following:

''(1) Research to determine the reasons underlying the elevated prevalence of lupus in women, including African-American women.

''(2) Basic research concerning the etiology and causes of the disease.

''(3) Epidemiological studies to address the frequency and natural history of the disease and the differences among the sexes and among racial and ethnic groups with respect to the disease.

''(4) The development of improved diagnostic techniques.

''(5) Clinical research for the development and evaluation of new treatments, including new biological agents.

''(6) Information and education programs for health care professionals and the public.

''(d) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2001 through 2003.''.

TITLE II—DELIVERY OF SERVICES REGARDING LUPUS

SEC. 201. ESTABLISHMENT OF PROGRAM OF GRANTS.

(a) IN GENERAL.—The Secretary of Health and Human Services shall in accordance with this title make grants to provide for projects for the establishment, operation, and coordination of effective and cost-efficient systems for the delivery of essential services to individuals with lupus and their families.

(b) RECIPIENTS OF GRANTS.—A grant under subsection (a) may be made to an entity only if the entity is a public or nonprofit private entity, which may include a State or local government; a public or nonprofit private hospital, community-based organization, hospice, ambulatory care facility, community health center, migrant health

center, or homeless health center; or other appropriate public or nonprofit private entity.

(c) CERTAIN ACTIVITIES.—To the extent practicable and appropriate, the Secretary shall ensure that projects under subsection (a) provide services for the diagnosis and disease management of lupus. Activities that the Secretary may authorize for such projects may also include the following:

(1) Delivering or enhancing outpatient, ambulatory, and home-based health and support services, including case management and comprehensive treatment services, for individuals with lupus; and delivering or enhancing support services for their families.

(2) Delivering or enhancing inpatient care management services that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate, from inpatient facilities of individuals with lupus.

(3) Improving the quality, availability, and organization of health care and support services (including transportation services, attendant care, homemaker services, day or respite care, and providing counseling on financial assistance and insur-

ance) for individuals with lupus and support services for their families.

(d) INTEGRATION WITH OTHER PROGRAMS.—To the extent practicable and appropriate, the Secretary shall integrate the program under this title with other grant programs carried out by the Secretary, including the program under section 330 of the Public Health Service Act.

SEC. 202. CERTAIN REQUIREMENTS.

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

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

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

(3) The applicant will abide by any limitations deemed appropriate by the Secretary on any charges to individuals receiving services pursuant to the grant. As deemed appropriate by the Secretary, such limitations on charges may vary based on the financial circumstances of the individual receiving services.

(4) The grant will not be expended to make payment for services authorized under section

201(a) to the extent that payment has been made, or can reasonably be expected to be made, with respect to such services—

(A) under any State compensation program, under an insurance policy, or under any Federal or State health benefits program; or

(B) by an entity that provides health services on a prepaid basis.

(5) The applicant will, at each site at which the applicant provides services under section 201(a), post a conspicuous notice informing individuals who receive the services of any Federal policies that apply to the applicant with respect to the imposition of charges on such individuals.

SEC. 203. TECHNICAL ASSISTANCE.

The Secretary may provide technical assistance to assist entities in complying with the requirements of this title in order to make such entities eligible to receive grants under section 201.

SEC. 204. DEFINITIONS.

For purposes of this title:

(1) The term ''official poverty line'' means the poverty line established by the Director of the Office of Management and Budget and revised by the Sec-

retary in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981.

(2) The term ''Secretary'' means the Secretary of Health and Human Services.

SEC. 205. AUTHORIZATION OF APPROPRIATIONS.

For the purpose of carrying out this title, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2001 through 2003.

Passed the House of Representatives October 10, 2000.

Attest:

Clerk.