Chairman Lipps and Members of the House Health Committee,

Thank you.

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

I am honored to be here this week to speak on behalf of those Ohioans with a rare disease. As one of the witness of last week had stated that there are no days off when someone has a rare disease and that goes with caregivers like me who was recovering from surgery two weeks ago.

My husband and daughter have a rare disease that is called Collagen VI Congenital Muscular Dystrophy. This disease has a broad spectrum of where 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 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 tested positive for 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.

Early 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.

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?

Education – Will the child qualify for an IEP? ADA compliance for the child at school? Transportation for the child?

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.

And finally, mental health - much discussion has been 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. Believe me – I have been there.

NORD estimates that one in ten persons are affected by one of the over 7,000 rare diseases. Here in Ohio the estimated number could be 1,169,000 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.