

109TH CONGRESS
1ST SESSION

S. 828

To enhance and further research into paralysis and to improve rehabilitation and the quality of life for persons living with paralysis and other physical disabilities, and for other purposes.

IN THE SENATE OF THE UNITED STATES

APRIL 18, 2005

Mr. HARKIN (for himself, Mr. SPECTER, Mr. KENNEDY, Mr. GRAHAM, Mrs. CLINTON, Mr. BINGAMAN, and Mr. KERRY) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To enhance and further research into paralysis and to improve rehabilitation and the quality of life for persons living with paralysis and other physical disabilities, 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 “Christopher Reeve Pa-
5 ralysis Act”.

6 **SEC. 2. TABLE OF CONTENTS.**

7 The table of contents of this Act is as follows:

- Sec. 1. Short title.
 Sec. 2. Table of contents.

TITLE I—PARALYSIS RESEARCH

- Sec. 101. Expansion and coordination of activities of the National Institutes of Health with respect to research on paralysis.

TITLE II—PARALYSIS REHABILITATION RESEARCH AND CARE

- Sec. 201. Expansion and coordination of activities of the National Institutes of Health with respect to research with implications for enhancing daily function for persons with paralysis.

TITLE III—IMPROVING QUALITY OF LIFE FOR PERSONS WITH PARALYSIS AND OTHER PHYSICAL DISABILITIES

- Sec. 301. Programs to improve quality of life for persons with paralysis and other physical disabilities.

TITLE IV—ACTIVITIES OF THE DEPARTMENT OF VETERANS AFFAIRS

- Sec. 401. Expansion and coordination of activities of the Veterans Health Administration.
 Sec. 402. Definitions.

1 TITLE I—PARALYSIS RESEARCH

2 SEC. 101. EXPANSION AND COORDINATION OF ACTIVITIES **3 OF THE NATIONAL INSTITUTES OF HEALTH** **4 WITH RESPECT TO RESEARCH ON PARALYSIS.**

5 (a) IN GENERAL.—

6 (1) ENHANCED COORDINATION OF ACTIVITIES.—The Director of the National Institutes of
7 Health (in this section referred to as the “Director”) **8**
9 may expand and coordinate the activities of such In-
10 stitutes with respect to research on paralysis. In
11 order to further expand upon the activities of this
12 section, the Director may consider the methods out-
13 lined in the report under section 2(b) of Public Law
14 108–427 with respect to spinal cord injury and pa-

1 ralysis research (relating to the Roadmap for Med-
2 ical Research of the National Institutes of Health).

3 (2) ADMINISTRATION OF PROGRAM; COLLABO-
4 RATION AMONG AGENCIES.—The Director shall carry
5 out this section acting through the Director of the
6 National Institute of Neurological Disorders and
7 Stroke (in this section referred to as the “Institute”)
8 and in collaboration with any other agencies that the
9 Director determines appropriate.

10 (b) COORDINATION.—

11 (1) IN GENERAL.—The Director may develop
12 mechanisms to coordinate the paralysis research and
13 rehabilitation activities of the agencies of the Na-
14 tional Institutes of Health in order to further ad-
15 vance such activities and avoid duplication of activi-
16 ties.

17 (2) REPORT.—Not later than December 1,
18 2005, the Director shall prepare and submit a report
19 to Congress that provides a description of the paral-
20 ysis activities of the Institute and strategies for fu-
21 ture activities.

22 (c) CHRISTOPHER REEVE PARALYSIS RESEARCH
23 CONSORTIA.—

24 (1) IN GENERAL.—The Director may under
25 subsection (a)(1) make awards of grants to public or

1 nonprofit private entities to pay all or part of the
2 cost of planning, establishing, improving, and pro-
3 viding basic operating support for consortia in paral-
4 ysis research. The Director shall designate each con-
5 sortium funded under grants as a Christopher Reeve
6 Paralysis Research Consortium.

7 (2) RESEARCH.—Each consortium under para-
8 graph (1)—

9 (A) may conduct basic and clinical paral-
10 ysis research;

11 (B) may focus on advancing treatments
12 and developing therapies in paralysis research;

13 (C) may focus on one or more forms of pa-
14 ralysis that result from central nervous system
15 trauma or stroke;

16 (D) may facilitate and enhance the dis-
17 semination of clinical and scientific findings;
18 and

19 (E) may replicate the findings of consortia
20 members for scientific and translational pur-
21 poses.

