**Sponsor Testimony- House Bill 412**

**House Health Committee**

**December 10, 2019**

Chairman Lipps, Vice-Chair Manning, Ranking Member West, and the members of the House Health Committee, thank you for the opportunity to provide sponsor testimony on House Bill 412. This legislation would create the Ohio Rare Disease Advisory Council, which would become a resource for our state and open the door to a collaborative approach to solving the problems those living with a rare disease face in the state. Some more well-known rare diseases include Down Syndrome, Leukemia, Cystic Fibrosis, Muscular Dystrophy, and Sickle Cell Anemia. There are 500 types of rare cancers and all pediatric cancers are considered rare.

As a parent and patient advocate for the past 15 years, I have served as a volunteer for numerous work groups, stakeholder groups, legislative task forces, state and national advocacy programs, and advisory councils for the Ohio Departments of Health and Medicaid, and non-profits. It has taught me a lot about coalition work and how to stand up for what is needed for those in the rare disease space. When you are part of a rare disorder community you know the importance of joining forces with other rare disorders, and that is why this council is not disease specific.

When I was called on to volunteer for these opportunities, it was usually for a short-term purpose or to address one issue, but most of the time the same organizations and caregivers were in the room. My first experience was in 2006 when I was appointed to a legislative task force to study the future funding for the Children with Medical Handicaps program. The most recent was in 2017 when I served on a stakeholder group for the Department of Medicaid to address issues that would impact transitioning children with special healthcare needs from Fee for Service to Medicaid Managed Care plans.

I was always willing to get involved, but it was not easy to commit to all those different groups. I believe Ohio owes it to our patients with rare diseases to do more to be proactive by having a standing advisory council for the legislature and administration. I have been asked if this could be a temporary council, but I believe our patient population is going to need us much longer than what a short task force could accomplish. This council would be much more efficient with experts already formed, rather than calling together emergency task forces every time an issue arises.

Additionally, as my joint sponsor has testified to, this council will be developed to continue to advise the legislature on research, diagnosis, and treatment efforts the statewide providers are working on to hopefully provide a coordination of statewide efforts to promote academic research and funding based on the make-up of rare diseases being treated here in Ohio. Unfortunately we do not currently know the prevalence of rare diseases in the state, because only a few rare diseases are tracked. Identifying the incidence of various rare diseases alone could lead to greater research and funding brought into the state.

This council could also help to identify and address the many challenges facing Ohioans with rare disorders. These challenges include delays in diagnosis, lack of training and awareness of rare diseases, shortages of medical specialists, limited access to therapies and medications, and dealing with a healthcare system that was not designed with them in mind. While there has been a great deal of progress in this field, we still lack many of the solutions that our citizens deserve.

Ten states have created Rare Disease Advisory Councils in the past three years, with at least ten others considering similar legislation as we speak. Our bill has taken into account all the legislation drafted in other states and was crafted to best serve our needs in Ohio. In Connecticut, their council spurred discussion that led to legislative changes like expanded newborn screenings and administrative changes like adding information about rare diseases to school nurse trainings. Some solutions can be simple, but can be life-saving for individuals living with a rare disease.

Our goal is that families and individuals with a rare disease will find that this council gives them a greater voice and representation in Ohio government. This council would pave the way for better health care policy for Ohio, not only for those living with rare diseases, but for all Ohioans. Bringing together all of the relevant stakeholders in the rare disease space would provide the needed collaboration and expertise to solve the issues those with a rare disease face.

I thank Representative Ginter and the twenty-four bipartisan co-sponsors for joining us on this legislation. I would also like to thank the many organizations that have stepped up to support this legislation including the American Heart Association, the Ohio Children’s Hospital Association, the Ohio State University Wexner Medical Center, the National Organization for Rare Disorders, and many more. I appreciate the committee’s time and am happy to answer any questions.