

2015 Regular Session

SENATE CONCURRENT RESOLUTION NO. 110

BY SENATOR WARD

COMMENDATIONS. Designates May 5, 2015, as Rare Disease Awareness Day in Louisiana in honor of Bailey Caroline Durham.

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 care-givers and friends provided they receive the training required under the Act; and

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

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

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

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

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

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

The original instrument and the following digest, which constitutes no part
of the legislative instrument, were prepared by J. Ashley Mitchell Carter.

	DIGEST	
SCR 110 Original	2015 Regular Session	Ward
Designates May 5, 2015, as Rare Disease Awareness Day in Louisiana in honor of Bailey Caroline Durham.		