

To Whom It May Concern:

I would like to formally request a proclamation for April 19, 2015 to be declared "A Day of Congenital Diaphragmatic Hernia Awareness".

Congenital Diaphragmatic Hernia (CDH) is a devastating birth defect that strikes 1600 babies each year (approximately 20 babies in Utah), taking the lives of 50%, or 800 babies lost. It occurs when the diaphragm fails to fully form, allowing abdominal organs into the chest cavity and preventing lung growth. The cause is unknown.

Congenital Diaphragmatic Hernia occurs as often as Spina Bifida and Cystic Fibrosis but has little awareness and even less research funding. Currently, we are supporting a bill in the US Senate, S.3396, to support more awareness and funding for CDH. You can learn more about CDH at www.SaveTheCherubs.org

CDH is a horrible birth defect that has affected my family greatly. In June 2007 our first child, a daughter, Evie, was born with CDH. She fought bravely but lost her battle with CDH after a short 14 hours. In February 2009, our second child, also a girl, Allyson was born with CDH. Allyson was the bravest and strongest little girl. She had 3 major surgeries and 4 hospitalizations in the first year of her life. Unfortunately after a 15 month battle that would test the mettle of any human, Allyson also lost her fight against CDH.

My story is not unique to the CDH community in general, or even the CDH community in Utah. There are many other families in our wonderful state that have similar stories.

My family is also part of CHERUBS, the world's first and largest CDH charity, CHERUBS, and we are working together with families in 5400 countries to raise awareness on April 19th by asking for proclamations, holding awareness events in many cities and wearing the CDH Awareness ribbon to tell the world about these babies and the need for research funding

Last year CHERUBS led families to reach out to our governors and mayors and together we gathered proclamations from 46 states for 2014 (including Utah) and 72 cities nationwide. Governor Herbert again declared April 19 A Day of Congenital Diaphragmatic Hernia for 2015.

I would be incredibly proud if you would sign a proclamation to help these babies and families. Utah also offers a unique support to the CDH community. Primary Children's Medical Center (PCMC) has an ECMO machine in the Neonatal ICU. ECMO is a blood oxygenating process that many CDH babies require. The ECMO machine at PCMC serves a five state area! That more than doubles the number of potential CDH babies treated in Utah each year.

My family and the families of all of the other CDH babies helped by Utah and PCMC very, very much appreciate your assistance for a proclamation for this year and for the support for families like ours.

Sincerely Yours,

Josh Hensley, CHERUBS Utah State Representative
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PROCLAMATION

Proclaiming April 19, 2015, a Day of Congenital Diaphragmatic Hernia Awareness

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

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

WHEREAS, CDH is as common as spina bifida and cystic fibrosis; however, very few people know about it or are aware of it; and

WHEREAS, 1,600 babies are born with CDH every year in the United States; and

WHEREAS, there are many people living in Utah who have been diagnosed with and have survived their CDH; although many families in Utah 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; and

WHEREAS, raising awareness of this congenital defect will help bring about acceptance and support for those suffering with it and will help advocate for urgently needed medical research and advances;

Now, Therefore, be it resolved that I, Chris Pengra, Mayor of Eagle Mountain City, and the Eagle Mountain City Council, proclaim April 19, 2015, a Day of Congenital Diaphragmatic Hernia Awareness

Dated this 7th day of April, 2015.

Christopher Pengra, Mayor

Ryan Ireland, City Council

Adam Bradley, City Council

Richard Steinkopf, City Council

Donna Burnham, City Council

Tom Westmoreland, City Council