

108TH CONGRESS  
1ST SESSION

# H. R. 1998

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.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 7, 2003

Mr. BILIRAKIS (for himself, Mr. BROWN of Ohio, Mr. YOUNG of Florida, Mr. LANGEVIN, Mr. HOUGHTON, Mr. HOYER, Mr. GREENWOOD, Mr. WAXMAN, Mr. FOSSELLA, Mr. TOWNS, Mr. ENGEL, Mr. STRICKLAND, Mr. RUSH, Mr. EVANS, and Mr. FILNER) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Veterans' Affairs, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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## 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 Reeve Pa-  
5 ralysis Act”.

1 **SEC. 2. TABLE OF CONTENTS.**

Sec. 1. Short title.

Sec. 2. Table of contents.

TITLE I—PARALYSIS RESEARCH

Sec. 101. Expansion and coordination of activities of the National Institutes of Health with respect to research on paralysis.

TITLE II—PARALYSIS REHABILITATION RESEARCH AND CARE

Sec. 201. Expansion and coordination of 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.

TITLE IV—ACTIVITIES OF THE DEPARTMENT OF VETERANS AFFAIRS

Sec. 401. Expansion and coordination of activities of the Veterans Health Administration.

2 **TITLE I—PARALYSIS RESEARCH**

3 **SEC. 101. EXPANSION AND COORDINATION OF ACTIVITIES**

4 **OF THE NATIONAL INSTITUTES OF HEALTH**

5 **WITH RESPECT TO RESEARCH ON PARALYSIS.**

6 (a) IN GENERAL.—

7 (1) ENHANCED COORDINATION OF ACTIVITIES.—The Director of the National Institutes of  
8 Health (in this section referred to as the “Director”)  
9 may expand and coordinate the activities of such In-  
10 stitutes with respect to research on paralysis.

11 (2) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES.—The Director shall carry  
12 out this section acting through the Director of the  
13  
14

1 National Institute of Neurological Disorders and  
2 Stroke (in this section referred to as the “Institute”)  
3 and in collaboration with any other agencies that the  
4 Director determines appropriate.

5 (b) COORDINATION.—

6 (1) IN GENERAL.—The Director may develop  
7 mechanisms to coordinate the paralysis research and  
8 rehabilitation activities of the agencies of the Na-  
9 tional Institutes of Health in order to further ad-  
10 vance such activities and avoid duplication of activi-  
11 ties.

12 (2) REPORT.—Not later than December 1,  
13 2003, the Director shall prepare a report to Con-  
14 gress that provides a description of the paralysis ac-  
15 tivities of the Institute and strategies for future ac-  
16 tivities.

17 (c) CHRISTOPHER REEVE PARALYSIS RESEARCH  
18 CONSORTIA.—

19 (1) IN GENERAL.—The Director may under  
20 subsection (a)(1) make awards of grants to public or  
21 nonprofit private entities to pay all or part of the  
22 cost of planning, establishing, improving, and pro-  
23 viding basic operating support for consortia in paral-  
24 ysis research. The Director shall designate each con-

1 consortium funded under grants as a Christopher Reeve  
2 Paralysis Research Consortium.

3 (2) RESEARCH.—Each consortium under para-  
4 graph (1)—

5 (A) may conduct basic and clinical paral-  
6 ysis research;

7 (B) may focus on advancing treatments  
8 and developing therapies in paralysis research;

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

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

15 (E ) may replicate the findings of consortia  
16 members for scientific and translational pur-  
17 poses.

18 (3) COORDINATION OF CONSORTIA; REPORTS.—

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

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

6           (d) PUBLIC INPUT.—The Director may under sub-  
7           section (a)(1) provide for a mechanism to educate and dis-  
8           seminate information on the existing and planned pro-  
9           grams and research activities of the National Institutes  
10          of Health with respect to paralysis and through which the  
11          Director can receive comments from the public regarding  
12          such programs and activities.

13          (e) AUTHORIZATION OF APPROPRIATIONS.—For the  
14          purpose of carrying out this section, there are authorized  
15          to be appropriated such sums as may be necessary for  
16          each of the fiscal years 2004 through 2007. Amounts ap-  
17          propriated under this subsection are in addition to any  
18          other amounts appropriated for such purpose.

