

113TH CONGRESS
1ST SESSION

H. RES. 144

Expressing support for designation of April 2013 as “National Congenital Diaphragmatic Hernia Awareness Month”.

IN THE HOUSE OF REPRESENTATIVES

APRIL 9, 2013

Mrs. ROBY (for herself and Mr. HOLDING) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for designation of April 2013 as “National Congenital Diaphragmatic Hernia Awareness Month”.

Whereas congenital diaphragmatic hernia occurs when the diaphragm fails to fully form, allowing abdominal organs to migrate into the chest cavity and prevent lung growth;

Whereas the Centers for Disease Control and Prevention defines congenital diaphragmatic hernia as a birth defect;

Whereas congenital diaphragmatic hernia occurs in 1 of every 2,500 births;

Whereas congenital diaphragmatic hernia affects approximately 1,600 babies each year in the United States;

Whereas the majority of congenital diaphragmatic hernia patients have underdeveloped lungs or poor pulmonary function;

Whereas congenital diaphragmatic hernia patients often endure long-term complications, including pulmonary hypertension, pulmonary hypoplasia, asthma, gastrointestinal reflex, feeding disorders, and developmental delays;

Whereas congenital diaphragmatic hernia survivors sometimes endure long-term mechanical ventilation dependency, skeletal malformations, supplemental oxygen dependency, enteral and parenteral nutrition, and hypoxic brain injury;

Whereas congenital diaphragmatic hernia patients have a survival rate ranging from 62 percent to 90 percent depending on the severity of the defect, the treatment available at delivery, and whether extracorporeal membrane oxygenation must be used;

Whereas congenital diaphragmatic hernia has affected more than 600,000 babies throughout the world since 2000;

Whereas babies born with congenital diaphragmatic hernia endure extended hospital stays in intensive care with multiple surgeries;

Whereas congenital diaphragmatic hernia is as common a birth defect as spina bifida and cystic fibrosis;

Whereas congenital diaphragmatic hernia is diagnosed in utero in only 75 percent of cases;

Whereas congenital diaphragmatic hernia is treated through mechanical ventilation, extracorporeal membrane oxygenation machines (commonly known as “heart and lung bypass machines”) and surgical repair;

Whereas patients often outgrow congenital diaphragmatic hernia surgical repair, leading to reherniation and requiring additional surgery;

Whereas the occurrence of congenital diaphragmatic hernia does not discriminate based on race, gender, or socioeconomic status;

Whereas the cause of congenital diaphragmatic hernia is unknown;

Whereas the average hospital bill for a congenital diaphragmatic hernia patient is \$500,000;

Whereas the total annual cost of medical care for children with congenital diaphragmatic hernia in the United States is more than \$800,000,000; and

Whereas the month of April 2013 would be an appropriate month to designate as “National Congenital Diaphragmatic Hernia Awareness Month”: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of “National Con-
3 genital Diaphragmatic Hernia Awareness Month”;

4 (2) declares that steps should be taken to—

5 (A) raise awareness of and increase public
6 knowledge about congenital diaphragmatic her-
7 nia;

8 (B) inform minority populations in the
9 United States about congenital diaphragmatic
10 hernia;

1 (C) disseminate information on the impor-
2 tance of good neonatal care for congenital dia-
3 phragmatic hernia patients;

4 (D) promote good prenatal care and the
5 use of ultrasounds to detect congenital dia-
6 phragmatic hernia in utero; and

7 (E) encourage research on congenital dia-
8 phragmatic hernia in order to discover its
9 causes, develop treatments, and find a cure;
10 and

11 (3) calls on the people of the United States, in-
12 terest groups, and affected persons to—

13 (A) promote awareness of congenital dia-
14 phragmatic hernia;

15 (B) take an active role in the fight against
16 this devastating birth defect; and

17 (C) observe National Congenital Diaphrag-
18 matic Hernia Awareness Month with appro-
19 priate ceremonies and activities.

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