

Union Calendar No. 570

106TH CONGRESS
2D SESSION

H. R. 762

[Report No. 106-950]

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 12, 1999

Mrs. MEEK of Florida (for herself, Ms. ROS-LEHTINEN, Ms. PELOSI, Mr. COOK, Mr. CLAY, Mrs. THURMAN, Ms. JACKSON-LEE of Texas, Mr. BONIOR, Mr. MEEKS of New York, Mr. GOODE, Mr. PASTOR, Mr. DEFazio, Mrs. MINK of Hawaii, Mr. HOLDEN, Mr. QUINN, Mr. SHOWS, Ms. KILPATRICK, Mr. GREEN of Texas, Mr. FILNER, Mr. BLAGOJEVICH, Mr. SERRANO, Mr. MORAN of Kansas, and Mr. BALDACCI) introduced the following bill; which was referred to the Committee on Commerce

OCTOBER 10, 2000

Additional sponsors: Mrs. MALONEY of New York, Mr. GEJDENSON, Mr. FROST, Mr. ROMERO-BARCELO, Mrs. CLAYTON, Mr. HALL of Ohio, Mr. MCGOVERN, Mr. ACKERMAN, Mr. UPTON, Mr. STARK, Mr. GUTIERREZ, Mrs. MORELLA, Mr. MORAN of Virginia, Mr. DELAHUNT, Mr. SANDLIN, Mr. DIXON, Mr. FORD, Ms. MILLENDER-MCDONALD, Mr. WAXMAN, Mr. TOWNS, Ms. SLAUGHTER, Mr. FRANK of Massachusetts, Mr. DAVIS of Illinois, Mr. WEXLER, Mr. RANGEL, Mr. FOLEY, Mr. WYNN, Mr. WALSH, Mr. PAYNE, Ms. LOFGREN, Mr. LEWIS of Georgia, Mr. LATOURETTE, Mr. MCHUGH, Mr. BENTSEN, Mr. HAYWORTH, Ms. KAPTUR, Mr. BISHOP, Mrs. LOWEY, Mr. NADLER, Mr. COYNE, Mrs. JONES of Ohio, Mr. RAHALL, Ms. WATERS, Mr. DIAZ-BALART, Mrs. CHRISTENSEN, Ms. RIVERS, Ms. BROWN of Florida, Ms. ROYBAL-ALARD, Mr. LIPINSKI, Mr. MENENDEZ, Mr. HASTINGS of Florida, Mr. NEAL of Massachusetts, Mr. FALEOMAVAEGA, Mr. HILLIARD, Mr. RUSH, Mr. BOEHLERT, Mr. WATT of North Carolina, Mrs. KELLY, Mr. PRICE of North Carolina, Mr. DEUTSCH, Mr. ETHERIDGE, Mr. HINCHEY, Mr. JEFFERSON, Mr. GRAHAM, Mr. MOLLOHAN, Mr. MATSUI, Mr. THOMPSON of Mississippi, Mr. BRADY of Pennsylvania, Mr. WEINER, Ms. MCKINNEY, Mr. CUMINGS, Mr. BORSKI, Mr. ENGLISH, Mr. VENTO, Mr. ANDREWS, Mr.

