



March 9, 2023

Hon. Julie Rogers  
Chair, Health Policy Committee  
Michigan House of Representatives  
N-890 Anderson House Office Building  
Lansing, MI 48933

**RE: Testimony in Support for House Bill 4167 – Michigan Rare Disease Advisory Council**

Dear Chair Rogers and Members of the House Health Policy Committee,

Good morning, I am Dr. Stephen Rapundalo, President and CEO of the Michigan Biosciences Industry Association or MichBio. We are the statewide organization that represents the interests of the biotechnology and pharmaceutical, medical devices, diagnostics and testing, healthcare information technologies, academic and clinical research, agricultural and industrial biotechnology, and bioscience distribution sectors, along with the professional service providers, suppliers and contract research and manufacturing organizations that support them. Michigan's bio-industry is one of the largest nationally and its mission is to innovate and develop products, treatments and therapies that improve and save lives for the patients we serve. MichBio sits at the interface between that innovation industry and patient groups, many of which are members of our organization. As such our role is to inform, educate and partner in support of patients' needs for better access to meaningful healthcare.

I encourage all of you to move HB 4167 through swiftly and bring relief and attention to the many rare disease stakeholders in Michigan burdened by daily challenges with no effective solutions. We have a tremendous potential to make positive changes through a Rare Disease Advisory Council that will benefit not only public health challenges and by extension, cost expenditures for the state, but improve patient quality of lives for those diagnosed. It would provide a sorely needed opportunity to recognize, investigate, and then implement changes accordingly which could benefit the whole rare disease community.

I'm confident that a RDAC can deliver on its stated mission. Many other states have implemented such advisory bodies since 2015, and several have delivered reports with policy recommendations on how to mitigate access and affordability issues facing rare disease patients and caregivers in their regions.

Closer to home, Michigan already has a model for the proposed RDAC – and that is the Community Values Advisory Board (CVAB) for the Michigan BioTrust for Health. The BioTrust is the DHHS program that oversees the state's newborn screening and stored blood spot program, and their use in public health research. The Community Values Advisory Board is a 15-member group appointed under the authority of the DHHS Director and represents the public voice in development and operations of the BioTrust. I've been privileged to be a member of that body since its inception some 15 years ago and have served as its chairperson for the last four years. A variety of stakeholders – representatives across the state from underserved and underrepresented like indigenous and minority communities, professionals with backgrounds in genetics, hospitals and healthcare, legal and bioethics, medical technologies, and public and environmental health, as well as the general public –

**Serving Michigan's Bio-Industry Since 1993**  
3520 Green Court, Suite 175 Ann Arbor, MI 48105  
(o) 734-527-9150 (f) 734-302-4933 [michbio.org](http://michbio.org)

provide counsel on the governance of the BioTrust, communication and education for engaging and informing mothers and parents about newborn screening, and on ethical issues including patient informed consent and what types of research are, or are not, acceptable uses of the dried blood spots. The group, much like that proposed for the RDAC, brings to light insights from a spectrum of backgrounds and experiences to ensure that the program and resources are impactful for parents, newborns, providers and public health generally. In fact, there can be strong synergies and overlaps between the two bodies for mutual benefit.

To close, I would suggest that a greater focus on rare diseases through the formation of a RDAC is critical and of value for three primary reasons.

First, rare diseases are not rare. As you've heard each individual rare disease affects fewer than 200,000 people, but there are over 7,000 rare diseases. All of us are touched in some way by a rare disease – a child, a spouse, a parent, a sibling, an extended family member, a friend, a work colleague.

Second, and at its core, a formal structure of a legislatively established RDAC will benefit the Michigan Legislature as it develops impactful policy solutions for challenges affecting the rare disease community.

Third, studying, researching and developing cures and therapies for rare diseases benefits rare disease patients of course, but rare disease R&D generates rich dividends for broader disease populations. Insights into the genetic causes of rare diseases, for example, helps build knowledge about the human genome generally and the genetic connections and misconceptions underpinning the causes and mechanisms of diseases broadly. Furthermore, it can be a catalyst for biomedical discovery and innovation at our research institutions, as well as commercialization and development of new treatments and therapies by new and existing Michigan companies – all of which will help sustain and grow the statewide biosciences industry.

Thank you for your consideration and support for HB 4167.

Sincerely,

A handwritten signature in black ink that reads "Stephen Rapundalo". The signature is written in a cursive, flowing style.

Stephen Rapundalo, PhD  
President and CEO  
Michigan Biosciences Industry Association (MichBio)