January 13, 2020

Dear Representative Lipps and Committee Members,

I am writing both as a wife and mother from Oxford, and as the Ohio Volunteer State Ambassador of the Rare Action Network to offer support for House Bill 412 to establish the Ohio Rare Disease Advisory Council.

As a young toddler, my daughter experienced unexplained leg pain and foot contractures. At first these symptoms were dismissed as growing pains. But by the time she was a teenager, we knew something was not right. So, we began our yearlong odyssey of finding the correct diagnosis. My daughter was diagnosed with Collagen 6A Congenital Muscular Dystrophy and based on her diagnosis we discovered that we have three generations of this disease. At that time her father, grandmother and aunt were one of only 2,000 in the world with that diagnosis. To this day there is no cure or treatment. Our family faces daily challenges dealing with mobility and pain management issues. We are active in the patient organization for this disease. Many rare diseases do not even have a national or international patient organization.

Which brings me to my other role and why I am writing this letter of support. I am the Ohio Volunteer State Ambassador of the Rare Action Network, the grassroots advocacy group of the National Organization of Rare Disorders. I am here to give a voice to those one in ten Ohioans that do NOT have a specific organization to advocate or support them. Currently there are over 7,000 rare diseases with only 10% with a cure or treatment. Here are some of the issues that a person with a rare disease or their caregiver faces on a daily basis:

Obtaining a correct diagnosis which may involve being sent from doctor to doctor and sometimes state to state

Insurance coverage and what is covered and not covered

Medicaid – lengthy wait time or a struggle to receive those benefits

ADA compliance for school/work

Access to affordable medication

So why a Rare Disease Advisory Council for the State of Ohio? This Council would bring together medical researchers, physicians, nurses, patients, lawmakers and state officials to begin addressing many of the issues facing those living with rare diseases.  The Council would be a voice for those with a rare disease and it would advise the Ohio General Assembly and the state government on legislation and policy that may have an impact on those with a rare disease. There are times that new legislation or policy may overlook this minority of Ohioans and their voices united need to be heard.

Currently the states of Kentucky, Minnesota, New Hampshire, Illinois, Alabama, North Carolina and Pennsylvania have such councils and there are other states that have pending legislation. I hope that Ohio can lead the way in helping those with a rare disease so that they too have a voice.

Charlene York

Oxford, Ohio