108TH CONGRESS 1ST SESSION

H. R. 3359

To increase awareness of and research on autoimmune diseases, such as lupus, multiple sclerosis, rheumatoid arthritis, and fibromyalgia, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

October 21, 2003

Mr. Kennedy of Rhode Island (for himself and Mr. Upton) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To increase awareness of and research on autoimmune diseases, such as lupus, multiple sclerosis, rheumatoid arthritis, and fibromyalgia, 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,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Prevention, Awareness,
- 5 and Research Auto-Immune Disease Act".
- 6 SEC. 2. FINDINGS.
- 7 The Congress finds as follows:
- 8 (1) The Lupus Foundation of America esti-
- 9 mates that at least 1.5 million Americans have a

- form of lupus, 9 out of 10 of these Americans are women, and 80 percent of all newly diagnosed cases of lupus are among women of childbearing age.
 - (2) According to a Lupus Foundation of America survey, more than half of the people with lupus suffered for 4 or more years and visited 3 or more doctors before obtaining a diagnosis of lupus.
 - (3) Early diagnosis of and commencement of treatment for lupus can prevent or reduce serious organ damage, disability, and death.
 - (4) About 1 out of 5 lupus sufferers receives disability payments, costing the Government several billion dollars each year for social security disability benefits, lost taxes, and medical care provided through Medicare and Medicaid.
 - (5) The average annual cost of medical treatment for an individual with lupus is \$6,000 to \$10,000; for some people, medical costs may exceed several thousand dollars every month.
 - (6) Despite the prevalence of lupus, public awareness and understanding of lupus remains low. According to a Lupus Foundation of America survey, only 1 out of 5 Americans can provide even basic information about lupus.

- (7) Awareness of lupus is lowest among adults ages 18 to 34, the age group most likely to develop symptoms of lupus. (8) Multiple sclerosis is a chronic and often dis-abling disease of the central nervous system which often first appears in people who are 20 to 50 years of age, with lifelong physical and emotional effects. (9) Multiple sclerosis is twice as common in women as in men. (10) An estimated 250,000 to 400,000 individ-uals have multiple sclerosis nationally.
 - (11) The average annual cost of multiple sclerosis to each affected individual is approximately \$50,000, and the total cost can exceed \$3,000,000 over an individual's lifetime.
 - (12) The annual cost of treating all people who suffer from multiple sclerosis in the United States is approximately \$20,000,000,000.
 - (13) Symptoms of multiple sclerosis can be mild (such as numbness in the limbs) or severe (such as paralysis or loss of vision).
 - (14) The progress, severity, and specific symptoms of multiple sclerosis in any one individual cannot yet be predicted.

1	(15) Arthritis is the number one cause of dis-
2	ability in the United States.
3	(16) Among the 2,100,000 people with rheu-
4	matoid arthritis in the United States, women out-
5	number men 3 to 1.
6	(17) The total direct costs of rheumatoid ar-
7	thritis, including money spent on treatments, hos-
8	pitalizations, medications, transportation, and spe-
9	cialist aids, is approximately \$1,200,000,000 each
10	year.
11	(18) The average medical care expenditures
12	over the course of a rheumatoid arthritis patient's
13	lifetime is \$225,000 to \$370,000.
14	(19) Fibromyalgia is believed to affect approxi-
15	mately 3,700,000 people (approximately 2 percent of
16	the United States population) and occurs more com-
17	monly in women than men.
18	(20) The exact cause of fibromyalgia is un-
19	known, but may be triggered by stress, trauma, or
20	possibly an infectious agent in susceptible people.
21	SEC. 3. GRANTS TO INCREASE AWARENESS OF AUTO
22	IMMUNE DISEASES.
23	(a) Purpose.—The purpose of this section is to in-
24	crease awareness of autoimmune diseases, such as lupus

25 multiple sclerosis, rheumatoid arthritis, and fibromyalgia,

- 1 in order to provide to the public a more complete under-
- 2 standing of these diseases, which affect 5 to 10 percent
- 3 of the people in the United States.
- 4 (b) AMENDMENTS.—Title III of the Public Health
- 5 Service Act (42 U.S.C. 241 et seq.) is amended—
- 6 (1) by moving section 317R so that such sec-
- 7 tion follows section 317Q; and
- 8 (2) by inserting after section 317R (as so
- 9 moved) the following:
- 10 "Sec. 317S. (a) Grants to Increase Awareness
- 11 OF AUTOIMMUNE DISEASES.—The Secretary, acting
- 12 through the Director of the Centers for Disease Control
- 13 and Prevention, shall award grants to eligible entities to
- 14 conduct public and professional awareness activities re-
- 15 garding autoimmune diseases, such as lupus, multiple scle-
- 16 rosis, rheumatoid arthritis, and fibromyalgia.
- 17 "(b) Use of Funds.—In conducting public and pro-
- 18 fessional awareness activities with a grant under this sec-
- 19 tion, an eligible entity may do any of the following:
- 20 "(1) Promote increased awareness of early
- 21 intervention and treatment so as to significantly im-
- prove the quality of life for people with autoimmune
- diseases, such as lupus, multiple sclerosis, rheu-
- 24 matoid arthritis, and fibromyalgia.