1 **TITLE II—PARALYSIS REHABILI-**  
2 **TATION RESEARCH AND CARE**

3 **SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES**  
4 **OF THE NATIONAL INSTITUTES OF HEALTH**  
5 **WITH RESPECT TO RESEARCH WITH IMPLICA-**  
6 **TIONS FOR ENHANCING DAILY FUNCTION**  
7 **FOR PERSONS WITH PARALYSIS.**

8 (a) IN GENERAL.—

9 (1) EXPANSION OF ACTIVITIES.—The Director  
10 of the National Institutes of Health (in this section  
11 referred to as the “Director”) may expand and co-  
12 ordinate the activities of such Institutes with respect  
13 to research with implications for enhancing daily  
14 function for people with paralysis.

15 (2) ADMINISTRATION OF PROGRAM; COLLABO-  
16 RATION AMONG AGENCIES.—The Director shall carry  
17 out this section acting through the Director of the  
18 National Institute on Child Health and Human De-  
19 velopment and the National Center for Medical Re-  
20 habilitation Research and in collaboration with the  
21 National Institute on Neurological Disorders and  
22 Stroke, the Centers for Disease Control and Preven-  
23 tion, and any other agencies that the Director deter-  
24 mines appropriate.

25 (b) PARALYSIS CLINICAL TRIALS NETWORKS.—

1           (1) IN GENERAL.—The Director may make  
2 awards of grants to public or nonprofit private enti-  
3 ties to pay all or part of the costs of planning, estab-  
4 lishing, improving, and providing basic operating  
5 support to multicenter networks of clinical sites that  
6 will collaborate to design clinical rehabilitation inter-  
7 vention protocols and measures of outcomes on one  
8 or more forms of paralysis that result from central  
9 nervous system trauma, disorders, or stroke, or any  
10 combination of such conditions.

11           (2) RESEARCH.—Each multicenter clinical trial  
12 network may—

13           (A) focus on areas of key scientific con-  
14 cern, including—

15                   (i) improving functional mobility;

16                   (ii) promoting behavioral adaptation  
17 to functional losses, especially to prevent  
18 secondary complications;

19                   (iii) assessing the efficacy and out-  
20 comes of medical rehabilitation therapies  
21 and practices and assistive technologies;

22                   (iv) developing improved assistive  
23 technology to improve function and inde-  
24 pendence; and

1 (v) understanding whole body system  
2 responses to physical impairments, disabil-  
3 ities, and societal and functional limita-  
4 tions; and

5 (B) replicate the findings of network mem-  
6 bers for scientific and translation purposes.

7 (3) COORDINATION OF CLINICAL TRIALS NET-  
8 WORKS.—The Director may, as appropriate, provide  
9 for the coordination of information among networks  
10 and ensure regular communication between members  
11 of the networks and may require the periodic prepa-  
12 ration of reports on the activities of the networks  
13 and submission of reports to the Director.

14 (c) REPORT.—Not later than December 1, 2003, the  
15 Director shall submit to the Congress a report that pro-  
16 vides a description of research activities with implications  
17 for enhancing daily function for persons with paralysis.

18 (d) AUTHORIZATION OF APPROPRIATIONS.—For the  
19 purpose of carrying out this section, there are authorized  
20 to be appropriated such sums as may be necessary for  
21 each of the fiscal years 2004 through 2007. Amounts ap-  
22 propriated under this subsection are in addition to any  
23 other amounts appropriated for such purpose.



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

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

8 (a) IN GENERAL.—The Secretary of Health and  
9 Human Services (in this Act referred to as the “Sec-  
10 retary”), acting through the Director of the Centers for  
11 Disease Control and Prevention, may study the unique  
12 health challenges associated with paralysis and other phys-  
13 ical disabilities and carry out projects and interventions  
14 to improve the quality of life and long-term health status  
15 of persons with paralysis and other physical disabilities.  
16 The Secretary may carry out such projects directly and  
17 through awards of grants or contracts.

