

February 9, 2023

Re: **HB 0302**
Public Health – Rare Disease Advisory Council

Chair Pena-Melnyk, Vice Chair Kelly, and Members of the Committee:

I am writing in support of HB0302 *with amendments*. For the record, this testimony is my own and does not reflect my institution. For background, I am a board-certified clinical biochemical geneticist and professor at the University of Maryland School of Medicine. I was on the Maryland State Advisory Council on Hereditary and Congenital Disorders from 2004-2013, serving as chair from 2010-2013.

I support the creation of a Rare Disease Advisory Council (RDAC) for the state of Maryland. However, HB0302, as written, requires some amendments and clarification.

Specific concerns:

- 13-4803 (A) (5) – should be deleted. All aspects of newborn screening, an essential public health service, are addressed by COMAR 13-101 to 13-110, which established by statute the Council on Hereditary and Congenital Disorders with mandated composition and responsibility to review conditions screened in newborns, methods, and the newborn screening follow-up program. The proposed RDAC does not need to duplicate this activity.
- The composition of the RDAC is confusing as written. We recommend that this committee
 - o specify one representative from each of the two academic medical centers in Maryland: Johns Hopkins University and University of Maryland. It is not clear whether the additional geneticist, physician, and scientist are separate or can be embodied in one individual (easily feasible in our State).
 - o Consider specifying that the representative from the academic medical center(s) be a board-certified clinical geneticist.
- Council on Hereditary and Congenital Disorders is also mandated to have a Senator and Delegate as members. From my involvement with this Council, it has been challenging to have a Senator or Delegate participate consistently. We are concerned about creating another with these requirements (although participation in both activities would be wonderful).

I would be pleased to work with the bill sponsors to modify this bill or share my thoughts.

Sincerely,



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