

108TH CONGRESS
1ST SESSION

S. 1010

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

MAY 7, 2003

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

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.

(2) RESEARCH.—Each consortium under paragraph (1)—

(A) may conduct basic and clinical paralysis research;

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

(C) may focus on one or more forms of paralysis that result from central nervous system trauma or stroke;

(D) may facilitate and enhance the dissemination of clinical and scientific findings; and

(E) may replicate the findings of consortia members for scientific and translational purposes.

(3) COORDINATION OF CONSORTIA; REPORTS.—

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

(4) ORGANIZATION OF CONSORTIA.—Each consortium 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 2004 through 2007. 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 December 1, 2003, 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 2004 through 2007. 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 health and wellness in order to enhance full
12 participation, independent living, self-sufficiency and
13 equality of opportunity in partnership with voluntary
14 health agencies focused on paralysis and other phys-
15 ical disabilities, to be carried out in coordination
16 with the State-based Comprehensive Paralysis and
17 Other Physical Disability Quality of Life Program of
18 the Centers for Disease Control 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 comprehensive, unique
 4 and innovative programs, services, and demonstra-
 5 tions within existing State-based disability and
 6 health programs of the Centers for Disease Control
 7 and Prevention which are designed to support and
 8 advance quality of life programs for persons living
 9 with paralysis and other physical disabilities focus-
 10 ing on—

11 (A) caregiver education;

12 (B) physical activity;

13 (C) education and awareness programs for
 14 health care providers;

15 (D) prevention of secondary complications;

16 (E) home and community-based interven-
 17 tions;

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

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

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

1 (1) To State and local health and disability
2 agencies for the purpose of—

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

5 (B) developing comprehensive paralysis
6 and other physical disability action plans and
7 activities focused on the items listed in sub-
8 section (b)(4);

9 (C) assisting State-based programs in es-
10 tablishing and implementing partnerships and
11 collaborations that maximize the input and sup-
12 port of people with paralysis and other physical
13 disabilities and their constituent organizations;

14 (D) coordinating paralysis and physical
15 disability activities with existing state-based dis-
16 ability and health programs;

17 (E) providing education and training op-
18 portunities and programs for health profes-
19 sionals and allied caregivers; and

20 (F) developing, testing, evaluating, and
21 replicating effective intervention programs to
22 maintain or improve health and quality of life.

23 (2) To nonprofit private health and disability
24 organizations for the purpose of—

1 (A) disseminating information to the pub-
2 lic;

3 (B) improving access to services for per-
4 sons living with paralysis and other physical
5 disabilities and their caregivers;

6 (C) testing model intervention programs to
7 improve health and quality of life; and

8 (D) coordinating existing services with
9 state-based disability and health programs.

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

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

19 (f) AUTHORIZATION OF APPROPRIATIONS.—For the
20 purpose of carrying out this section, there are authorized
21 to be appropriated such sums as may be necessary for
22 each of the fiscal years 2004 through 2007.

1 **TITLE IV—ACTIVITIES OF THE**
 2 **DEPARTMENT OF VETERANS**
 3 **AFFAIRS**

4 **SEC. 401. EXPANSION AND COORDINATION OF ACTIVITIES**
 5 **OF THE VETERANS HEALTH ADMINISTRA-**
 6 **TION.**

7 (a) IN GENERAL.—

8 (1) ENHANCED COORDINATION OF ACTIVI-
 9 TIES.—The Secretary of Veterans Affairs may ex-
 10 pand and coordinate activities of the Veterans
 11 Health Administration of the Department of Vet-
 12 erans Affairs with respect to research on paralysis.

13 (2) ADMINISTRATION OF PROGRAM.—The Sec-
 14 retary shall carry out this section through the Direc-
 15 tor of the Office of Research and Development of
 16 the Veterans Health Administration and in collabo-
 17 ration with the National Institutes of Health and
 18 other agencies the Secretary determines appropriate.

19 (b) ESTABLISHMENT OF PARALYSIS RESEARCH,
 20 EDUCATION, AND CLINICAL CARE CENTER.—

21 (1) IN GENERAL.—The Secretary may establish
 22 within the Department of Veterans Affairs centers
 23 for paralysis research, education and clinical activi-
 24 ties. Such centers shall be established at Depart-
 25 ment medical centers through the award of grants to

1 Department medical centers that are affiliated with
2 medical schools or other organizations the Secretary
3 considers appropriate. Such grants may be used to
4 pay all or part of the cost of planning, establishing,
5 improving, and providing basic operating support for
6 such centers.

