

Calendar No. 326

110TH CONGRESS
1ST SESSION

S. 1183

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 23, 2007

Mr. HARKIN (for himself, Mr. COCHRAN, Mr. KENNEDY, Mr. BURR, Mrs. CLINTON, Mr. COLEMAN, Mr. BINGAMAN, Mr. SMITH, Mrs. BOXER, Mr. DURBIN, Mr. INOUE, Mr. LEAHY, Mr. LEVIN, Ms. MIKULSKI, Mr. REED, Mr. BROWN, Mr. GRAHAM, Mr. WHITEHOUSE, Mrs. MURRAY, Mr. JOHNSON, Mr. SCHUMER, Mr. MENENDEZ, Mr. LAUTENBERG, Mr. KERRY, Mr. SPECTER, Mr. CASEY, Mrs. FEINSTEIN, Mr. DODD, Mr. SANDERS, and Mr. OBAMA) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

AUGUST 3, 2007

Reported by Mr. KENNEDY, with an amendment

[Strike out all after the enacting clause and insert the part printed in *italic*]

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 and Dana
 5 Reeve Paralysis 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.

7 **TITLE I—PARALYSIS RESEARCH**

8 **SEC. 101. EXPANSION AND COORDINATION OF ACTIVITIES**

9 **OF THE NATIONAL INSTITUTES OF HEALTH**

10 **WITH RESPECT TO RESEARCH ON PARALYSIS.**

11 **(a) IN GENERAL.—**

12 **(1) ENHANCED COORDINATION OF ACTIVI-**

13 **TIES.—**The Director of the National Institutes of

14 Health (in this section referred to as the “Director”)

15 may expand and coordinate the activities of such In-

16 stitutes with respect to research on paralysis. In

17 order to further expand upon the activities of this

section, the Director may consider the methods outlined in the report under section 2(b) of Public Law 108-427 with respect to spinal cord injury and paralysis research (relating to the Roadmap for Medical Research of the National Institutes of Health).

(2) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES.—The Director shall carry out this section acting through the Director of the National Institute of Neurological Disorders and Stroke (in this section referred to as the “Institute”) and in collaboration with any other agencies that the Director determines appropriate.

(b) COORDINATION.—

(1) IN GENERAL.—The Director may develop mechanisms to coordinate the paralysis research and rehabilitation activities of the agencies of the National Institutes of Health in order to further advance such activities and avoid duplication of activities.

(2) REPORT.—Not later than December 1, 2008, the Director shall prepare a report to Congress that provides a description of the paralysis activities of the Institute and strategies for future activities.

1 ~~(c) CHRISTOPHER AND DANA REEVE PARALYSIS RE-~~
 2 ~~SEARCH CONSORTIA.—~~

3 ~~(1) IN GENERAL.—~~The Director may under
 4 subsection (a)(1) make awards of grants to public or
 5 nonprofit private entities to pay all or part of the
 6 cost of planning, establishing, improving, and pro-
 7 viding basic operating support for consortia in paral-
 8 ysis research. The Director shall designate each con-
 9 sortium funded under grants as a Christopher and
 10 Dana Reeve Paralysis Research Consortium.

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

13 ~~(A)~~ may conduct basic and clinical paral-
 14 ysis research;

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

17 ~~(C)~~ may focus on one or more forms of pa-
 18 ralysis that result from central nervous system
 19 trauma or stroke;

20 ~~(D)~~ may facilitate and enhance the dis-
 21 semination of clinical and scientific findings;
 22 and

23 ~~(E)~~ may replicate the findings of consortia
 24 members for scientific and translational pur-
 25 poses.

1 ~~(3) COORDINATION OF CONSORTIA; REPORTS.—~~

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

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

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

21 ~~(e) AUTHORIZATION OF APPROPRIATIONS.—~~For the
22 purpose of carrying out this section, there are authorized
23 to be appropriated such sums as may be necessary for the
24 fiscal years 2008 through 2011. Amounts appropriated

1 under this subsection are in addition to any other amounts
 2 appropriated for such purpose.

