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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

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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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Congenital Diaphragmatic Hernia Research Act of 2012''.

SEC. 2. FINDINGS.

Congress finds as follows:

(1) Congenital Diaphragmatic Hernia is a birth defect.

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

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

(4) Congenital Diaphragmatic Hernia occurs when the diaphragm fails to fully form, allowing abdominal organs to migrate into the chest cavity and preventing lung growth.

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

(6) Congenital Diaphragmatic Hernia patients often endure long-term complications such as pulmonary hypertension, pulmonary hypoplasia, asthma, gastrointestinal reflex, feeding disorders, and developmental delays.

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

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

(9) Congenital Diaphragmatic Hernia has affected more than 600,000 babies worldwide since 2000.

(10) Babies born with Congenital Diaphragmatic Hernia endure extended hospital stays in intensive care with multiple surgeries. Extended hospital stays in some cases have exceeded 1 year.

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

(12) Congenital Diaphragmatic Hernia is diagnosed in utero in only 75 percent of cases.

(13) Congenital Diaphragmatic Hernia is treated through mechanical ventilation, heart and lung bypass (Extracorporeal Membrane Oxygenation) machines and surgical repair.

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

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

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

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

(18) The estimated total annual economic impact of Congenital Diaphragmatic Hernia in the United States is in excess of $800,000,000.

(19) Annual Federal support for Congenital Diaphragmatic Hernia research at the National Institutes of Health is currently estimated at less than $4,000,000.

SEC. 3. NATIONAL CDH PUBLIC AWARENESS CAMPAIGN.

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

"SEC. 399V–6. NATIONAL CDH PUBLIC AWARENESS CAMPAIGN.

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

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

''(1) the dissemination of information on the definition of Congenital Diaphragmatic Hernia;

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

''(3) the outreach to minority populations regarding Congenital Diaphragmatic Hernia; and

''(4) the promotion of good prenatal care and ultrasound to detect Congenital Diaphragmatic Hernia in utero.

''(c) EVALUATION.—The Director of the National Institutes of Health shall conduct an evaluation of the amount of Federal assistance provided for Congenital Diaphragmatic Hernia research at the National Institute for Health to determine whether funding levels are adequate.

''(d) SENSE OF THE SENATE.—It is the Sense of the Senate that the Director of the National Institutes of Health should consider allocating funds and other resources for Congenital Diaphragmatic Hernia research.''.

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