

104TH CONGRESS  
1ST SESSION

# H. R. 1462

To amend the Public Health Service Act to provide for programs of research regarding Parkinson's disease, and for other purposes.

---

## IN THE HOUSE OF REPRESENTATIVES

APRIL 6, 1995

Mr. WAXMAN (for himself, Mr. UPTON, Mr. DINGELL, Mr. ABERCROMBIE, Mr. ANDREWS, Mr. COYNE, Mr. DEUTSCH, Mr. DIXON, Mr. FRANK of Massachusetts, Mr. GREENWOOD, Mr. KLECZKA, Mrs. LOWEY, Mr. MARKEY, Mr. McDERMOTT, Mr. MILLER of California, Mrs. MINK of Hawaii, Mrs. MORELLA, Mr. OBERSTAR, Mr. PALLONE, Mr. PASTOR, Mr. SISISKY, Mr. STUDDS, Mr. TOWNS, and Ms. WOOLSEY) introduced the following bill; which was referred to the Committee on Commerce

---

## A BILL

To amend the Public Health Service Act to provide for programs of research regarding Parkinson's disease, 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, Assistance, and Education Act of  
6 1995".

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 the af-  
15 flicted individuals incapable of caring for themselves.  
16 In addition to causing disability and suffering for  
17 the afflicted individuals, Parkinson’s places tremen-  
18 dous and prolonged physical, emotional, and finan-  
19 cial strain on family and loved 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 \$26,000,000 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 afflicted individuals and their family caregivers.

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

12          Part B of title IV of the Public Health Service Act  
13          (42 U.S.C. 284 et seq.) is amended by adding at the end  
14          the following section:

15                                “PARKINSON'S DISEASE

16          “SEC. 409B. (a) IN GENERAL.—The Director of  
17          NIH shall establish a program for the conduct and sup-  
18          port of research and training, the dissemination of health  
19          information, and other programs with respect to Parkin-  
20          son's disease.

21          “(b) INTERAGENCY COORDINATING COMMITTEE.—

22                                “(1) IN GENERAL.—The Director of NIH shall  
23          establish a committee to be known as the Inter-  
24          agency Coordinating Committee on Parkinson's Dis-  
25          ease (in this subsection referred to as the ‘Coordi-  
26          nating Committee’).

1           “(2) DUTIES.—With respect to Parkinson’s, the  
2           Coordinating Committee shall—

3                   “(A) provide for the coordination of the ac-  
4                   tivities of the national research institutes; and

5                   “(B) coordinate the aspects of all Federal  
6                   health programs and activities relating to Par-  
7                   kinson’s in order to assure the adequacy, effec-  
8                   tiveness, and technical soundness of such pro-  
9                   grams and activities and in order to provide for  
10                  the full communication and exchange of infor-  
11                  mation necessary to maintain adequate coordi-  
12                  nation of such programs and activities.

13           “(3) COMPOSITION.—The Coordinating Com-  
14           mittee shall be composed of—

15                   “(A) the directors of each of the national  
16                   research institutes and other agencies involved  
17                   in research with respect to Parkinson’s;

18                   “(B) one representative of the relevant  
19                   Federal departments and agencies whose pro-  
20                   grams involve health functions or responsibil-  
21                   ities relevant to such disease;

22                   “(C) individuals with the disease and indi-  
23                   viduals who have a family history with the dis-  
24                   ease; and

1           “(D) health professionals or allied health  
2           professionals.

3           “(4) CHAIR.—The Coordinating Committee  
4           shall be chaired by the Director of NIH (or the des-  
5           ignee of the Director). The Committee shall meet at  
6           the call of the chair, but not less often than once  
7           each year.

8           “(5) ANNUAL REPORT.—Not later than 120  
9           days after the end of each fiscal year, the Coordinat-  
10          ing Committee shall prepare and submit to the Sec-  
11          retary, the Director of NIH, and the directors speci-  
12          fied in paragraph (3)(A) a report detailing the ac-  
13          tivities of the Committee in such fiscal year in carry-  
14          ing out paragraph (2).

15          “(c) MORRIS K. UDALL RESEARCH CENTERS.—

16                 “(1) IN GENERAL.—The Director of NIH shall  
17                 award Core Center Grants to encourage the develop-  
18                 ment of innovative multidisciplinary research and  
19                 provide training concerning Parkinson’s. The Direc-  
20                 tor shall award not more than 10 Core Center  
21                 Grants and designate each center funded under such  
22                 grants as a Morris K. Udall Center for Research on  
23                 Parkinson’s Disease.

