

In request of a Congressional Bill for the benefit of Congenital Diaphragmatic Hernia Research

Submitted by CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support  
3650 Rogers Rd. #290  
Wake Forest, NC 27587  
919-610-0129  
research@cdhsupport.org

## A BILL

To amend the Public Health Service Act to provide for the national collection of data on babies born with Congenital Diaphragmatic Hernia in a standardized manner, 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 ‘CDH Research Act of 2010’.

### SECTION 2. FINDINGS.

The 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 and/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%.

- (9) Congenital Diaphragmatic Hernia has affected over 600,000 babies worldwide since the year 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 one 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% 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, religion, economic status or lack of prenatal care.
- (16) The cause of Congenital Diaphragmatic Hernia is unknown.
- (17) Congenital Diaphragmatic Hernia takes more lives in the average year in the United States than lightning strikes, tornadoes, hurricanes and floods combined.
- (18) The average hospital bill per Congenital Diaphragmatic Hernia patient is \$500,000.
- (19) The estimated total annual economic impact of Congenital Diaphragmatic Hernia in the United States is in excess of \$800,000,000.
- (20) Annual Federal support for Congenital Diaphragmatic Hernia research at the National Institutes of Health is currently estimated at less than \$5,000,000.

### SECTION 3. SENSE OF CONGRESS ON NIH FUNDING FOR CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH.

- (1) In General- It is the sense of the Congress that the Director of the National Institutes of Health should increase the allocation of funds and other resources for Congenital Diaphragmatic Hernia research.
- (2) Measures To Increase the Research of Congenital Diaphragmatic Hernia shall include—
- (a) Funds for national CDH patient registries through current databases kept by research organizations such as The International Congenital Diaphragmatic Hernia Study Group and CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support for the purposes of finding commonalities

in the search of possible causes and better treatments of Congenital Diaphragmatic Hernia.

(b) Funds for national CDH patient registries through current databases kept by research organizations such as The International Congenital Diaphragmatic Hernia Study Group and CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support for the purposes of researching the long term health of survivors of Congenital Diaphragmatic Hernia.

(c) Funds for genetic research into possible causes of Congenital Diaphragmatic Hernia.

(d) Funds for research into more successful surgical and neonatal medical procedures that may increase the survival rate of babies born with Congenital Diaphragmatic Hernia.

#### SECTION 4. NATIONAL PUBLIC AWARENESS CAMPAIGN.

(1) In General- The Secretary of Health and Human Services shall carry out a national campaign to increase public awareness and knowledge of Congenital Diaphragmatic Hernia

(2) Measures To Increase the Public Awareness of Congenital Diaphragmatic Hernia under the national campaign under subsection (1) shall include—

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

(b) the dissemination of information on good neonatal care of Congenital Diaphragmatic Hernia patients; and

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