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Alaska Legislature

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House Concurrent Resolution 9 Sponsor Statement

The diaphragm is formed in the first trimester of pregnancy and controls the lungs' ability to inhale and exhale. Congenital diaphragmatic hernias (CDH) occur when the diaphragm fails to form or to close totally and an opening allows abdominal organs into the chest cavity. This inhibits lung growth. CDH has a mortality rate of roughly 50%, and occurs in approximately 1 in every 2,500 births (1,600 cases in the U.S. each year). Of the 50% that do survive, most will endure long hospital stays, feeding issues, asthma and other problems. A few of the survivors suffer from severe long-term medical issues. The cause of CDH is not yet known.

CDH occurs as frequently as Spina Bifida and Cystic Fibrosis, yet there is comparatively very little research being done and virtually no media coverage. House Concurrent Resolution 9 aims to raise awareness of this condition, provide support and for victims and their families, and encourage the research needed to establish the cause and possible prevention by proclaiming April 19th, 2015 as a CDH Day of Action. CDH Days of Action for 2015 have been proclaimed in 14 states and 9 towns, including Anchorage.

Municipality of Anchorage Alaska

PROCLAMATION

WHEREAS, one in every 2,500 pregnancies is diagnosed with a congenital diaphragmatic hernia (CDH); and

WHEREAS, since 2000 it is estimated that over 500,000 babies have been born with CDH, with only 50 percent of those babies surviving; and

WHEREAS, CDH is as common as spina bifida and cystic fibrosis, yet very few people know about it or are aware of it and 1,600 babies are born with CDH every year in the United States; and

WHEREAS, there are people living in Anchorage who have been diagnosed with and have survived CDH, and there are local families which have endured the horrible pain and grief associated with the loss of loved ones with CDH; and

WHEREAS, those with CDH often endure multiple surgeries and possible medical complication beyond their diagnosis that include heart defects, pulmonary complications, gastric and intestinal problems, developmental delays, and may require respiratory and medicinal support for years.

NOW THEREFORE, I, Dan Sullivan, Mayor of Anchorage, Alaska, do hereby proclaim April 19, 2015, as

Congenital Diaphragmatic Hernia Day

IN Anchorage, and urge local residents to understand the importance of awareness of CDC which will help bring about acceptance and support for those suffering with this congenital defect and will help advocate for urgently needed medical research and advances.




MAYOR

CDH Statistics



U.S CDH Stats

There are approximately 6 million pregnancies every year throughout the United States:

4,058,000 live births

1,995,840 pregnancy losses

1 in 2500 babies is diagnosed with CDH

Over 1600 babies are born with Congenital Diaphragmatic Hernia EVERY YEAR in the United States alone.

With a **50% survival rate**, 800 of those babies will die.

Today, and every day, at least 4 families will be devastated with the news of CDH.

Global CDH Stats

147 babies will be born with CDH every day

The World Census Bureau estimates that in 2008 over 350,000 babies are born in the world every day

Every 10 minutes a baby is born with Congenital Diaphragmatic Hernia

IDB (International Database) from the U.S. Census site, 257 people are born every minute globally.

Over 700,000 babies have been born with CDH since January 1, 2000

Other Global CDH Facts & Statistics

No one knows how to prevent CDH.

The cause of CDH is still unknown.

It has been associated with several genetic anomalies such as Fryns Syndrome, Cornelia deLange System, Trisomy 18, 21, & 22.

Vitamin A diet deficiency is known to cause CDH in lab rats.

It has been suggested in some medical journals, but not proven, that thalidomide, quinine, phenmetrazine, and nitrofen may also cause CDH.

20% of CDH pregnancies also are diagnosed with polyhydramnios (an overabundance of amniotic fluid).

CHERUBS and the CDH Study Group are the only 2 organizations actively researching Congenital Diaphragmatic Hernia on a global platform. CHERUBS is the only organization offering global support to families of children born with CDH, with members in 38 countries.

1 CDH strikes 1 in every 2500 babies

[A population-based study of congenital diaphragmatic hernia.](#) - Torfs CP, Curry CJ, Bateson TF, Honoré LH. California Birth Defects Monitoring Program, Emeryville 94608. Congenital

Diaphragmatic Hernia; Prem Puri; Current Problems in Surgery; Volume XXI Number 10
October 1994

Medical Research Society; Communications for the Spring Meeting of the Medical Research Society, held in conjunction with the Academy of Medical Sciences and the Royal College of Physicians, London on 28th February 2005 at the Royal College of Physicians, London.

2 There are more babies born with CDH than with Cystic Fibrosis (1 in 3900) and it's almost as common as Spina Bifida (7 in 10,000)

Alder Hey Doctors Leading the Way on Child Health; Royal Liverpool Children's NHS Trust; 2001

Royal Liverpool Children's NHS Trust - Alder Hey; Research Board Meeting; Royal Liverpool Children's NHS Trust; 2004

Improving lung growth in babies before birth - Edwin Jesudason , Academy of Medical Sciences, Alder Hey Children's Hospital, Liverpool ; 2003

Fog2 Is Required for Normal Diaphragm and Lung Development in Mice and Humans -Kate G Ackerman, Bruce J Herron, Sara O Vargas, Hailu Huang, Sergei G Tevosian, Lazaros Kochilas, Cherie Rao, Barbara R Pober, Randal P Babiuk, Jonathan A Epstein, John J Greer, and David R Beier

Fetal Surgery for Congenital Diaphragmatic Hernia: The North American Experience - Darrell L. Cass MD Texas Center for Fetal Surgery, Texas Children's Hospital and the Michael E. DeBaakey Department of Surgery, and Department of Pediatrics, Baylor College of Medicine, Houston, TX.

Small lungs and suspect smooth muscle: congenital diaphragmatic hernia and the smooth muscle hypothesis. - Jesudason EC. Department of Pediatric Surgery, Alder Hey Children's Hospital, Division of Child Health, School of Reproductive and Developmental Medicine, University of Liverpool, Liverpool, UK.

Congenital diaphragmatic defects and associated syndromes, malformations, and chromosome anomalies: A retrospective study of 60 patients and literature review - Gregory M. Enns, Victoria A. Cox, Ruth B. Goldstein , David L. Gibbs , Michael R. Harrison , Mahin Golabi

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3 CHERUBS is working hard to raise Congenital Diaphragmatic Hernia Awareness!

Rainbow of Hope first used this term on-line in July, 2006

So? Blog post by Elizabeth Doyle-Propst in which she concedes that CHERUBS used the term "Congenital Diaphragmatic Hernia Awareness" before Breath of Hope, Inc.

Letter by Stacy Everett-Harding in which she concedes that Jana Llewellyn and Rainbow of Hope used the term "Congenital Diaphragmatic Hernia Awareness" before Breath of Hope, Inc.