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

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

1 ical disabilities, to be carried out in coordination  
2 with the State-based Comprehensive Paralysis and  
3 Other Physical Disability Quality of Life Program of  
4 the Centers for Disease Control and Prevention;

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

10 (3) in collaboration with other centers and na-  
11 tional voluntary health agencies, establish a hospital-  
12 based paralysis registry and conduct relevant popu-  
13 lation-based research; and

14 (4) the development of comprehensive, unique  
15 and innovative programs, services, and demonstra-  
16 tions within existing State-based disability and  
17 health programs of the Centers for Disease Control  
18 and Prevention which are designed to support and  
19 advance quality of life programs for persons living  
20 with paralysis and other physical disabilities focus-  
21 ing on—

22 (A) caregiver education;

23 (B) physical activity;

24 (C) education and awareness programs for

25 health care providers;

1 (D) prevention of secondary complications;

2 (E) home and community-based interven-  
3 tions;

4 (F) coordinating services and removing  
5 barriers that prevent full participation and inte-  
6 gration into the community; and

7 (G) recognizing the unique needs of under-  
8 served populations.

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

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

13 (A) establishing paralysis registries for the  
14 support of relevant population-based research;

15 (B) developing comprehensive paralysis  
16 and other physical disability action plans and  
17 activities focused on the items listed in sub-  
18 section (b)(4);

19 (C) assisting State-based programs in es-  
20 tablishing and implementing partnerships and  
21 collaborations that maximize the input and sup-  
22 port of people with paralysis and other physical  
23 disabilities and their constituent organizations;

1 (D) coordinating paralysis and physical  
2 disability activities with existing state-based dis-  
3 ability and health programs;

4 (E) providing education and training op-  
5 portunities and programs for health profes-  
6 sionals and allied caregivers; and

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

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

12 (A) disseminating information to the pub-  
13 lic;

14 (B) improving access to services for per-  
15 sons living with paralysis and other physical  
16 disabilities and their caregivers;

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

19 (D) coordinating existing services with  
20 state-based disability and health programs.

21 (d) COORDINATION OF ACTIVITIES.—The Secretary  
22 shall assure that activities under this section are coordi-  
23 nated as appropriate with other agencies of the Public  
24 Health Service.

1 (e) REPORT TO CONGRESS.—Not later than Decem-  
 2 ber 1, 2003, the Secretary shall submit to the Congress  
 3 a report describing the results of the evaluation under sub-  
 4 section (a), and as applicable, the strategies developed  
 5 under such subsection.

6 (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
 7 purpose of carrying out this section, there are authorized  
 8 to be appropriated such sums as may be necessary for  
 9 each of the fiscal years 2004 through 2007.

10 **TITLE IV—ACTIVITIES OF THE**  
 11 **DEPARTMENT OF VETERANS**  
 12 **AFFAIRS**

13 **SEC. 401. EXPANSION AND COORDINATION OF ACTIVITIES**  
 14 **OF THE VETERANS HEALTH ADMINISTRA-**  
 15 **TION.**

16 (a) IN GENERAL.—

17 (1) ENHANCED COORDINATION OF ACTIVI-  
 18 TIES.—The Secretary of Veterans Affairs may ex-  
 19 pand and coordinate activities of the Veterans  
 20 Health Administration of the Department of Vet-  
 21 erans Affairs with respect to research on paralysis.

22 (2) ADMINISTRATION OF PROGRAM.—The Sec-  
 23 retary shall carry out this section through the Direc-  
 24 tor of the Office of Research and Development of  
 25 the Veterans Health Administration and in collabo-

1 ration with the National Institutes of Health and  
2 other agencies the Secretary determines appropriate.

3 (b) ESTABLISHMENT OF PARALYSIS RESEARCH,  
4 EDUCATION, AND CLINICAL CARE CENTER.—

5 (1) IN GENERAL.—The Secretary may establish  
6 within the Department of Veterans Affairs centers  
7 for paralysis research, education and clinical activi-  
8 ties. Such centers shall be established at Depart-  
9 ment medical centers through the award of grants to  
10 Department medical centers that are affiliated with  
11 medical schools or other organizations the Secretary  
12 considers appropriate. Such grants may be used to  
13 pay all or part of the cost of planning, establishing,  
14 improving, and providing basic operating support for  
15 such centers.

16 (2) RESEARCH.—Each center under paragraph  
17 (1)—

18 (A) may focus on basic biomedical research  
19 on paralysis;

20 (B) may focus on rehabilitation research  
21 on paralysis;

22 (C) may focus on health services and clin-  
23 ical trials for paralysis that result from central  
24 nervous system trauma or stroke;

1           (D) may facilitate and enhance the dis-  
2           semination of clinical and scientific findings;  
3           and

4           (E) may replicate the findings of centers  
5           for scientific and translational purposes.

