

107TH CONGRESS
2D SESSION

S. 3000

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

SEPTEMBER 24, 2002

Mr. HARKIN (for himself, Mr. BROWNBACK, Mr. KENNEDY, and Mr. SPECTER) 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.**

Sec. 1. Short title.

Sec. 2. Table of contents.

TITLE I—PARALYSIS RESEARCH

Sec. 101. Expansion and coordination of activities of 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 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—COORDINATION OF PARALYSIS RESEARCH AND PROGRAMS

Sec. 401. Coordination.

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 may expand and coordinate the activities of such In-
9 stitutes with respect to research on paralysis.

11 (2) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES.—The Director shall carry
12 out this section acting through the Director of the
13 National Institute of Neurological Disorders and
14 Stroke (in this section referred to as the “Institute”)
15

1 and in collaboration with any other agencies that the
2 Director determines appropriate.

3 (b) COORDINATION.—

4 (1) IN GENERAL.—The Director may develop
5 mechanisms to coordinate the paralysis research and
6 rehabilitation activities of the agencies of the Na-
7 tional Institutes of Health in order to further ad-
8 vance such activities and avoid duplication of activi-
9 ties.

10 (2) REPORT.—Not later than December 1,
11 2003, the Director shall prepare a report to Con-
12 gress that provides a description of the paralysis ac-
13 tivities of the Institute and strategies for future ac-
14 tivities.

15 (c) CHRISTOPHER REEVE PARALYSIS RESEARCH
16 CONSORTIA.—

17 (1) IN GENERAL.—The Director may under
18 subsection (a)(1) make awards of grants to public or
19 nonprofit private entities to pay all or part of the
20 cost of planning, establishing, improving, and pro-
21 viding basic operating support for consortia in paral-
22 ysis research. The Director shall designate each con-
23 sortium funded under grants as a Christopher Reeve
24 Paralysis Research Consortium.

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

3 (A) may conduct basic and clinical paral-
4 ysis research;

5 (B) may focus on advancing treatments
6 and developing therapies in paralysis research;

7 (C) may focus on one or more forms of pa-
8 ralysis that result from central nervous system
9 trauma or stroke;

10 (D) may facilitate and enhance the dis-
11 semination of clinical and scientific findings;
12 and

13 (E) may replicate the findings of consortia
14 members for scientific and translational pur-
15 poses.

16 (3) COORDINATION OF CONSORTIA; REPORTS.—

17 The Director may, as appropriate, provide for the
18 coordination of information among consortia under
19 paragraph (1) and ensure regular communication
20 between members of the consortia, and may require
21 the periodic preparation of reports on the activities
22 of the consortia and the submission of the reports to
23 the Director.

24 (4) ORGANIZATION OF CONSORTIA.—Each con-
25 sortium under paragraph (1) may use the facilities

1 of a single lead institution, or be formed from sev-
 2 eral cooperating institutions, meeting such require-
 3 ments as may be prescribed by the Director.

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

11 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
 12 purpose of carrying out this section, there are authorized
 13 to be appropriated such sums as may be necessary for
 14 each of the fiscal years 2003 through 2006. Amounts ap-
 15 propriated under this subsection are in addition to any
 16 other amounts appropriated for such purpose.

17 **TITLE II—PARALYSIS REHABILI-**
 18 **TATION RESEARCH AND CARE**

19 **SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES**
 20 **OF NATIONAL INSTITUTES OF HEALTH WITH**
 21 **RESPECT TO RESEARCH WITH IMPLICATIONS**
 22 **FOR ENHANCING DAILY FUNCTION FOR PER-**
 23 **SONS WITH PARALYSIS.**

24 (a) IN GENERAL.—

1 (1) EXPANSION OF ACTIVITIES.—The Director
 2 of the National Institutes of Health (in this section
 3 referred to as the “Director”) may expand and co-
 4 ordinate the activities of such Institutes with respect
 5 to research with implications for enhancing daily
 6 function for people with paralysis .

