

March 17, 2016

*The Honorable Nikki R. Haley
Office of the Governor
1205 Pendleton St
Columbia, SC 29201*

Dear Governor Haley,

Families of Children with congenital diaphragmatic hernia and adults with congenital diaphragmatic hernias are joining forces to have April 19th, 2016 to be Proclaimed in all 50 states as Congenital Diaphragmatic Hernia Awareness Day has been proclaimed by 44 States in the United States and many cities and countries in the U.S.

On April 14, 2010, the United States Senate agreed to SR204 without amendment and with 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 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 congenital diaphragmatic hernia birth defect. Cystic Fibrosis occurs in 1 in 3,000 live births in the United States; the Spina Bifida has an occurrence of 7 in 10,000 or 1 in 1,478 live births. Currently, the general public hears of both cystic fibrosis and spina bifida, although congenital diaphragmatic hernias occur just as often, with fatal results. Congenital Diaphragmatic Hernia are considered a "low profile" birth defect to the general public and have not received the attention and awareness reached.

On June 23, 2014 my husband and I received devastating news that our daughter had Congenital Diaphragmatic Hernia (known as CDH). On that day our lives completely changed. Our daughter Kaegan was given a 50/50 chance to live. As we left the doctor's office confused, hurt and sad, we had no idea what CDH was. We got home and started researching. Everything we found was so confusing and didn't understand the severity of this condition. Percentages showed 50/50 chances, 75 % chances and sometimes a survival rate of 0-5 % chance. As we continued this journey through several doctors' appointments a week. We began to realize our daughter would be fighting for her life. Our doctors kept a close eye on Kaegan as she was growing inside my tummy. They kept watching her development, her weight gain, and how much she was growing. As we continued to learn about Kaegan's condition we found she had a small hole in her diaphragm on the left side. This allowed her intestines and her liver to push up into her chest cavity which caused her heart to shift over to the right and not allowing her lungs to develop and grow like they should. As we continued with our lives as Kaegan was growing we

were doing the things a "normal" pregnant couple would do. We had baby showers, took maternity pictures, and decorated her nursery, washed her little baby clothes and had everything set up. As her due date approached, we were driving back and forth to Charleston to get prepared to having Kaegan. They did ultrasounds, stress test and everything else they could to make sure she was growing properly and gaining weight like she should. On October 28, 2014 Kaegan Noelle Dampier came into this world via C-Section weighing 7 lbs, 13 oz and 19 3/4 inches long. She was perfect in every way. She was officially a resident of Charleston SC and would be staying at MUSC in the NNICU for an undetermined amount of time. As soon as Kaegan was born she was rushed over to be intubated. Being intubated meant that she needed a tube entered in her mouth down her throat to her lungs to breathe for her due to her lungs being underdeveloped and having CDH. Early in the morning of the next day after Kaegan was born I had her team in my room asking me to make some very important decisions. Either let our baby girl pass peacefully or put her on ECMO (Extracorporeal Membrane Oxygenation) which is a technique of providing both cardiac and respiratory support to patient whose heart and lungs are so severely diseased or damaged that they can no longer served their function. After they got Kaegan on the ECMO, her team came back in my room to discuss another birth defect they had found. Now at this point we were clueless. Only thing we were ever told about was her CDH. Our baby girl had a heart defect. She had a small aortic valve (which made it hard to get the ECMO tube ran to her heart) and hole in the bottom of her heart. We were devastated. We then realized our baby girl was very sick. We didn't talk much about the repair for heart as it would come later. First we had to take care of her hernia repair and getting off of ECMO. Kaegan's lung capacity was nowhere near where it should have been. One lung was 20% and the other lung 70% in size. On November 3, 2014 Kaegan had her Hernia Repair on ECMO which was highly dangerous due to the machine thinning her blood and her being on blood thinner. But the doctor's had no choice but to do it on the machine, because she couldn't with stand not being on ECMO. Kaegan went through surgery and pulled through like a fighter. Kaegan endured a lot of blood transfusions, being poked, several echo's, CDH surgery, chest tube placed in and removed, and changing of 3 different ventilators. While on ECMO Kaegan had good days, she had okay days and she had bad days. On November 14th, 2014 after we had visited Kaegan she started declining in the night. On November 15th, 2014 around 8 am we got a call from Dr. Kiker. He told me we needed to get to the hospital so we could discuss what best options would be for Kaegan. She had declined a lot through the night and we needed to decide to let her pass peacefully that day or either let her try to fight the weekend and go through another clamp off on Monday. That Saturday I witnessed Kaegan's blood pressure drop and go back up, setting on ECMO machine going up to help her rest, and had already developed several blood clots that day. We called all family to let them know what was going on. We had decided to Kaegan pass peacefully. We knew she was tired; she had fought so hard for her life for 2 and half weeks. But God needed her as an angel and needed her more in Heaven with him then we did. Kaegan passed away around 10 pm that night in the arms of her mommy and daddy. We never got to hear our daughter take her first breath, hear her first cry, smile, laugh, "coo", change a diaper, give her first bath. We held her for the first and last time as she passed away. Kaegan was my husband's and I first baby girl. Our hearts are still broken. We were 22 and 23 at the time this happen. Just a young couple trying to start a family. We kept our faith and knew God did this for a reason. He never puts more on you than you can handle. Still to this day, no cure has been discovered as to why this happens or what causes CDH.

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, ventilator, and surgical expertise are available. This avoids the unnecessary mortality associated with transporting the sick neonate, and the delay in appropriate medical and ventilator 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 organization, Breath of Hope, CHERUBS, Help4CDHFamilies and several other support groups which are committed to supporting parents, children, family members and friends facing the diagnosis of a CDH birth defect.

I would be extremely honored if the State of South Carolina would continue to participate in making April 19th 2016, a special day to recognize people born with congenital diaphragmatic hernias, to remember loved ones who have lost their battle to CDH, and to honor dedicated health professionals who work with us. Enclosed is a copy of the proclamation the State of South Carolina did last year.

I would be most grateful if you 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,

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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

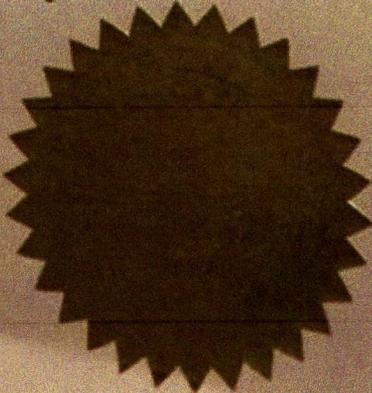
WHEREAS, CDH is as common as spina bifida and cystic fibrosis; however, very few people know about or are aware of it; and

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