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TO: The Honorable Peter A. Hammen, Chairman
Members, House Health & Government Operations Committee
The Honorable Anthony O'Donnell

FROM: Joseph A. Schwartz, III
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DATE: February 18, 2014

RE: **OPPOSE** – House Bill 891 – *Public Health – Newborn Screening Program – Lysosomal Storage Disorders (Lily's Law)*

On behalf of MedChi, the Maryland State Medical Society (MedChi) and the Maryland Chapter of the American Academy of Pediatrics (MDAAP), we wish to respectfully express their opposition to House Bill 891.

There is sincere respect and appreciation for the challenges that families face who have children who suffer from lysosomal storage disorders. However, there are a number of reasons why they should not be added to Maryland's newborn screening program.

First, a number of years ago, the General Assembly made a decision to remove the list of conditions that must be included in the newborn screening panel and place them in regulation. Maryland's Advisory Council on Hereditary and Congenital Disorders (Advisory Council) recommend conditions to be added to the required screening panel. The Advisory Council meets regularly and is comprised of appointed members from the public, academic institutions, professional organizations and legislators. The Advisory Council is very deliberative in its review of proposed new screening requirements. The State's process for to revising and adding newborn screening requirements has resulted in an extremely responsive and scientifically based process for review and recommendations. If the panel recommends the addition of a new test and the Secretary of DHMH agrees with the recommendation, the test is added by regulation with no need for legislation. Consequently, adding new tests by legislation undermines the well-respected and effective process currently in place.

It should also be noted that lysosomal disorders have been considered at various times at the federal level for inclusion in its recommended screening requirements.

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The Secretary of Health and Human Services makes recommendations for disorders to be included on the Recommended Uniform Screening Panel (RUSP) and Maryland's Advisory Council typically makes recommendations to add disorders that are on the RUSP. The disorders reflected in House Bill 891 are not included in RUSP.

Finally, Maryland's Advisory Council considered testimony in October of 2013 regarding inclusion of lysosomal storage disorders, particularly Krabbe's. The Advisory Council referred the request for inclusion to geneticists for further review and recommendation. It is our understanding that the Advisory Council will consider those recommendations at its February meeting.

Maryland has historically been a leader in newborn screening nationally. MedChi and MDAAP urge the Committee to maintain the integrity of the process the General Assembly created for addition of new screening disorders. An unfavorable report is requested.

For more information call:

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