7 (2) ADMINISTRATION OF PROGRAM; COLLABO-
 8 RATION AMONG AGENCIES.—The Director shall carry
 9 out this section acting through the Director of the
 10 National Institute on Child Health and Human De-
 11 velopment and the National Center for Medical Re-
 12 habilitation Research and in collaboration with the
 13 National Institute on Neurological Disorders and
 14 Stroke, the Centers for Disease Control and Preven-
 15 tion, and any other agencies that the Director deter-
 16 mines appropriate.

17 (b) PARALYSIS CLINICAL TRIALS NETWORKS.—

18 (1) IN GENERAL.—The Director may make
 19 awards of grants to public or nonprofit private enti-
 20 ties to pay all or part of the costs of planning, estab-
 21 lishing, improving, and providing basic operating
 22 support to multicenter networks of clinical sites that
 23 will collaborate to design clinical rehabilitation inter-
 24 vention protocols and measures of outcomes on one
 25 or more forms of paralysis that result from central

nervous system trauma, disorders, or stroke, or any combination of such conditions.

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

(A) focus on areas of key scientific concern, including—

(i) improving functional mobility;

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

(iii) assessing the efficacy and outcomes of medical rehabilitation therapies and practices and assistive technologies;

(iv) developing improved assistive technology to improve function and independence; and

(v) understanding whole body system responses to physical impairments, disabilities, and societal and functional limitations; and

(B) replicate the findings of network members for scientific and translation purposes.

(3) COORDINATION OF CLINICAL TRIALS NETWORKS.—The Director may, as appropriate, provide for the coordination of information among networks

1 and ensure regular communication between members
 2 of the networks and may require the periodic prepa-
 3 ration of reports on the activities of the networks
 4 and submission of reports to the Director.

5 (c) REPORT.—Not later than January 10, 2004, the
 6 Director shall submit to the Congress a report that pro-
 7 vides a description of research activities with implications
 8 for enhancing daily function for persons with paralysis.

9 (d) AUTHORIZATION OF APPROPRIATIONS.—For the
 10 purpose of carrying out this section, there are authorized
 11 to be appropriated such sums as may be necessary for
 12 each of the fiscal years 2003 through 2006. Amounts ap-
 13 propriated under this subsection are in addition to any
 14 other amounts appropriated for such purpose.

15 **TITLE III—IMPROVING QUALITY**
 16 **OF LIFE FOR PERSONS WITH**
 17 **PARALYSIS AND OTHER PHYS-**
 18 **ICAL DISABILITIES**

19 **SEC. 301. PROGRAMS TO IMPROVE QUALITY OF LIFE FOR**
 20 **PERSONS WITH PARALYSIS AND OTHER**
 21 **PHYSICAL DISABILITIES.**

22 (a) IN GENERAL.—The Secretary of Health and
 23 Human Services (in this Act referred to as the “Sec-
 24 retary”), acting through the Director of the Centers for
 25 Disease Control and Prevention, may study the unique

1 health challenges associated with paralysis and other phys-
2 ical disabilities and carry out projects and interventions
3 to improve the quality of life and long-term health status
4 of persons with paralysis and other physical disabilities.
5 The Secretary may carry out such projects directly and
6 through awards of grants or contracts.

7 (b) CERTAIN ACTIVITIES.—Activities under sub-
8 section (a) include—

9 (1) the development of a national paralysis and
10 physical disability quality of life action plan, to pro-
11 mote full participation, independent living, self-suffi-
12 ciency and equality of opportunity in partnership
13 with voluntary health agencies focused on paralysis
14 and other physical disabilities, to be carried out in
15 coordination with the State-based Comprehensive
16 Paralysis and Other Physical Disability and Quality
17 of Life Program of the Centers for Disease Control
18 and Prevention;

