

103<sup>D</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 4789

To amend the Public Health Service Act to provide for the expansion and coordination of research concerning Parkinson's disease and related disorders, and to improve care and assistance for its victims and their family caregivers, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 19, 1994

Mr. WAXMAN (for himself, Mr. UPTON, and Mr. RICHARDSON) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to provide for the expansion and coordination of research concerning Parkinson's disease and related disorders, and to improve care and assistance for its victims and their family caregivers, 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 "Morris K. Udall Par-  
5 kinson's Research, Education, and Assistance Act of  
6 1994".

1 **SEC. 2. FINDINGS AND PURPOSE.**

2 (a) FINDINGS.—Congress finds the following:

3 (1) Parkinson’s disease and related disorders  
4 (hereafter referred to in this Act as “Parkinson’s”)  
5 is a neurological disorder affecting as many as  
6 1,500,000 Americans.

7 (2) Approximately 40 percent of persons with  
8 Parkinson’s are under the age of 60.

9 (3) While science has yet to determine what  
10 causes the disease, research has found that cells that  
11 produce a neurochemical called dopamine  
12 inexplicably degenerate, causing uncontrollable trem-  
13 ors, muscle stiffness, and loss of motor function.

14 (4) Eventually, Parkinson’s renders its victims  
15 incapable of caring for themselves. In addition to  
16 causing disability and suffering for its victims, Par-  
17 kinson’s places tremendous and prolonged physical,  
18 emotional, and financial strain on family and loved  
19 ones.

20 (5) It is estimated that the disease costs society  
21 nearly \$6,000,000,000 annually.

22 (6) To date, the federally funded research effort  
23 has been grossly underfunded. Only \$30,000,000 is  
24 allocated specifically for research on Parkinson’s, or  
25 only about one dollar for every \$200 in annual soci-  
26 etal costs.

1           (7) In order to take full advantage of the tre-  
2           mendous potential for finding a cure or effective  
3           treatment, the Federal investment in Parkinson’s  
4           must be expanded, as well as the coordination  
5           strengthened among the National Institutes of  
6           Health research institutes.

7           (b) PURPOSE.—It is the purpose of this Act to pro-  
8           vide for the expansion and coordination of research con-  
9           cerning Parkinson’s, and to improve care and assistance  
10          for its victims and their family caregivers.

11 **SEC. 3. BIOMEDICAL RESEARCH ON PARKINSON’S DISEASE.**

12          Part E of title IV of the Public Health Service Act  
13          (42 U.S.C. 287 et seq.) is amended by adding at the end  
14          thereof the following new subpart:

15                **“Subpart 4—Parkinson’s Disease Research**

16 **“SEC. 485G. PARKINSON’S DISEASE RESEARCH.**

17                “(a) EXPANSION OF BIOMEDICAL RESEARCH.—

18                       “(1) COORDINATION COUNCIL.—The Director  
19                       of the National Institutes of Health shall establish  
20                       a council to coordinate Parkinson’s research activi-  
21                       ties. Members of the council shall include the Direc-  
22                       tor of the National Institutes of Health, the Director  
23                       of the National Institute of Neurological Disorders  
24                       and Stroke, the Director of the National Institute on  
25                       Aging, the Director of the National Institute of En-

1 vironmental Health Sciences, patient advocates, and  
2 representatives of other departments and agencies  
3 conducting or supporting research on Parkinson's.

4 “(2) NATIONAL CONSENSUS CONFERENCE.—  
5 The council established under paragraph (1) shall  
6 convene a National Consensus Conference on Par-  
7 kinson's Disease and Related Neuro-degenerative  
8 Disorders to aid in the development of a broad-based  
9 strategy for identifying the cause of and treating  
10 such disorders.

11 “(3) RESEARCH AGENDA.—Not later than 180  
12 days after the date of enactment of this section, and  
13 annually thereafter, the Secretary, in consultation  
14 with the council established under paragraph (1),  
15 shall develop and submit to the Energy and Com-  
16 merce Committee and the Appropriations Committee  
17 of the House of Representatives and the Labor and  
18 Human Resources Committee and the Appropria-  
19 tions Committee of the Senate, a coordinated re-  
20 search agenda.

21 “(4) RESEARCH CENTERS.—The Secretary shall  
22 provide for the establishment of 10 Parkinson's Re-  
23 search Centers. Such centers shall—

1           “(A) conduct research into the cause, pre-  
2           vention, treatment, and management of Parkin-  
3           son’s;

4           “(B) disseminate clinical information con-  
5           cerning Parkinson’s and provide patient care  
6           services;

7           “(C) provide training for health care per-  
8           sonnel concerning Parkinson’s;

9           “(D) coordinate research with other such  
10          Centers and related public and private research  
11          institutions;

12          “(E) develop and maintain, where appro-  
13          priate, a tissue bank to collect specimens relat-  
14          ed to the research and treatment of Parkin-  
15          son’s; and

16          “(F) enhance community awareness con-  
17          cerning Parkinson’s and promote the involve-  
18          ment of advocate groups.

19          “(b) MORRIS K. UDALL FEASIBILITY STUDY  
20          GRANTS.—The Secretary may award feasibility study  
21          grants under this section to support the development of  
22          preliminary data sufficient to provide the basis for the  
23          submission of applications for independent research sup-  
24          port grants or establishment of a Center under this sec-  
25          tion.