3 **TITLE II—PARALYSIS REHABILI-** 4 **TATION RESEARCH AND CARE**

5 **SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES** 6 **OF THE NATIONAL INSTITUTES OF HEALTH** 7 **WITH RESPECT TO RESEARCH WITH IMPLICA-** 8 **TIONS FOR ENHANCING DAILY FUNCTION** 9 **FOR PERSONS WITH PARALYSIS.**

10 (a) IN GENERAL.—

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

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

tion, and any other agencies that the Director determines appropriate.

(b) PARALYSIS CLINICAL TRIALS NETWORKS.—

(1) IN GENERAL.—The Director may make awards of grants to public or nonprofit private entities to pay all or part of the costs of planning, establishing, improving, and providing basic operating support to multicenter networks of clinical sites that will collaborate to design clinical rehabilitation intervention protocols and measures of outcomes on one 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 assisting technologies;

1 (iv) developing improved assistive
2 technology to improve function and inde-
3 pendence; and

4 (v) understanding whole body system
5 responses to physical impairments, disabil-
6 ities, and societal and functional limita-
7 tions; and

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

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

18 ~~(c) REPORT.—~~Not later than December 1, 2008, the
19 ~~Director shall submit to the Congress a report that pro-~~
20 ~~vides a description of research activities with implications~~
21 ~~for enhancing daily function for persons with paralysis.~~

22 ~~(d) AUTHORIZATION OF APPROPRIATIONS.—~~For the
23 ~~purpose of carrying out this section, there are authorized~~
24 ~~to be appropriated such sums as may be necessary for the~~
25 ~~fiscal years 2008 through 2011. Amounts appropriated~~

1 under this subsection are in addition to any other amounts
 2 appropriated for such purpose.

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

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

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

20 (b) CERTAIN ACTIVITIES.—Activities under sub-
 21 section (a) may include—

22 (1) the development of a national paralysis and
 23 physical disability quality of life action plan, to pro-
 24 mote health and wellness in order to enhance full
 25 participation, independent living, self-sufficiency and

1 equality of opportunity in partnership with voluntary
 2 health agencies focused on paralysis and other phys-
 3 ical disabilities; to be carried out in coordination
 4 with the State-based Comprehensive Paralysis and
 5 Other Physical Disability Quality of Life Program of
 6 the Centers for Disease Control and Prevention;

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

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

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

24 (A) caregiver education;

25 (B) physical activity;

1 (C) education and awareness programs for
2 health care providers;

3 (D) prevention of secondary complications;

4 (E) home and community-based interven-
5 tions;

6 (F) coordinating services and removing
7 barriers that prevent full participation and inte-
8 gration into the community; and

9 (G) recognizing the unique needs of under-
10 served populations.

11 (e) GRANTS.—The Secretary may award grants in ac-
12 cordance with the following:

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

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

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

21 (C) assisting State-based programs in es-
22 tablishing and implementing partnerships and
23 collaborations that maximize the input and sup-
24 port of people with paralysis and other physical
25 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 ensure 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, 2008, the Secretary shall submit to the Congress~~
 3 ~~a report 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 such sums as may be necessary for the~~
 9 ~~fiscal years 2008 through 2011.~~

10 **SECTION 1. SHORT TITLE.**

11 *This Act may be cited as the “Christopher and Dana*
 12 *Reeve Paralysis Act”.*

13 **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.

