

SENATE CONCURRENT RESOLUTION NO. 110

BY SENATOR WARD

A CONCURRENT RESOLUTION

To designate May 5, 2015, as "Rare Disease Awareness Day" in Louisiana in honor of
Bailey Caroline Durham.

WHEREAS, the National Organization of Rare Diseases (NORD) states that a
disease is considered a Rare Disease if it affects less than two hundred thousand individuals;
and

WHEREAS, there are currently thirty million Americans affected by seven thousand
rare diseases; and

WHEREAS, there is an average of six hundred thousand Louisiana citizens with
some form of rare disease; and

WHEREAS, Bailey Caroline Durham was one of only one hundred ten people in the
world diagnosed with Ponto Cerebellar Hypoplasia, a rare neurological disorder, that
required constant care for Bailey twenty-four hours a day, seven days a week; and

WHEREAS, state law required that a registered nurse administer medication to
Bailey which was necessary on a daily basis; and

WHEREAS, Act 507 of the 2014 Regular Session by Representative Kenny Havard
allows the administration of this necessary medication by family caregivers and friends
provided they receive the training required under the Act; and

WHEREAS, this Act, which became known as Bailey's Law, is of immense value
to persons with disabilities and their families toward enhancing their well-being and quality
of life; and

WHEREAS, on October 1, 2014, Bailey left her physical body and is now dancing,
singing, laughing, and eating at the Lord's banquet table; and

WHEREAS, she will forever live on through her story, as she touched countless lives
and influenced more with the testimony of her struggles; and

WHEREAS, Bailey's smile was infectious, her eyes lit up every room she entered and she has become a beacon of light and a champion for spreading awareness of this rare disease.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana hereby designates May 5, 2015, as "Rare Disease Awareness Day" in Louisiana in recognition of the sacrifice of Bailey Caroline Durham and the efforts of her family in bringing awareness of this dreaded rare disease to the citizens of our state.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the family of Bailey Caroline Durham.

PRESIDENT OF THE SENATE

SPEAKER OF THE HOUSE OF REPRESENTATIVES