**ENROLLED**

2019 Regular Session

HOUSE CONCURRENT RESOLUTION NO. 34

BY REPRESENTATIVE DAVIS

A CONCURRENT RESOLUTION

To urge and request the Louisiana Department of Health to study the costs and benefits associated with the potential addition of mucopolysaccharidosis type I and Pompe disease to the state's newborn screening panel, to report findings of the study to the legislative committees on health and welfare, and to add these conditions to the newborn screening panel expeditiously when funding for this purpose is available.

WHEREAS, mucopolysaccharidosis type I, known commonly as "MPS I", is a genetic condition that results in afflictions including but not limited to macrocephaly (enlarged head), hydrocephalus (buildup of fluid in the brain), heart valve abnormalities, hepatosplenomegaly (enlarged liver and spleen), macroglossia (enlarged tongue), and laryngotracheal stenosis (narrowed airway); and

WHEREAS, though children with MPS I often have no signs or symptoms of the condition at birth, the condition can be detected easily through a special screening; and

WHEREAS, children with severe MPS I generally begin to show signs and symptoms of the disorder within the first year of life and experience a decline in intellectual function and a more rapid disease progression, while children with an attenuated (less severe) form have milder features that develop later in childhood; and

WHEREAS, in cases of severe MPS I, developmental delay is usually present by age one and the child eventually loses basic functional skills; and

WHEREAS, children with severe MPS I usually have a shortened lifespan, sometimes living only into late childhood, while individuals with attenuated MPS I typically live into adulthood, but may have intellectual impairments and fatal heart disease or airway obstruction; and

WHEREAS, according to the National Institutes of Health, severe MPS I occurs in approximately one in one hundred thousand newborns and attenuated MPS I occurs in about one in five hundred thousand newborns; and

WHEREAS, Pompe disease is an inherited disorder caused by the buildup of a complex sugar called glycogen in the cells of the body, impairing the ability of certain organs and tissues, particularly muscles, to function normally; and

WHEREAS, like MPS I, Pompe disease can be detected easily through screening for the condition; and

WHEREAS, the "classic" form of infantile-onset Pompe disease begins within a few months of birth and causes muscle weakness, an enlarged liver, heart defects, breathing problems, and failure of the infant to gain weight and grow at the expected rate (failure to thrive); if untreated, this form of Pompe disease leads to death from heart failure in the first year of life; and

WHEREAS, the "non-classic" form of infantile-onset Pompe disease usually appears by age one and is characterized by delayed motor skills, progressive muscle weakness, an enlarged heart, and serious breathing problems; most children with this form of the disease live only into early childhood; and

WHEREAS, Pompe disease affects approximately one in forty thousand people in the United States; and

WHEREAS, MPS I and Pompe disease are included on the list of disorders comprising the Recommended Uniform Screening Panel, which is the set of conditions that the secretary of the United States Department of Health and Human Services recommends for inclusion in the newborn screening panel of each state; and

WHEREAS, the newborn screening panel of this state is established in R.S. 40:1081.2, which lists disorders for which all newborns in Louisiana must be screened and authorizes the Louisiana Department of Health to add conditions to this list by rule; and

WHEREAS, as of the date of filing of this Resolution, the newborn screening panel of this state does not include MPS I or Pompe disease.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to study the costs and benefits associated with the potential addition of mucopolysaccharidosis type I and Pompe disease to the newborn screening panel of this state.

BE IT FURTHER RESOLVED that in conducting the study requested in this Resolution, the department shall engage, collaborate with, and obtain information and

perspective from the Genetic Diseases Program Advisory Committee created and provided for in LAC 48:V.6901 et seq., and any other stakeholder groups as deemed necessary or appropriate by the assistant secretary of the office of public health.

BE IT FURTHER RESOLVED that the department shall submit a written report of its findings resulting from the study requested in this Resolution to the House Committee on Health and Welfare and the Senate Committee on Health and Welfare on or before January 1, 2020.

BE IT FURTHER RESOLVED that the department shall add mucopolysaccharidosis type I and Pompe disease to the newborn screening panel expeditiously when funding for this purpose is available.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Louisiana Department of Health and to each member of the Genetic Diseases Program Advisory Committee.

SPEAKER OF THE HOUSE OF REPRESENTATIVES

PRESIDENT OF THE SENATE