

111TH CONGRESS
1ST SESSION

H. R. 307

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

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 research on paralysis.

TITLE II—PARALYSIS REHABILITATION RESEARCH AND CARE

Sec. 201. 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. ACTIVITIES OF THE NATIONAL INSTITUTES OF**
 3 **HEALTH WITH RESPECT TO RESEARCH ON**
 4 **PARALYSIS.**

5 (a) COORDINATION.—The Director of the National
 6 Institutes of Health (referred to in this Act as the “Direc-
 7 tor”), pursuant to the general authority of the Director,
 8 may develop mechanisms to coordinate the paralysis re-
 9 search and rehabilitation activities of the Institutes and
 10 Centers of the National Institutes of Health in order to
 11 further advance such activities and avoid duplication of
 12 activities.

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

15 (1) IN GENERAL.—The Director may make
 16 awards of grants to public or private entities to pay
 17 all or part of the cost of planning, establishing, im-
 18 proving, and providing basic operating support for

1 consortia in paralysis research. The Director shall
2 designate each consortium funded through such
3 grants as a Christopher and Dana Reeve Paralysis
4 Research Consortium.

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

7 (A) may conduct basic, translational, and
8 clinical paralysis research;

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

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

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

17 (E) may replicate the findings of consortia
18 members or other researchers for scientific and
19 translational purposes.

20 (3) COORDINATION OF CONSORTIA; REPORTS.—

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

1 of the consortia and the submission of the reports to
 2 the Director.

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

8 (c) PUBLIC INPUT.—The Director may provide for a
 9 mechanism to educate and disseminate information on the
 10 existing and planned programs and research activities of
 11 the National Institutes of Health with respect to paralysis
 12 and through which the Director can receive comments
 13 from the public regarding such programs and activities.

14 **TITLE II—PARALYSIS REHABILI-** 15 **TATION RESEARCH AND CARE**

16 **SEC. 201. ACTIVITIES OF THE NATIONAL INSTITUTES OF** 17 **HEALTH WITH RESPECT TO RESEARCH WITH** 18 **IMPLICATIONS FOR ENHANCING DAILY FUNC-** 19 **TION FOR PERSONS WITH PARALYSIS.**

20 (a) IN GENERAL.—The Director, pursuant to the
 21 general authority of the Director, may make awards of
 22 grants to public or private entities to pay all or part of
 23 the costs of planning, establishing, improving, and pro-
 24 viding basic operating support to multicenter networks of
 25 clinical sites that will collaborate to design clinical reha-

1 bilitation intervention protocols and measures of outcomes
2 on one or more forms of paralysis that result from central
3 nervous system trauma, disorders, or stroke, or any com-
4 bination of such conditions.

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

7 (1) focus on areas of key scientific concern, in-
8 cluding—

9 (A) improving functional mobility;

10 (B) promoting behavioral adaptation to
11 functional losses, especially to prevent sec-
12 ondary complications;

13 (C) assessing the efficacy and outcomes of
14 medical rehabilitation therapies and practices
15 and assisting technologies;

16 (D) developing improved assistive tech-
17 nology to improve function and independence;
18 and

19 (E) understanding whole body system re-
20 sponses to physical impairments, disabilities,
21 and societal and functional limitations; and

22 (2) replicate the findings of network members
23 or other researchers for scientific and translation
24 purposes.

1 (c) COORDINATION OF CLINICAL TRIALS NETWORKS;
 2 REPORTS.—The Director may, as appropriate, provide for
 3 the coordination of information among networks funded
 4 through this section and ensure regular communication
 5 among members of the networks, and may require the
 6 periodic preparation of reports on the activities of the net-
 7 works and submission of reports to the Director.

8 **TITLE III—IMPROVING QUALITY**
 9 **OF LIFE FOR PERSONS WITH**
 10 **PARALYSIS AND OTHER PHYS-**
 11 **ICAL DISABILITIES**

12 **SEC. 301. PROGRAMS TO IMPROVE QUALITY OF LIFE FOR**
 13 **PERSONS WITH PARALYSIS AND OTHER**
 14 **PHYSICAL DISABILITIES.**

15 (a) IN GENERAL.—The Secretary of Health and
 16 Human Services (in this title referred to as the “Sec-
 17 retary”) may study the unique health challenges associ-
 18 ated with paralysis and other physical disabilities and
 19 carry out projects and interventions to improve the quality
 20 of life and long-term health status of persons with paral-
 21 ysis and other physical disabilities. The Secretary may
 22 carry out such projects directly and through awards of
 23 grants or contracts.

24 (b) CERTAIN ACTIVITIES.—Activities under sub-
 25 section (a) may include—

1 (1) the development of a national paralysis and
2 physical disability quality of life action plan, to pro-
3 mote health and wellness in order to enhance full
4 participation, independent living, self-sufficiency,
5 and equality of opportunity in partnership with vol-
6 untary health agencies focused on paralysis and
7 other physical disabilities, to be carried out in co-
8 ordination with the State-based Disability and
9 Health Program of the Centers for Disease Control
10 and Prevention;

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

16 (3) in collaboration with other centers and na-
17 tional voluntary health agencies, the establishment
18 of a population-based database that may be used for
19 longitudinal and other research on paralysis and
20 other disabling conditions; and

21 (4) the replication and translation of best prac-
22 tices and the sharing of information across States,
23 as well as the development of comprehensive, unique,
24 and innovative programs, services, and demonstra-
25 tions within existing State-based disability and

1 health programs of the Centers for Disease Control
2 and Prevention which are designed to support and
3 advance quality of life programs for persons living
4 with paralysis and other physical disabilities focus-
5 ing on—

6 (A) caregiver education;

7 (B) promoting proper nutrition, increasing
8 physical activity, and reducing tobacco use;

9 (C) education and awareness programs for
10 health care providers;

11 (D) prevention of secondary complications;

12 (E) home- and community-based interven-
13 tions;

14 (F) coordinating services and removing
15 barriers that prevent full participation and inte-
16 gration into the community; and

17 (G) recognizing the unique needs of under-
18 served populations.

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

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

23 (A) establishing a population-based data-
24 base that may be used for longitudinal and

1 other research on paralysis and other disabling
2 conditions;

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

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

12 (D) coordinating paralysis and physical
13 disability activities with existing State-based
14 disability and health programs;

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

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

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

23 (A) disseminating information to the pub-
24 lic;

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

4 (C) testing model intervention programs to
5 improve health and quality of life; and

6 (D) coordinating existing services with
7 State-based disability and health programs.

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

12 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
13 purpose of carrying out this section, there is authorized
14 to be appropriated \$25,000,000 for each of fiscal years
15 2010 through 2013.

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