7 (2) RESEARCH.—Each center under paragraph
8 (1)—

9 (A) may focus on basic biomedical research
10 on paralysis;

11 (B) may focus on rehabilitation research
12 on paralysis;

13 (C) may focus on health services and clin-
14 ical trials for paralysis that result from central
15 nervous system 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 centers
20 for scientific and translational purposes.

21 (3) COORDINATION OF CENTERS INTO CON-
22 SORTIA.—The Secretary may, as appropriate, pro-
23 vide for the linkage and coordination of information
24 among centers under paragraph (1) in order to cre-
25 ate national consortia of centers and ensure regular

1 communications between members of the centers.

2 Each such consortium—

3 (A) may conduct large-scale clinical trials
4 for greater statistical significance;

5 (B) may operate in an interdisciplinary re-
6 habilitation team;

7 (C) may focus on determining current
8 standards of care and best practices; and

9 (D) may identify research gaps for specific
10 populations and identify future research needs.

11 (4) ORGANIZATION OF CONSORTIA.—Each con-
12 sortium under paragraph (3) may use the facilities
13 of a single lead institution, or be formed from sev-
14 eral cooperating institutions, meeting such require-
15 ment as prescribed by the Secretary.

16 (5) REPORTS.—The Secretary may require the
17 periodic preparation of reports on the activities of
18 the centers and consortia and submission of such re-
19 ports to the Secretary.

20 (c) ESTABLISHMENT OF QUALITY ENHANCEMENT
21 RESEARCH INITIATIVES FOR PARALYSIS.—

22 (1) IN GENERAL.—The Secretary may carry out
23 initiatives for quality enhancement of research on
24 paralysis to translate clinical findings and rec-
25 ommendations into practices within the Veterans

1 Health Administration. The Secretary shall carry
2 out those initiatives through the award of grants to
3 Department of Veterans Affairs medical centers that
4 are affiliated with medical schools or other partners
5 the Secretary considers appropriate. Such grants
6 may be used to pay all or part of the cost of plan-
7 ning, establishing, improving and providing basic op-
8 erating support for the initiatives.

9 (2) ACTIVITIES.—Each medical center for
10 which funds are provided under paragraph (1)—

11 (A) may identify high-risk/high volume dis-
12 eases or problems;

13 (B) may formulate evidence-based clinical
14 research;

15 (C) may define existing practice patterns
16 and outcomes across the Veterans Health Ad-
17 ministration and current variation from best
18 practices;

19 (D) may identify and implement interven-
20 tions (including performance criteria) to pro-
21 mote best practices;

22 (E) may document that best practices im-
23 prove outcomes;

1 (F) may document that improved patient
2 outcomes are associated with improved health-
3 related quality of life;

4 (G) may develop, test, and refine, and fa-
5 cilitate active distribution of, tools and products
6 designed to promote clinical quality improve-
7 ments;

8 (H) may plan and prepare to launch at
9 least one project to implement and evaluate a
10 quality enhancement intervention program for
11 the translation of clinical research findings into
12 routine clinical practice within the Administra-
13 tion; and

14 (I) may compete for other Veterans Health
15 Administration and non-Veterans Health Ad-
16 ministration research projects to leverage core
17 support.

18 (d) MAINTENANCE OF EFFORT.—The Secretary may
19 make an award under this section only if, with respect
20 to activities for which the award is authorized to be ex-
21 pended, the applicant for the award agrees to maintain
22 expenditures of non-Federal amounts for such activities
23 at a level that is not less than the level of such expendi-
24 tures maintained by the applicant for the fiscal year pre-

1 ceding the first fiscal year for which the entity receives
2 such an award.

3 (e) PUBLIC INPUT.—The Secretary may under sub-
4 sections (a)(1) and (c)(1) provide for a mechanism—

5 (1) to educate the public on, and disseminate
6 information to the public on, the existing and
7 planned programs and research activities of the Vet-
8 erans Health Administration with respect to paral-
9 ysis; and

10 (2) through which the Secretary can receive
11 comments from the public regarding those programs
12 and activities.

13 (f) AUTHORIZATION OF APPROPRIATIONS.—For the
14 purposes of carrying out this section, there are authorized
15 to be appropriated such sums as may be necessary for
16 each of fiscal years 2004 through 2007. Amounts appro-
17 priated under this section are in addition to any other
18 amounts appropriated for such purpose.

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