LANTOS, Mr. OBERSTAR, Ms. WOOLSEY, Mr. JACKSON of Illinois, Mr. ROTHMAN, Mrs. CAPPS, Mr. CONYERS, Mr. MARTINEZ, Mr. MOORE, Mr. KUCINICH, Mr. HOUGHTON, Mr. COSTELLO, Mr. LUCAS of Oklahoma, Mr. GOODLING, Mr. DAVIS of Virginia, Mr. CAPUANO, Mr. OLVER, Mr. STUPAK, Ms. EDDIE BERNICE JOHNSON of Texas, Mr. KING, Mr. INSLEE, Mr. KILDEE, Mr. CLEMENT, Mr. LARSON, Mr. BOUCHER, Mr. HOEFFEL, Mr. MASCARA, Mr. PALLONE, Mr. WOLF, Ms. PRYCE of Ohio, Ms. VELAZQUEZ, Mr. GONZALEZ, Mr. LAMPSON, Ms. NORTON, Mr. BERRY, Mrs. JOHNSON of Connecticut, Mr. WU, Mr. SCOTT, Mr. ENGEL, Mr. KENNEDY of Rhode Island, Ms. CARSON, Mr. McNULTY, Mr. LAHOOD, Mrs. MCCARTHY of New York, Mr. CLYBURN, Mr. SHAW, Ms. LEE, Mr. LEWIS of California, Mr. OWENS, Ms. SCHAKOWSKY, Mr. FATTAH, Mr. FARR of California, Mr. SMITH of New Jersey, Mr. SAXTON, Mr. REYES, Mr. HOLT, Mr. PASCRELL, Mr. WISE, Mr. ALLEN, Mr. BARRETT of Wisconsin, Mr. GILCHREST, Mr. OSE, Ms. STABENOW, Mr. McDERMOTT, Mr. SHERWOOD, Mr. MCCARTHY of Missouri, Mr. LAFALCE, Mr. MALONEY of Connecticut, Mr. SPRATT, Mr. GILMAN, Mr. NEY, Mr. DOYLE, Mr. SKELTON, Mr. MURTHA, Mr. BILBRAY, Ms. DANER, Mr. BROWN of Ohio, Mr. EVANS, Mr. SANDERS, Mr. BERMAN, Mr. BOSWELL, Mr. ROEMER, Mr. ISAKSON, Mr. RODRIGUEZ, Mr. GARY MILLER of California, Mr. KLINK, Mrs. TAUSCHER, Mrs. EMERSON, Mr. MOAKLEY, Mr. CROWLEY, Mrs. NAPOLITANO, Mr. BARTLETT of Maryland, Mr. DREIER, Mr. DICKS, Mr. PHELPS, Ms. SANCHEZ, Mr. MCINTYRE, Mr. SHERMAN, Mr. ORTIZ, Mr. YOUNG of Alaska, Mr. ABERCROMBIE, Mr. SWEENEY, Mrs. CHENOWETH-HAGE, Mr. BARCIA, Ms. BERKLEY, Mr. BURTON of Indiana, Mr. GEPHARDT, Mr. MEEHAN, Ms. BALDWIN, Mr. SCHAFFER, Mr. FORBES, Mr. BLUNT, Mr. MCINTOSH, Mr. PETERSON of Minnesota, Mr. SPENCE, Mr. KLECZKA, Ms. ESHOO, Mr. HINOJOSA, Mrs. ROUKEMA, Mr. JOHN, Mr. THOMPSON of California, Mr. DICKEY, Mr. GEORGE MILLER of California, Mr. KANJORSKI, Mr. BAIRD, Mr. EWING, Mr. HALL of Texas, Mr. YOUNG of Florida, Mr. DEAL of Georgia, Mr. CALVERT, Mr. HORN, Mr. TURNER, Mr. CRAMER, Mr. SISISKY, Mr. JENKINS, Mr. DUNCAN, Mr. COOKSEY, Mr. SMITH of Washington, Mr. VISLOSKY, Mrs. FOWLER, Mr. STRICKLAND, Mr. GORDON, Mr. REYNOLDS, Mr. FRANKS of New Jersey, Ms. HOOLEY of Oregon, Mr. GALLEGLY, Mr. TOOMEY, and Mr. LOBIONDO

OCTOBER 10, 2000

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

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

[For text of introduced bill, see copy of bill as introduced on February 12, 1999]

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 2000”.*

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;*

10 (2) *lupus affects women 9 times more often than*
11 *men;*

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

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

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

6 (6) *lupus disproportionately affects African-*
7 *American women, as the prevalence of the disease*
8 *among such women is 3 times the prevalence among*
9 *white women, and an estimated 1 in 250 African-*
10 *American women between the ages of 15 and 65 devel-*
11 *ops the disease;*

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

16 (8) *current treatments for the disease can be ef-*
17 *fective, but may lead to damaging side effects;*

18 (9) *many victims of the disease suffer debili-*
19 *tating pain and fatigue, making it difficult to main-*
20 *tain employment and lead normal lives; and*

21 (10) *in fiscal year 1996, the amount allocated by*
22 *the National Institutes of Health for research on*
23 *lupus was \$33,000,000, which is less than 1/2 of 1 per-*
24 *cent of the budget for such Institutes.*

1 **TITLE I—RESEARCH ON LUPUS**

2 **SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVI-**
3 **TIES.**

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

7 “LUPUS

8 “SEC. 441A. (a) *IN GENERAL.*—*The Director of the In-*
9 *stitute shall expand and intensify research and related ac-*
10 *tivities of the Institute with respect to lupus.*

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

18 “(c) *PROGRAMS FOR LUPUS.*—*In carrying out sub-*
19 *section (a), the Director of the Institute shall conduct or*
20 *support research to expand the understanding of the causes*
21 *of, and to find a cure for, lupus. Activities under such sub-*
22 *section shall include conducting and supporting the fol-*
23 *lowing:*

1 “(1) *Research to determine the reasons under-*
2 *lying the elevated prevalence of lupus in women, in-*
3 *cluding African-American women.*

