

Department of Genetic Medicine

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February 9, 2023

The Honorable Joseline Peña-Melnyk
Chair, Health and Government Operations Committee

HB302
Favorable with Amendments

Re: House Bill 302
Public Health – Rare Disease Advisory Council

Dear Chair Peña-Melnyk, Vice Chair Kelly and committee members,

I am writing in support of HB302 with amendments. I am writing in my personal capacity and not representing Johns Hopkins University. For background, I am the Clinical Director of the Department of Genetic Medicine at JHUSOM, a board-certified clinical and biochemical geneticist, and served as the Chair of the State Advisory Council on Hereditary and Congenital Disorders from 2001-2009. I am also the director of the NORD Rare Disease Center of Excellence at Johns Hopkins Medicine / Kennedy Krieger Institute.

I support the creation of a Rare Disease Advisory Council for the state of Maryland. However, HB302, as written needs amendments, clarification, and funding.

Specific concerns: Strike 13-4803 (A) (5). The RDAC does not need to concern itself with newborn screening as all aspects of this 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 remit to review conditions screened in newborns, methods, and the newborn screening follow up program.

The composition of the RDAC is confusing as written. We recommend that this committee 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 person (easily feasible in our state).

An additional concern is that the Council on Hereditary and Congenital Disorders is also mandated to have a Senator and Delegate as members. Over the >20 years of my involvement with that Council, it has been challenging to have a Senator or Delegate participate consistently. I am concerned about creating another Council with this issue (although participation in both activities would be wonderful).

I am happy to work with the committee to modify this bill to address these concerns.

Sincerely,

A handwritten signature in black ink that reads "Ada Hamosh".

Ada Hamosh, MD, MPH