

Union Calendar No. 15

111TH CONGRESS
1ST SESSION

H. R. 307

[Report No. 111-45]

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

JANUARY 8, 2009

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

MARCH 23, 2009

Additional sponsors: Ms. HERSETH SANDLIN, Mr. GORDON of Tennessee, Ms. SUTTON, Mr. MARKEY of Massachusetts, Mr. INSLEE, and Ms. SCHAKOWSKY

MARCH 23, 2009

Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

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. Activities of the National Institutes of Health with respect to re-
 search on paralysis.

TITLE II—PARALYSIS REHABILITATION RESEARCH AND CARE

Sec. 201. Activities of the National Institutes of Health with respect to re-
 search with implications for enhancing daily function for per-
 sons 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. ACTIVITIES OF THE NATIONAL INSTITUTES OF**

9 **HEALTH WITH RESPECT TO RESEARCH ON**

10 **PARALYSIS.**

11 (a) COORDINATION.—The Director of the National
 12 Institutes of Health (referred to in this Act as the “Direc-
 13 tor”), pursuant to the general authority of the Director,
 14 may develop mechanisms to coordinate the paralysis re-
 15 search and rehabilitation activities of the Institutes and
 16 Centers of the National Institutes of Health in order to

1 further advance such activities and avoid duplication of
2 activities.

3 (b) CHRISTOPHER AND DANA REEVE PARALYSIS RE-
4 SEARCH CONSORTIA.—

5 (1) IN GENERAL.—The Director may make
6 awards of grants to public or private entities to pay
7 all or part of the cost of planning, establishing, im-
8 proving, and providing basic operating support for
9 consortia in paralysis research. The Director shall
10 designate each consortium funded through such
11 grants as a Christopher and Dana Reeve Paralysis
12 Research Consortium.

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

15 (A) may conduct basic, translational, and
16 clinical paralysis research;

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

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

22 (D) may facilitate and enhance the dis-
23 semination of clinical and scientific findings;
24 and

1 (E) may replicate the findings of consortia
2 members or other researchers for scientific and
3 translational purposes.

4 (3) COORDINATION OF CONSORTIA; REPORTS.—

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

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

17 (c) PUBLIC INPUT.—The Director may provide for a
18 mechanism to educate and disseminate information on the
19 existing and planned programs and research activities of
20 the National Institutes of Health with respect to paralysis
21 and through which the Director can receive comments
22 from the public regarding such programs and activities.

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

3 **SEC. 201. ACTIVITIES OF THE NATIONAL INSTITUTES OF**
4 **HEALTH WITH RESPECT TO RESEARCH WITH**
5 **IMPLICATIONS FOR ENHANCING DAILY FUNC-**
6 **TION FOR PERSONS WITH PARALYSIS.**

7 (a) IN GENERAL.—The Director, pursuant to the
8 general authority of the Director, may make awards of
9 grants to public or private entities to pay all or part of
10 the costs of planning, establishing, improving, and pro-
11 viding basic operating support to multicenter networks of
12 clinical sites that will collaborate to design clinical reha-
13 bilitation intervention protocols and measures of outcomes
14 on one or more forms of paralysis that result from central
15 nervous system trauma, disorders, or stroke, or any com-
16 bination of such conditions.

17 (b) RESEARCH.—A multicenter network of clinical
18 sites funded through this section may—

19 (1) focus on areas of key scientific concern, in-
20 cluding—

21 (A) improving functional mobility;

22 (B) promoting behavioral adaptation to
23 functional losses, especially to prevent sec-
24 ondary complications;

1 (C) assessing the efficacy and outcomes of
2 medical rehabilitation therapies and practices
3 and assisting technologies;

4 (D) developing improved assistive tech-
5 nology to improve function and independence;
6 and

7 (E) understanding whole body system re-
8 sponses to physical impairments, disabilities,
9 and societal and functional limitations; and

10 (2) replicate the findings of network members
11 or other researchers for scientific and translation
12 purposes.

13 (c) COORDINATION OF CLINICAL TRIALS NETWORKS;
14 REPORTS.—The Director may, as appropriate, provide for
15 the coordination of information among networks funded
16 through this section and ensure regular communication
17 among members of the networks, and may require the
18 periodic preparation of reports on the activities of the net-
19 works and submission of reports to the 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**
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”) may study the unique health challenges associ-
11 ated with paralysis and other physical disabilities and
12 carry out projects and interventions to improve the quality
13 of life and long-term health status of persons with paral-
14 ysis and other physical disabilities. The Secretary may
15 carry out such projects directly and through awards of
16 grants or contracts.

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

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

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

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

9 (3) in collaboration with other centers and na-
10 tional voluntary health agencies, the establishment
11 of a population-based database that may be used for
12 longitudinal and other research on paralysis and
13 other disabling conditions; and

14 (4) the replication and translation of best prac-
15 tices and the sharing of information across States,
16 as well as 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;

1 (B) promoting proper nutrition, increasing
2 physical activity, and reducing tobacco use;

3 (C) education and awareness programs for
4 health care providers;

5 (D) prevention of secondary complications;

6 (E) home- and community-based interven-
7 tions;

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

11 (G) recognizing the unique needs of under-
12 served populations.

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

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

17 (A) establishing a population-based data-
18 base that may be used for longitudinal and
19 other research on paralysis and other disabling
20 conditions;

21 (B) developing comprehensive paralysis
22 and other physical disability action plans and
23 activities focused on the items listed in sub-
24 section (b)(4);

1 (C) assisting State-based programs in es-
2 tablishing and implementing partnerships and
3 collaborations that maximize the input and sup-
4 port of people with paralysis and other physical
5 disabilities and their constituent organizations;

6 (D) coordinating paralysis and physical
7 disability activities with existing State-based
8 disability and health programs;

9 (E) providing education and training op-
10 portunities and programs for health profes-
11 sionals and allied caregivers; and

12 (F) developing, testing, evaluating, and
13 replicating effective intervention programs to
14 maintain or improve health and quality of life.

15 (2) To private health and disability organiza-
16 tions for the purpose of—

17 (A) disseminating information to the pub-
18 lic;

19 (B) improving access to services for per-
20 sons living with paralysis and other physical
21 disabilities and their caregivers;

22 (C) testing model intervention programs to
23 improve health and quality of life; and

24 (D) coordinating existing services with
25 State-based disability and health programs.

1 (d) COORDINATION OF ACTIVITIES.—The Secretary
2 shall ensure that activities under this section are coordi-
3 nated as appropriate by the agencies of the Department
4 of Health and Human Services.

5 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
6 purpose of carrying out this section, there is authorized
7 to be appropriated \$25,000,000 for each of fiscal years
8 2010 through 2013.

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