

105TH CONGRESS
2D SESSION

S. 2605

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.

IN THE SENATE OF THE UNITED STATES

OCTOBER 9 (legislative day, OCTOBER 2), 1998

Mr. TORRICELLI (for himself and Mr. LAUTENBERG) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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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