



June 1, 2020

The Honorable Dave Burke
Chair, Senate Health, Human Services, and Medicaid Committee
Ohio State Senate
1 Capitol Square
Columbus, OH 43215

Re: Support for HB 412 – an Act to Create a Rare Disease Advisory Council

Dear Chairman Burke,

On behalf of the 1-in-10 individuals in Ohio with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for the opportunity to submit testimony in support of House Bill 412 (HB 412), legislation that would establish a Rare Disease Advisory Council. HB 412 passed the Ohio House of Representatives by a vote of 95-0 in February and maintains broad support from the rare disease community. We look forward to working with you and members of your committee to enact this much needed legislation that would give a voice to the rare disease community within Ohio's government.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research.

Creating an RDAC in Ohio will give rare disease patients, caregivers and other stakeholders an opportunity to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on their diagnostic journey to identifying best practices throughout the nation, the council will coordinate with legislators and other government leaders to improve public policy for the entire state. What is more, because this legislation requires broad participation from the different health care sectors present in Ohio – doctors, hospitals, insurers, manufacturers, and researchers are all represented on the council – it will also serve as an educational resource to all stakeholders about the ways in which rare disease patients interact with our health care system.

In creating this council, Ohio will be joining fourteen other states who have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois,



Kentucky, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Pennsylvania, Tennessee, Utah, and West Virginia.

Once again, on behalf of the Ohio rare disease community, we thank you for today's hearing on this important legislation. For any questions, please feel free to contact NORD's Director of State Policy, Heidi Ross (hross@rarediseases.org).

Sincerely,

Heidi Ross
Director of State Policy

CC: Members of the Senate Health, Human Services, and Medicaid Committee