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HOUSE JOINT RESOLUTION NO. 164

Offered January 14, 2004

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Directing the Joint Commission on Health Care to study the adequacy of Virginia's infant screening program for metabolic disorders. Report.

Patron—Plum

Referred to Committee on Rules

WHEREAS, metabolic disorders involve defects produced by inactive genes that prevent the body from making enzymes necessary to break down certain amino acids or fats; and

WHEREAS, metabolic disorders are rare, but the consequences of these disorders if undetected or untreated are usually severe, often resulting in neurological impairment, mental retardation, and even death; and

WHEREAS, these harmful effects can often be reduced or even avoided when such disorders are detected in infants and the appropriate dietary or other treatment is prescribed; and

WHEREAS, state law currently provides that "In order to prevent mental retardation, permanent disability or death, every infant who is born in this Commonwealth shall be subjected to a screening test for biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, congenital adrenal hyperplasia, and Maple Syrup Urine Disease, and each infant determined at risk shall be subject to a screening test for sickle cell diseases"; and

WHEREAS, the Board of Health is required to recommend procedures for treating these disorders, and is required to provide such treatment for infants in medically indigent families; and

WHEREAS, many metabolic disorders may still go undetected and untreated because current screening requirements are too limited or current screening procedures are not utilizing available, improved technologies; and

WHEREAS, new technologies such as tandem mass spectrometry can improve diagnoses and expand infant screening to 20 or more metabolic disorders; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study the adequacy of Virginia's infant screening program for metabolic disorders.

In conducting its study, the Commission shall propose a plan to expand Virginia's infant screening program to include screening for all metabolic disorders as detectable by the most recent technological advances, including tandem mass spectrometry. The Commission shall also develop budget estimates for such expansion of the infant screening program.

Technical assistance shall be provided to the Commission by the State Health Department. All agencies of the Commonwealth shall provide assistance to the Commission for this study, upon request.

The Commission shall complete its meetings by November 30, 2004, and the Chairman shall submit to the Division of Legislative Automated Systems an executive summary of its findings and recommendations no later than the first day of the 2005 Regular Session of the General Assembly. The executive summary shall state whether the Commission intends to submit to the General Assembly and the Governor a report of its findings and recommendations (for publication as a document). The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

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