Proponent Testimony of Ohio House Bill 412
Elizabeth Stapleton
Ohio Senate Health, Human Services and Medicaid Committee

Chairman Burke, Vice-Chair Dr. Huffman, Ranking Member Antonio and members of the Senate Health, Human Services and Medicaid Committee, I want to thank you for the opportunity to offer written testimony in support of House Bill 412, sponsored by Representative Randi Clites and Representative Tim Ginter.

My name is Elizabeth Stapleton, and I have three confirmed and one possible additional rare disease.
I believe that a Rare Disease Advisory Council can help Ohioans who have rare diseases by working with the National Organization for Rare Disorders (NORD) and more disease-specific organizations to make sure that orphan drugs are covered by insurance companies in Ohio, collect statistics on the number of people in Ohio with rare disorders, and act as an advocate for those of us who cannot speak for ourselves.

I have Alport syndrome, which affects my kidneys and is causing me to progress towards end stage renal failure, hearing loss, and problems with collagen in my system meaning that my skin is becoming more fragile. I will probably need a kidney transplant in the next 10 to 15 years.

I have common variable immune deficiency type hypogammaglobulinemia, which means I do not have enough gamma globulin in my body to help me fight off respiratory illnesses, which exacerbates my asthma when I get sick. I am currently pursuing treatment with a gamma globulin replacement therapy, but it is difficult to obtain.

I also have hyperekplexia, which is a startle syndrome that may cause me to have symptoms similar to a grand mal seizure when I am startled, stressed, or ill. This has an orphan treatment with clonazepam, causing some doctors to question whether I am a drug seeker. It is also important for me to note that I was misdiagnosed and treated for 9 months for a conversion disorder called psychogenic non-epileptic seizures, until I found the right doctor who knew how to diagnose hyperekplexia. There are at least two other people in Ohio who have hyperekplexia.

There is also the possibility that I have MURCS Association, which is a combination of physical features that is less understood than the other three diseases.

As I said before, misdiagnosis can be a major problem not only for the patient but also for the medical community in general. We need a government that is aware and receptive to those of us who call ourselves "zebras," because we are the rare animals in herds of horses.

Thank you for the opportunity to give my testimony and please feel free to reach out to me if I can be a resource and assist you with this effort.

Sincerely,
Elizabeth Stapleton, M.L.I.S.