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104TH CONGRESS

2D SESSION H. R. 3514 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 MAY 22, 1996 Mr. SMITH of the New Jersey (for himself, Mr. VOLKMER, and Mr. FLANA- GAN) 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 ‘‘Parkinson’s Research,

5 Assistance, and Education Act of 1996’’.
6 SEC. 2. FINDINGS AND PURPOSE.
7 (a) FINDINGS.—The Congress finds that—

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1 (1) Parkinson’s disease and related disorders
2 are neurological disorders affecting over 1,000,000

3 Americans; and
4 (2) approximately $28,000,000 in Federal

5 funds was allocated by the National Institutes of
6 Health in fiscal year 1995 for research specifically
7 on Parkinson’s disease.

8 (b) PURPOSE.—It is the purpose of this Act to pro-
9 vide for the expansion and coordination of research con-10 cerning Parkinson’s disease and related disorders, to im-

11 prove care and assistance for afflicted individuals and
12 their families, and to improve public awareness about such
13 conditions.
14 SEC. 3. BIOMEDICAL RESEARCH ON PARKINSON’S DISEASE.
15 Part B of title IV of the Public Health Service Act
16 (42 U.S.C. 284 et seq.) is amended by adding at the end
17 the following section:
18 ‘‘PARKINSON’S DISEASE
19 ‘‘SEC. 409B. (a) IN GENERAL.—The Director of

20 NIH shall establish a program for the conduct and sup-21 port of research and training, the dissemination of health

22 information, and other programs with respect to Parkin-
23 son’s disease and related disorders (in this section referred
24 to as Parkinson’s).
25 ‘‘(b) INTERAGENCY COORDINATING COMMITTEE.—

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1 ‘‘(1) IN GENERAL.—The Director of NIH shall
2 establish a committee to be known as the Inter-

3 agency Coordinating Committee on Parkinson’s Dis-
4 ease (in this subsection referred to as the ‘Coordi-
5 nating Committee’).

6 ‘‘(2) DUTIES.—With respect to Parkinson’s, the
7 Coordinating Committee shall—

8 ‘‘(A) provide for the coordination of the ac-
9 tivities of the national research institutes; and
10 ‘‘(B) coordinate the aspects of all Federal

11 health programs and activities relating to Par-
12 kinson’s in order to assure the adequacy, effec-

13 tiveness, and technical soundness of such pro-
14 grams and activities and in order to provide for

15 the full communication and exchange of infor-
16 mation necessary to maintain adequate coordi-
17 nation of such programs and activities.

18 ‘‘(3) COMPOSITION.—The Coordinating Com-
19 mittee shall be composed of—
20 ‘‘(A) the directors of each of the national

21 research institutes and other agencies involved
22 in research with respect to Parkinson’s;

23 ‘‘(B) one representative of the relevant
24 Federal departments and agencies whose pro-

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1 grams involve health functions or responsibil-
2 ities relevant to such disease;
3 ‘‘(C) individuals with the disease and indi-

4 viduals who have a family history with the dis-

5 ease; and
6 ‘‘(D) health professionals or allied health
7 professionals.

8 ‘‘(4) CHAIR.—The Coordinating Committee
9 shall be chaired by the Director of NIH (or the des-
10 ignee of the Director). The Committee shall meet at

11 the call of the chair, but not less often than once
12 each year.
13 ‘‘(5) ANNUAL REPORT.—Not later than 120

14 days after the end of each fiscal year, the Coordinat-
15 ing Committee shall prepare and submit to the Sec-

16 retary, the Director of NIH, and the directors speci-
17 fied in paragraph (3)(A) a report detailing the ac-

18 tivities of the Committee in such fiscal year in carry-
19 ing out paragraph (2).
20 ‘‘(c) MORRIS K. UDALL RESEARCH CENTERS.—

21 ‘‘(1) IN GENERAL.—The Director of NIH shall
22 award Core Center Grants to encourage the develop-

23 ment of innovative multidisciplinary research and
24 provide training concerning Parkinson’s. The Direc-

25 tor shall award not more than 10 Core Center

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1 Grants and designate each center funded under such
2 grants as a Morris K. Udall Center for Research on
3 Parkinson’s Disease.

