January 28th 2013

Dear Don Willard,

Families of children with congenital diaphragmatic hernia and adults with congenital diaphragmatic hernias are joining forces to have the last week in March (25th – 31st) 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 42 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 Raymond, Maine we are requesting that you help us reach our goal by making an executive proclamation declaring this special week in March. Our State did issue an executive proclamation in 2012.

A congenital diaphragmatic hernia birth defect occurs in 1 in 2,000 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 September 30th 2011 my son was born with a congenital diaphragmatic hernia. Until that day, I had never heard of congenital diaphragmatic hernia.

September 30th 2011, my son Ethan was born at CMMC. Once the umbilical cord was cut he stopped breathing. Doctors and nurses were rushed into the delivery room to revive our son. Ethan was only treated for 8 hours at CMMC in the NICU, and then was life flighted to Boston Children's Hospital where he stayed for 8 weeks. At 3 days old, Ethan underwent surgery to have his spleen, small and large intestines removed from his chest cavity, as well as repositioning his heart and stomach. Ethan had two

holes in his diaphragm; one hole was closed up with a large gortex patch, the other hole they were able to close up without a patch. Ethan was on a breathing machine until he was 4 weeks old. We finally got to hold our son for the first time, at 4 weeks old. Ethan remained on a feeding tube until he was just over 5 weeks old. While treating in Boston our son had several blood transfusions, pneumonia, and three blood infections, as well as high pulmonary tension caused by CDH. Ethan was discharged from Boston two days before Thanksgiving in 2011. He came home with oxygen and O2 monitors, lots of medicines, as well as a visiting nurse, occupational therapist and physical therapist. Due to my sons condition I had closed my state licensed in home Daycare, so I could tend to him.

During the months of August 2012 and September 2012 Ethan was sick; I was taking him to his primary doctor's office several times a week as well as taking him to both CMMC and Maine medical center Emergency rooms. He was repeatedly getting misdiagnosed due to the lack of knowledge on his condition in Maine. Finally after six and a half weeks of Ethan being misdiagnosed finally learned that he had rehirniated. This meant back to Boston for surgery. Ethan was transported from MMC to Boston Children's Hospital by ambulance. Ethan's diaphragm had grown away from his Gortex patch causing a gap which allowed his small intestine to move through, up into his chest cavity. Ethan had his second repair surgery on Sept. 26th 2012. He was able to come home just in time for his first birthday.

Today Ethan is a happy 15 month old boy. As of December 2012 he was discharged from Occupation therapy and Physical therapy. Ethan still has a visiting nurse that comes once a month during the winter to administer Synagis (RSV) vaccine to him, due to his undeveloped lungs. We travel to Boston every three months to visit the CDH clinic and once a year for pulmonology doctor.

Last year I was asked to give a speech at the March of dimes walk in Lewiston, in doing so I provided knowledge on CDH. I continue to work close with March of Dimes and will be doing the walk again this year, in honor of my son.

I got proclamation passed last year in the State of Maine through the governor; however it was signed after the requested day there for I was unable to do an event. This year I'm requesting proclamation through our home town, so we can do a community based event. I hope to do a walk in honor of Ethan. As well as having a day of fun activities to bring awareness to the community on CDH and raise money for CDH research in hopes we can help increase the survival rate. Ethan is part of the Boston's Children's Hospital CDH research program. I would also like to look into getting a medical seminar in Maine to update doctors and nurses on CDH, so they can have the most recent and up to date information on CDH. As well as making sure local hospitals have what they need to care for a child who is born with CDH. CDH is often diagnosed during routine ultrasounds but at times it is missed, like our sons. I'm looking at March 30th to do CDH awareness family fun day in Raymond.

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 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 Raymond, Maine, would participate in making March 25th – 31st a special week 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 March. Raymond, Maines 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,

Melissa Smith

Melissa Smith
#590-8288

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January 29, 2013

Don Willard, Town Manager
Town of Raymond
401 Webbs Mills Road
Raymond, ME 04071

Dear Mr. Willard:

I am writing to encourage you to support the request of Mrs. Melissa Smith from Raymond, Maine. Mrs. Smith would like you to consider issuing a proclamation to have a Congenital Diaphragmatic Hernia (CDH) Awareness Day.

CDH is a congenital malformation (birth defect) of the diaphragm. It occurs when the diaphragm fails to fully form, allowing abdominal organs into the chest cavity and preventing lung growth. CDH occurs in 1 of every 2500 births; somewhere in the world, a baby is born with CDH every 10 minutes. 50% of babies diagnosed with CDH do not survive. The cause is not known. Over a half million babies have been born with CDH since 2000. CDH is as common as Spina Bifida and Cystic Fibrosis but there is very little awareness.

Mr. & Mrs. Smith's son, Ethan, was born with CDH. He was flown from Central Maine Medical Center to Children's Hospital Boston, via LifeFlight of Maine. He underwent surgery at 3 days old to properly position his stomach, spleen, intestines, kidneys and heart.

In the first four months of his life, he has experienced more medical trauma than most people experience their entire lives. With each new doctor or medical emergency relating to their son, the Smiths have to explain his condition because CDH is not a condition that is widely known. It is my hope, along with the Smiths, that an Awareness Day would help to increase public and medical knowledge of CDH.

Thank you for your time and consideration. Please do not hesitate to contact me if you should have further questions about this letter of support.

Sincerely,

Mike McClellan
State Representative
District 103

TOWN OF RAYMOND, MAINE

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 2,000 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 Week 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, March 25th - 31st is recognized as Congenital Diaphragmatic Hernia Awareness Week.

NOW THEREFORE, I, _____, town manager of Raymond,maine do hereby proclaim March 25th - 31st as

CONGENITAL DIAPHRAGMATIC HERNIA AWARENESS WEEK

In 2013 and urge our residents to learn more about congenital diaphragmatic hernias and support those who are affected.