

CHRISTOPHER AND DANA REEVE PARALYSIS ACT

MARCH 23, 2009.—Committed to the Committee of the Whole House on the State
of the Union and ordered to be printed

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

R E P O R T

[To accompany H.R. 307]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (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, having considered the same, report favorably thereon without amendment and recommend that the bill do pass.

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PURPOSE AND SUMMARY

The purpose of H.R. 307, 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, among other purposes. The bill authorizes the appropriation of \$25 million for each of the fiscal years 2010 through 2013 for the Secretary of Health and Human Services to carry out projects and interventions to improve the quality of life and long-term health status of persons with paralysis and other physical disabilities. In addition, the bill authorizes the Director of the National Institutes of Health to develop mechanisms to coordinate research on paralysis and to support multicenter networks of clinical sites that will collaborate to design clinical rehabilitation protocols and measures of outcomes of interventions for persons with paralysis.

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 did not hold hearings on the legislation.

COMMITTEE CONSIDERATION

The Committee on Energy and Commerce met in open markup session on Wednesday, March 4, 2009, and, pursuant to a motion by Mr. Waxman, agreed by unanimous consent to consider and ap-

prove H.R. 307 and several other bills en bloc. H.R. 307 was ordered favorably reported to the House by a voice vote. No amendments were offered during full Committee consideration of H.R. 307.

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 recorded votes taken during consideration or ordering H.R. 307 reported to the House.

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. 307 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. 307 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. 307 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. 307 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. 307 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 on H.R. 307 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 on H.R. 307 provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

H.R. 307—Christopher and Dana Reeve Paralysis Act

Summary: H.R. 307 would authorize the appropriation of \$25 million a year for fiscal years 2010 through 2013 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 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 2010 and \$95 million over the 2010–2014 period, assuming the appropriation of the authorized amounts. Enacting H.R. 307 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. 307 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—					
	2010	2011	2012	2013	2014	2010–2014
CHANGES IN SPENDING SUBJECT TO APPROPRIATION						
Authorization Level	25	25	25	25	0	100
Estimated Outlays	10	10	25	25	15	95

Basis of estimate: For this estimate, CBO assumes that H.R. 307 will be enacted near the start of fiscal year 2010 and that the authorized amounts will be appropriated for each year.

HHS GRANTS FOR PARALYSIS-RELATED ACTIVITIES

H.R. 307 would authorize the appropriation of \$25 million for each of fiscal years 2010 through 2013 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 those programs would cost \$10 million in 2010 and \$95 million over the 2009–2014 period.

NIH SUPPORT FOR RESEARCH CONSORTIA

H.R. 307 would 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 involve 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 multicenter 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 2008, the NIH spent \$296 million on stroke research, \$85 million on traumatic brain injury research, and \$66 million on spinal cord injury research. Among the efforts funded with this money are several research networks. 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 multicenter clinical trials to understand neurological emergencies. The National Institute for Child Health and Human Development (NICHD) funds several research networks. For example, to date, NICHD has funded six grants to build research infrastructure in the field of medical rehabilitation.

If H.R. 307 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. 307 would not have any significant cost.

Intergovernmental and private-sector impact: H.R. 307 contains no intergovernmental or private-sector mandates as defined in UMR. 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.

Estimate prepared by: Federal costs: Jamease Kowalczyk; Impact on state, local, and tribal governments: Lisa Ramirez-Branum; Impact on private sector: Patrick Bernhardt.

Estimate approved by: Peter H. Fontaine, Assistant Director for Budget Analysis.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of federal mandates regarding H.R. 307 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 H.R. 307.

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 H.R. 307 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 this 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 of 1995.

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

Section 101. 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 the coordination of information among consortia and 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

Section 201. Activities of the National Institutes of Health 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: (1) improving functional mobility; (2) promoting behavioral adaptation to functional losses, especially to prevent secondary complications; (3) assessing the efficacy and outcomes of medical rehabilitation therapies and practices and assisting technologies; (4) developing improved assistive technology to improve function and independence; and (5) 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

Section 301. 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) collaboration 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 2010 through 2013.