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) *COORDINATION.*—*The Director of the National In-*
6 *stitutes of Health (referred to in this Act as the “Director”),*
7 *pursuant to the general authority of the Director, may de-*
8 *velop mechanisms to coordinate the paralysis research and*
9 *rehabilitation activities of the Institutes and Centers of the*
10 *National Institutes of Health in order to further advance*
11 *such activities and avoid duplication of activities.*

12 (b) *CHRISTOPHER AND DANA REEVE PARALYSIS RE-*
13 *SEARCH CONSORTIA.*—

14 (1) *IN GENERAL.*—*The Director may under sub-*
15 *section (a) make awards of grants to public or private*
16 *entities to pay all or part of the cost of planning, es-*
17 *tablishing, improving, and providing basic operating*
18 *support for consortia in paralysis research. The Di-*
19 *rector shall designate each consortium funded under*
20 *grants as a Christopher and Dana Reeve Paralysis*
21 *Research Consortium.*

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

24 (A) *may conduct basic, translational and*
25 *clinical paralysis research;*

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

3 (C) may focus on one or more forms of pa-
4 ralysis that result from central nervous system
5 trauma or stroke;

6 (D) may facilitate and enhance the dissemi-
7 nation of clinical and scientific findings; and

8 (E) may replicate the findings of consortia
9 members or other researchers for scientific and
10 translational purposes.

11 (3) COORDINATION OF CONSORTIA; REPORTS.—

12 *The Director may, as appropriate, provide for the co-*
13 *ordination of information among consortia under*
14 *paragraph (1) and ensure regular communication be-*
15 *tween members of the consortia, and may require the*
16 *periodic preparation of reports on the activities of the*
17 *consortia and the submission of the reports to the Di-*
18 *rector.*

19 (4) ORGANIZATION OF CONSORTIA.—*Each con-*
20 *sortium under paragraph (1) may use the facilities of*
21 *a single lead institution, or be formed from several co-*
22 *operating institutions, meeting such requirements as*
23 *may be prescribed by the Director.*

24 (c) PUBLIC INPUT.—*The Director may provide for a*
25 *mechanism to educate and disseminate information on the*

1 *existing and planned programs and research activities of*
 2 *the National Institutes of Health with respect to paralysis*
 3 *and through which the Director can receive comments from*
 4 *the public regarding such programs and activities.*

5 ***TITLE II—PARALYSIS REHABILI-***
 6 ***TATION RESEARCH AND CARE***

7 ***SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES***
 8 ***OF THE NATIONAL INSTITUTES OF HEALTH***
 9 ***WITH RESPECT TO RESEARCH WITH IMPLICA-***
 10 ***TIONS FOR ENHANCING DAILY FUNCTION***
 11 ***FOR PERSONS WITH PARALYSIS.***

12 *(a) IN GENERAL.—The Director, pursuant to the gen-*
 13 *eral authority of the Director, may make awards of grants*
 14 *to public or private entities to pay all or part of the costs*
 15 *of planning, establishing, improving, and providing basic*
 16 *operating support to multicenter networks of clinical sites*
 17 *that will collaborate to design clinical rehabilitation inter-*
 18 *vention protocols and measures of outcomes on one or more*
 19 *forms of paralysis that result from central nervous system*
 20 *trauma, disorders, or stroke, or any combination of such*
 21 *conditions.*

22 *(b) RESEARCH.—Each multicenter clinical trial net-*
 23 *work may—*

24 *(1) focus on areas of key scientific concern, in-*
 25 *cluding—*

1 (A) *improving functional mobility;*

2 (B) *promoting behavioral adaptation to*
 3 *functional losses, especially to prevent secondary*
 4 *complications;*

5 (C) *assessing the efficacy and outcomes of*
 6 *medical rehabilitation therapies and practices*
 7 *and assisting technologies;*

8 (D) *developing improved assistive tech-*
 9 *nology to improve function and independence;*
 10 *and*

11 (E) *understanding whole body system re-*
 12 *sponses to physical impairments, disabilities,*
 13 *and societal and functional limitations; and*

14 (2) *replicate the findings of network members for*
 15 *scientific and translation purposes.*

16 (c) *COORDINATION OF CLINICAL TRIALS NETWORKS;*
 17 *REPORTS.—The Director may, as appropriate, provide for*
 18 *the coordination of information among networks and ensure*
 19 *regular communication between members of the networks,*
 20 *and may require the periodic preparation of reports on the*
 21 *activities of the networks and submission of reports to the*
 22 *Director.*

