



January 14, 2020

Ohio House of Representatives – Health Committee  
77 South High Street  
Columbus, OH 43215

Dear Chairman Lipps, Vice Chair Manning, Ranking Member West and Members of the Health Committee,

On behalf of those living with cystic fibrosis (CF) in Ohio, the Cystic Fibrosis Foundation thanks you for the opportunity to submit testimony in support of HB 412, which would establish the Rare Disease Advisory Council.

Cystic fibrosis is a life-threatening genetic disease that affects approximately 1,550 people in Ohio and 30,000 people in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. As the world's leader in the search for a cure for CF, the Cystic Fibrosis Foundation accredits more than 130 care centers nationally, including 13 in Ohio. These care centers provide multidisciplinary, patient-centered care in accordance with systematically reviewed, evidence-based clinical practice guidelines.

Establishing the Rare Disease Advisory Council will raise awareness of cystic fibrosis and other rare diseases impacting Ohioans and inform stakeholders about how they can better serve this community. For instance, it will serve as an educational resource about research, diagnosis, treatment, and the ways in which rare disease patients experience the health care system. We also appreciate that a diversity of viewpoints will be represented through membership on the council – including medical researchers, providers, patients living with a rare disease, and a representative from the Department of Health's Children with Medical Handicaps program (CMH), which serves as a vital safety net for people with CF and their families. We further hope that the council will highlight the importance of ensuring patients are able to access their care as the healthcare and treatment landscape evolves.

In creating this council, Ohio will join several other states, including Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, North Carolina, and Pennsylvania, that have passed similar laws in support of the rare disease community.

The Cystic Fibrosis Foundation asks members of the Health committee to support HB 412 and the creation of the Rare Disease Advisory Council. We look forward to continuing our partnership with the state of Ohio to improve the lives of all people with CF.

Sincerely,



Mary B. Dwight  
Senior Vice President of Policy & Advocacy



Lisa Feng, DrPH  
Senior Director of Policy & Advocacy