

112TH CONGRESS
2D SESSION

S. 3396

To amend the Public Health Service Act to provide for a national campaign to increase public awareness and knowledge of Congenital Diaphragmatic Hernia, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JULY 18, 2012

Mr. SESSIONS (for himself and Mr. CARDIN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to provide for a national campaign to increase public awareness and knowledge of Congenital Diaphragmatic Hernia, 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 “Congenital Diaphragm-
5 matic Hernia Research Act of 2012”.

6 **SEC. 2. FINDINGS.**

7 Congress finds as follows:

1 (1) Congenital Diaphragmatic Hernia is a birth
2 defect.

3 (2) Congenital Diaphragmatic Hernia has a
4 rate of occurrence of 1 in every 2500 babies.

5 (3) Congenital Diaphragmatic Hernia affects
6 approximately 1600 babies each year in the United
7 States.

8 (4) Congenital Diaphragmatic Hernia occurs
9 when the diaphragm fails to fully form, allowing ab-
10 dominal organs to migrate into the chest cavity and
11 preventing lung growth.

12 (5) The majority of Congenital Diaphragmatic
13 Hernia patients have underdeveloped lungs or poor
14 pulmonary function.

15 (6) Congenital Diaphragmatic Hernia patients
16 often endure long-term complications such as pul-
17 monary hypertension, pulmonary hypoplasia, asth-
18 ma, gastrointestinal reflex, feeding disorders, and
19 developmental delays.

20 (7) Congenital Diaphragmatic Hernia survivors
21 sometimes endure long-term mechanical ventilation
22 dependency, skeletal malformations, supplemental
23 oxygen dependency, enteral and parenteral nutrition,
24 and hypoxic brain injury.

1 (8) Congenital Diaphragmatic Hernia has a
2 survival rate of 50 percent.

3 (9) Congenital Diaphragmatic Hernia has af-
4 fected more than 600,000 babies worldwide since
5 2000.

6 (10) Babies born with Congenital Diaphrag-
7 matic Hernia endure extended hospital stays in in-
8 tensive care with multiple surgeries. Extended hos-
9 pital stays in some cases have exceeded 1 year.

10 (11) Congenital Diaphragmatic Hernia is as
11 common as Spina Bifida and Cystic Fibrosis.

12 (12) Congenital Diaphragmatic Hernia is diag-
13 nosed in utero in only 75 percent of cases.

14 (13) Congenital Diaphragmatic Hernia is treat-
15 ed through mechanical ventilation, heart and lung
16 bypass (Extracorporeal Membrane Oxygenation) ma-
17 chines and surgical repair.

18 (14) Congenital Diaphragmatic Hernia surgical
19 repair is often outgrown thus leading to reherniation
20 and requiring additional surgery.

21 (15) Congenital Diaphragmatic Hernia does not
22 discriminate based on race, gender, or socioeconomic
23 status.

24 (16) The cause of Congenital Diaphragmatic
25 Hernia is unknown.

1 (17) The average hospital bill per Congenital
2 Diaphragmatic Hernia patient is \$500,000.

3 (18) The estimated total annual economic im-
4 pact of Congenital Diaphragmatic Hernia in the
5 United States is in excess of \$800,000,000.

6 (19) Annual Federal support for Congenital Di-
7 aphragmatic Hernia research at the National Insti-
8 tutes of Health is currently estimated at less than
9 \$4,000,000.

10 **SEC. 3. NATIONAL CDH PUBLIC AWARENESS CAMPAIGN.**

11 Part P of title III of the Public Health Service Act
12 (42 U.S.C. 280g et seq.) is amended by adding at the end
13 the following:

14 **“SEC. 399V-6. NATIONAL CDH PUBLIC AWARENESS CAM-**
15 **PAIGN.**

16 “(a) IN GENERAL.—The Secretary shall carry out a
17 national campaign to increase public awareness and
18 knowledge of Congenital Diaphragmatic Hernia.

19 “(b) COMPONENTS OF CAMPAIGN.—The measures to
20 increase the public awareness and knowledge of Congenital
21 Diaphragmatic Hernia under the national campaign under
22 subsection (a) shall include—

23 “(1) the dissemination of information on the
24 definition of Congenital Diaphragmatic Hernia;

1 “(2) the dissemination of information on good
2 neonatal care of Congenital Diaphragmatic Hernia
3 patients;

4 “(3) the outreach to minority populations re-
5 garding Congenital Diaphragmatic Hernia; and

6 “(4) the promotion of good prenatal care and
7 ultrasound to detect Congenital Diaphragmatic Her-
8 nia in utero.

9 “(c) EVALUATION.—The Director of the National In-
10 stitutes of Health shall conduct an evaluation of the
11 amount of Federal assistance provided for Congenital Dia-
12 phragmatic Hernia research at the National Institute for
13 Health to determine whether funding levels are adequate.

14 “(d) SENSE OF THE SENATE.—It is the Sense of the
15 Senate that the Director of the National Institutes of
16 Health should consider allocating funds and other re-
17 sources for Congenital Diaphragmatic Hernia research.”.

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