

Maryland Department of Health

Advisory Council on Hereditary and Congenital Disorders

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, Acting Secretary

Current Members

February 10, 2023

Jamie L. Fraser, MD, PhD, FACMG
Chair

Re: HB302: Public Health – Rare Disease Advisory Council

Robert Brosius,
Vice Chair

Thank you for the opportunity to review and provide comments on House Bill 302, related to an Act concerning Public Health – Rare Disease Advisory Council. As a medical genetics physician-scientist and the Chair of the Maryland State Advisory Council on Hereditary and Congenital Disorders (ACHCD), it is my honor to convey the considerations of our Council concerning the proposed Rare Disease Advisory Council legislation before the Maryland legislature (HB302, SB188). We are grateful that the legislature has recognized the impact of rare disorders on citizens of our state, and we support the formation of a council focused on these needs with important amendments.

Shannan Dixon

Sharon Dols

The ACHCD was founded by state legislation in 1982. Our Council serves those Maryland citizens who have a hereditary and/or congenital disorder of a genetic basis, the vast majority of which are rare disorders. Because approximately 80% of rare disorders are genetic, hereditary, and/or congenital, this Council is responsible for improving outcomes and access to services for people with rare disorders. The ACHCD also serves as the policy recommendation body to the Secretary of Health on hereditary and congenital disorders, including newborn screening. With this extensive background and history of working on a State Advisory Council focused on the concerns of this special population and on newborn screening, we hereby provide some thoughts and comments on this legislation.

John McGing

Gerald Raymond, MD

David Myles, MD

Michelle Smith

Dominique Sessa

Delegate - vacant

Our Council strongly urges that section 13-4804 (A) (5) of the proposed legislation be eliminated. The ACHCD is mandated by existing legislation and already serves this function. Removing this section eliminates one task from the RDAC and the potentially dangerous overlap between the two Councils.

Senator - vacant

Ex-Officio Members

Other concerns the Council shares relate to definitions, including definitions of membership, member roles, and fiscal concerns. The following outline our suggestions for improving the bill.

Fizza Gulamali-Majid, PhD

Robert Meyers, PhD

- The definition of “Rare Disease” needs to be included in the legislation.
- The proposed Rare Disease Advisory Council (RDAC) requires a clear understanding of their purview if they are to be successful.
- The proposed makeup of the RDAC is quite broad (16 members), yet it restricts the number of individuals living with a rare disease, their family members, and advocates. We would recommend at least one more of each to ensure that their voices are represented effectively.
- We would encourage expanding the required medical genetics role to include medical genetics professionals beyond the clinical geneticist, e.g. genetic counselors, clinical laboratory geneticists, metabolic dieticians, advanced practice providers.
- With 16 (or more) members, logistical issues with setting meetings and reaching quorum present significant challenges.
- The requirement for monthly meetings of such a group for the first year is ambitious and demands much of an all-volunteer Council.
- The legislation states that the Department of Health will provide staff for the Council but provides no funding for such support. The legislation further recommends that the Council pursue grant funding, but that effort also requires staff or volunteers familiar

Stacy Taylor

Council Coordinator

Johnna Watson, RN

with writing grant proposals. We are concerned because the legislation charges the Council with 10 broad and ambitious goals and tasks, which cannot be completed without a full-time staff.

- The extent of this request for uncompensated effort by individuals with a rare disease, their family members, and advocates appears to go uncalculated as a cost within the legislation.

While there is overlap in the citizens served by the Rare Disorders Advisory Council and ACHCD, each Council is focused on different priorities for these citizens. In places where both Councils find common concerns, such as patient access to necessary medical care, insurance coverage, genetic or other testing, medically necessary dietary changes, etc., we anticipate synergy in these collaborations and look forward to continuing to serve the rare disease community in Maryland.

Thank you again for the opportunity to review and provide our Council's comments and thoughts. If you or your staff have any questions, please feel free to contact me. I can be reached at 843-814-5086.

Respectfully,



Jamie L. Fraser MD, PhD, FACMG (she/her)
Chair, Advisory Council on Hereditary and Congenital Disorders