NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

June 4, 2025

The Honorable Jerry C. Cirino
Chair, Ohio Senate Committee on Finance
Senate Building
1 Capitol Square
First Floor, 127
Columbus, Ohio 43215

Re: Testimony of the National Organization for Rare Disorders Regarding the Proposed Elimination of Ohio's Rare Disease Advisory Council

Dear Chair Cirino, Vice-Chair Chavez, Ranking Member Hicks-Hudson and Dedicated Members of the Ohio Senate Committee on Finance,

The National Organization for Rare Disorders (NORD) writes today with genuine concern about proposed budget actions which would repeal Ohio's Rare Disease Advisory Council (RDAC). We respectfully ask for the Committee's reconsideration and implore the committee to preserve the voice of Ohio's rare disease community in state government by striking the language eliminating the RDAC in Sub. H.B. No. 96 §105.40.

NORD is hopeful we can find a path forward that preserves this vital infrastructure for Ohio's rare disease community while respecting your fiscal responsibilities. We hope this testimony will provide additional context that may not have been available when this provision was initially considered.

As context for our advocacy, with a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the estimated 1-in-10 Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

Ohio has been part of the now 32-state network of Rare Disease Advisory Councils since 2020, with states like Arizona, Montana, and Mississippi among the most recent additions. These operate as formal advisory committees within state government structures, bringing together diverse expertise to inform policy decisions affecting the rare disease community. Like the overwhelming majority of these councils nationwide, the Ohio RDAC is housed within the State Health Department, leveraging existing state infrastructure to give Ohio's rare disease community a direct voice in their own government.

The Ohio RDAC is comprised entirely of Ohio-based stakeholders from across the rare disease ecosystem - patients and caregivers, healthcare providers, academic researchers, biotechnology and pharmaceutical industry representatives, health plan representatives, and state lawmakers. In fact, the state just sent reappointment letters to these council members, and eliminating the council now would break faith with Ohio citizens who committed their time to serve.

The council requires no separate appropriation and operates on minimal administrative funds - any savings from elimination would be negligible compared to the loss of this critical infrastructure for Ohio's rare disease community. More importantly, the Ohio RDAC delivers tangible results. The council just completed a two-year cycle and is ready to deliver concrete recommendations from their Research, Diagnosis, and Treatment subgroups - real solutions, not just meetings. Looking ahead, with major federal policy changes affecting rare diseases on the horizon, this council ensures Ohio can respond quickly and protect residents' interests rather than being reactive. It serves as an early warning system, staffed by Ohio experts who understand the state's unique needs.

For these reasons, NORD respectfully urges the Committee to strike the language eliminating the Ohio Rare Disease Advisory Council from Sub. H.B. No. 96 §105.40 and preserve this vital voice for Ohio's rare disease community.

NORD thanks you for providing us with the opportunity to submit testimony for your consideration. We hope you all consider the National Organization for Rare Disorders a resource for you in the development of policies and programs that will improve the lives of rare disease patients and their families living in Ohio.

For additional information on any of the issues raised here, please contact Carolyn Sheridan, State Policy Manager (csheridan@rarediseases.org).

Sincerely,

C Sheridan

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Notice: please note a correction was made on 6/5/2025 after testimony had been submitted on the record. There is a nationwide network of 32 councils not 33 (yet!).