

105TH CONGRESS  
2D SESSION

# H. R. 4800

To amend the Public Health Service Act to provide for the establishment of a national program of traumatic brain injury and spinal cord injury registries.

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## IN THE HOUSE OF REPRESENTATIVES

OCTOBER 10, 1998

Mr. PASCRELL (for himself and Mr. GREENWOOD) introduced the following bill; which was referred to the Committee on Commerce

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## A BILL

To amend the Public Health Service Act to provide for the establishment of a national program of traumatic brain injury and spinal cord injury registries.

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 “Traumatic Brain In-  
5 jury and Spinal Cord Injury Registry Act”.

6 **SEC. 2. FINDINGS.**

7 Congress finds that—

1           (1) traumatic brain and spinal cord injury are  
2       severe and disabling, have enormous personal and  
3       societal costs;

4           (2) 51,000 people die each year from traumatic  
5       brain injury and 4,500,000 people live with lifelong  
6       and severe disability as a result of a traumatic brain  
7       injury;

8           (3) approximately 10,000 people sustain spinal  
9       cord injuries each year, and 200,000 live with life-  
10      long and severe disability; and

11          (4) a nationwide system of registries will help  
12      better define—

13                (A) who sustains such injuries and the im-  
14      pact of such injuries;

15                (B) the range of impairments and disabil-  
16      ity associated with such injuries; and

17                (C) better mechanisms to refer persons  
18      with traumatic brain injuries or spinal cord in-  
19      juries to available services.

20   **SEC. 3. TRAUMATIC BRAIN INJURY AND SPINAL CORD IN-**  
21                   **JURY REGISTRIES PROGRAM.**

22      Title III of the Public Health Service Act (42 U.S.C.  
23   241 et seq.) is amended by adding at the end the follow-  
24   ing:

1 “PART O—NATIONAL PROGRAM FOR TRAUMATIC BRAIN  
2 INJURY AND SPINAL CORD INJURY REGISTRIES

3 **“SEC. 399N. NATIONAL PROGRAM FOR TRAUMATIC BRAIN**  
4 **INJURY AND SPINAL CORD INJURY REG-**  
5 **ISTRIES.**

6 “(a) IN GENERAL.—The Secretary, acting through  
7 the Director of the Centers for Disease Control and Pre-  
8 vention, may make grants to States or their designees to  
9 operate the State’s traumatic brain injury and spinal cord  
10 injury registry, and to academic institutions to conduct  
11 applied research that will support the development of such  
12 registries, to collect data concerning—

13 “(1) demographic information about each trau-  
14 matic brain injury or spinal cord injury;

15 “(2) information about the circumstances sur-  
16 rounding the injury event associated with each trau-  
17 matic brain injury and spinal cord injury;

18 “(3) administrative information about the  
19 source of the collected information, dates of hos-  
20 pitalization and treatment, and the date of injury;

21 “(4) information characterizing the clinical as-  
22 pects of the traumatic brain injury or spinal cord in-  
23 jury, including the severity of the injury, the types  
24 of treatments received, and the types of services uti-  
25 lized;

1           “(5) information on the outcomes associated  
2       with traumatic brain injuries and spinal cord inju-  
3       ries, such as impairments, functional limitations,  
4       and disability;

5           “(6) information on the outcomes associated  
6       with traumatic brain injuries and spinal cord inju-  
7       ries which do not result in hospitalization; and

8           “(7) other elements determined appropriate by  
9       the Secretary.

10       “(b) ELIGIBILITY FOR GRANTS.—

11           “(1) IN GENERAL.—No grant shall be made by  
12       the Secretary under subsection (a) unless an appli-  
13       cation has been submitted to, and approved by, the  
14       Secretary. Such application shall be in such form,  
15       submitted in such a manner, and be accompanied by  
16       such information, as the Secretary may specify. No  
17       such application may be approved unless it contains  
18       assurances that the applicant will use the funds pro-  
19       vided only for the purposes specified in the approved  
20       application and in accordance with the requirements  
21       of subsection (a), that the application will establish  
22       such fiscal control and fund accounting procedures  
23       as may be necessary to assure proper disbursement  
24       and accounting of Federal funds paid to the appli-  
25       cant under subsection (a) of this section, and that

1 the applicant will comply with review requirements  
2 under sections 491 and 492.

3 “(2) ESTABLISHMENT OF REGISTRIES.—Each  
4 applicant, prior to receiving Federal funds under  
5 subsection (a), shall provide for the establishment of  
6 a registry that will—

7 “(A) comply with appropriate standards of  
8 completeness, timeliness, and quality of data  
9 collection;

10 “(B) provide for periodic reports of trau-  
11 matic brain injury and spinal cord injury reg-  
12 istry data; and

13 “(C) provide for the authorization under  
14 State law of the statewide traumatic brain in-  
15 jury and spinal cord injury registry, including  
16 promulgation of regulations providing—

17 “(i) a means to assure timely and  
18 complete reporting of brain injuries and  
19 spinal cord injuries (as described in sub-  
20 section (a)) to the statewide traumatic  
21 brain injury and spinal cord injury registry  
22 by hospitals or other facilities providing di-  
23 agnostic or acute care or rehabilitative so-  
24 cial services to patients with respect to

1 traumatic brain injury and spinal cord in-  
2 jury;

