

**SUFFOLK COUNTY
DEPARTMENT OF HEALTH SERVICES**



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NEWS RELEASE

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County Executive Steve Bellone Declares October 10th Alveolar Capillary Dysplasia Awareness Day

In memory of Fallon Jade Rilling, County Executive Steve Bellone has declared October 10th Alveolar Capillary Dysplasia Awareness Day. Fallon Jade was a Suffolk County resident who was diagnosed with Alveolar Capillary Dysplasia in October of the 2013, shortly after her birth. Fallon Jade was the daughter of Kristin and Robert Rilling.

“Today is a time to remember Fallon’s brief life on this earth and join with her family and the Alveolar Capillary Dysplasia Association to raise awareness, search for answers, and hope for a cure,” said Executive Bellone.

Alveolar capillary dysplasia (ACD) is a rare, fatal disorder of the newborn, affecting the infant’s lungs and the blood system serving the lungs. Infants with the disorder show signs of lack of oxygen and severely increased pulmonary hypertension. As there has been no treatment available, life expectancy of the infant is very short. However, studies reveal that there is reason to hope.

Advances in genetics research and support from the CDC and NIH are offering stimulus for ongoing research regarding ACD. “Our goal is to increase awareness and disseminate information about ACD across a broad spectrum of health-care providers so that we may assist researchers in their progress and understanding of this rare and little known disorder,” said Dr. James Tomarken, Commissioner of Health Services.

Until recently, the primary clinical focus has been on early recognition and accurate diagnosis of ACD to spare patients and their families from invasive and non-beneficial interventions. However, according to study published in the *American Journal of Respiratory and Critical Care Medicine* (July 15, 2011), “...Advances in understanding of the genetics, pathology, and clinical features of the disease have begun to shed light on both the disease burden (revealing a potentially higher prevalence than originally thought) and underlying physiological mechanisms.” *

Additionally reports of infants who have had a sudden onset of ACD symptoms, well beyond the neonatal period and up to 7 months of age, have begun to emerge, offering the possibility that there may be survivors with milder forms of the disease.

Health care providers are encouraged to learn more about ACD. For more information on, visit <http://www.acd-association.com/>

*Am J Respir Crit Care Med. Jul 15, 2011; 184(2): 172–179. Published online Mar 11, 2011. doi: 10.1164/rccm.201010-1697CI
PMCID: PMC3172887. Naomi B. Bishop,corresponding author1 Pawel Stankiewicz,2 and Robin H. Steinhorn3
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3172887/#_sec21title

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