22 (3) COORDINATION OF CONSORTIA; REPORTS.—

23 The Director may, as appropriate, provide for the
24 coordination of information among consortia under
25 paragraph (1) and ensure regular communication

1 between members of the consortia, and may require
2 the periodic preparation of reports on the activities
3 of the consortia and the submission of the reports to
4 the Director.

5 (4) ORGANIZATION OF CONSORTIA.—Each con-
6 sortium under paragraph (1) may use the facilities
7 of a single lead institution, or be formed from sev-
8 eral cooperating institutions, meeting such require-
9 ments as may be prescribed by the Director.

10 (d) PUBLIC INPUT.—The Director may under sub-
11 section (a)(1) provide for a mechanism to educate and dis-
12 seminate information on the existing and planned pro-
13 grams and research activities of the National Institutes
14 of Health with respect to paralysis and through which the
15 Director can receive comments from the public regarding
16 such programs and activities.

17 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
18 purpose of carrying out this section, there are authorized
19 to be appropriated in the aggregate \$25,000,000 for the
20 fiscal years 2006 through 2009. Amounts appropriated
21 under this subsection are in addition to any other amounts
22 appropriated for such purpose.

1 **TITLE II—PARALYSIS REHABILI-**
 2 **TATION RESEARCH AND CARE**

3 **SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES**
 4 **OF THE NATIONAL INSTITUTES OF HEALTH**
 5 **WITH RESPECT TO RESEARCH WITH IMPLICA-**
 6 **TIONS FOR ENHANCING DAILY FUNCTION**
 7 **FOR PERSONS WITH PARALYSIS.**

8 (a) IN GENERAL.—

9 (1) EXPANSION OF ACTIVITIES.—The Director
 10 of the National Institutes of Health (in this section
 11 referred to as the “Director”) may expand and co-
 12 ordinate the activities of such Institutes with respect
 13 to research with implications for enhancing daily
 14 function for people with paralysis.

15 (2) ADMINISTRATION OF PROGRAM; COLLABO-
 16 RATION AMONG AGENCIES.—The Director shall carry
 17 out this section acting through the Director of the
 18 National Institute on Child Health and Human De-
 19 velopment and the National Center for Medical Re-
 20 habilitation Research and in collaboration with the
 21 National Institute on Neurological Disorders and
 22 Stroke, the Centers for Disease Control and Preven-
 23 tion, and any other agencies that the Director deter-
 24 mines appropriate.

25 (b) PARALYSIS CLINICAL TRIALS NETWORKS.—

1 (1) IN GENERAL.—The Director may make
 2 awards of grants to public or nonprofit private enti-
 3 ties to pay all or part of the costs of planning, estab-
 4 lishing, improving, and providing basic operating
 5 support to multicenter networks of clinical sites that
 6 will collaborate to design clinical rehabilitation inter-
 7 vention protocols and measures of outcomes on one
 8 or more forms of paralysis that result from central
 9 nervous system trauma, disorders, or stroke, or any
 10 combination of such conditions.

11 (2) RESEARCH.—Each multicenter clinical trial
 12 network may—

13 (A) focus on areas of key scientific con-
 14 cern, including—

15 (i) improving functional mobility;

16 (ii) promoting behavioral adaptation
 17 to functional losses, especially to prevent
 18 secondary complications;

19 (iii) assessing the efficacy and out-
 20 comes of medical rehabilitation therapies
 21 and practices and assisting technologies;

22 (iv) developing improved assistive
 23 technology to improve function and inde-
 24 pendence; and

1 (v) understanding whole body system
2 responses to physical impairments, disabil-
3 ities, and societal and functional limita-
4 tions; and

5 (B) replicate the findings of network mem-
6 bers for scientific and translation purposes.

7 (3) COORDINATION OF CLINICAL TRIALS NET-
8 WORKS; REPORTS.—The Director may, as appro-
9 priate, provide for the coordination of information
10 among networks and ensure regular communication
11 between members of the networks, and may require
12 the periodic preparation of reports on the activities
13 of the networks and submission of reports to the Di-
14 rector.

15 (c) REPORT.—Not later than December 1, 2005, the
16 Director shall submit to the Congress a report that pro-
17 vides a description of research activities with implications
18 for enhancing daily function for persons with paralysis.

