

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 1727
OFFERED BY MS. BALDWIN OF WISCONSIN AND
MRS. BONO OF CALIFORNIA**

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE.

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

4 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
19 consortia in paralysis research. The Director shall
20 designate each consortium funded through such
21 grants as a Christopher and Dana Reeve Paralysis
22 Research Consortium.

23 (2) RESEARCH.—Each consortium under para-
24 graph (1)—

1 (A) may conduct basic, translational and
2 clinical paralysis research;

3 (B) may focus on advancing treatments
4 and developing therapies in paralysis research;

5 (C) may focus on one or more forms of pa-
6 ralysis that result from central nervous system
7 trauma or stroke;

8 (D) may facilitate and enhance the dis-
9 semination of clinical and scientific findings;
10 and

11 (E) may replicate the findings of consortia
12 members or other researchers for scientific and
13 translational purposes.

14 (3) COORDINATION OF CONSORTIA; REPORTS.—

15 The Director may, as appropriate, provide for the
16 coordination of information among consortia under
17 paragraph (1) and ensure regular communication
18 among members of the consortia, and may require
19 the periodic preparation of reports on the activities
20 of the consortia and the submission of the reports to
21 the Director.

22 (4) ORGANIZATION OF CONSORTIA.—Each con-
23 sortium under paragraph (1) may use the facilities
24 of a single lead institution, or be formed from sev-

1 eral cooperating institutions, meeting such require-
2 ments as may be prescribed by the Director.

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

9 **TITLE II—PARALYSIS REHABILI-**
10 **TATION RESEARCH AND CARE**

11 **SEC. 201. ACTIVITIES OF THE NATIONAL INSTITUTES OF**
12 **HEALTH WITH RESPECT TO RESEARCH WITH**
13 **IMPLICATIONS FOR ENHANCING DAILY FUNC-**
14 **TION FOR PERSONS WITH PARALYSIS.**

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

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

3 (1) focus on areas of key scientific concern, in-
4 cluding—

5 (A) improving functional mobility;

6 (B) promoting behavioral adaptation to
7 functional losses, especially to prevent sec-
8 ondary complications;

9 (C) assessing the efficacy and outcomes of
10 medical rehabilitation therapies and practices
11 and assisting technologies;

12 (D) developing improved assistive tech-
13 nology to improve function and independence;
14 and

15 (E) understanding whole body system re-
16 sponses to physical impairments, disabilities,
17 and societal and functional limitations; and

18 (2) replicate the findings of network members
19 or other researchers for scientific and translation
20 purposes.

21 (c) COORDINATION OF CLINICAL TRIALS NETWORKS;
22 REPORTS.—The Director may, as appropriate, provide for
23 the coordination of information among networks funded
24 through this section and ensure regular communication
25 among members of the networks, and may require the

1 periodic preparation of reports on the activities of the net-
2 works and submission of reports to the Director.

3 **TITLE III—IMPROVING QUALITY**
4 **OF LIFE FOR PERSONS WITH**
5 **PARALYSIS AND OTHER PHYS-**
6 **ICAL DISABILITIES**

7 **SEC. 301. PROGRAMS TO IMPROVE QUALITY OF LIFE FOR**
8 **PERSONS WITH PARALYSIS AND OTHER**
9 **PHYSICAL DISABILITIES.**

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

19 (b) CERTAIN ACTIVITIES.—Activities under sub-
20 section (a) may include—

21 (1) the development of a national paralysis and
22 physical disability quality of life action plan, to pro-
23 mote health and wellness in order to enhance full
24 participation, independent living, self-sufficiency,
25 and equality of opportunity in partnership with vol-

1 untary health agencies focused on paralysis and
2 other physical disabilities, to be carried out in co-
3 ordination with the State-based Disability and
4 Health Program of the Centers for Disease Control
5 and Prevention;

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

11 (3) in collaboration with other centers and na-
12 tional voluntary health agencies, establish a popu-
13 lation-based database that may be used for longitu-
14 dinal and other research on paralysis and other dis-
15 abling conditions; and

16 (4) the replication and translation of best prac-
17 tices and the sharing of information across States,
18 as well as the development of comprehensive, unique,
19 and innovative programs, services, and demonstra-
20 tions within existing State-based disability and
21 health programs of the Centers for Disease Control
22 and Prevention which are designed to support and
23 advance quality of life programs for persons living
24 with paralysis and other physical disabilities focus-
25 ing on—

1 (A) caregiver education;

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

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

6 (D) prevention of secondary complications;

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

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

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

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

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

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

22 (B) developing comprehensive paralysis
23 and other physical disability action plans and
24 activities focused on the items listed in sub-
25 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 2008 through 2011.