

June 5, 2020

Chairman Dave Burke  
Senate Health, Human Services and Medicaid Committee  
1 Capitol Square  
Ground Floor  
Columbus, OH 43215

**RE: Support of HB 412**

The Immune Deficiency Foundation (IDF) **strongly supports HB 412**, which would establish a Rare Disease Advisory Council that would give a voice to the rare disease community, including individuals with primary immunodeficiencies, within Ohio.

IDF is dedicated to improving the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency (PI) through fostering a community empowered by advocacy, education, and research. PIs are a group of more than 400 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. There are an estimated 250,000 people diagnosed with a form of PI in the U.S. alone, and thousands more go undetected. These disorders are caused by genetic defects and are not contagious. Many are first recognized shortly after birth or in early childhood, but many more are not diagnosed until much later in life. Because of their condition, individuals with PI are far more susceptible to infections from even relatively modest viruses. There is variety between the different forms of PI, but everyone with the diagnosis struggles to varying degrees, with recurring infections and persistent illnesses, even when treatments are available that lessen the impact of the diagnoses.

In medical school, many doctors learn the saying, "when you hear hoof beats, think horses, not zebras," and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. Individuals with PI and other rare diseases are the zebras of the medical world. While policymakers make every effort to fully understand a subject prior to legislating or regulating it, there are numerous unique needs and challenges that individuals with PI, or zebras, have that only those with an intimate knowledge of the disorders are familiar with. This gap in knowledge can lead to many unintended consequences for members of the PI community.

With HB 412, Ohio would join a number of other states that have created Rare Disease Advisory Councils to give individuals with rare diseases, such as PI, a voice in state government and provide educational resources for elected leaders on critical issues related to access, coverage, and the diseases themselves. The Council would advise the State on and help coordinate the State's activities around rare diseases, which includes coordination with other stakeholders. The Council would also conduct research to increase the State's understanding of rare diseases and to improve both access to and quality of care for rare disease patients in Ohio.

Primary immunodeficiencies make up a small portion of the estimated 7,000 known rare diseases, each with their own unique needs and challenges, and each needing their voice heard

in Ohio. **We ask for your support on HB 412 and respectfully request the committee issue a favorable report on this vital legislation to give a voice to the Rare Disease Community, including those with PI, within the State.**

Sincerely,

A handwritten signature in blue ink, appearing to read "Jamie N. Sexton".

Jamie N. Sexton, JD  
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