

113TH CONGRESS
2^D SESSION

H. R. 4251

To direct the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, to establish a surveillance system regarding traumatic brain injury, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 14, 2014

Mr. PASCARELL (for himself and Mr. ROONEY) introduced the following bill;
which was referred to the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, to establish a surveillance system regarding traumatic brain injury, 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 “National Traumatic
5 Brain Injury Research and Treatment Improvement Act
6 of 2014”.

1 **SEC. 2. FINDINGS.**

2 (a) FINDINGS.—The Congress finds as follows:

3 (1) State data and monitoring systems provide
4 reliable data on injury causes and risk factors, iden-
5 tify trends in the incidence of traumatic brain in-
6 jury, enable the development of cause-specific pre-
7 vention strategies focused on populations at greatest
8 risk, and monitor the effectiveness of such strate-
9 gies.

10 (2) Since 1995, when the Centers for Disease
11 Control and Prevention published Guidelines for
12 Surveillance of Central Nervous System Injury, ad-
13 ditional causes of traumatic brain injury have
14 emerged: military-related traumatic brain injuries;
15 sports-related concussions; traffic injuries resulting
16 from texting while driving; and increasing numbers
17 of falls-related traumatic brain injuries among older
18 adults.

19 (3) In their 2013 report, Sports-Related Con-
20 cussions in Youth: Improving the Science, Changing
21 the Culture, the Institute on Medicine and the Na-
22 tional Research Council noted that there is currently
23 a lack of data to accurately estimate the incidence
24 of sports-related concussions across a variety of
25 sports and for youth across the pediatric age spec-
26 trum. The report recommended that the Centers for

1 Disease Control and Prevention establish and over-
2 see a national surveillance system to accurately de-
3 termine the incidence of sports-related concussions,
4 including those in youth ages 5 to 21, taking into
5 account Federal efforts to collect information on
6 traumatic brain injury.

7 (4) Traumatic brain injury is a substantial pub-
8 lic health problem among older persons. As the pop-
9 ulation of older persons continues to grow in the
10 United States, the need to design and implement
11 proven and cost-effective prevention measures that
12 focus on the leading causes of traumatic brain injury
13 becomes more urgent.

14 (5) In order to implement this Act, the Centers
15 for Disease Control and Prevention needs to collabo-
16 rate with Federal agencies reporting military-related
17 traumatic brain injuries, school systems reporting
18 traumatic brain injuries, Medicaid and other Federal
19 programs, and State agencies.

20 **SEC. 3. ESTABLISHING REQUIREMENTS TO IMPROVE THE**
21 **RESEARCH AND TREATMENT OF TRAUMATIC**
22 **BRAIN INJURY.**

23 (a) IN GENERAL.—The Secretary, acting through the
24 Director of the Centers for Disease Control and Preven-
25 tion, shall—

1 (1) evaluate existing surveillance and data col-
2 lections systems that track the incidence and cir-
3 cumstances of traumatic brain injury, including con-
4 cussion;

5 (2) not later than 9 months after the date of
6 enactment of this Act, submit a report to the Con-
7 gress outlining the findings of the evaluation under
8 paragraph (1); and

9 (3) establish a statistically sound, scientifically
10 credible, integrated surveillance system regarding
11 traumatic brain injury, to be known as the “Na-
12 tional Traumatic Brain Injury Surveillance System”.

13 (b) RESEARCH.—The Secretary shall ensure that the
14 National Traumatic Brain Injury Surveillance System is
15 designed in a manner that facilitates further research on
16 brain injury.

17 (c) CONTENT.—In carrying out subsection (a), the
18 Secretary—

19 (1) shall provide for the collection and storage
20 of information (excluding personally identifiable in-
21 formation) on the incidence and prevalence of trau-
22 matic brain injury, including concussion, in the
23 United States across the lifespan;

24 (2) to the extent practicable, shall provide for
25 the collection and storage of other available informa-

1 tion (excluding personally identifiable information)
2 on traumatic brain injury, such as information con-
3 cerning demographics and other information associ-
4 ated with the incidence of a traumatic brain injury,
5 such as—

6 (A) age;

7 (B) race and ethnicity;

8 (C) sex;

9 (D) geographic location;

10 (E) history of head injury (including injury
11 type and the approximate date of injury);

12 (F) pre-existing conditions, such as learn-
13 ing disabilities and attention deficit hyper-
14 activity disorder; and

15 (G) co-occurring issues, such as substance
16 abuse or post-traumatic stress disorder;

17 (3) to the extent practicable, shall provide for
18 the collection and storage of information relevant to
19 analysis on traumatic brain injury, such as informa-
20 tion concerning—

21 (A) impact location on the body and na-
22 ture of the impact;

23 (B) qualifications of personnel making the
24 traumatic brain injury diagnosis;

1 (C) assessment tool used to make the diag-
2 nosis;

3 (D) signs and symptoms consistent with a
4 head injury;

5 (E) sport or activity and the level of com-
6 petition (if a sports-related activity);

7 (F) use of protective equipment and im-
8 pact monitoring devices; and

9 (G) severity of the traumatic brain injury;
10 and

11 (4) may address issues identified during the
12 consultation process under subsection (d).

