

Regular Session, 2014

HOUSE CONCURRENT RESOLUTION NO. 81

BY REPRESENTATIVE PEARSON

A CONCURRENT RESOLUTION

To authorize and direct the Department of Health and Hospitals to submit a report to the Senate and House committees on health and welfare evaluating the health benefits and healthcare cost of adding adrenoleukodystrophy to the list of mandatory screenings performed on newborns when it is recommended by the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee.

WHEREAS, adrenoleukodystrophy is a genetically determined neurological disorder that affects one in every seventeen thousand nine hundred boys worldwide; and

WHEREAS, the presentation of symptoms occurs somewhere between the ages of four and ten; and

WHEREAS, adrenoleukodystrophy affects the brain with demyelination, damage to the myelin sheath, an insulating membrane that surrounds nerve cells in the brain; and

WHEREAS, adrenoleukodystrophy does not have any specific treatment regimen and the prognosis is poor; and

WHEREAS, the childhood form is a progressive disease that declines with age; and

WHEREAS, screening for adrenoleukodystrophy in a newborn child is relatively new and, at this time, the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee have not recommended screening newborn children for adrenoleukodystrophy.

THEREFORE, BE IT RESOLVED by the Legislature of Louisiana that the Department of Health and Hospitals shall submit a report to the House and Senate committees on health and welfare evaluating the health benefits and healthcare cost of

adding adrenoleukodystrophy to the current list of mandatory newborn screenings to be performed when it is recommended by the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Department of Health and Hospitals.

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SPEAKER OF THE HOUSE OF REPRESENTATIVES

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PRESIDENT OF THE SENATE