

114TH CONGRESS
1ST SESSION

H. R. 2313

To amend the Public Health Service Act to enhance and expand infrastructure and activities to track the epidemiology of hydrocephalus, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 13, 2015

Mr. SMITH of New Jersey introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to enhance and expand infrastructure and activities to track the epidemiology of hydrocephalus, 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 “Advancing Research
5 for Hydrocephalus Act of 2015”.

1 **SEC. 2. NATIONAL HYDROCEPHALUS SURVEILLANCE SYS-**
2 **TEM.**

3 Part P of title III of the Public Health Service Act
4 (42 U.S.C. 280g et seq.) is amended by adding at the end
5 the following:

6 **“SEC. 399V-6. SURVEILLANCE OF HYDROCEPHALUS.**

7 “(a) IN GENERAL.—The Secretary, acting through
8 the Director of the Centers for Disease Control and Pre-
9 vention, shall—

10 “(1) enhance and expand infrastructure and ac-
11 tivities to track the epidemiology of hydrocephalus;
12 and

13 “(2) incorporate information obtained through
14 such activities into a statistically sound, scientifically
15 credible, integrated surveillance system, to be known
16 as the National Hydrocephalus Surveillance System.

17 “(b) RESEARCH.—The Secretary shall ensure that
18 the National Hydrocephalus Surveillance System is de-
19 signed in a manner that facilitates further research on hy-
20 drocephalus.

21 “(c) CONTENT.—In carrying out subsection (a), the
22 Secretary—

23 “(1) shall provide for the collection and storage
24 of information on the incidence and prevalence of
25 hydrocephalus in the United States;

1 “(2) to the extent practicable, shall provide for
2 the collection and storage of other available informa-
3 tion on hydrocephalus, such as information con-
4 cerning—

5 “(A) demographics and other information
6 associated or possibly associated with hydro-
7 cephalus, such as age, race, ethnicity, sex, geo-
8 graphic location, and family history; and

9 “(B) any changes over time with respect to
10 the incidence and prevalence of hydrocephalus
11 in children and adults;

12 “(3) may provide for the collection and storage
13 of information relevant to analysis on hydrocephalus
14 such as information concerning—

15 “(A) the epidemiology of the condition;

16 “(B) the history of congenital and acquired
17 hydrocephalus;

18 “(C) the detection, management, and
19 treatment approaches for the condition;

20 “(D) the events or influences that occur
21 during fetal development, or genetic abnormali-
22 ties that lead to the condition; and

23 “(E) the development of outcomes meas-
24 ures; and

1 “(4) may address issues identified during the
2 consultation process under subsection (d).

3 “(d) CONSULTATION.—In carrying out this section,
4 the Secretary shall consult with individuals with appro-
5 priate expertise, including—

6 “(1) epidemiologists with experience in disease
7 surveillance or registries;

8 “(2) representatives of national voluntary
9 health associations that—

10 “(A) focus on hydrocephalus; and

11 “(B) have demonstrated experience in re-
12 search, care, or patient services;

13 “(3) health information technology experts or
14 other information management specialists;

15 “(4) clinicians with expertise in hydrocephalus
16 diseases; and

17 “(5) research scientists with experience con-
18 ducting translational research or utilizing surveil-
19 lance systems for scientific research purposes.

20 “(e) GRANTS.—The Secretary may award grants to,
21 or enter into contracts or cooperative agreements with,
22 public or private nonprofit entities to carry out activities
23 under this section.

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

1 tional Hydrocephalus Surveillance System available, as ap-
2 propriate, to the public, including researchers.

3 “(g) PRIVACY.—The Secretary shall ensure that pri-
4 vacy and security protections applicable to the National
5 Hydrocephalus Surveillance System are at least as strin-
6 gent as the privacy and security protections under HIPAA
7 privacy and security law (as defined in section
8 3009(a)(2)).

9 “(h) REPORT.—Not later than 4 years after the date
10 of the enactment of this section, the Secretary shall sub-
11 mit a report to the Congress concerning the implementa-
12 tion of this section. Such report shall include information
13 on—

14 “(1) the development and maintenance of the
15 National Hydrocephalus Surveillance System;

16 “(2) the type of information collected and
17 stored in the National Hydrocephalus Surveillance
18 System;

19 “(3) the use and availability of such informa-
20 tion, including guidelines for such use; and

21 “(4) the use and coordination of databases that
22 collect or maintain information on the National Hy-
23 drocephalus Surveillance System.”.

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