110TH CONGRESS
1st Session
HOUSE OF REPRESENTATIVES
REPORT
110–378

CHRISTOPHER AND DANA REEVE PARALYSIS ACT

OCTOBER 15, 2007.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. DINGELL, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 1727]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (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, having considered the same, report favorably thereon with an amendment and recommend that the bill as amended do pass.

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69–006

AMENDMENT

The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

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

SEC. 2. TABLE OF CONTENTS.

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 "Director"), pursuant to the general authority of the Director, may develop mechanisms to coordinate the paralysis research 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 RESEARCH 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, improving, 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 paragraph (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 paralysis that result from central nervous system trauma or stroke;

(D) may facilitate and enhance the dissemination 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.

(c) 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 coordination 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 2008 through 2011.

PURPOSE AND SUMMARY

The purpose of H.R. 1727, the Christopher and Dana Reeve Paralysis Act, is 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.

BACKGROUND AND NEED FOR LEGISLATION

It is estimated that a quarter of a million Americans are currently living with spinal cord injuries and approximately 4 to 5 million Americans are living with paralysis of the extremities. There are an estimated 10,000 to 12,000 spinal cord injuries every year in the United States.

Spinal cord injuries often occur because, although the hard bones of the spinal column protect the soft tissues of the spinal cord, vertebrae can still be broken or dislocated in a variety of ways and cause traumatic injury to the spinal cord. Injuries can occur at any level of the spinal cord. The segment of the cord that is injured, and the severity of the injury, will determine which body functions are compromised or lost. Because the spinal cord acts as the main information pathway between the brain and the rest of the body, a spinal cord injury can have significant physiological consequences.

Catastrophic falls, being thrown from a horse or through a windshield, or any kind of physical trauma that crushes and compresses the vertebrae in the neck, can cause irreversible damage at the cervical level of the spinal cord and below. Paralysis of most of the body including the arms and legs, called quadriplegia, is the likely result. Automobile accidents are often responsible for spinal cord damage in the middle back—the thoracic or lumbar area—which can cause paralysis of the lower trunk and lower extremities, called paraplegia.

Most injuries to the spinal cord do not completely sever the spinal cord. Instead, an injury is more likely to cause fractures and compression of the vertebrae, which then crush and destroy the axons—extensions of nerve cells that carry signals up and down the spinal cord between the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or nearly all of these axons. Some injuries will allow almost complete recovery, while others will result in complete paralysis.

HEARINGS

The Committee on Energy and Commerce has not held hearings on the legislation.

COMMITTEE CONSIDERATION

On Thursday, September 27, 2007, the Committee on Energy and Commerce met in open markup session and ordered H.R. 1727 favorably reported to the House, amended, by a voice vote.

COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. There were no record votes taken during consideration or in ordering reported H.R. 1727 to the House. A motion by Mr. Dingell to order H.R. 1727 favorably reported to the House, amended, was agreed to by a voice vote.

COMMITTEE OVERSIGHT FINDINGS

Regarding clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the oversight findings of the Committee are reflected in this report.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

H.R. 1727 states that the Director of the National Institutes of Health (NIH) may develop mechanisms to coordinate the paralysis research and rehabilitation activities of the Institutes and Centers of NIH in order to further advance such activities and avoid duplication of activities. H.R. 1727 permits the Director of NIH to make awards of grants to public or private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for consortia in paralysis research and requires that the Director shall designate each consortium, funded through such grants, as a Christopher and Dana Reeve Paralysis Research Consortium. This legislation permits the Secretary of Health and Human Services (HHS) to study the 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 individuals with such conditions. H.R. 1727 permits the Secretary to award grants for activities related to paralysis, including to: (1) establish paralysis registries, and (2) disseminate information to the public.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 1727 would result in no new or increased budget authority, entitlement authority, or tax expenditures.

EARMARKS AND TAX AND TARIFF BENEFITS

In compliance with clause 9 of rule XXI of the Rules of the House of Representatives, H.R. 1727 does not contain any congressional earmarks, limited tax benefits, or limited tariff benefits as defined in clause 9(d), 9(e), or 9(f) of rule XXI.

COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, October 15, 2007.

Hon. JOHN D. DINGELL,
Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 1727, the Christopher and Dana Reeve Paralysis Act.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Sarah Evans.

Sincerely,

ROBERT A. SUNSHINE
(For Peter R. Orszag, Director).

Enclosure.

H.R. 1727—Christopher and Dana Reeve Paralysis Act

Summary: H.R. 1727 would authorize the appropriation of $25 million a year for fiscal years 2008 through 2011 for the Secretary of Health and Human Services (HHS) to undertake activities to improve the quality of life of those with paralysis and to establish a population-based database to be used for paralysis research. The bill also would authorize the Director of the National Institutes of

Health (NIH) to award grants for the cost of planning, establishing, improving, and providing basic operating support to consortia focused on paralysis research and for multicenter networks focused on paralysis rehabilitation.

CBO estimates that implementing the bill would cost $10 million in 2008 and $93 million over the 2008–2012 period, assuming the appropriation of the authorized amounts. Enacting H.R. 1727 would not affect direct spending or revenues.

The bill contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act (UMRA); any costs to state and local governments would be incurred voluntarily.