19 (d) AUTHORIZATION OF APPROPRIATIONS.—For the
20 purpose of carrying out this section, there are authorized
21 to be appropriated in the aggregate \$25,000,000 for the
22 fiscal years 2006 through 2009. Amounts appropriated
23 under this subsection are in addition to any other amounts
24 appropriated for such purpose.

1 **TITLE III—IMPROVING QUALITY**
2 **OF LIFE FOR PERSONS WITH**
3 **PARALYSIS AND OTHER PHYS-**
4 **ICAL DISABILITIES**

5 **SEC. 301. PROGRAMS TO IMPROVE QUALITY OF LIFE FOR**
6 **PERSONS WITH PARALYSIS AND OTHER**
7 **PHYSICAL DISABILITIES.**

8 (a) IN GENERAL.—The Secretary of Health and
9 Human Services (in this title referred to as the “Sec-
10 retary”), acting through the Director of the Centers for
11 Disease Control and Prevention, may study the unique
12 health challenges associated with paralysis and other phys-
13 ical disabilities and carry out projects and interventions
14 to improve the quality of life and long-term health status
15 of persons with paralysis and other physical disabilities.
16 The Secretary may carry out such projects directly and
17 through awards of grants or contracts.

18 (b) CERTAIN ACTIVITIES.—Activities under sub-
19 section (a) include—

20 (1) the development of a national paralysis and
21 physical disability quality of life action plan, to pro-
22 mote health and wellness in order to enhance full
23 participation, independent living, self-sufficiency and
24 equality of opportunity in partnership with voluntary
25 health agencies focused on paralysis and other phys-

1 ical disabilities, to be carried out in coordination
2 with the State-based Comprehensive Paralysis and
3 Other Physical Disability Quality of Life Program of
4 the Centers for Disease Control and Prevention;

5 (2) support for programs to disseminate infor-
6 mation involving care and rehabilitation options and
7 quality of life grant programs supportive of commu-
8 nity based programs and support systems for per-
9 sons with paralysis and other physical disabilities;

10 (3) in collaboration with other centers and na-
11 tional voluntary health agencies, establish a hospital-
12 based paralysis registry and conduct relevant popu-
13 lation-based research; and

14 (4) the development of comprehensive, unique
15 and innovative programs, services, and demonstra-
16 tions within existing State-based disability and
17 health programs of the Centers for Disease Control
18 and Prevention which are designed to support and
19 advance quality of life programs for persons living
20 with paralysis and other physical disabilities focus-
21 ing on—

22 (A) caregiver education;

23 (B) physical activity;

24 (C) education and awareness programs for
25 health care providers;

- 1 (D) prevention of secondary complications;
- 2 (E) home and community-based interven-
- 3 tions;
- 4 (F) coordinating services and removing
- 5 barriers that prevent full participation and inte-
- 6 gration into the community; and
- 7 (G) recognizing the unique needs of under-
- 8 served populations.

9 (c) GRANTS.—The Secretary may award grants in ac-
10 cordance with the following:

- 11 (1) To State and local health and disability
- 12 agencies for the purpose of—

- 13 (A) establishing paralysis registries for the
- 14 support of relevant population-based research;

- 15 (B) developing comprehensive paralysis
- 16 and other physical disability action plans and
- 17 activities focused on the items listed in sub-
- 18 section (b)(4);

- 19 (C) assisting State-based programs in es-
- 20 tablishing and implementing partnerships and
- 21 collaborations that maximize the input and sup-
- 22 port of people with paralysis and other physical
- 23 disabilities and their constituent organizations;

1 (D) coordinating paralysis and physical
 2 disability activities with existing State-based
 3 disability and health programs;

4 (E) providing education and training op-
 5 portunities and programs for health profes-
 6 sionals and allied caregivers; and

7 (F) developing, testing, evaluating, and
 8 replicating effective intervention programs to
 9 maintain or improve health and quality of life.

10 (2) To nonprofit private health and disability
 11 organizations for the purpose of—

12 (A) disseminating information to the pub-
 13 lic;

14 (B) improving access to services for per-
 15 sons living with paralysis and other physical
 16 disabilities and their caregivers;

17 (C) testing model intervention programs to
 18 improve health and quality of life; and

19 (D) coordinating existing services with
 20 State-based disability and health programs.

21 (d) COORDINATION OF ACTIVITIES.—The Secretary
 22 shall assure that activities under this section are coordi-
 23 nated as appropriate with other agencies of the Public
 24 Health Service.

