HOUSE BILL 891

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By: **Delegates O'Donnell and Hubbard**
Introduced and read first time: February 5, 2014
Assigned to: Health and Government Operations

A BILL ENTITLED

AN ACT concerning

Public Health – Newborn Screening Program – Lysosomal Storage Disorders (Lily's Law)

FOR the purpose of requiring that the Department of Health and Mental Hygiene's Newborn Screening Program include screening for certain Lysosomal Storage Disorders; and generally relating to newborn screening.

BY repealing and reenacting, with amendments,
Article – Health – General
Section 13–111
Annotated Code of Maryland
(2009 Replacement Volume and 2013 Supplement)

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article – Health – General

13–111.

(a) The Department shall establish a coordinated statewide system for screening all newborn infants in the State for certain hereditary and congenital disorders associated with severe problems of health or development, except when the parent or guardian of the newborn infant objects.

(b) Except as provided in § 13–112 of this subtitle, the Department's public health laboratory is the sole laboratory authorized to perform tests on specimens from newborn infants collected to screen for hereditary and congenital disorders as determined under subsection (d)(2) of this section.

(c) The system for newborn screening shall include:

EXPLANATION: **CAPITALS INDICATE MATTER ADDED TO EXISTING LAW**.
[Brackets**]** indicate matter deleted from existing law.

(1) Laboratory testing and the reporting of test results; **[**and**]**

(2) Follow–up activities to facilitate the rapid identification and treatment of an affected child**; AND**

(3) SCREENING FOR THE FOLLOWING LYSOSOMAL STORAGE DISORDERS:

(I) KRABBE LEUKODYSTROPHY;

(II) POMPE DISEASE;

(III) GAUCHER DISEASE;

(IV) NIEMANN–PICK DISEASE;

(V) FABRY DISEASE; AND

(VI) HURLER SYNDROME.

(d) In consultation with the State Advisory Council on Hereditary and Congenital Disorders, the Department shall:

(1) Establish protocols for a health care provider to obtain and deliver test specimens to the Department's public health laboratory;

(2) Determine the screening tests that the Department's public health laboratory is required to perform;

(3) Maintain a coordinated statewide system for newborn screening that carries out the purpose described in subsection (c) of this section that includes:

(i) Communicating the results of screening tests to the health care provider of the newborn infant;

(ii) Locating newborn infants with abnormal test results;

(iii) Sharing newborn screening information between hospitals, health care providers, treatment centers, and laboratory personnel; and

(iv) Delivering needed clinical, diagnostic, and treatment information to health care providers, parents, and caregivers; and

(4) Adopt regulations that set forth the standards and requirements for newborn screening for hereditary and congenital disorders that are required under this subtitle, including:

(i) Performing newborn screening tests;

(ii) Coordinating the reporting, follow–up, and treatment activities with parents, caregivers, and health care providers; and

(iii) Establishing fees for newborn screening that do not exceed an amount sufficient to cover the administrative, laboratory, and follow–up costs associated with the performance of screening tests under this subtitle.

(e) Notwithstanding any other provision of law, if the Secretary of Health and Human Services issues federal recommendations on critical congenital heart disease screening of newborns, the Department shall adopt the federal screening recommendations.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2014.