



Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, M.D., M.P.H., Acting Secretary

February 14, 2023

The Honorable Joseline A. Peña-Melnyk  
Chair, House Health and Government Operations Committee  
Room 241, House Office Building  
Annapolis, Maryland 21401

**RE: HB 302 - Public Health - Rare Disease Advisory Council – Letter of Information**

Dear Chair Peña-Melnyk and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information for House Bill (HB) 302 - Public Health - Rare Disease Advisory Council. HB 302 establishes the Rare Disease Advisory Council to study and make recommendations on matters relating to individuals with rare diseases in the State. This bill requires the Council to maintain a website, develop and distribute educational material, operationalize the procurement and distribute the Council's funds, and submit an annual report. MDH must provide staff for the Council.

HB 302 requires the Council to “evaluate and make recommendations to implement necessary improvements to state newborn screening programs.” MDH notes that this requirement is duplicative of the requirements of the established State Advisory Council on Hereditary and Congenital Disorders in Maryland, as stated in Health-General §13–108 (2).<sup>1</sup> This advisory council is staffed by the Newborn Screening-Follow up program in the MDH Prevention and Health Promotion Administration/Maternal and Child Health Bureau/Office for Genetics and People with Special Health Care Needs. An example of an implemented recommendation from this Council includes the addition of Spinal Muscular Atrophy (SMA) screening to the Maryland newborn screening panel. In March 2018 the Advisory Council recommended adding this item and the recommendation was implemented on May 30, 2019. To date, 15 babies have been identified with SMA in the newborn period.

A rare disease is defined as a disease or condition that impacts less than 200,000 people in the US.<sup>2</sup> According to the National Institutes of Health, there are approximately 7,000 known rare diseases, and collectively in the US, approximately 30 million people have a rare disease.<sup>3</sup> Examples of rare diseases include Thyroid Eye Disease and Gallbladder Cancer. Currently, there is no office in MDH that provides information on rare diseases. While many of the 50+ newborn

---

<sup>1</sup> Health-General §13–108.

<https://mgaleg.maryland.gov/mgawebsite/Laws/StatuteText?article=ghg&section=13-108&enactments=False&archived=False>

<sup>2</sup> Orphan Drug Act. Public Law 97-414- Jan. 4 , 1983. <https://www.fda.gov/media/99546/download>

<sup>3</sup> NIH. About GARD. <https://rarediseases.info.nih.gov/about>. Accessed 24 January 2023.

screening metabolic diseases are rare diseases, they make up less than one percent of the total number of rare diseases. Rare diseases affect both pediatric and adult populations.

If you would like further information please contact Megan Peters, Acting Director of Governmental Affairs at [megan.peters@maryland.gov](mailto:megan.peters@maryland.gov) or (410) 260-3190.

Sincerely,

A handwritten signature in blue ink, appearing to read "LH Scott".

Laura Herrera Scott, M.D., M.P.H.  
Acting Secretary