



November 9, 2021

The Honorable Jason Wentworth  
Speaker of the House  
Michigan House of Representatives  
164 Capitol Building  
P.O. Box 30014  
Lansing, MI 48909

**RE: Support for House Bill 4654 (H-3) -Michigan Rare Disease Advisory Council**

Dear Speaker Wentworth:

On behalf of the 1-in-10 individuals in Michigan with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for putting House Bill 4654 (H-3) (HB 4654) on the House of Representative's agenda for consideration. HB 4654 establishes clear membership, duties and accountability for a Rare Disease Advisory Council (RDAC), which if passed, would help to give a voice to the rare disease community within Michigan's state government. NORD urges you to support HB 4654 (H-3) and swiftly pass it out of the House of Representatives.

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.

As outlined in HB 4654 (H-3), the RDAC will act as the advisory body on rare diseases to the Michigan Legislature and state departments. Additionally, the RDAC will be tasked with: 1) convening public hearings, making inquiries, and soliciting comments from the general public; 2) consulting with experts to develop policy recommendations; 3) researching and identifying policy priorities related to treatment and services; 4) identifying best practices that could improve the education, care, and treatment of adults and minors with rare diseases in the state; and 5) coordinating with other rare disease advisory bodies, community-based organizations, and other public and private organizations.

This year, the Michigan Legislature approved, as part of the FY 2022 General Omnibus budget, a \$70,000 appropriation for the establishment of an RDAC in the state. Representative Cara Clemente's legislation, HB 4654 (H-3), is an opportunity for the Legislature to provide



additional direction on how the Council should be implemented and the appropriated funds utilized.

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

Once again, on behalf of the Michigan rare disease community, we thank you for putting HB 4654 (H-3) on the House of Representative's agenda and urge its swift passage. For any questions, please feel free to contact Annissa Reed via email at [areed@rarediseases.org](mailto:areed@rarediseases.org). Thank you for your consideration.

Sincerely,

Heidi Ross  
Director of Policy  
National Organization for Rare Disorders

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

CC: Members of the House of Representatives