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 PHYS-***
 7 ***ICAL DISABILITIES.***

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

16 (b) *CERTAIN ACTIVITIES.*—Activities under subsection
 17 (a) may include—

18 (1) *the development of a national paralysis and*
 19 *physical disability quality of life action plan, to pro-*
 20 *mote health and wellness in order to enhance full par-*
 21 *ticipation, independent living, self-sufficiency and*
 22 *equality of opportunity in partnership with vol-*
 23 *untary health agencies focused on paralysis and other*
 24 *physical disabilities, to be carried out in coordination*

1 *with the State-based Disability and Health Program*
 2 *of the Centers for Disease Control and Prevention;*

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

8 (3) *in collaboration with other centers and na-*
 9 *tional voluntary health agencies, establish a popu-*
 10 *lation-based database that may be used for longitu-*
 11 *dinal and other research on paralysis and other dis-*
 12 *abling conditions; and*

13 (4) *the replication and translation of best prac-*
 14 *tices and the sharing of information across States, as*
 15 *well as the development of comprehensive, unique and*
 16 *innovative programs, services, and demonstrations*
 17 *within existing State-based disability and health pro-*
 18 *grams of the Centers for Disease Control and Preven-*
 19 *tion which are designed to support and advance qual-*
 20 *ity of life programs for persons living with paralysis*
 21 *and other physical disabilities focusing on—*

22 (A) *caregiver education;*

23 (B) *promoting proper nutrition, increasing*
 24 *physical activity, and reducing tobacco use;*

1 (C) education and awareness programs for
2 health care providers;

3 (D) prevention of secondary complications;

4 (E) home and community-based interven-
5 tions;

6 (F) coordinating services and removing bar-
7 riers that prevent full participation and integra-
8 tion into the community; and

9 (G) recognizing the unique needs of under-
10 served populations.

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

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

15 (A) establishing a population-based data-
16 base that may be used for longitudinal and other
17 research on paralysis and other disabling condi-
18 tions;

19 (B) developing comprehensive paralysis and
20 other physical disability action plans and activi-
21 ties focused on the items listed in subsection
22 (b)(4);

23 (C) assisting State-based programs in estab-
24 lishing and implementing partnerships and col-
25 laborations that maximize the input and support

1 *of people with paralysis and other physical dis-*
 2 *abilities and their constituent organizations;*

3 *(D) coordinating paralysis and physical*
 4 *disability activities with existing State-based*
 5 *disability and health programs;*

6 *(E) providing education and training op-*
 7 *portunities and programs for health professionals*
 8 *and allied caregivers; and*

9 *(F) developing, testing, evaluating, and rep-*
 10 *licating effective intervention programs to main-*
 11 *tain or improve health and quality of life.*

12 *(2) To private health and disability organiza-*
 13 *tions for the purpose of—*

14 *(A) disseminating information to the pub-*
 15 *lic;*

16 *(B) improving access to services for persons*
 17 *living with paralysis and other physical disabil-*
 18 *ities and their caregivers;*

19 *(C) testing model intervention programs to*
 20 *improve health and quality of life; and*

21 *(D) coordinating existing services with*
 22 *State-based disability and health programs.*

23 *(d) COORDINATION OF ACTIVITIES.—The Secretary*
 24 *shall ensure that activities under this section are coordi-*

1 *nated as appropriate with other agencies of the Department*
2 *of Health and Human Services.*

3 *(e) AUTHORIZATION OF APPROPRIATIONS.—For the*
4 *purpose of carrying out this section, there are authorized*
5 *to be appropriated \$25,000,000 for each of fiscal years 2008*
6 *through 2011.*

Calendar No. 326

110TH CONGRESS
1ST Session

S. 1183

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.

AUGUST 3, 2007

Reported with an amendment