4 ‘‘(2) REQUIREMENTS.—
5 ‘‘(A) IN GENERAL.—With respect to Par-

6 kinson’s, each center assisted under this sub-
7 section shall—

8 ‘‘(i) use the facilities of a single insti-
9 tution or a consortium of cooperating insti-

10 tutions, and meet such qualifications as
11 may be prescribed by the Director of the
12 NIH; and
13 ‘‘(ii) conduct basic and clinical re-

14 search and provide patient care services.
15 ‘‘(B) DISCRETIONARY REQUIREMENTS.—

16 With respect to Parkinson’s, each center as-
17 sisted under this subsection may—

18 ‘‘(i) conduct training programs for
19 scientists and health professionals;
20 ‘‘(ii) conduct programs to provide in-

21 formation and continuing education to
22 health professionals;

23 ‘‘(iii) conduct programs for the dis-
24 semination of information to the public;

25 and

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1 ‘‘(iv) develop and maintain, where ap-
2 propriate, a brain bank to collect speci-
3 mens related to the research and treatment
4 of Parkinson’s.

5 ‘‘(3) STIPENDS REGARDING TRAINING PRO-

6 GRAMS.—A center may use funds provided under
7 paragraph (1) to provide stipends for scientists and

8 health professionals enrolled in training programs
9 under paragraph (2)(C).
10 ‘‘(4) DURATION OF SUPPORT.—Support of a

11 center under this subsection may be for a period not
12 exceeding five years. Such period may be extended

13 by the Director of NIH for one or more additional
14 periods of not more than five years if the operations

15 of such center have been reviewed by an appropriate
16 technical and scientific peer review group established
17 by the Director and if such group has recommended

18 to the Director that such period should be extended.
19 ‘‘(d) DATA SYSTEM; INFORMATION CLEARING-

20 HOUSE.—

21 ‘‘(1) DATA SYSTEM.—The Director of NIH
22 shall establish the National Parkinson’s Disease

23 Data System for the collection, storage, analysis, re-
24 trieval, and dissemination of data derived from pa-

25 tient populations with such disease, including, where

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1 possible, data involving general populations for the
2 purpose of detection of individuals with a risk of de-

3 veloping the disease.
4 ‘‘(2) INFORMATION CLEARINGHOUSE.—The Di-

5 rector of NIH shall establish the National Parkin-

6 son’s Disease Information Clearinghouse to facilitate
7 and enhance knowledge and understanding of such

8 disease on the part of health professionals, patients,
9 and the public through the effective dissemination of

10 information.

11 ‘‘(e) MORRIS K. UDALL LEADERSHIP AND EXCEL-
12 LENCE AWARDS.—The Director of NIH shall establish a

13 grant program to support scientists who have distin-14 guished themselves in the field of Parkinson’s research.

15 Grants under this subsection shall be utilized to enable
16 established investigators to devote greater time and re-
17 sources in laboratories to conduct research on Parkinson’s

18 and to encourage the development of a new generation of 19 investigators, with the support and guidance of the most

20 productive and innovative senior researchers.
21 ‘‘(f) NATIONAL PARKINSON’S DISEASE EDUCATION
22 PROGRAM.—The Director of NIH shall establish a na-

23 tional education program that is designed to foster a na-

24 tional focus on Parkinson’s and the care of those with Par-

25 kinson’s. Activities under such program shall include—

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1 ‘‘(1) the bringing together of public and private
2 organizations to develop better ways to provide care

3 to individuals with Parkinson’s, and assist the fami-
4 lies of such individuals; and
5 ‘‘(2) the provision of technical assistance to

6 public and private organizations that offer support
7 and aid to individuals with Parkinson’s and their
8 families.

9 ‘‘(g) AUTHORIZATION OF APPROPRIATIONS.—
10 ‘‘(1) IN GENERAL.—For the purpose of carry-

11 ing out this section, there are authorized to be ap-
12 propriated $100,000,000 for fiscal year 1997, and

13 such sums as may be necessary for each of the fiscal
14 years 1998 through 2000.
15 ‘‘(2) AVAILABILITY.—Of the amount appro-

16 priated under paragraph (1), the Secretary shall
17 make available not to exceed $10,000,000 for fiscal

18 year 1997, and such sums as may be necessary for
19 each of the fiscal years 1998 through 2000, to es-

20 tablish Morris K. Udall Centers under subsection
21 (c).
22 ‘‘(3) LIMITATION ON USE OF FUNDS.—Notwith-

23 standing any other provision of law, none of the
24 amounts made available under this Act may be ex-
25 pended for any research on Parkinson’s that uses

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1 human fetal tissue, cells, or organs obtained from a
2 living or dead human embryo or fetus during or

3 after an induced abortion, or for any therapeutic ap-
4 plication for Parkinson’s that uses such human fetal

5 tissue, cells, or organs. This paragraph does not
6 apply to human fetal tissue, cells, or organs obtained
7 from a spontaneous abortion or an ectopic preg-

8 nancy.’’.

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