6           (3) COORDINATION OF CENTERS INTO CON-  
7           SORTIA.—The Secretary may, as appropriate, pro-  
8           vide for the linkage and coordination of information  
9           among centers under paragraph (1) in order to cre-  
10          ate national consortia of centers and ensure regular  
11          communications between members of the centers.  
12          Each such consortium—

13                 (A) may conduct large-scale clinical trials  
14                 for greater statistical significance;

15                 (B) may operate in an interdisciplinary re-  
16                 habilitation team;

17                 (C) may focus on determining current  
18                 standards of care and best practices; and

19                 (D) may identify research gaps for specific  
20                 populations and identify future research needs.

21           (4) ORGANIZATION OF CONSORTIA.—Each con-  
22           sortium under paragraph (3) may use the facilities  
23           of a single lead institution, or be formed from sev-  
24           eral cooperating institutions, meeting such require-  
25           ment as prescribed by the Secretary.

1           (5) REPORTS.—The Secretary may require the  
2           periodic preparation of reports on the activities of  
3           the centers and consortia and submission of such re-  
4           ports to the Secretary.

5           (c) ESTABLISHMENT OF QUALITY ENHANCEMENT  
6 RESEARCH INITIATIVES FOR PARALYSIS.—

7           (1) IN GENERAL.—The Secretary may carry out  
8           initiatives for quality enhancement of research on  
9           paralysis to translate clinical findings and rec-  
10          ommendations into practices within the Veterans  
11          Health Administration. The Secretary shall carry  
12          out those initiatives through the award of grants to  
13          Department of Veterans Affairs medical centers that  
14          are affiliated with medical schools or other partners  
15          the Secretary considers appropriate. Such grants  
16          may be used to pay all or part of the cost of plan-  
17          ning, establishing, improving and providing basic op-  
18          erating support for the initiatives.

19          (2) ACTIVITIES.—Each medical center for  
20          which funds are provided under paragraph (1)—

21                 (A) may identify high-risk/high volume dis-  
22                 eases or problems;

23                 (B) may formulate evidence-based clinical  
24                 research;



1 (C) may define existing practice patterns  
2 and outcomes across the Veterans Health Ad-  
3 ministration and current variation from best  
4 practices;

5 (D) may identify and implement interven-  
6 tions (including performance criteria) to pro-  
7 mote best practices;

8 (E) may document that best practices im-  
9 prove outcomes;

10 (F) may document that improved patient  
11 outcomes are associated with improved health-  
12 related quality of life;

13 (G) may develop, test, and refine, and fa-  
14 cilitate active distribution of, tools and products  
15 designed to promote clinical quality improve-  
16 ments;

17 (H) may plan and prepare to launch at  
18 least one project to implement and evaluate a  
19 quality enhancement intervention program for  
20 the translation of clinical research findings into  
21 routine clinical practice within the Administra-  
22 tion; and

23 (I) may compete for other Veterans Health  
24 Administration and non-Veterans Health Ad-

1           ministration research projects to leverage core  
2           support.

3           (d) MAINTENANCE OF EFFORT.—The Secretary may  
4 make an award under this section only if, with respect  
5 to activities for which the award is authorized to be ex-  
6 pended, the applicant for the award agrees to maintain  
7 expenditures of non-Federal amounts for such activities  
8 at a level that is not less than the level of such expendi-  
9 tures maintained by the applicant for the fiscal year pre-  
10 ceding the first fiscal year for which the entity receives  
11 such an award.

12           (e) PUBLIC INPUT.—The Secretary may under sub-  
13 sections (a)(1) and (c)(1) provide for a mechanism—

14           (1) to educate the public on, and disseminate  
15 information to the public on, the existing and  
16 planned programs and research activities of the Vet-  
17 erans Health Administration with respect to paral-  
18 ysis; and

19           (2) through which the Secretary can receive  
20 comments from the public regarding those programs  
21 and activities.

