

March 14, 2016

*The Honorable Nikki R. Haley  
Office of the Governor  
1205 Pendleton Street  
Columbia, South Carolina 29201*

*Dear Governor Haley,*

*Families of children with congenital diaphragmatic hernia, and adults with congenital diaphragmatic hernias are joining forces to have April 19<sup>th</sup>, 2016 to be Proclaimed in all 50 states as Congenital Diaphragmatic Hernia Awareness Week. Since March 31, 2008 Congenital Diaphragmatic Hernia Awareness Day has been proclaimed by 44 States in the United States and many cities and counties in the U.S.*

*On April 14, 2010, the United States Sentate agreed to SR204 without amendment and with a preamble by Unanimous Consent a resolution designating March 31, 2010 National Congenital Diaphragmatic Hernia Awareness Day .*

*As residents of South Carolina we are requesting that you help us reach our goal by making an executive proclamation declaring this special day in April. Our State did/did not issue an executive proclamation in 2008/2009/2010/2011/2012/2013/2014.*

*A congenital diaphragmatic hernia birth defect occurs in 1 in 2,500 live births in the United States and accounts for 8% of all major congenital anomalies. With the rate of live births in the United States at 4,115,590 in 2004 (See, National Center for Health Statistics), this translates to approximately 1,800 live births with the congenital diaphragmatic hernia birth defect. Cystic Fibrosis occurs in 1 in 3,000 live births in the United States, and Spina Bifida has an occurrence of 7 in 10,000 or 1 in 1,478 live births. Currently, the general public has heard of both cystic fibrosis and spina bifida, although congenital diaphragmatic hernias occur just as often, with fatal results. Congenital Diaphragmatic Hernias are considered a "low profile" birth defect to the general public and have not received the attention and awareness needed.*

*On October 28<sup>th</sup>, 2014 my granddaughter, Kaegan, was born with a congenital diaphragmatic hernia. Until that day, I had never heard of a congenital diaphragmatic hernia. On November 3<sup>rd</sup>, 2014, she had her CDH repair surgery. She fought hard the entire time she was in the hospital at MUSC. Because of the hole in her diaphragm her intestines were allowed to get into her chest cavity resulting in her left lung only being 20% in size. The intestines also pushing her heart over to the right side resulting in her right lung being 70% in size. Immediately after birth she was placed on a ventilator. Her parents never heard her first cry. During the night she had to be placed on an ECMO machine (Extracorporeal Membrane Oxygenation) which is a technique of providing both cardiac and respiratory support to patients whose heart and lungs are so severely diseased or damaged that they can no longer serve their function. An ECMO machine is similar to a heart-lung machine. The ECMO machine continuously pumps blood from the patient through a membrane oxygenator that imitates the gas exchange*

process of the lungs, removing carbon dioxide and adding oxygen. Oxygenated blood is then returned to the patient. Kaegan also had 2 heart issues that would have to be surgically repaired IF she could survive off of the ECMO machine. Kaegan developed blood clots & to our heart's despair, she passed away in her parent's arms on November 15<sup>th</sup>, 2014. They never once heard her cry or "coo". They never saw her smile. They never changed her diaper. They never held her alive until she was close to passing away & then once again after she had passed. Our hearts will forever be broken. Her parents, my son, Andy & daughter in law, Kristin are in their early 20's and their faith in God has been there from day one of the diagnosis & even now after her passing. They know God has a reason for this. Of course they wonder if her defect was something they did wrong, even though it's not. As the doctors say "it's just one of those things & we can't identify what causes it."

To this day still approximately 50% of all cases result in death.

One of the most important advantages of prenatal diagnosis is the ability to anticipate a desperately ill newborn. "It is imperative that the mother be transferred to an appropriate perinatal center, where neonatal, ventilatory, and surgical expertise are available. This avoids the unnecessary mortality associated with transporting the sick neonate, and the delay in appropriate medical and ventilatory care that this entails." *Fetal Ther* 1987.

Since that day, I have been telling my story in an effort to raise awareness to the congenital diaphragmatic hernia birth defect. After finding little to no information or support, I joined forces with the organization, Breath of Hope, Inc., which is committed to supporting parents, children, family members and friends facing the diagnosis of a congenital diaphragmatic hernia birth defect.

I would be extremely honored if South Carolina would participate in making April 19<sup>th</sup>, 2016 a special day to recognize people born with congenital diaphragmatic hernias, to remember loved ones who lost their battle with congenital diaphragmatic hernias, and to honor the dedicated health professionals who work with us. Enclosed is a rough draft of what we imagine a proclamation would look like.

I would be most grateful if you could send the proclamation as soon as possible so that we can make plans for promotion and celebration during the month of April. South Carolina's participation in this event will have a profound impact on thousands of families and individuals. I thank you for your time and consideration.

Respectfully submitted,

Lori Norton  
1012 Woodman Drive  
Hartsville, SC 29550  
843-307-0251





# State of South Carolina

## Governor's Proclamation

**WHEREAS,** congenital diaphragmatic hernia (CDH) is a birth defect that occurs when the diaphragm fails to fully form, allowing abdominal organs into the chest cavity and preventing lung growth; and

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

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

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

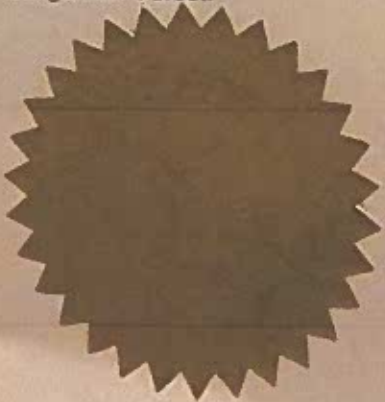
**WHEREAS,** CDH is as common as spina bifida and cystic fibrosis; however, very few people know about or are aware of it; and

**WHEREAS,** the 2015 observance of A Day of Congenital Diaphragmatic Hernia Action and Awareness provides an opportunity to recognize the courage of those with CDH and their families, remember loved ones lost to this devastating birth defect, and raise awareness of the need for continued research into this condition.

**NOW, THEREFORE, I, Nikki R. Haley, Governor of the great State of South Carolina, do hereby proclaim April 19, 2015, as**

### A DAY OF CONGENITAL DIAPHRAGMATIC HERNIA ACTION AND AWARENESS

throughout the state and encourage all South Carolinians to work together to learn more about CDH and help bring about acceptance and support for those suffering with this congenital defect.



**NIKKI R. HALEY**  
**GOVERNOR**  
**STATE OF SOUTH CAROLINA**