



December 7, 2021

The Honorable Curtis VanderWall
 Chair
 Senate Health Policy and Human Services Committee
 P.O. Box 30036
 Lansing, MI 48909

Re: Support for House Bill 4654

Dear Chair VanderWall and Members of the Senate Health Policy and Human Services Committee:

On behalf of the undersigned organizations representing individuals with rare diseases in Michigan, we urge you to add House Bill 4654 (HB 4654) to the Senate Health Policy and Human Services Committee’s agenda. HB 4654 establishes a Rare Disease Advisory Council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Michigan.

Rare diseases are present across a broad spectrum of medical conditions. 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.

This year, the Michigan Legislature approved, as part of the FY 2022 General Omnibus budget, a \$70,000 appropriation for the establishment of a rare disease advisory council in the state. Representative Cara Clemente’s legislation, HB 4654, is an opportunity for the Legislature to provide additional direction on how the Council should be implemented and the appropriated funds utilized. Creating an RDAC in Michigan will give rare disease patients a unified voice in Michigan’s state government to help address challenges that are faced by the rare disease

community. 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.

Our organizations were pleased to see the robust set of duties and responsibilities for Council listed in HB 4654; however, we strongly recommend amending the legislation to remove the provision that would require the Council to annually select one rare disease to investigate and make recommendations on that individual disease back to the legislature. There are approximately 7,000 known rare diseases and while each disease is unique, the rare disease community often faces similar challenges, so it is essential that the RDAC remain inclusive of the needs of all rare disease patients. With this modification, the RDAC established through HB 4654 will provide decision-makers in Michigan with the information they need to better understand and meet the needs of needs of everyone in Michigan's diverse rare disease community.

The RDAC represents enormous value to our organizations and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges that Michigan's rare disease community faces. In addition, the RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Michigan government decisionmakers with one community voice.

In creating this council, Michigan will 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 undersigned organizations, we urge you to add HB 4654 to the Senate Health Policy and Human Services Committee's agenda and push for swift passage of the bill as amended to reflect our organizations suggested modification. For any questions, please feel free to contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
ACS CAN
American Behcet's Disease Association (ABDA)

American Kidney Fund
Amyloidosis Foundation
APS Foundation of America, Inc
Be The Match/National Marrow Donor Program
Epilepsy Foundation of Michigan
Global Healthy Living Foundation
Hemophilia Federation of America
Hemophilia Foundation of Michigan
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
The Leukemia and Lymphoma Society