UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Department of Pediatrics
Division of Human Genetics

Administrative Office
737 W Lombard R 195
Baltimore, MD 21201-1559
Phone: (410) 328-3335 Fax: (410) 328-5484

February 9, 2023

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

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

I am writing in support of HB 302 *with amendments*. For the record, this testimony is my own, I do not know the position of my institution with respect to this bill. For background, I am a board-certified Clinical Geneticist and Professor at the University of Maryland School of Medicine, and I am the Director of clinical genetic services for the UMSOM/UMMS. Since 2005 I have regularly participated in meetings of the Maryland State Advisory Council on Hereditary and Congenital Disorders, including serving on and chairing various ad-hoc work groups assisting the Council with tasks relating to newborn screening and other aspects of hereditary and congenital disorders.

I support the creation of a Rare Disease Advisory Council (RDAC) for the state of Maryland. However, SB0188, as written, requires some amendments and clarification.

My 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. Not only is there no need for the proposed RDAC to duplicate this activity, such duplication would lead to confusion and therefore would harm babies and families in Maryland.
- The composition of the RDAC is confusing as written. I recommend that this committee
    - specify the RDAC should include 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).
    - I recommend specifying that the representative from the each academic medical center(s) be a board-certified clinical genetics professional. I am well aware that not all rare disorders are genetic; however, the vast majority (~80%) of rare disorders are genetic and the vast majority of genetic disorders are rare. It follows that Geneticists are more likely to understand and to be able to advocate for individuals with rare disorders as a group, rather than for any individual rare disorder.

I would be very happy to work with the bill sponsors to modify this bill to address these concerns.

Sincerely,

Carol L. Greene, MD.

Carol L. Greene, MD, FACMG
Professor of Pediatrics; Obstetrics; Gynecology & Reproductive Sciences,
Interim Chief, Division of Human Genetics, Pediatrics; carol.greene@som.umaryland.edu