

## 2015-K993

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim February 2016 as chILD Awareness Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious issues that affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, it is the sense of this Legislative Body to memorialize Governor Andrew M. Cuomo to proclaim February 2016 as chILD Awareness Month in the State of New York; and

WHEREAS, Founded in 2004, chILD is a non-profit organization which strives to accelerate research to cure all forms of Children's Interstitial and Diffuse Lung Disease and to provide compassionate support, education, and hope to children and families affected by these life-altering diseases; and

WHEREAS, chILD works closely with the Children's Interstitial and Diffuse Lung Disease Research Network (chILDRN), a group of the top pediatric pulmonologists, pathologists, and radiologists in the United States, to support chILD families and to increase each child's quality of care; and

WHEREAS, Children's Interstitial Lung Disease (chILD) is a group of approximately 20 rare diseases which affect a child's ability to breathe and supply oxygen to the body; these diseases have similar symptoms, such as chronic cough, rapid breathing, and shortness of breath; and

WHEREAS, These diseases also harm the lungs in similar ways; for example, they damage the tissues which surround the lungs' alveoli and bronchial tubes; sometimes these diseases directly damage the air sacs and airway; and

WHEREAS, Since there are several forms of chILD, the outcomes differ

in severity; some children will require oxygen only while they are asleep or ill, while others need oxygen at all times, and for the worst cases, the child will need a lung transplant to have any hope of survival; unfortunately, because all of these disorders are rare there is little funding for research and very few treatment options are available; and

WHEREAS, As of 2016, chILD has not received any federal funds for research, and there are no FDA approved drugs or treatments for any form of chILD; and

WHEREAS, Researchers have only begun to study, define, and understand chILD within the last decade; currently, it is not known how many children have chILD, or how many children have each type of chILD because of the difficulty in diagnosing this debilitating condition; and

WHEREAS, One of these complex diseases is Neuroendocrine cell Hyperplasia of Infancy (NEHI), a rare lung disease which starts in young children and causes rapid, labored breathing and low blood oxygen levels which can last for years; the cause is unknown, but chILD physicians believe too much air is trapped in the lungs, making it more difficult for these children to breathe; and

WHEREAS, Unlike asthma, children with NEHI do not usually wheeze or cough, but their lungs crackle when their doctor listens to them; almost all children with NEHI require oxygen supplementation and nutritional support during infancy and early childhood; and

WHEREAS, Fortunately, most children with NEHI become less oxygen-dependent as they get older and many are able to stop using oxygen altogether; however, we do not know if NEHI will affect the child's longevity or lead to adult lung disease, as children initially diagnosed years ago are just entering their 20s; and

WHEREAS, Since 2005, there have been fewer than 500 confirmed cases of NEHI diagnosed within the United States; however, this prevalence is increasing rapidly as more physicians recognize the disease; and

WHEREAS, Currently, children with NEHI and other chILD disorders are being enrolled and tracked by chILDRN in an international database; much more research needs to be done to find the cause of NEHI, improve treatment and to get answers for these families; and

WHEREAS, It is important to increase awareness of this serious and often difficult to diagnose disease, as well as educate the public and the medical community on chILD detection and treatment for those affected by this condition; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim February 2016 as chILD Awareness Month in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York.