



March 16, 2015

Dear Governor Haley,

They say a picture is worth a thousand words. Enclosed is a picture of my grandson, Andy and his wife, Kristin as they watch their 18 day old baby girl, Kaegan, breathe her last breath.

I had never heard of this devastating birth defect until our sweet Kaegan. Everyone in this great state as well as this great country we live in need to be more aware of this horrible experience. Education is the key to helping families understand what this birth defect is all about. There is NO known reason why the diaphragm does not close and allows the lower organs to slip into the upper cavity of the body.

Lori Norton, Andy's mom, has already made this request of you but I am just backing her and hoping you will be able to make this proclamation for our sweet Kaegan and all families that have experienced this horrible birth defect and great loss.

Sincerely,

Eileen S. Hampier

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March 3, 2015

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 19th, 2015 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 Senate 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.

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 28th, 2014 our great-granddaughter, Kaegan, was born with a congenital diaphragmatic hernia. Until that day, I had never heard of a congenital diaphragmatic hernia. On November 3rd, 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 15th, 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 grandson, Andy & granddaughter-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 had 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 19th, 2015, 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,



*Evelyn Dampier
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PROCLAMATION

WHEREAS, a Congenital Diaphragmatic Hernia is an opening in the diaphragm that allows the abdominal organs to push into the chest cavity; and

WHEREAS, a Congenital Diaphragmatic Hernia is often a life-threatening birth defect because it limits the growth of the lungs; and

WHEREAS, a Congenital Diaphragmatic Hernia occurs in every 1 in 2,500 live births in the United States; and

WHEREAS, Congenital Diaphragmatic Hernias account for 8% of all major congenital anomalies; and

WHEREAS, proactive diagnosis and appropriate management of fetuses with congenital diaphragmatic hernias minimizes the incidence of emergency situations, dramatically improving survival rates; and

WHEREAS, there is a need for increased public awareness of congenital diaphragmatic hernias; and

WHEREAS, Congenital Diaphragmatic Hernia Awareness Day provides an opportunity for families whose lives have been affected to celebrate life and to remember loved ones lost, to honor dedicated health professionals, and to meet others and know they are not alone; and

WHEREAS, groups such as Breath of Hope, Inc. are working to promote public awareness and encourage research efforts to one day prevent or successfully treat all those diagnosed with a congenital diaphragmatic hernia; and

WHEREAS, The establishment of Congenital Diaphragmatic Hernia Awareness Week will provide the opportunity to share experience and information with the public and the media in order to raise public awareness about the Congenital Diaphragmatic Hernia birth defect; and

WHEREAS, April 19th, 2015 is recognized as Congenital Diaphragmatic Hernia Awareness Day.

NOW THEREFORE, I, _____, Governor of the State of _____, do hereby proclaim April 19th, 2015 as

CONGENITAL DIAPHRAGMATIC HERNIA AWARENESS DAY

in South Carolina and urge our residents to learn more about congenital diaphragmatic hernias and support those who are affected.