

# Maryland Department of Health Rare Disease Advisory Council

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March 10, 2026

Re: House Bill 1625  
Support, with amendment

The Honorable Pamel Beidle, Chair  
The Honorable Antonio Hayes, Vice Chair  
Maryland Senate Finance Committee  
3 East Miller Senate Office Building  
Annapolis, Maryland 21401

Dear Chair Beidle and members of the Finance Committee,


I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in support with amendments of House Bill 1625. The RDAC is a legislated Governor's Advisory Council tasked with improving access to care and outcomes for people in Maryland living with Rare Disease.

We would recommend changing the date in Health- General 13-111 (e) (1) (i) to a time when the composition of the Recommended Uniform Screening Panel is known (e.g. 1/1/26) as opposed to a future date. We support this bill to ensure that the newborns in Maryland continue to receive the most up to date and efficient tests, follow up and care for conditions that can be detected by newborn screening. Since the dissolution of the federal committee considering additions to the Recommended Universal Screening Panel in April 2025, there is no national review. Fortunately, in Maryland we have the legislated Department of Health Secretary's Advisory Committee on Hereditary and Congenital Disorders. This committee composition is legislated and its purpose has always been to review and evaluate the newborn screening panel and program. This bill will allow that committee to assess conditions and testing for addition to the Maryland Newborn Screening (NBS) Panel. It also extends time to implementation to 24 months from 18 months to allow the State Lab to buy necessary equipment and reagents and to establish standards and cutoffs appropriate to our State's population of newborns. It also reinforces that NBS should be cost neutral, i.e., the cost of the test should cover the cost of reagents and equipment, so that there is not a drawn out procurement process. The RDAC supports all of these measures.

The RDAC's purpose is to increase awareness of rare disease and improve access to care and outcomes for people living with rare diseases. This is certainly accomplished by improved testing, early detection, and preventative treatment with those rare diseases that are detectable by NBS.

Please don't hesitate to reach out to me if you have any questions about this bill or about rare disease.

Sincerely,



Ada Hamosh, MD, MPH,  
Chair