**Sponsor Testimony- House Bill 412**

**Senate Health, Human Services, and Medicaid Committee**

**March 4, 2020**

Chairman Burke, Vice-Chair Huffman, Ranking Member Antonio, and the members of the Senate Health, Human Services, and Medicaid 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. There are 7,000 known rare diseases and it is estimated that 1 in 10 Americans live with a rare disease. Unfortunately, only about 5% of rare diseases still do not have FDA-approved treatment options.

As a parent and patient advocate for the past 15 years, I have served as a volunteer for numerous work groups, legislative task forces, state and national advocacy programs, and advisory councils for the Ohio Departments of Health and Medicaid, and non-profits. When I was called on to volunteer for these opportunities, it was usually for a short-term purpose or to address one emergent issue. 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. This council would be much more efficient, with a team of experts already formed, rather than calling together emergency task forces every time an issue arises.

Additionally, this council will be developed to continue to advise the legislature on research, diagnosis, and treatment efforts that providers are working on to 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 would 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.

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 for joining me in sponsoring this bill. I appreciate the committee’s time and am happy to answer any questions.