24                 “(2) REQUIREMENTS.—

1           “(A) IN GENERAL.—With respect to Par-  
2           kinson’s, each center assisted under this sub-  
3           section shall—

4                   “(i) use the facilities of a single insti-  
5                   tution or a consortium of cooperating insti-  
6                   tutions, and meet such qualifications as  
7                   may be prescribed by the Director of the  
8                   NIH; and

9                   “(ii) conduct basic and clinical re-  
10                  search and provide patient care services.

11           “(B) DISCRETIONARY REQUIREMENTS.—  
12           With respect to Parkinson’s, each center as-  
13           sisted under this subsection may—

14                   “(i) conduct training programs for  
15                   scientists and health professionals;

16                   “(ii) conduct programs to provide in-  
17                   formation and continuing education to  
18                   health professionals;

19                   “(iii) conduct programs for the dis-  
20                   semination of information to the public;  
21                   and

22                   “(iv) develop and maintain, where ap-  
23                   propriate, a brain bank to collect speci-  
24                   mens related to the research and treatment  
25                   of Parkinson’s.

1           “(3) STIPENDS REGARDING TRAINING PRO-  
2           GRAMS.—A center may use funds provided under  
3           paragraph (1) to provide stipends for scientists and  
4           health professionals enrolled in training programs  
5           under paragraph (2)(C).

6           “(4) DURATION OF SUPPORT.—Support of a  
7           center under this subsection may be for a period not  
8           exceeding five years. Such period may be extended  
9           by the Director of NIH for one or more additional  
10          periods of not more than five years if the operations  
11          of such center have been reviewed by an appropriate  
12          technical and scientific peer review group established  
13          by the Director and if such group has recommended  
14          to the Director that such period should be extended.

15          “(d) DATA SYSTEM; INFORMATION CLEARING-  
16          HOUSE.—

17                 “(1) DATA SYSTEM.—The Director of NIH  
18                 shall establish the National Parkinson’s Disease  
19                 Data System for the collection, storage, analysis, re-  
20                 trieval, and dissemination of data derived from pa-  
21                 tient populations with such disease, including, where  
22                 possible, data involving general populations for the  
23                 purpose of detection of individuals with a risk of de-  
24                 veloping the disease.

1           “(2) INFORMATION CLEARINGHOUSE.—The Di-  
2           rector of NIH shall establish the National Parkin-  
3           son’s Disease Information Clearinghouse to facilitate  
4           and enhance knowledge and understanding of such  
5           disease on the part of health professionals, patients,  
6           and the public through the effective dissemination of  
7           information.

8           “(e) MORRIS K. UDALL LEADERSHIP AND EXCEL-  
9           LENCE AWARDS.—The Director of NIH shall establish a  
10          grant program to support scientists who have distin-  
11          guished themselves in the field of Parkinson’s research.  
12          Grants under this subsection shall be utilized to enable  
13          established investigators to devote greater time and re-  
14          sources in laboratories to conduct research on Parkinson’s  
15          and to encourage the development of a new generation of  
16          investigators, with the support and guidance of the most  
17          productive and innovative senior researchers.

18          “(f) NATIONAL PARKINSON’S DISEASE EDUCATION  
19          PROGRAM.—The Director of NIH shall establish a na-  
20          tional education program that is designed to foster a na-  
21          tional focus on Parkinson’s and the care of those with Par-  
22          kinson’s. Activities under such program shall include—

23                  “(1) the bringing together of public and private  
24                  organizations to develop better ways to provide care

1 to individuals with Parkinson's, and assist the fami-  
2 lies of such individuals; and

3 “(2) the provision of technical assistance to  
4 public and private organizations that offer support  
5 and aid to individuals with Parkinson's and their  
6 families.

7 “(g) AUTHORIZATION OF APPROPRIATIONS.—

8 “(1) IN GENERAL.—For the purpose of carry-  
9 ing out this section, there are authorized to be ap-  
10 propriated \$100,000,000 for fiscal year 1996, and  
11 such sums as may be necessary for each of the fiscal  
12 years 1997 through 2000.

13 “(2) AVAILABILITY.—Of the amount appro-  
14 priated under paragraph (1), the Secretary shall  
15 make available not to exceed \$10,000,000 for fiscal  
16 year 1996, and such sums as may be necessary for  
17 each of the fiscal years 1997 through 2000, to es-  
18 tablish Morris K. Udall Centers under subsection  
19 (c).”.

○