



HOUSE BILL 1014: NC Pre-K Conforming Change/Taylor's Law.

2015-2016 General Assembly

Committee:		Date:	July 8, 2016
Introduced by:		Prepared by:	Jennifer Mundt
Analysis of:	S.L. 2016-30		Legislative Analyst

OVERVIEW: *S.L. 2016-30 makes technical and conforming changes to replace references to "More at Four" with "NC Pre-K" in the General Statutes and renames Part 6 of Article 1B of Chapter 130A of the General Statutes to "Taylor's Law Establishing the Advisory Council on Rare Diseases."*

This act became effective June 22, 2016.

BILL ANALYSIS:

Sections 1 and 2 of the act make technical and conforming changes to replace the obsolete reference to "More at Four" with "NC Pre-K" in two sections of the General Statutes.

Section 3 of the act renames the Advisory Council on Rare Diseases, as established by S.L. 2015-199, "Taylor's Law Establishing the Advisory Council on Rare Diseases."

EFFECTIVE DATE: This act became effective June 22, 2016.

BACKGROUND: The Advisory Council on Rare Diseases was established in 2015 within the School of Medicine of the University of North Carolina at Chapel Hill to provide advice to the Governor, the Secretary of Health and Human Services, and the General Assembly on research, diagnosis, treatment, and education relating to rare diseases¹.

Taylor King is a 17-year old resident of Charlotte who was diagnosed with Batten Disease, an extremely rare neurodegenerative disorder, when she was 7. Batten Disease causes the buildup of fatty substances called lipopigments in the body's tissues. This buildup leads to the death of neurons in the retina, brain, and central nervous system. Batten Disease is always fatal and there is no known treatment or cure. Taylor's Tale is a volunteer organization dedicated to the fight against Batten Disease and other rare diseases.

Jason Moran-Bates, counsel to the Senate Health Care Committee, contributed to this summary.

¹ Under 21 U.S.C. § 360bb "rare disease or condition" is defined to mean any disease or condition which (i) affects less than 200,000 persons in the United States, or (ii) affects more than 200,000 in the United States and for which there is no reasonable expectation that the cost of developing and making available in the United States a drug for such disease or condition will be recovered from sales in the United States of such drug.

Karen Cochrane-Brown
Director



Legislative Analysis
Division
919-733-2578