4 “(2) *Basic research concerning the etiology and*
5 *causes of the disease.*

6 “(3) *Epidemiological studies to address the fre-*
7 *quency and natural history of the disease and the dif-*
8 *ferences among the sexes and among racial and ethnic*
9 *groups with respect to the disease.*

10 “(4) *The development of improved diagnostic*
11 *techniques.*

12 “(5) *Clinical research for the development and*
13 *evaluation of new treatments, including new biologi-*
14 *cal agents.*

15 “(6) *Information and education programs for*
16 *health care professionals and the public.*

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

21 **TITLE II—DELIVERY OF**
22 **SERVICES REGARDING LUPUS**

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

24 (a) *IN GENERAL.—The Secretary of Health and*
25 *Human Services shall in accordance with this title make*

1 grants to provide for projects for the establishment, oper-
2 ation, and coordination of effective and cost-efficient sys-
3 tems for the delivery of essential services to individuals with
4 lupus and their families.

5 (b) *RECIPIENTS OF GRANTS.*—A grant under sub-
6 section (a) may be made to an entity only if the entity
7 is a public or nonprofit private entity, which may include
8 a State or local government; a public or nonprofit private
9 hospital, community-based organization, hospice, ambula-
10 tory care facility, community health center, migrant health
11 center, or homeless health center; or other appropriate pub-
12 lic or nonprofit private entity.

13 (c) *CERTAIN ACTIVITIES.*—To the extent practicable
14 and appropriate, the Secretary shall ensure that projects
15 under subsection (a) provide services for the diagnosis and
16 disease management of lupus. Activities that the Secretary
17 may authorize for such projects may also include the fol-
18 lowing:

19 (1) *Delivering or enhancing outpatient, ambula-*
20 *tory, and home-based health and support services, in-*
21 *cluding case management and comprehensive treat-*
22 *ment services, for individuals with lupus; and deliv-*
23 *ering or enhancing support services for their families.*

24 (2) *Delivering or enhancing inpatient care man-*
25 *agement services that prevent unnecessary hos-*

1 *pitalization or that expedite discharge, as medically*
2 *appropriate, from inpatient facilities of individuals*
3 *with lupus.*

4 (3) *Improving the quality, availability, and or-*
5 *ganization of health care and support services (in-*
6 *cluding transportation services, attendant care, home-*
7 *maker services, day or respite care, and providing*
8 *counseling on financial assistance and insurance) for*
9 *individuals with lupus and support services for their*
10 *families.*

11 (d) *INTEGRATION WITH OTHER PROGRAMS.—To the*
12 *extent practicable and appropriate, the Secretary shall inte-*
13 *grate the program under this title with other grant pro-*
14 *grams carried out by the Secretary, including the program*
15 *under section 330 of the Public Health Service Act.*

16 **SEC. 202. CERTAIN 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 be*
20 *used for administration, accounting, reporting, and*
21 *program oversight functions.*

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

1 (3) *The applicant will abide by any limitations*
2 *deemed appropriate by the Secretary on any charges*
3 *to individuals receiving services pursuant to the*
4 *grant. As deemed appropriate by the Secretary, such*
5 *limitations on charges may vary based on the finan-*
6 *cial circumstances of the individual receiving services.*

7 (4) *The grant will not be expended to make pay-*
8 *ment for services authorized under section 201(a) to*
9 *the extent that payment has been made, or can rea-*
10 *sonably be expected to be made, with respect to such*
11 *services—*

12 (A) *under any State compensation pro-*
13 *gram, under an insurance policy, or under any*
14 *Federal or State health benefits program; or*

15 (B) *by an entity that provides health serv-*
16 *ices on a prepaid basis.*

17 (5) *The applicant will, at each site at which the*
18 *applicant provides services under section 201(a), post*
19 *a conspicuous notice informing individuals who re-*
20 *ceive the services of any Federal policies that apply*
21 *to the applicant with respect to the imposition of*
22 *charges on such individuals.*

23 **SEC. 203. TECHNICAL ASSISTANCE.**

24 *The Secretary may provide technical assistance to as-*
25 *sist entities in complying with the requirements of this title*

1 *in order to make such entities eligible to receive grants*
2 *under section 201.*

3 **SEC. 204. DEFINITIONS.**

4 *For purposes of this title:*

5 *(1) The term “official poverty line” means the*
6 *poverty line established by the Director of the Office*
7 *of Management and Budget and revised by the Sec-*
8 *retary in accordance with section 673(2) of the Omni-*
9 *bus Budget Reconciliation Act of 1981.*

10 *(2) The term “Secretary” means the Secretary of*
11 *Health and Human Services.*

12 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

13 *For the purpose of carrying out this title, there are*
14 *authorized to be appropriated such sums as may be nec-*
15 *essary for each of the fiscal years 2001 through 2003.*

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