

110TH CONGRESS
1ST SESSION

H. R. 1727

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 HOUSE OF REPRESENTATIVES

MARCH 28, 2007

Ms. BALDWIN (for herself, Mrs. BONO, Mr. LANGEVIN, and Mr. BILIRAKIS) introduced the following bill; which was referred to the Committee on Energy and Commerce

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.

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. In
 10 order to further expand upon the activities of this
 11 section, the Director may consider the methods out-
 12 lined in the report under section 2(b) of Public Law
 13 108–427 with respect to spinal cord injury and pa-
 14 ralysis research (relating to the Roadmap for Med-
 15 ical Research of the National Institutes of Health).

17 (2) ADMINISTRATION OF PROGRAM; COLLABO-
 18 RATION AMONG AGENCIES.—The Director shall carry

1 out this section acting through the Director of the
2 National Institute of Neurological Disorders and
3 Stroke (in this section referred to as the “Institute”)
4 and in collaboration with any other agencies that the
5 Director determines appropriate.

6 (b) COORDINATION.—

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

13 (2) REPORT.—Not later than December 1,
14 2008, the Director shall prepare a report to Con-
15 gress that provides a description of the paralysis ac-
16 tivities of the Institute and strategies for future ac-
17 tivities.

18 (c) CHRISTOPHER AND DANA REEVE PARALYSIS RE-
19 SEARCH CONSORTIA.—

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

1 consortium funded under grants as a Christopher and
2 Dana Reeve Paralysis Research Consortium.

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

5 (A) may conduct basic and clinical paral-
6 ysis research;

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

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

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

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

18 (3) COORDINATION OF CONSORTIA; REPORTS.—

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

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

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

13 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
14 purpose of carrying out this section, there are authorized
15 to be appropriated such sums as may be necessary for the
16 fiscal years 2008 through 2011. Amounts appropriated
17 under this subsection are in addition to any other amounts
18 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 of 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 of 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, 2008, 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 such sums as may be necessary for the
22 fiscal years 2008 through 2011. 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) may 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 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.

○