

EMILY SHETTY
Legislative District 18
Montgomery County

Appropriations Committee

Vice Chair, Health and
Social Services Subcommittee



Annapolis Office
The Maryland House of Delegates
6 Bladen Street, Room 350
Annapolis, Maryland 21401
410-841-3181 · 301-858-3181
800-492-7122 Ext. 3181
Emily.Shetty@house.state.md.us

THE MARYLAND HOUSE OF DELEGATES
ANNAPOLIS, MARYLAND 21401

HB 302
Public Health - Rare Disease Advisory Council
Testimony in SUPPORT

Chair Pena-Melnyk, Vice Chair Kelly and esteemed members of the Health and Government Operations Committee:

I am writing to respectfully request favorable consideration of HB 302, legislation that will establish a Rare Disease Advisory Council that will study and make policy and regulatory recommendations on behalf of patients with rare diseases to advise and report to the Governor and General Assembly.

Currently in Maryland, we have the Advisory Council on Hereditary and Congenital Diseases, which does very important work overseeing our newborn screening program, among other critical priorities for the patient population with hereditary and congenital disorders. However, not all patients with rare diseases fall into this category. Because individual rare diseases are so uncommon, it is often very hard for impacted families to gain the attention of researchers, the medical community, or policy makers. To address this issue, members of the broader rare disease community have begun to work together to develop rare disease advisory committees in each state. Currently, 24 states have rare disease advisory committees and 7 states in addition to Maryland are considering legislation to create a committee.

The Federal Orphan Drug Act defines a rare disease as one that affects fewer than 200,000 people nationally. While these individual diseases affect small populations, combined more than 25 million Americans suffer from one of the 7,000 known rare diseases. Some well known rare diseases include sickle cell disease, cystic fibrosis, ALS, and hemophilia. However, there are thousands of other rare and ultra-rare diseases that are not as well known to the general public.

While these diseases vary, there is value in individuals with rare diseases working together, learning from one another, and offering support. Rare Disease Advisory Committees that have been established in other states bring together individuals with a variety of different connections to the rare disease community and task them with developing recommendations on how a state can better support individuals with rare diseases. The work of a Rare Disease Advisory Committee can include recommendations on improving insurance coverage, supporting the transition to adulthood for kids with rare diseases, or educating the public about resources

available to individuals with rare diseases. As policymakers, this input could be extremely helpful to the work that we do to support patients across this state.

Under HB 302, the Advisory Council would be established with support from the Maryland Department of Health with the Council's first meeting occurring no later than December 30, 2024. The Council's membership would include broad representation from government, patients, caregivers, government, and a cross section of the health industry including a geneticist, nurse, hospital administrator, pharmacist, health insurance carrier, scientist, and more.

I have brought sponsor amendments for your consideration that mirror sponsor amendments to the Senate cross-filed bill to do the following: further broaden the Council's representation of important medical stakeholders, add representation from the State Advisory Council on Hereditary and Congenital Disorders, and to stagger the terms of the members to ensure continuity.

Thank you for the committee's consideration, and I respectfully request a favorable report on HB302.