February 19, 2020



Hank Vaupel, DVM Chair, Health Policy Committee Michigan House of Representatives P.O. Box 30014 Lansing, MI 48909-7514

Dear Dr. Vaupel,

On behalf of the biosciences industry in Michigan, and its many biotechnology and pharmaceutical companies engaged in research and manufacturing of life-saving therapeutics, the MichBio urges you and the House Health Policy Committee to pass HB 5465. This legislation to establish a Rare Disease Review Committee within the Department of Health and Human Services (DHHS) would give a strong voice to the rare diseases community in Michigan.

Michigan's bio-industry is committed to the identification, treatment and cure of rare disorders through the development of novel therapies and drugs, education, advocacy and patient support. Our companies span a range of therapeutic areas, just as rare diseases are present across a broad spectrum of medical conditions.

The Review Committee will give rare disease patients a unified voice in our state government by providing them a forum to make recommendations about pressing health care issues. Coupled with DHHS' nationally leading Newborn Screening Program, i.e., the Michigan BioTrust for Health, the Rare Disease Review Committee would give the state a compelling ability to improve knowledge, awareness and management of rare diseases in Michigan, and bring together various stakeholders in the healthcare ecosystem to improve public policy regarding rare diseases. The results will be a great aid for patients and their families.

In creating this Rare Disease Review Committee, Michigan will be joining ten other states who have already enacted related legislation in support of their rare disease community.

Thank you for the opportunity to comment on this legislation and for your support of HB 5465. Please do not hesitate to contact us for any further information.

Sincerely,

Stephen Rapundalo, PhD President and CEO

Stephen Kapundalo