22           (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
23 purposes of carrying out this section, there are authorized  
24 to be appropriated such sums as may be necessary for  
25 each of fiscal years 2004 through 2007. Amounts appro-

1 priated under this section are in addition to any other  
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4 **OF THE NATIONAL INSTITUTES OF HEALTH**

5 **WITH RESPECT TO RESEARCH ON PARALYSIS.**

6 (a) IN GENERAL.—

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1 National Institute of Neurological Disorders and  
2 Stroke (in this section referred to as the “Institute”)  
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17 (c) CHRISTOPHER REEVE PARALYSIS RESEARCH  
18 CONSORTIA.—

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20 subsection (a)(1) make awards of grants to public or  
21 nonprofit private entities to pay all or part of the  
22 cost of planning, establishing, improving, and pro-  
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10 ralysis that result from central nervous system  
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13 semination of clinical and scientific findings;  
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18 (3) COORDINATION OF CONSORTIA; REPORTS.—

19 The Director may, as appropriate, provide for the  
20 coordination of information among consortia under  
21 paragraph (1) and ensure regular communication  
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10          of Health with respect to paralysis and through which the  
11          Director can receive comments from the public regarding  
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2 **TATION RESEARCH AND CARE**

3 **SEC. 201. EXPANSION AND COORDINATION OF ACTIVITIES**  
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5 **WITH RESPECT TO RESEARCH WITH IMPLICA-**  
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21 National Institute on Neurological Disorders and  
22 Stroke, the Centers for Disease Control and Preven-  
23 tion, and any other agencies that the Director deter-  
24 mines appropriate.

25 (b) PARALYSIS CLINICAL TRIALS NETWORKS.—



1           (1) IN GENERAL.—The Director may make  
2           awards of grants to public or nonprofit private enti-  
3           ties to pay all or part of the costs of planning, estab-  
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6           will collaborate to design clinical rehabilitation inter-  
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8           or more forms of paralysis that result from central  
9           nervous system trauma, disorders, or stroke, or any  
10          combination of such conditions.

11          (2) RESEARCH.—Each multicenter clinical trial  
12          network may—

13                (A) focus on areas of key scientific con-  
14                cern, including—

15                       (i) improving functional mobility;

16                       (ii) promoting behavioral adaptation  
17                       to functional losses, especially to prevent  
18                       secondary complications;

19                       (iii) assessing the efficacy and out-  
20                       comes of medical rehabilitation therapies  
21                       and practices and assistive technologies;

22                       (iv) developing improved assistive  
23                       technology to improve function and inde-  
24                       pendence; and

1                   (v) understanding whole body system  
2                   responses to physical impairments, disabil-  
3                   ities, and societal and functional limita-  
4                   tions; and

5                   (B) replicate the findings of network mem-  
6                   bers for scientific and translation purposes.

7                   (3) COORDINATION OF CLINICAL TRIALS NET-  
8                   WORKS.—The Director may, as appropriate, provide  
9                   for the coordination of information among networks  
10                  and ensure regular communication between members  
11                  of the networks and may require the periodic prepa-  
12                  ration of reports on the activities of the networks  
13                  and submission of reports to the Director.

14                  (c) REPORT.—Not later than December 1, 2003, the  
15                  Director shall submit to the Congress a report that pro-  
16                  vides a description of research activities with implications  
17                  for enhancing daily function for persons with paralysis.

18                  (d) AUTHORIZATION OF APPROPRIATIONS.—For the  
19                  purpose of carrying out this section, there are authorized  
20                  to be appropriated such sums as may be necessary for  
21                  each of the fiscal years 2004 through 2007. Amounts ap-  
22                  propriated under this subsection are in addition to any  
23                  other amounts appropriated for such purpose.

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

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

8 (a) IN GENERAL.—The Secretary of Health and  
9 Human Services (in this Act referred to as the “Sec-  
10 retary”), acting through the Director of the Centers for  
11 Disease Control and Prevention, may study the unique  
12 health challenges associated with paralysis and other phys-  
13 ical disabilities and carry out projects and interventions  
14 to improve the quality of life and long-term health status  
15 of persons with paralysis and other physical disabilities.  
16 The Secretary may carry out such projects directly and  
17 through awards of grants or contracts.

