



February 20, 2020

The Honorable Hank Vaupel
Chair, Health Policy Committee
100 N Capitol Ave
Lansing, MI 48933

The Honorable Ben Frederick
Majority Vice Chair, Health Policy Committee
100 N Capitol Ave
Lansing, MI 48933

The Honorable Frank Liberati
Minority Vice Chair, Health Policy Committee
100 N Capitol Ave
Lansing, MI 48933

Re: Michigan Rare Disease Advisory Council

Dear Chairman Vaupel, Vice Chair Frederick and Vice Chair Liberati,

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 the opportunity to submit testimony on House Bill 5465, legislation that would establish a rare disease review committee. We commend Chairman Vaupel for introducing this legislation and look forward to working with you and members of the House of Representatives to better understand and address the barriers that the rare disease community faces here in Michigan.

NORD is a unique federation of more than 300 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. NORD also operates the Rare Action Network, which has more than 560 members in Michigan working hard to ensure equitable access to timely diagnosis, treatment and care for everyone impacted by rare diseases.

For the last several years, NORD has been working across the country with stakeholders in numerous states to establish rare disease advisory councils. To date, eleven states have passed legislation establishing rare disease advisory councils: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, Nevada, New Hampshire, New York, North Carolina, and Pennsylvania.

In Michigan, NORD is grateful to have partnered with your former colleague, Rep. Jim Tedder, who introduced legislation in the Michigan House of Representatives in 2018 to create a rare



disease advisory council, as well as Rep. Cara Clemente who has been critical to NORD's efforts to raise awareness about rare diseases. Today's hearing is another exciting step forward in efforts to give the rare disease community a united voice in their state government. In fact, the timing of today's hearing couldn't have been better, as several organizations are partnering together for year's Michigan Rare Disease Day event, which is being held today in the Capitol. NORD is grateful for the high-level, bipartisan support enjoyed by these councils both in Michigan and around the country, and

While each rare disease advisory council is tailored to best meet the needs of their state and its government structure, based on feedback from advocates and our experience in several states, NORD has identified some best practices for rare disease advisory councils to enable them to effectively carry out their mission:

- First, it is critical that councils focus their efforts on issues of concern for all patients with rare disease and not focus on one disease over another. Furthermore, by limiting the scope of the rare disease advisory council to only a few diseases, it can be challenging to secure enough committed stakeholders specific to those diseases to participate on the council and make meaningful recommendations.
- Second, it is important that the council identify a committed entity to host the council, such as an outside nonprofit, academic institution, or health department, that will meet on a regular basis. This will allow for a smooth transition once the council is enacted into law.
- Third, the ultimate goal of all RDACs should be to develop policy recommendations and best practices to share widely within the state. To that end, NORD recommends that every council have membership that includes the following representatives from the rare disease stakeholder community:
 - Elected legislative officials (or their designees)
 - Health department officials
 - Academic researchers
 - Health providers (physicians, nurses, geneticists, pharmacists, etc.)
 - Hospital administrators
 - Patients and caregivers
 - Health industry representation (drug manufacturers, insurance companies, etc.)

NORD supports Michigan's efforts to strengthen their rare disease community by giving patients a unified voice in state government by providing a forum to raise their concerns. We look forward to working with members of the Health Policy Committee to see a rare disease advisory council created here in Michigan.

Thank you for the opportunity to comment on the importance of rare disease advisory committees. For further questions, please do not hesitate to contact me at HRoss@rarediseases.org.



Sincerely,

/s/

Heidi Ross
Director of State Policy

CC: Members of the House Health Policy Committee