13 (d) CONSULTATION.—In carrying out this section,
14 the Secretary shall consult with individuals with appro-
15 priate expertise, including—

16 (1) epidemiologists with experience in disease
17 surveillance or registries;

18 (2) representatives of national health associa-
19 tions that—

20 (A) focus on brain injury; and

21 (B) have demonstrated experience in re-
22 search, care, or patient services;

23 (3) State public health agencies;

24 (4) health information technology experts or
25 other information management specialists;

1 (5) clinicians with expertise in brain injury;

2 (6) research scientists with experience con-
3 ducting brain research or utilizing surveillance sys-
4 tems for scientific research purposes;

5 (7) medical facilities of the Department of Vet-
6 erans Affairs; and

7 (8) behavioral health centers.

8 (e) GRANTS.—The Secretary may award grants to,
9 or enter into contracts or cooperative agreements with,
10 public or private nonprofit entities to carry out activities
11 under this section.

12 (f) COORDINATION WITH OTHER FEDERAL AGEN-
13 CIES.—Subject to subsection (h), the Secretary shall make
14 information and analysis in the National Traumatic Brain
15 Injury Surveillance System available, as appropriate, to
16 Federal departments and agencies, such as the National
17 Institutes of Health, the Health Resources and Services
18 Administration, the Food and Drug Administration, the
19 Centers for Medicare & Medicaid Services, the Agency for
20 Healthcare Research and Quality, the Department of Edu-
21 cation, the Department of Veterans Affairs, and the De-
22 partment of Defense.

23 (g) PUBLIC ACCESS.—Subject to subsection (h), the
24 Secretary shall make information and analysis in the Na-

1 tional Traumatic Brain Injury Surveillance System avail-
2 able, as appropriate, to the public, including researchers.

3 (h) PRIVACY.—The Secretary shall ensure that pri-
4 vacy and security protections applicable to the National
5 Traumatic Brain Injury Surveillance System are at least
6 as stringent as the privacy and security protections under
7 HIPAA privacy and security law, including nondisclosure
8 of personally identifiable information.

9 (i) REPORT.—Not later than 2 years after the date
10 of enactment of this Act, the Secretary shall submit a re-
11 port to the Congress concerning the implementation of
12 this section. Such report shall include information on—

13 (1) the development and maintenance of the
14 National Traumatic Brain Injury Surveillance Sys-
15 tem;

16 (2) the type of information collected and stored
17 in the System;

18 (3) the use and availability of such information,
19 including guidelines for such use; and

20 (4) the use and coordination of databases that
21 collect or maintain information on traumatic brain
22 injury.

23 (j) DEFINITION.—In this Act:

24 (1) NATIONAL HEALTH ASSOCIATION.—The
25 term “national health association” means a national

1 nonprofit organization with chapters, other affiliated
2 organizations, or networks in States throughout the
3 United States.

4 (2) HIPAA PRIVACY AND SECURITY LAW.—The
5 term “HIPAA privacy and security law” has the
6 meaning given to that term in section 3009 of the
7 Public Health Service Act (42 U.S.C. 300jj–19).

8 (3) PERSONALLY IDENTIFIABLE INFORMA-
9 TION.—The term “personally identifiable informa-
10 tion” means information which can be used to dis-
11 tinguish or trace an individual’s identity (such as
12 their name, social security number, or biometric
13 records) either alone or when combined with other
14 personal or identifying information which is linked
15 or linkable to a specific individual (such as date of
16 birth, place of birth, and mother’s maiden name).

17 (4) SECRETARY.—The term “Secretary” means
18 the Secretary of Health and Human Services.

19 (5) SURVEILLANCE.—The term “surveillance”
20 means the ongoing, systematic collection, analysis,
21 interpretation, and dissemination of data (other than
22 personally identifiable information) regarding a
23 health-related event for use in public health action
24 to reduce morbidity and mortality and to improve
25 health.

1 (6) TRAUMATIC BRAIN INJURY.—The term
2 “traumatic brain injury” means an injury to the
3 head arising from blunt or penetrating trauma or
4 from acceleration or deceleration forces associated
5 with one or more of the following: decreased level of
6 consciousness, amnesia, objective neurologic or
7 neuropsychological abnormalities, skull fractures, di-
8 agnosed intracranial lesions, or head injury listed as
9 a cause of death in the death certificate.

10 (k) AUTHORIZATION OF APPROPRIATIONS.—To carry
11 out this Act, there are authorized to be appropriated such
12 sums as may be necessary.

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