February 14, 2023

The Honorable Joseline A. Pena-Melnyk
Chair
House Health and Government Operations Committee
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

The Honorable Ariana B. Kelly
Vice Chair
House Health and Government Operations Committee
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

RE: Support for House Bill 302 - Maryland Rare Disease Advisory Council

Dear Chair Pena-Melnyk, Vice Chair Kelly, and Members of the House Health and Government Operations Committee:

On behalf of the 1-in-10 individuals in Maryland with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for adding House Bill 302 (HB 302) to the House Health and Government Operations Committee's agenda. If passed and signed into law, HB 302 would establish a Rare Disease Advisory Council (RDAC) which would help give a stronger voice to people living with a rare disease in Maryland.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting more than 25 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the large variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they usually provide a forum to analyze the needs of the community and produce recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry,

researchers, patient advocacy organizations, and state government officials. The Council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts on how to improve access to quality health care, or compile resources related to rare diseases.

In many ways, the state of Maryland has been a leader in the rare disease community, with nationally recognized health care institutions and distinguished health care providers with expertise in a variety of rare diseases. Furthermore, the Maryland State Advisory Council on Hereditary and Congenital Disorders has done important work for four decades, but NORD still believes an RDAC would be a valuable resource in Maryland, particularly on issues related to access to care and treatment for non-inherited or congenital disorders. NORD wants to ensure that both councils are well-resourced, collaborative, and can fulfill their individual mandates to avoid duplication and overlap in their work.

In creating this council, Maryland would join twenty-four other states that have already enacted similar legislation in support of their rare disease community and have proven that the RDAC can be an invaluable resource. Those states are Alabama, Colorado, Connecticut, Florida, Georgia, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

We thank Delegate Shetty for her leadership and sponsorship of HB 302 and urge all Committee members to support its swift passage. For any questions, please contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

Annissa Reed

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the House Health and Government Operations Committee