Chairman Burke and Members of the Ohio Senate Health, Human Services and Medicaid Committee,

My name is Charlene York of Oxford and I am the Ohio Rare Action Volunteer State Ambassador for the Rare Action Network a grassroots advocacy arm of the National Organization for Rare Disorders.

I am honored to be here today to speak on behalf of those Ohioans with a rare disease in support of HB 412 – legislation that would establish a rare disease advisory council in our state.

My husband and daughter have a rare disease called Collagen VI Congenital Muscular Dystrophy. This disease has a broad spectrum - a child may lose their ability to walk within the first two decades of their life or sooner or where a young adult would begin to show symptoms of muscle weakness like my daughter. We were fortunate that this disease could be easily diagnosed through genetic testing and it explained those symptoms that my husband has that were easily dismissed by doctors as old age. Having one person in the family with a rare disease can be stressful for a caregiver, but having two family members (not to mention extended family members that have subsequently been found to have this disease) brings a whole different level of stress to a caregiver like me. So many doctor visits, so much paperwork, and so many times sounding like a broken record where WE had to educate the doctors and others on what my family has. There is still no cure or treatment for this disease. We are active in the disease specific advocacy organization and we are lucky to have one. Yet there are many diseases that do not have a rare disease specific organization for those affected.

Earlier testimony was given on the medical aspects such as treatment or finding a cure of those with a rare disease. But I also want to bring attention to some of the other issues faced by those with a rare disease and their caregivers and how this Rare Disease Advisory Council can help government officials and other state policy makers as they work to figure out issues around:

- Health Insurance – What will be covered? What will not be covered? Pre-existing conditions? Prescription drugs – Will the insurance cover the new drug/treatment that is out there? What will be the out of pocket expense?
- Work – There are many affected people who are working and want to continue to work. My husband is fortunate that his employer has accommodated my husband’s request and he can continue to work mainly from home. His other alternative would be to go onto disability.
- Mental health – So much attention is focused on the health issues of affected people, but the mental health aspects are so easily overlooked. Anxiety, social isolation and depression are some of the symptoms with those with a rare disease and their caregiver experience. And at this time with us in a pandemic, members of the rare disease

community feel more isolated than ever. Believe me – I have been there and we need to ensure we have access to good, affordable mental health services.

A Rare Disease Advisory Council presents an enormous opportunity to gather rare disease community input and make informed policy recommendations to help address many of the issues I outlined above.

NORD estimates that one in ten persons are affected by one of the over 7,000 rare diseases identified. Here in Ohio, the estimated number could be more than 1.1 million affected people. When I travel throughout the State of Ohio, I like to take the backroads to avoid the billboards and traffic. And when I do, I look across the landscape and wonder how many of those homes have someone struggling with a rare disease. I wonder if he or she feels alone knowing that they are possibly the only person in Ohio with their specific disease. I want them to know that they are not alone here in Ohio. I want them to know that their government is here for them. I want them to know that by establishing the Ohio Rare Disease Advisory Council that their voice can and will be heard.

Thank you.