19 (2) support for programs to disseminate infor-
20 mation involving care and rehabilitation options and
21 quality of life grant programs supportive of commu-
22 nity based programs and support systems for per-
23 sons with paralysis and other physical disabilities;

24 (3) in collaboration with other centers and na-
25 tional voluntary health agencies, establish a hospital-

1 based paralysis registry and conduct relevant popu-
2 lation-based research; and

3 (4) the development of a Comprehensive Paral-
4 ysis and Other Physical Disability Quality of Life
5 Program to develop State-based, unique and innova-
6 tive programs, services and demonstrations designed
7 to support and advance quality of life programs for
8 persons living with paralysis and other physical dis-
9 abilities focusing on—

10 (A) caregiver education;

11 (B) physical activity;

12 (C) prevention of secondary complications;

13 (D) home and community-based interven-
14 tions;

15 (E) education and awareness programs for
16 health care providers; and

17 (F) coordinating services and removing
18 barriers that prevent full participation and inte-
19 gration into the community; and

20 (G) recognizing the unique needs of under-
21 served populations.

22 (c) GRANTS.—The Secretary may award grants to
23 nonprofit private health and disability organizations for
24 the purpose of—

1 (1) coordinating existing services with State-
2 based paralysis and physical disability programs;

3 (2) disseminating information to the public;

4 (3) improving access to services for persons liv-
5 ing with paralysis and other physical disabilities and
6 their caregivers; and

7 (4) testing model intervention programs to im-
8 prove health and quality of life.

9 (d) COORDINATION OF ACTIVITIES.—The Secretary
10 shall assure that activities under this section are coordi-
11 nated as appropriate with other agencies of the Public
12 Health Service.

13 (e) REPORT TO CONGRESS.— Not later than October
14 1, 2003, the Secretary shall submit to the Congress a re-
15 port describing the results of the evaluation under sub-
16 section (a), and as applicable, the strategies developed
17 under such subsection.

18 (f) AUTHORIZATION OF APPROPRIATIONS.—For the
19 purpose of carrying out this section, there are authorized
20 to be appropriated such sums as may be necessary for
21 each of the fiscal years 2003 through 2006.

1 **TITLE IV—COORDINATION OF**
2 **PARALYSIS RESEARCH AND**
3 **PROGRAMS**

4 **SEC. 401. COORDINATION.**

5 (a) ESTABLISHMENT OF WORKING GROUP.—The
6 Secretary may convene a working group for the purpose
7 of coordinating paralysis research, public health, and reha-
8 bilitation training at the Federal level.

9 (b) COMPOSITION.—The working group may include
10 representatives of—

- 11 (1) the National Institutes of Health;
- 12 (2) the Centers for Disease Control and Preven-
13 tion;
- 14 (3) the Health Resources and Services Adminis-
15 tration;
- 16 (4) the Agency for Healthcare Research and
17 Quality;
- 18 (5) the Centers for Medicare & Medicaid Serv-
19 ices;
- 20 (6) the Department of Veterans Affairs;
- 21 (7) the Department of Education;
- 22 (8) the Rehabilitation Services Administration;
- 23 (9) the National Aeronautics and Space Admin-
24 istration;

- 1 (10) the National Institute on Standards and
2 Technology (Department of Commerce);
3 (11) the Department of Defense;
4 (12) the Department of Labor;
5 (13) the National Institute on Disability and
6 Rehabilitation Research;
7 (14) the Social Security Administration; and
8 (15) private entities determined appropriate by
9 the Secretary.

10 (c) DISSEMINATION.—The working group may annu-
11 ally prepare and submit to the Secretary a report con-
12 cerning the status of successful and emerging opportuni-
13 ties in Federal paralysis research, education and training,
14 quality of life, or surveillance efforts.

15 (d) AUTHORIZATION OF APPROPRIATIONS.—For the
16 purpose of carrying out this section, there are authorized
17 to be appropriated such sums as may be necessary for
18 each of the fiscal years 2003 through 2006.

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