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**HOUSE JOINT RESOLUTION NO. 164**  
**AMENDMENT IN THE NATURE OF A SUBSTITUTE**  
(Proposed by the House Committee on Rules  
on February 14, 2004)  
(Patron Prior to Substitute—Delegate Plum)

*Directing the Joint Commission on Health Care to collect information concerning infant screening program for metabolic disorders. Report.*

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, § 32.1-65 of the Code of Virginia 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 collect information concerning infant screening program for metabolic disorders.

In collecting the information, the Joint Commission on Health Care shall compile a list of the (i) types of metabolic disorders for which infants are screened in other states, including a summary of the benefits of such screening; and (ii) the costs of such screening programs.

Technical assistance shall be provided to the Commission by the State Health Department and the Department of Mental Health, Mental Retardation and Substance Abuse Services. All agencies of the Commonwealth shall provide assistance to the Commission in collecting the information, upon request.

The Joint Commission on Health Care shall submit to the Division of Legislative Automated Systems an executive summary and the information collected on infant screening programs for metabolic disorders no later than the first day of the 2005 Regular Session of the General Assembly. The executive summary and information 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.