3 “(ii) a means to assure the complete  
4 reporting of brain injuries and spinal cord  
5 injuries (as defined in subsection (a)) to  
6 the statewide traumatic brain injury and  
7 spinal cord injury registry by physicians,  
8 surgeons, and all other health care practi-  
9 tioners diagnosing or providing treatment  
10 for traumatic brain injury and spinal cord  
11 injury patients, except for cases directly re-  
12 ferred to or previously admitted to a hos-  
13 pital or other facility providing diagnostic  
14 or acute care or rehabilitative services to  
15 patients in that State and reported by  
16 those facilities;

17 “(iii) a means for the statewide trau-  
18 matic brain injury and spinal cord injury  
19 registry to access all records of physicians  
20 and surgeons, hospitals, outpatient clinics,  
21 nursing homes, and all other facilities, in-  
22 dividuals, or agencies providing such serv-  
23 ices to patients which would identify cases  
24 of traumatic brain injury or spinal cord in-  
25 jury or would establish characteristics of

1 the injury, treatment of the injury, or med-  
2 ical status of any identified patient; and

3 “(iv) for the reporting of traumatic  
4 brain injury and spinal cord injury case  
5 data to the statewide traumatic brain in-  
6 jury and spinal cord injury registry in such  
7 a format, with such data elements, and in  
8 accordance with such standards of quality  
9 timeliness and completeness, as may be es-  
10 tablished by the Secretary.

11 “(3) APPLIED RESEARCH.—Applicants for ap-  
12 plied research shall conduct applied research as de-  
13 termined by the Secretary, acting through the Direc-  
14 tor of the Centers for Disease Control and Preven-  
15 tion, to be necessary to support the development of  
16 registry activities as defined in this section.

17 “(4) ASSURANCES FOR CONFIDENTIALITY OF  
18 REGISTRY DATA.—Each applicant shall provide to  
19 the satisfaction of the Secretary for—

20 “(A) a means by which confidential case  
21 data may in accordance with State law be dis-  
22 closed to traumatic brain injury and spinal cord  
23 injury researchers for the purposes of the pre-  
24 vention, control and research of brain injuries  
25 and spinal cord injuries;

1           “(B) the authorization or the conduct, by  
2           the statewide traumatic brain injury and spinal  
3           cord injury registry or other persons and orga-  
4           nizations, of studies utilizing statewide trau-  
5           matic brain injury and spinal cord injury reg-  
6           istry data, including studies of the sources and  
7           causes of traumatic brain injury and spinal  
8           cord injury, evaluations of the cost, quality, ef-  
9           ficacy, and appropriateness of diagnostic, reha-  
10          bilitative, and preventative services and pro-  
11          grams relating to traumatic brain injury and  
12          spinal cord injury, and any other clinical, epide-  
13          miological, or other traumatic brain injury and  
14          spinal cord injury research;

15          “(C) the protection of individuals comply-  
16          ing with the law, including provisions specifying  
17          that no person shall be held liable in any civil  
18          action with respect to a traumatic brain injury  
19          and spinal cord injury case report provided to  
20          the statewide traumatic brain injury and spinal  
21          cord injury registry, or with respect to access to  
22          traumatic brain injury and spinal cord injury  
23          case information provided to the statewide trau-  
24          matic brain injury and spinal cord injury reg-  
25          istry; and

1                   “(D) the protection of individual privacy  
2                   and confidentiality consistent with Federal and  
3                   State laws.

4   **“SEC. 399O. TECHNICAL ASSISTANCE IN OPERATIONS OF**  
5                   **STATEWIDE REGISTRIES.**

6           “The Secretary, acting through the Director of the  
7   Centers for Disease Control and Prevention, may, directly  
8   or through grants and contracts, or both, provide technical  
9   assistance to the States in the establishment and operation  
10  of statewide registries, including assistance in the develop-  
11  ment of model legislation for statewide traumatic brain in-  
12  jury and spinal cord injury registries and assistance in es-  
13  tablishing a computerized reporting and data processing  
14  system. In providing such assistance, the Secretary shall  
15  encourage States to utilize standardized procedures where  
16  appropriate.

17   **“SEC. 399P. AUTHORIZATION OF APPROPRIATIONS.**

18           “For the purpose of carrying out this part, there are  
19  authorized to be appropriated \$10,000,000 for fiscal year  
20  1999, and such sums as may be necessary for each of the  
21  fiscal years 2000 through 2004.

22   **“SEC. 399Q. DEFINITIONS.**

23           “In this part:

24                   “(1) SPINAL CORD INJURY.—The term ‘spinal  
25           cord injury’ means an acquired injury to the spinal

1 cord. Such term does not include spinal cord dys-  
2 function caused by congenital or degenerative dis-  
3 orders, vascular disease, or tumors, or spinal column  
4 fractures without a spinal cord injury.

5 “(2) TRAUMATIC BRAIN INJURY.—The term  
6 ‘traumatic brain injury’ means an acquired injury to  
7 the brain, including brain injuries caused by anoxia  
8 due to near-drowning. Such term does not include  
9 brain dysfunction caused by congenital or degenera-  
10 tive disorders, cerebral vascular disease, tumors, or  
11 birth trauma. The Secretary may revise the defini-  
12 tion of such term as the Secretary determines appro-  
13 priate.”.

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