1       “(c) MORRIS K. UDALL LEADERSHIP AND EXCEL-  
2       LENCE AWARDS.—The Secretary shall establish a grant  
3       program to support scientists who have distinguished  
4       themselves in the field of Parkinson’s research. Grants  
5       under this subsection shall be utilized to enable established  
6       investigators to devote greater time and resources in lab-  
7       oratories to conduct research on Parkinson’s and to en-  
8       courage the development of a new generation of investiga-  
9       tors, with the support and guidance of the most productive  
10      and innovative senior researchers.

11      “(d) PATIENT AND FAMILY REGISTRIES.—The Sec-  
12      retary shall establish a registry for screening and collect-  
13      ing patient and family data that may be useful in deter-  
14      mining incidence and possible risk factors concerning Par-  
15      kinson’s.

16      “(e) MORRIS K. UDALL HEALTH PROFESSIONS  
17      TRAINING GRANTS.—The Secretary may award grants to  
18      schools of medicine, nursing, social work, and health serv-  
19      ices administration, and other appropriate institutions, for  
20      the provision of training and continuing education con-  
21      cerning health and long-term care of individuals with Par-  
22      kinson’s. In awarding grants under this subsection the  
23      Secretary shall ensure appropriate geographic coverage.

24      “(f) NATIONAL PARKINSON’S DISEASE EDUCATION  
25      PROGRAM.—The Secretary shall establish a national edu-

1 cation program that is designed to foster a national focus  
2 on Parkinson's and the care of those with Parkinson's.  
3 Activities under such program shall include—

4           “(1) the bringing together of public and private  
5 organizations to develop better ways to provide care  
6 to individuals with Parkinson's, and assist the fami-  
7 lies of such individuals;

8           “(2) the provision of technical assistance to  
9 public and private organizations that offer support  
10 and aid to families caring for individuals with Par-  
11 kinson's; and

12           “(3) the establishment of a clearinghouse that  
13 will disseminate the most up-to-date research, treat-  
14 ment, and training information to families, health  
15 professionals, and the general public concerning Par-  
16 kinson's.

17           “(g) APPLICATION.—To be eligible to receive a grant  
18 or other assistance under this section, an individual or en-  
19 tity shall prepare and submit to the Secretary an applica-  
20 tion at such time, in such manner, and containing such  
21 information as the Secretary may require.

22           “(h) AUTHORIZATION OF APPROPRIATIONS.—

23           “(1) IN GENERAL.—For carrying out the activi-  
24 ties described in this section, there are authorized to  
25 be appropriated \$75,000,000 for fiscal year 1996,

1       \$100,000,000 for fiscal year 1997, \$200,000,000 for  
2       fiscal year 1998, and such sums as may be nec-  
3       essary for each of the fiscal years 1999 and 2000.  
4       Of amounts so appropriated, the Secretary shall  
5       make available—

6               “(A) \$10,000,000 for fiscal year 1996,  
7               \$20,000,000 for fiscal year 1997, \$30,000,000  
8               for fiscal year 1998, and such sums as may be  
9               necessary for each of the fiscal years 1999 and  
10              2000, for establishing centers under subsection  
11              (a)(4); and

12             “(B) \$2,000,000 for fiscal year 1996,  
13             \$4,000,000 for fiscal year 1997, \$6,000,000 for  
14             fiscal year 1998, and such sums as may be nec-  
15             essary for each of the fiscal years 1999 and  
16             2000 for carrying out feasibility study grants  
17             under subsection (b).

18             “(2) LEADERSHIP AND EXCELLENCE  
19             AWARDS.—For carrying out activities under sub-  
20             section (c), there are authorized to be appropriated  
21             \$10,000,000 for fiscal year 1996, \$15,000,000 for  
22             fiscal year 1997, \$20,000,000 for fiscal year 1998,  
23             and such sums as may be necessary for each of the  
24             fiscal years 1999 and 2000.

1           “(3) PATIENT AND FAMILY REGISTRIES.—For  
2 carrying out activities under subsection (d), there  
3 are authorized to be appropriated \$2,000,000 for  
4 each of fiscal years 1996, 1997, and 1998, and such  
5 sums as may be necessary for each of the fiscal  
6 years 1999 and 2000.

7           “(4) HEALTH PROFESSIONS TRAINING PRO-  
8 GRAMS.—For carrying out activities under sub-  
9 section (e), there are authorized to be appropriated  
10 \$2,000,000 for fiscal year 1996, \$5,000,000 for fis-  
11 cal year 1997, \$8,000,000 for fiscal year 1998, and  
12 such sums as may be necessary for each of the fiscal  
13 years 1999 and 2000.

14           “(5) NATIONAL PARKINSON’S DISEASE EDU-  
15 CATION PROGRAM.—For carrying out activities  
16 under subsection (f), there are authorized to be ap-  
17 propriated \$2,000,000 for fiscal year 1996,  
18 \$3,000,000 for fiscal year 1997, \$4,000,000 for fis-  
19 cal year 1998, and such sums as may be necessary  
20 for each of the fiscal years 1999 and 2000.”.

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