



June 14, 2018

Anderson House Office Bldg
124 North Capitol Avenue
Lansing, MI 48909

Dear Chairman Vaupel and Members of the Health Policy Committee:

As organizations representing millions of Americans with rare diseases and other severe chronic conditions, we are writing to you in support of H 5983, the Michigan Rare Disease Advisory Council bill.

Our organizations are committed to improving public policy for people with rare “orphan” diseases and the communities that support them. Any disease affecting fewer than 200,000 Americans is considered rare. With 7,000 rare diseases identified and 30 million Americans affected, it is estimated that nearly 1 in 10 Michigan residents are living with a rare disease.

Rare diseases are present across a broad spectrum of medical conditions. For example, all forms of pediatric cancer are considered rare, as are brain, pancreatic, ovarian, thyroid, and stomach cancers. Other examples of rare diseases include lysosomal storage diseases, blood disorders, eye diseases, and autoimmune disorders. 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.

The Michigan Rare Disease Advisory Council will give rare disease patients a unified voice in our state government by providing them a forum to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on the

provider-patient relationship to identifying best practices throughout the nation, the council will coordinate with legislators and other government leaders to improve public policy for the entire state. What is more, because this legislation requires broad participation from the different health care sectors present in Michigan – doctors, hospitals, insurers, manufacturers, and researchers are all represented on the council –, it will also serve as an educational resource to all stakeholders about the ways in which rare disease patients interact with our health care system.

We hope you consider the incredible support that a Rare Disease Advisory Council could provide for Michigan's rare disease community. Please join us in giving a voice to Michigan residents living with rare diseases – many of whom are too young or too sick to speak for themselves – by supporting H 5983.

Sincerely,

Amyloidosis Foundation

DYRK1A Syndrome International Association

Epilepsy Foundation of Michigan

Hemophilia Foundation of Michigan

National Organization for Rare Disorders (NORD) & RareMI

Sickle Cell Disease Association of America, Michigan Chapter

Susan G. Komen Michigan