



May 12, 2021

The Honorable Bronna Kahle
Chair
House Health Policy Committee
Anderson House Office Building
N-991 House Office Building
Lansing, MI 48933

Re: Support for House Bill 4654

Dear Chair Kahle and Members of the House Health Policy Committee:

On behalf of the undersigned organizations representing individuals with rare diseases in Michigan, we thank you for adding House Bill 4654 (HB 4654) to the House Health Policy Committee's agenda for consideration. 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.

Though we are facing unprecedented times during the COVID-19 pandemic, we urge you to work to pass HB 4654 this session. Rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, in a 2020 survey conducted by the National Organization for Rare Disorders, 74% of rare disease patients reported having had a medical appointment cancelled due to COVID-19 and approximately 70% of respondents were concerned about medication and medical supply shortages.¹

Creating an RDAC in Michigan will give rare disease patients a unified voice in Michigan's state government and help to address these COVID-19 challenges and many others faced by the rare disease community outside the pandemic. 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.

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 would join seventeen 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, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge you to swiftly pass HB 4654 out of your Committee to help give a voice to Michigan residents living with rare diseases. 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
American Behcet's Disease Association (ABDA)
American Cancer Society Cancer Action Network
American Kidney Fund

¹ <https://rarediseases.org/new-community-survey-from-nord-reveals-significant-impact-of-covid-19-on-americans-living-with-rare-diseases/>

Amyloidosis Foundation

Epilepsy Foundation of Michigan

Hemophilia Federation of America

Immune Deficiency Foundation

International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)

MitoAction

Rare Disease Innovations Institute, Inc.

The Bonnell Foundation: Living with cystic fibrosis