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. BILI-Rakis) 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.
Be it enacted by the Senate and House of Representa-
tives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

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.

TITLE I—PARALYSIS RESEARCH

SEC. 101. ACTIVITIES OF THE NATIONAL INSTITUTES OF
HEALTH WITH RESPECT TO RESEARCH ON
PARALYSIS.

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

(b) Christopher and Dana Reeve Paralysis Re-
search Consortia.—

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

(2) Research.—Each consortium under para-
graph (1)—

(A) may conduct basic, translational, 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 pa-
ralysis that result from central nervous system
trauma or stroke;

(D) may facilitate and enhance the dis-
semination of clinical and scientific findings; and
(E) may replicate the findings of consortia members or other researchers 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 among 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 of a single lead institution, or be formed from several cooperating institutions, meeting such requirements as may be prescribed by the Director.

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

(a) In General.—The Director, pursuant to the general authority of the Director, may make awards of grants to public or 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.

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

(1) focus on areas of key scientific concern, including—

(A) improving functional mobility;

(B) promoting behavioral adaptation to functional losses, especially to prevent secondary complications;
(C) assessing the efficacy and outcomes of medical rehabilitation therapies and practices and assisting technologies;
(D) developing improved assistive technology to improve function and independence; and
(E) understanding whole body system responses to physical impairments, disabilities, and societal and functional limitations; and
(2) replicate the findings of network members or other researchers for scientific and translation purposes.

(e) COORDINATION OF CLINICAL TRIALS NETWORKS;

REPORTS.—The Director may, as appropriate, provide for the coordination of information among networks funded through this section and ensure regular communication among members of the networks, and may require the periodic preparation of reports on the activities of the networks and submission of reports to the Director.
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.

(a) In general.—The Secretary of Health and Human Services (in this title referred to as the “Secretary”) may study the unique health challenges associated with paralysis and other physical disabilities and carry out projects and interventions to improve the quality of life and long-term health status of persons with paralysis and other physical disabilities. The Secretary may carry out such projects directly and through awards of grants or contracts.

(b) Certain activities.—Activities under subsection (a) may include—

(1) the development of a national paralysis and physical disability quality of life action plan, to promote health and wellness in order to enhance full participation, independent living, self-sufficiency, and equality of opportunity in partnership with voluntary health agencies focused on paralysis and other physical disabilities, to be carried out in co-
ordination with the State-based Disability and Health Program of the Centers for Disease Control and Prevention;

(2) support for programs to disseminate information involving care and rehabilitation options and quality of life grant programs supportive of community-based programs and support systems for persons with paralysis and other physical disabilities;

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

(4) the replication and translation of best practices and the sharing of information across States, as well as the development of comprehensive, unique, and innovative programs, services, and demonstrations within existing State-based disability and health programs of the Centers for Disease Control and Prevention which are designed to support and advance quality of life programs for persons living with paralysis and other physical disabilities focusing on—

(A) caregiver education;
(B) promoting proper nutrition, increasing physical activity, and reducing tobacco use;

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

(D) prevention of secondary complications;

(E) home- and community-based interventions;

(F) coordinating services and removing barriers that prevent full participation and integration into the community; and

(G) recognizing the unique needs of underserved populations.

(c) GRANTS.—The Secretary may award grants in accordance with the following:

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

(A) establishing a population-based database that may be used for longitudinal and other research on paralysis and other disabling conditions;

(B) developing comprehensive paralysis and other physical disability action plans and activities focused on the items listed in subsection (b)(4);
(C) assisting State-based programs in establishing and implementing partnerships and collaborations that maximize the input and support of people with paralysis and other physical disabilities and their constituent organizations;

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

(E) providing education and training opportunities and programs for health professionals and allied caregivers; and

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

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

(A) disseminating information to the public;

(B) improving access to services for persons living with paralysis and other physical disabilities and their caregivers;

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

(D) coordinating existing services with State-based disability and health programs.
(d) COORDINATION OF ACTIVITIES.—The Secretary shall ensure that activities under this section are coordinated as appropriate by the agencies of the Department of Health and Human Services.

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

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