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

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

1 ical disabilities, to be carried out in coordination  
2 with the State-based Comprehensive Paralysis and  
3 Other Physical Disability Quality of Life Program of  
4 the Centers for Disease Control and Prevention;

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

10 (3) in collaboration with other centers and na-  
11 tional voluntary health agencies, establish a hospital-  
12 based paralysis registry and conduct relevant popu-  
13 lation-based research; and

14 (4) the development of comprehensive, unique  
15 and innovative programs, services, and demonstra-  
16 tions within existing State-based disability and  
17 health programs of the Centers for Disease Control  
18 and Prevention which are designed to support and  
19 advance quality of life programs for persons living  
20 with paralysis and other physical disabilities focus-  
21 ing on—

22 (A) caregiver education;

23 (B) physical activity;

24 (C) education and awareness programs for

25 health care providers;

1 (D) prevention of secondary complications;

2 (E) home and community-based interven-  
3 tions;

4 (F) coordinating services and removing  
5 barriers that prevent full participation and inte-  
6 gration into the community; and

7 (G) recognizing the unique needs of under-  
8 served populations.

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

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

13 (A) establishing paralysis registries for the  
14 support of relevant population-based research;

15 (B) developing comprehensive paralysis  
16 and other physical disability action plans and  
17 activities focused on the items listed in sub-  
18 section (b)(4);

19 (C) assisting State-based programs in es-  
20 tablishing and implementing partnerships and  
21 collaborations that maximize the input and sup-  
22 port of people with paralysis and other physical  
23 disabilities and their constituent organizations;

1 (D) coordinating paralysis and physical  
2 disability activities with existing state-based dis-  
3 ability and health programs;

4 (E) providing education and training op-  
5 portunities and programs for health profes-  
6 sionals and allied caregivers; and

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

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

12 (A) disseminating information to the pub-  
13 lic;

14 (B) improving access to services for per-  
15 sons living with paralysis and other physical  
16 disabilities and their caregivers;

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

19 (D) coordinating existing services with  
20 state-based disability and health programs.

21 (d) COORDINATION OF ACTIVITIES.—The Secretary  
22 shall assure that activities under this section are coordi-  
23 nated as appropriate with other agencies of the Public  
24 Health Service.

1 (e) REPORT TO CONGRESS.— Not later than Decem-  
2 ber 1, 2003, the Secretary shall submit to the Congress  
3 a report describing the results of the evaluation under sub-  
4 section (a), and as applicable, the strategies developed  
5 under such subsection.

6 (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
7 purpose of carrying out this section, there are authorized  
8 to be appropriated such sums as may be necessary for  
9 each of the fiscal years 2004 through 2007.

10 **TITLE IV—ACTIVITIES OF THE**  
11 **DEPARTMENT OF VETERANS**  
12 **AFFAIRS**

13 **SEC. 401. EXPANSION AND COORDINATION OF ACTIVITIES**  
14 **OF THE VETERANS HEALTH ADMINISTRA-**  
15 **TION.**

16 (a) IN GENERAL.—

17 (1) ENHANCED COORDINATION OF ACTIVI-  
18 TIES.—The Secretary of Veterans Affairs may ex-  
19 pand and coordinate activities of the Veterans  
20 Health Administration of the Department of Vet-  
21 erans Affairs with respect to research on paralysis.

22 (2) ADMINISTRATION OF PROGRAM.—The Sec-  
23 retary shall carry out this section through the Direc-  
24 tor of the Office of Research and Development of  
25 the Veterans Health Administration and in collabo-

1 ration with the National Institutes of Health and  
2 other agencies the Secretary determines appropriate.

3 (b) ESTABLISHMENT OF PARALYSIS RESEARCH,  
4 EDUCATION, AND CLINICAL CARE CENTER.—

5 (1) IN GENERAL.—The Secretary may establish  
6 within the Department of Veterans Affairs centers  
7 for paralysis research, education and clinical activi-  
8 ties. Such centers shall be established at Depart-  
9 ment medical centers through the award of grants to  
10 Department medical centers that are affiliated with  
11 medical schools or other organizations the Secretary  
12 considers appropriate. Such grants may be used to  
13 pay all or part of the cost of planning, establishing,  
14 improving, and providing basic operating support for  
15 such centers.

16 (2) RESEARCH.—Each center under paragraph  
17 (1)—

18 (A) may focus on basic biomedical research  
19 on paralysis;

20 (B) may focus on rehabilitation research  
21 on paralysis;

22 (C) may focus on health services and clin-  
23 ical trials for paralysis that result from central  
24 nervous system trauma or stroke;



1           (D) may facilitate and enhance the dis-  
2           semination of clinical and scientific findings;  
3           and

4           (E) may replicate the findings of centers  
5           for scientific and translational purposes.