- 1 "(2) Target minority communities that may be
- 2 underserved or disproportionately affected by auto-
- 3 immune diseases, such as lupus, multiple sclerosis,
- 4 rheumatoid arthritis, and fibromyalgia.
- 5 "(3) Target women (who are disproportionately
- 6 affected by autoimmune diseases, such as lupus,
- 7 multiple sclerosis, rheumatoid arthritis, and
- 8 fibromyalgia) so as to help reduce the amount of
- 9 time taken for correct diagnosis of such diseases,
- which often takes more than 1 year.
- 11 "(c) Eligible Entity.—For purposes of this sec-
- 12 tion, the term 'eligible entity' means a nonprofit organiza-
- 13 tion, a consumer group, an institution of higher education
- 14 (as defined in section 101 of the Higher Education Act
- 15 of 1965 (20 U.S.C. 1001)), a Federal, State, or local gov-
- 16 ernmental agency, or a media organization.
- 17 "(d) Authorization of Appropriations.—There
- 18 are authorized to be appropriated to carry out this section
- 19 \$18,000,000 for each of fiscal years 2004 and 2005.".
- 20 SEC. 4. GRANTS FOR EDUCATION ON RELATIONSHIP BE-
- TWEEN AUTOIMMUNE DISEASES AND MEN-
- TAL ILLNESSES.
- Title III of the Public Health Service Act (42 U.S.C.
- 24 241 et seq.), as amended by section 3 of this Act, is
- 25 amended by inserting after section 317S the following:

- 1 "Sec. 317T. (a) Grants for Education on Rela-
- 2 TIONSHIP BETWEEN AUTOIMMUNE DISEASES AND MEN-
- 3 TAL ILLNESSES.—The Secretary, acting through the Ad-
- 4 ministrator of the Health Resources and Services Admin-
- 5 istration, shall award grants to eligible entities for the
- 6 education of health care providers on potential links be-
- 7 tween autoimmune diseases, such as lupus, multiple scle-
- 8 rosis, rheumatoid arthritis, and fibromyalgia, and cog-
- 9 nitive and mood disorders, such as depression.
- 10 "(b) Eligible Entity.—For purposes of this sec-
- 11 tion, the term 'eligible entity' means a nonprofit organiza-
- 12 tion, a consumer group, an institution of higher education
- 13 (as defined in section 101 of the Higher Education Act
- 14 of 1965 (20 U.S.C. 1001)), a Federal, State, or local gov-
- 15 ernmental agency, or a media organization.
- 16 "(c) Authorization of Appropriations.—There
- 17 are authorized to be appropriated to carry out this section
- 18 \$5,000,000 for each of fiscal years 2004 and 2005.".
- 19 SEC. 5. LOAN REPAYMENT PROGRAM REGARDING PHYSI-
- 20 CIAN RESEARCH ON AUTOIMMUNE DISEASES.
- 21 Title IV of the Public Health Service Act (42 U.S.C.
- 22 281 et seq.) is amended—
- 23 (1) by redesignating the second section 487F as
- section 487G; and

1	(2) by inserting after section 487G (as so re-
2	designated) the following:
3	"SEC. 487H. LOAN REPAYMENT PROGRAM REGARDING PHY-
4	SICIAN RESEARCH ON AUTOIMMUNE DIS-
5	EASES.
6	"(a) Establishment.—To the extent and in the
7	amounts provided in advance in appropriations Acts, the
8	Secretary, acting through the Administrator of the Health
9	Resources and Services Administration, shall establish a
10	program to enter into contracts with qualified physicians
11	under which such qualified physicians agree to conduct re-
12	search for a period of at least 3 years regarding auto-
13	immune diseases, such as lupus, multiple sclerosis, rheu-
14	matoid arthritis, and fibromyalgia, in consideration of the
15	Federal Government agreeing to repay, for each year of
16	service conducting such research, not more than \$35,000
17	of the principal and interest of the educational loans of
18	such qualified physicians.
19	"(b) Application of Provisions.—Except as in-
20	consistent with this section, the provisions of sections
21	338B, 338C, and 338E shall apply to the program estab-
22	lished under this section to the same extent and in the
23	same manner as such provisions apply to the National
24	Health Service Corps Loan Repayment Program estab-
25	lished in subpart III of part D of title III.

"(c) QUALIFIED PHYSICIAN.—For purposes of this 1 section, the term 'qualified physician' means any individual who has received, or will have received by the time 3 4 of the research to be conducted under this section, a degree of doctor of medicine or its equivalent and is licensed to practice medicine in the United States. 7 "(d) Funding.— "(1) AUTHORIZATION OF APPROPRIATIONS.— 8 9 For the purpose of carrying out this section, there 10 are authorized to be appropriated such sums as may 11 be necessary for each fiscal year. "(2) AVAILABILITY.—Amounts appropriated for 12 13 carrying out this section shall remain available until the expiration of the second fiscal year beginning 14

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made available.".

after the fiscal year for which the amounts were

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