

115TH CONGRESS
1ST SESSION

S. RES. 128

Designating April 2017 as “National Congenital Diaphragmatic Hernia Awareness Month”.

IN THE SENATE OF THE UNITED STATES

APRIL 7, 2017

Mr. CARDIN (for himself and Mr. STRANGE) submitted the following resolution; which was referred to the Committee on the Judiciary

APRIL 25, 2017

Committee discharged; considered and agreed to

RESOLUTION

Designating April 2017 as “National Congenital Diaphragmatic Hernia Awareness Month”.

Whereas congenital diaphragmatic hernia (referred to in this preamble as “CDH”) occurs in individuals in which the diaphragm fails to fully form, allowing abdominal organs to migrate into the chest cavity and preventing lung growth;

Whereas the Director of the Centers for Disease Control and Prevention recognizes CDH as a birth defect;

Whereas the majority of CDH patients suffer from under-developed lungs or poor pulmonary function;

Whereas babies born with CDH endure extended hospital stays in intensive care with multiple surgeries;

Whereas CDH patients often endure long-term complications, such as pulmonary hypertension, pulmonary hypoplasia, asthma, gastrointestinal reflux, feeding disorders, and developmental delays;

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

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

Whereas surgical repair is often not a permanent solution for CDH and can lead to reherniation and require additional surgery;

Whereas CDH is diagnosed in utero in less than 50 percent of cases;

Whereas infants born with CDH have a high mortality rate, ranging from 20 to 60 percent, depending on the severity of the defect and interventions available at delivery;

Whereas CDH has a rate of occurrence of 1 in every 2,500 live births worldwide;

Whereas in the United States, CDH affects approximately 1,600 babies each year;

Whereas since 2000, CDH has affected more than 700,000 babies worldwide since 2000;

Whereas CDH does not discriminate based on race, gender, or socioeconomic status;

Whereas the cause of CDH is unknown;

Whereas the average CDH survivor will face postnatal care that totals not less than \$100,000; and

Whereas Federal support for CDH research at the National Institutes of Health for 2017 is estimated to be not more than \$4,000,000: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates April 2017 as “National Con-
3 genital Diaphragmatic Hernia Awareness Month”;

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

5 (A) raise awareness of and increase public
6 knowledge about congenital diaphragmatic her-
7 nia (referred to in this resolving clause as
8 “CDH”);

9 (B) inform all Americans about the dan-
10 gers of CDH, especially groups of people that
11 may be disproportionately affected by CDH or
12 have lower survival rates;

13 (C) disseminate information on the impor-
14 tance of quality neonatal care of CDH patients;

15 (D) promote quality prenatal care and
16 ultrasounds to detect CDH in utero; and

17 (E) support research funding of CDH to—

18 (i) improve screening and treatment
19 for CDH;

20 (ii) discover the causes of CDH; and

- 1 (iii) develop a cure for CDH; and
- 2 (3) calls on the people of the United States, in-
- 3 terest groups, and affected persons to—
- 4 (A) promote awareness of CDH;
- 5 (B) take an active role in the fight against
- 6 this devastating birth defect; and
- 7 (C) observe National Congenital Diaphrag-
- 8 matic Hernia Awareness Month with appro-
- 9 priate ceremonies and activities.

○