1 (e) REPORT TO CONGRESS.—Not later than Decem-
 2 ber 1, 2005, the Secretary shall submit to Congress a re-
 3 port describing the results of the evaluation under sub-
 4 section (a), and as applicable, the strategies developed
 5 under such subsection.

6 (f) AUTHORIZATION OF APPROPRIATIONS.—For the
 7 purpose of carrying out this section, there are authorized
 8 to be appropriated in the aggregate \$25,000,000 for the
 9 fiscal years 2006 through 2009.

10 **TITLE IV—ACTIVITIES OF THE** 11 **DEPARTMENT OF VETERANS** 12 **AFFAIRS**

13 **SEC. 401. EXPANSION AND COORDINATION OF ACTIVITIES** 14 **OF THE VETERANS HEALTH ADMINISTRA-** 15 **TION.**

16 (a) IN GENERAL.—

17 (1) ENHANCED COORDINATION OF ACTIVI-
 18 TIES.—The Secretary may expand and coordinate
 19 activities of the Veterans Health Administration of
 20 the Department of Veterans Affairs with respect to
 21 research on paralysis.

22 (2) ADMINISTRATION OF PROGRAM.—The Sec-
 23 retary shall carry out this section through the Chief
 24 Research and Development Officer of the Adminis-
 25 tration in collaboration with the National Institutes

1 of Health and other agencies the Secretary deter-
2 mines appropriate.

3 (b) ESTABLISHMENT OF PARALYSIS RESEARCH,
4 EDUCATION, AND CLINICAL CARE.—

5 (1) IN GENERAL.—The Secretary may establish
6 within the Department of Veterans Affairs centers
7 to be known as Paralysis Research, Education and
8 Clinical Care Centers. Such centers shall be estab-
9 lished through the awarding of grants to Adminis-
10 tration medical centers that are affiliated with med-
11 ical schools or other organizations the Secretary con-
12 siderers appropriate. Such grants may be used to pay
13 all or part of the costs of planning, establishing, im-
14 proving, and providing basic operating support for
15 such centers.

16 (2) RESEARCH.—Each center under paragraph
17 (1)—

18 (A) may focus on basic biomedical research
19 on the types of paralysis that result from
20 neurologic dysfunction, neurodegeneration, or
21 trauma;

22 (B) may focus on clinical science research
23 on the types of paralysis that result from
24 neurologic dysfunction, neurodegeneration, or
25 trauma;

1 (C) may focus on rehabilitation research
2 on the types of paralysis that result from
3 neurologic dysfunction, neurodegeneration, or
4 trauma;

5 (D) may focus on health services research
6 on the types of paralysis that result from
7 neurologic dysfunction, neurodegeneration, or
8 trauma to improve health outcomes, increase
9 the cost-effectiveness of service, and implement
10 best practices in the treatment of such types of
11 paralysis; and

12 (E) may facilitate and enhance the dis-
13 semination of scientific findings and evidence-
14 based practices.

15 (3) COORDINATION OF CENTERS INTO CON-
16 SORTIA.—The Secretary may, as appropriate, pro-
17 vide for the linkage and coordination of information
18 among centers under paragraph (1) in order to cre-
19 ate national consortia of centers and to ensure reg-
20 ular communications between members of the cen-
21 ters. Each consortium—

22 (A) may expand the capacity of its Admin-
23 istration medical centers to conduct basic, clin-
24 ical, rehabilitation, and health-sciences research

1 with respect to paralysis by increasing the avail-
2 able research resources;

3 (B) may identify gaps in research, clinical
4 service, or implementation strategies;

5 (C) may operate as a multidisciplinary re-
6 search and clinical care team to determine best
7 practices, to develop standards of care, and to
8 establish guidelines for implementation through-
9 out the Administration;

10 (D) may use the facilities of a single lead
11 institution, or facilities formed from several co-
12 operating institutions, that meet such require-
13 ments as prescribed by the Secretary;

14 (E) may provide core funding that will en-
15 hance ongoing research by bringing together
16 paralysis health care and research communities
17 in a manner that will enrich the effectiveness of
18 clinical care, present research and future direc-
19 tions; and

20 (F) may include administrative, research,
21 clinical, educational and implementation cores,
22 and other cores that may be proposed.