Estimated cost to the Federal Government: The estimated budgetary impact of H.R. 1727 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—				
	2008	2009	2010	2011	2012
CHANGES IN SPENDING SUBJECT TO APPROPRIATION					
Authorization Level	25	25	25	25	0
Estimated Outlays	10	20	24	24	15

Basis of estimate: For this estimate, CBO assumes that H.R. 1727 will be enacted near the start of fiscal year 2008 and that the authorized amounts will be appropriated for each year.

HHS grants for paralysis-related activities

H.R. 1727 would authorize the appropriation of $25 million for each of fiscal years 2008 through 2011 for the Secretary of Health and Human Services to conduct studies and undertake activities to improve the quality of life with persons with paralysis, and to make grants to state and local agencies to establish a research database on paralysis. Based on historical spending patterns for similar activities, CBO estimates that implementing H.R. 1727 would cost $10 million in 2008 and $93 million over the 2008–2012 period.

NIH support for research consortia

H.R. 1727 would explicitly authorize the Director of the NIH to award grants to public or private organizations for the cost of planning, establishing, improving, and providing basic operating support for consortia focused on paralysis research. Each consortium, which could be a single institution or multiple institutions, would be designated as a Christopher and Dana Reeve Paralysis Research Consortium.

The bill also would authorize the Director of the NIH to award grants to public or private entities for planning, establishing, improving, and providing basic operating support for multi-center networks that would collaborate to design protocols for clinical intervention.

According to officials at the NIH, the institutes are currently funding such activities. In fiscal year 2006, the NIH spent $342 million on stroke research, $85 million on traumatic brain injury research, and $66 million on spinal cord injury research. Among the research funded with this money are several research net-

works. For example, the Neurological Emergency Treatment Trials network funded through the National Institutes of Neurological Disorders and Stroke seeks to engage providers on the front lines in emergency rooms to carry out multi-center clinical trials to understand neurological emergencies. The National Institute for Child Health and Human Development (NICHD) funds several research networks. For example, in fiscal year 2006, NICHD funded six grants to build research infrastructure in the field of medical rehabilitation.

If H.R. 1727 were enacted, the most significant change at NIH would likely be the naming of research consortia after Christopher and Dana Reeve. CBO estimates that the NIH provisions of H.R. 1727 would not have any significant cost.

Intergovernmental and private-sector impact: H.R. 1727 contains no intergovernmental or private-sector mandates as defined in UMRA. Grants and research activities authorized in the bill for the study and treatment of paralysis and other physical disabilities would benefit state and local governments. Any costs to those governments to comply with grant conditions would be incurred voluntarily.

Previous CBO estimate: On September 6, 2007, CBO transmitted an estimate for S. 1183 as reported by the Senate Committee on Health, Education, Labor and Pensions on August 3, 2007. The two versions of the legislation are similar, and the estimated costs over five years are the same.

Estimate prepared by: Federal costs: Sarah Evans and Tim Gronniger; Impact on state, local, and tribal governments: Lisa Ramirez-Branum; Impact on the private sector: Keisuke Nakagawa.

Estimate approved by: Keith J. Fontenot, Deputy Assistant Director for Health and Human Resources, Budget Analysis Division.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for this legislation is provided in the provisions of Article I, section 8, clause 1, that relate to expending funds to provide for the general welfare of the United States.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 establishes the short title of the Act as the "Christopher and Dana Reeve Paralysis Act."

Section 2. Table of contents

Section 2 contains the table of contents.

TITLE I. PARALYSIS RESEARCH

Title I of this legislation addresses the activities of the National Institutes of Health with respect to research on paralysis. Section 101 states that the Director of NIH may develop mechanisms to coordinate the paralysis research and rehabilitation activities of the Institutes and Centers of NIH in order to further advance such activities and avoid duplication of activities. The NIH Director may also award grants to public or private entities to pay all, or part of, the cost of planning, establishing, improving, and providing basic operating support for consortia in paralysis research. Each consortium funded under these grants will be designated as part of the Christopher and Dana Reeve Paralysis Research Consortium. The Director of NIH may provide for a mechanism to educate and disseminate information on the existing and planned programs and research activities of NIH with respect to paralysis and through which NIH can receive comments from the public regarding such programs and activities.

TITLE II. PARALYSIS REHABILITATION RESEARCH AND CARE

Title II of this legislation addresses the activities of NIH with respect to research with implications for enhancing daily function for persons with paralysis. Section 201 states that the Director of NIH 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. A multicenter network of clinical sites funded through this legislation may replicate the findings of network members or other researchers for scientific and translation purposes and may 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. The Director of NIH may provide for the coordination of information among networks and ensure regular communication between members of the networks and may require the periodic preparation of reports on the activities of the networks and submission of reports.

TITLE III. IMPROVING QUALITY OF LIFE FOR PERSONS WITH PARALYSIS AND OTHER PHYSICAL DISABILITIES

Title III of this legislation focuses on programs to improve quality of life for persons with paralysis and other physical disabilities. Section 301 states that the Secretary of HHS 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. The grants or contracts may be used to fund activities such as (1) 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; (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) collaborating with other centers and national voluntary health agencies to establish 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. For the purpose of carrying out Title III, there are authorized to be appropriated $25,000,000 for each of the fiscal years 2008 through 2011.