The Ohio House of Representatives

Health Committee

Testimony in Support of House Bill 412 -- The Establishment of the Ohio Rare Disease Advisory Council

January 14, 2020

Dear Chairperson Lipps, Vice Chairperson Manning, Ranking Member Boyd, and Members of the House Health Committee,

My name is Andrea Hoffman. I am a resident of Marion County and attend Ohio Northern University in Ada, Ohio, where I am a sophomore double majoring in Political Science and Public Relations and pursuing a minor in Public Policy. I am nineteen years old, and I am living with the rare disease, cystic fibrosis (CF). On behalf of those in Ohio who are living with rare diseases and their families, I wish to provide this testimony and witness in support of the establishment of the Ohio Rare Disease Advisory Council. I apologize that I cannot be with you in person as classes for the spring semester are beginning this week.

I am a lifetime patient at Nationwide Children's Hospital in Columbus, Ohio, and I am fortunate for the care and treatment I have received and continue to receive at the Cystic Fibrosis Care Center, which cares for both children and adults. There are approximately 30,000 individuals who are living with CF in the United States, including 1500 Ohioans, according to the Cystic Fibrosis Foundation Patient Registry. Because of the limited amount of those living with CF, it is considered a rare orphan disease. CF is a progressive genetic disease that primarily affects the lungs and the digestive system but also can have a serious impact on every system of the body. There is much treatment and care required behind the scenes to battle this disease. Due to advancements in medical treatments and knowledge of this rare disease, the average life expectancy is currently in the mid-forties.

Like other rare diseases, CF requires constant advocacy for life-saving treatments, access to quality care and medications, education and awareness about these rare diseases, incentives directed at future practitioners and specialists to enter into specific medical fields to care for rare diseases, and the promotion of vital life-saving research. Not having access to these improvements and advancements in medicine and science is a matter of life and death.

For example, when I was born here in the state of Ohio, even though newborn screening for this devastating disease was available on a national level, the State of Ohio had not yet adopted and required the newborn screening for CF. My twin sister (who is also living with CF) and I went four months without being diagnosed, fortunately, surviving life-threatening symptoms. After our diagnosis experience, my parents, along with other parents and providers, advocated for CF to be added to the newborn screening protocol. Today, here in Ohio, both those with the disease and carriers of the disease are identified at birth which triggers immediate appropriate treatment and genetic counseling.

What is adequate for some conditions is not always adequate for those living with rare diseases. I am insured by two robust private family health insurance plans, but know first-hand that this is not always enough coverage and rely upon the benefits of the Children with Medical Handicaps program of the

Ohio Department of Health. I have witnessed the struggles my parents have endured to make sure that we always have access to the care and treatment that we need to lengthen and strengthen our lives.

I believe that constant education and awareness are also necessary to inform providers and caregivers, public and private insurers, researchers, and employers about the unique demands of rare diseases. I, personally, have advocated for adequate safety-net coverage through the Children with Medical Handicaps program of the Ohio Department of Health, a program that promotes secondary coverage for the unique often high cost of healthcare associated with rare childhood diseases.

People with rare diseases, like CF, and their families, have unique expertise in how their disease affects them and how the context of their situation affects how they can be productive citizens and live their lives to their fullest. By acknowledging respective roles, those living with rare diseases and their families, clinicians and practitioners, researchers, insurers and benefits program administrators, legislators, and others can work together to develop policies that align together to improve the health and care of the most vulnerable Ohioans.

In addition to providing this testimony, I also volunteer and stand ready to serve on the Rare Disease Advisory Council if that opportunity presents itself. Serving in that capacity is the least that I can do to give back for all that I have been fortunate enough to receive.

Thank you for the opportunity to provide this testimony.

Sincerely,

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