23 (4) COORDINATION OF INFORMATION; RE-
24 PORTS.—The Secretary may, as appropriate, provide
25 for the coordination of information among centers

1 and consortia under this section and ensure regular
 2 communication with respect to the activities of the
 3 centers and consortia, and may require the periodic
 4 preparation of reports on the activities of the centers
 5 and consortia, and require the submission of such
 6 reports.

7 (c) ESTABLISHMENT OF QUALITY ENHANCEMENT
 8 RESEARCH INITIATIVES FOR PARALYSIS.—

9 (1) IN GENERAL.—The Secretary may make
 10 grants to medical centers of the Administration for
 11 the purpose of carrying out projects to translate
 12 clinical findings and recommendations with respect
 13 to paralysis into evidence-based best practices for
 14 use by the Administration. Such projects shall be
 15 designated by the Secretary as Quality Enhancement
 16 Research Initiative projects (referred to in this sub-
 17 section as “QUERI projects”).

18 (2) REQUIREMENT.—A grant may be made
 19 under paragraph (1) to a medical center described in
 20 such paragraph only if the center is affiliated with
 21 a school of medicine or with another entity deter-
 22 mined by the Secretary to be appropriate.

23 (3) CERTAIN USES OF GRANT.—The activities
 24 for which a grant under paragraph (1) may be ex-
 25 pended by a QUERI project include the following:

1 (A) To pay all or part of the costs of plan-
2 ning, establishing, improving and providing
3 basic operating support for the project.

4 (B) To work toward implementing best
5 practices identified under paragraph (1)
6 throughout the Administration through efforts
7 to facilitate comprehensive organizational
8 change, and to evaluate and refine such imple-
9 mentation efforts through the collection, anal-
10 ysis, and reporting of data on critical patient
11 outcomes and system performance.

12 (C) To identify high-risk or high-volume
13 primary or secondary consequences of paralysis
14 that results from neurologic dysfunction,
15 neurodegeneration, or trauma.

16 (D) To systematically examine quality of
17 care for persons with paralysis from neurologic
18 dysfunction, neurodegeneration, or trauma.

19 (E) To define existing practice patterns
20 and outcomes for persons with paralysis
21 throughout the Administration and current var-
22 iation from best practices both within and out-
23 side of the Department of Veterans Affairs.

24 (F) To enhance ongoing research by bring-
25 ing together paralysis clinical care and health

1 service research communities to identify the
2 health care needs of the paralysis community,
3 examine standard practices, determine best
4 practices and to implement best practices for
5 persons with paralysis and their families.

6 (G) To formulate health service research
7 protocols aimed at determining paralysis-care
8 related best practices, closing the gap between
9 current practices in paralysis care in the De-
10 partment of Veterans Affairs, assessing the best
11 practices within and outside of the Department
12 of Veterans Affairs, and developing strategies
13 for the implementation of best practices.

14 (H) To implement information, tools, prod-
15 ucts and other interventions determined to be in
16 the best interest of persons with paralysis (in-
17 cluding performance criteria for clinicians and
18 psychosocial interventions for veterans and their
19 families).

20 (I) To disseminate findings in scientific
21 peer-reviewed journals and other venues deemed
22 appropriate, such as veteran service organiza-
23 tion publications.

24 (4) ORGANIZATION OF PROJECT.—Each
25 QUERI project may use the facilities of a single

1 lead medical center, or be formed from cooperating
2 such centers that meet such requirements as may be
3 prescribed by the Secretary.

4 (5) MAINTENANCE OF EFFORT.—A grant may
5 be made under paragraph (1) only if, with respect
6 to activities for which the award is authorized to be
7 expended, the applicant for the award agrees to
8 maintain expenditures of non-Federal amounts for
9 such activities at a level that is not less than the
10 level of such expenditures maintained by the appli-
11 cant for the fiscal year preceding the first fiscal year
12 for which the applicant receives such an award.

13 (d) AUTHORIZATION OF APPROPRIATIONS.—For the
14 purpose of carrying out this section, there are authorized
15 to be appropriated in the aggregate \$25,000,000 for fiscal
16 years 2006 through 2009. Amounts appropriated under
17 this section are in addition to any other amounts appro-
18 priated for such purpose.

19 **SEC. 402. DEFINITIONS.**

20 For purposes of this title:

21 (1) The term “Administration” means the Vet-
22 erans Health Administration of the Department of
23 Veterans Affairs.

- 1 (2) The term “Secretary” means the Secretary
2 of Veterans Affairs.

