



**Dr. Norman C. Christopher, MD
Chairman, Department of Pediatrics**

**Dr. Bruce H. Cohen, MD, FAAN
Director, Neurodevelopmental Science Center
Interim Vice-President and Medical Director, Rebecca D. Considine Research Institute**

**Proponent Testimony, Ohio House Bill 412 (HB 412)
Ohio House Health Committee
January 14, 2020**

Chairman Lipps, Vice-Chair Manning, Ranking Member West, and members of the House Health Committee:

Thank you for this opportunity to offer proponent testimony on the benefits of House Bill 412. This legislation proposes the creation of the Ohio Rare Disease Advisory Council, which would become a key resource for policymakers and promote collaborative opportunities to overcome the problems encountered by Ohioans of all ages living with a rare disease.

We would like to express our appreciation to Representative Clites and Representative Ginter for their time and effort drafting this legislation. It represents a comprehensive, thoughtful approach to documenting and raising awareness about the realities faced by those living with rare diseases, more than half of whom are children, and include conditions such as cystic fibrosis, congenital anomalies, Down syndrome, muscular dystrophy, sickle cell anemia, leukemia and other pediatric cancers, as well as many others. At Akron Children's Hospital, our providers often play the key role of medical detective in helping patients and parents find answers to explain the series of symptoms their children are experiencing and shed some light on the causes of their child's mental and/or physical developmental delays. As you might imagine, with approximately 7,000 known rare diseases to consider, this can be a slow and tedious exercise.

HB 412 creates the Ohio Rare Disease Advisory Council, an appointed council of individuals representing diverse agencies or government entities that impact, in some way, the lives of those who deal with the many day-to-day challenges caused by rare diseases. More important than its makeup, however, is the work of the Council included within the draft of this bill. Specifically, this includes providing to each subsequent session of the Ohio General Assembly a report documenting the studying of incidence, recommendations for research, as well as efforts to promote collaboration in addressing rare diseases. These are all important components of documenting the status of our

efforts to our state's leaders, and these reports will become important baselines by which to determine the progress of future efforts.

For those living with a rare disease, in addition to the challenge of dealing with their symptoms, many face struggles related to receiving an accurate diagnosis, accessing appropriate treatment and finding helpful information and resources. These difficulties can be compounded by the rarity of some of these diseases, which hinders the medical research into causes and cures. We believe the creation of the Ohio Rare Disease Advisory Council, as well as the important work of that body as outlined in the bill, will lay the foundation for the promotion of sound policy and collaborative research principles that will improve the lives of thousands of patients and their families.

Thank you again for this opportunity to express Akron Children's Hospital's support for HB 412.