6           (3) COORDINATION OF CENTERS INTO CON-  
7           SORTIA.—The Secretary may, as appropriate, pro-  
8           vide for the linkage and coordination of information  
9           among centers under paragraph (1) in order to cre-  
10          ate national consortia of centers and ensure regular  
11          communications between members of the centers.  
12          Each such consortium—

13           (A) may conduct large-scale clinical trials  
14           for greater statistical significance;

15           (B) may operate in an interdisciplinary re-  
16           habilitation team;

17           (C) may focus on determining current  
18           standards of care and best practices; and

19           (D) may identify research gaps for specific  
20           populations and identify future research needs.

21          (4) ORGANIZATION OF CONSORTIA.—Each con-  
22          sortium under paragraph (3) may use the facilities  
23          of a single lead institution, or be formed from sev-  
24          eral cooperating institutions, meeting such require-  
25          ment as prescribed by the Secretary.

1           (5) REPORTS.—The Secretary may require the  
2           periodic preparation of reports on the activities of  
3           the centers and consortia and submission of such re-  
4           ports to the Secretary.

5           (c) ESTABLISHMENT OF QUALITY ENHANCEMENT  
6 RESEARCH INITIATIVES FOR PARALYSIS.—

7           (1) IN GENERAL.—The Secretary may carry out  
8           initiatives for quality enhancement of research on  
9           paralysis to translate clinical findings and rec-  
10          ommendations into practices within the Veterans  
11          Health Administration. The Secretary shall carry  
12          out those initiatives through the award of grants to  
13          Department of Veterans Affairs medical centers that  
14          are affiliated with medical schools or other partners  
15          the Secretary considers appropriate. Such grants  
16          may be used to pay all or part of the cost of plan-  
17          ning, establishing, improving and providing basic op-  
18          erating support for the initiatives.

19          (2) ACTIVITIES.—Each medical center for  
20          which funds are provided under paragraph (1)—

21                  (A) may identify high-risk/high volume dis-  
22                  eases or problems;

23                  (B) may formulate evidence-based clinical  
24                  research;

1 (C) may define existing practice patterns  
2 and outcomes across the Veterans Health Ad-  
3 ministration and current variation from best  
4 practices;

5 (D) may identify and implement interven-  
6 tions (including performance criteria) to pro-  
7 mote best practices;

8 (E) may document that best practices im-  
9 prove outcomes;

10 (F) may document that improved patient  
11 outcomes are associated with improved health-  
12 related quality of life;

13 (G) may develop, test, and refine, and fa-  
14 cilitate active distribution of, tools and products  
15 designed to promote clinical quality improve-  
16 ments;

17 (H) may plan and prepare to launch at  
18 least one project to implement and evaluate a  
19 quality enhancement intervention program for  
20 the translation of clinical research findings into  
21 routine clinical practice within the Administra-  
22 tion; and

23 (I) may compete for other Veterans Health  
24 Administration and non-Veterans Health Ad-

1           ministration research projects to leverage core  
2           support.

3           (d) MAINTENANCE OF EFFORT.—The Secretary may  
4 make an award under this section only if, with respect  
5 to activities for which the award is authorized to be ex-  
6 pended, the applicant for the award agrees to maintain  
7 expenditures of non-Federal amounts for such activities  
8 at a level that is not less than the level of such expendi-  
9 tures maintained by the applicant for the fiscal year pre-  
10 ceding the first fiscal year for which the entity receives  
11 such an award.

12           (e) PUBLIC INPUT.—The Secretary may under sub-  
13 sections (a)(1) and (c)(1) provide for a mechanism—

14           (1) to educate the public on, and disseminate  
15 information to the public on, the existing and  
16 planned programs and research activities of the Vet-  
17 erans Health Administration with respect to paral-  
18 ysis; and

19           (2) through which the Secretary can receive  
20 comments from the public regarding those programs  
21 and activities.

22           (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
23 purposes of carrying out this section, there are authorized  
24 to be appropriated such sums as may be necessary for  
25 each of fiscal years 2004 through 2007. Amounts appro-

1 priated under this section are in addition to any other  
2 amounts appropriated for such purpose.

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