My name is Sara E.B. Sharpe, and I am writing you today in support of HB 412 to Establish a Rare Disease Advisory Council. I am writing both as a rare disease patient, and as a local advocate for our rare disease community in the greater Cincinnati area. I also serve as a board member for Cincy Zebras, the Cincinnati area support group for Ehlers-Danlos Syndrome (EDS) & related conditions, many of which are are also considered rare diseases, and am proud to represent them today in support of this bill which we believe will be essential in giving voice to our community. EDS is a disorder of the connective tissue, or the glue that holds your body together, and therefore can impact any and every bodily system. It is not unusual for EDS patients to have multiple rare disease diagnoses. Some of the common related conditions include: disorders of the autonomic nervous system, Mast Cell Disease, and Gastrointestinal Motility disorders. In simpler terms, our bodies do not like to do the things that your body is supposed to do automatically, such as regulate heart rate, blood pressure, and digestion. I also have a primary immunodeficiency, which means that my immune system doesn't fight off germs like it should, and has a poor memory for infections or vaccines.

Like many of you who serve by representing us in our state legislature, my first introduction to rare disease was not as a patient or caregiver. As a graduate student, and then as a school psychologist, my job introduced me to many families impacted by rare disease. As I made an earnest attempt to learn as much as I could in order to best help these complex and interesting students, I noticed early on that rare disease families were special. Out of necessity, these families become experts in all aspects of caring for their children, in order to keep them safe and ensure they have the best possible outcome. I knew a little about this from my experience as the sister of someone with Type 1 Diabetes. Although Type 1 Diabetes is not a rare disease, I had watched my mother learn to function as my brothers' pancreas, riding the highs and lows of his blood sugar, and so I wasn’t at all surprised to find rare disease parents and patients reading medical journals, connected to national organizations, and advocating so effectively for their children's' needs.

I also came across many rare disease families who were equally as devoted, but didn't yet have answers. I related to them in a profound way, as I was just at the beginning of my own diagnostic odyssey. Odyssey is not an understatement. Even in a state where we are blessed to have some of the best hospitals and healthcare in the world, the time from symptom onset to diagnosis of rare disease is often a long and harrowing journey, averaging as much as five years for most rare diseases, and ten years for Primary Immunodeficiency. Diagnosis is critical to rare disease patients; this may appear obvious, but it is so much more than a name. With each rare diagnosis, I received not only a name for what was happening, but an idea of what might happen in the future, a community of people who were also living with similar problems, and potential paths for treatment (although not all rare diseases have treatment, or treatment that has been FDA approved).

As I learned more about my conditions, and transitioned from a newcomer in the community facing a large learning curve, to a leader in the local rare disease space, I began to wonder where I would be without my education and privilege. The skills I had learned as a graduate student doing research, and as a school psychologist lent themselves well to figuring out how to build my medical team, advocate for myself, and seek avenues for treatment. I was and am lucky to have excellent insurance coverage, both through my school, and then through my husband's employer since having to leave my career. I have the ability to see doctors at the Cleveland Clinic, Cincinnati Children's Hospital, and other great locations throughout our state, and the midwest who are at the top of their fields. I have been able to receive IVIG for my immune deficiency. Often called liquid gold, IVIG is derived from donor blood plasma. It is both in short supply, and incredibly expensive. I don't like to think about where I would be without all of these advantages.

As a leader of Cincy Zebas, both online and in person, a group of over 1000 (mostly from Ohio), I talk to members every day who face barriers to diagnosis and treatment. I try to help mitigate their learning curve, provide them with resources, point them in the direction of a doctor or medical professional who might be able to help, but I am just one person, and Cincy Zebras serves only a small geographical area and one rare disease process out of thousands impacting Ohioans. This I believe, will be the power of the Rare Disease Advisory Committee. It will bring together all of the wonderful resources we have in this state: legislators like you, medical professionals, researchers, hospitals, insurers, and patient experts like myself, whose knowledge was forged in the fire, in order to expedite diagnosis, break down barriers to treatment and services for our community, and to support the future of rare disease treatment through research.

I thank you for your time, and for your support of HB412, a bill that provides a unique opportunity to work together and pool our state resources to improve the lives of Ohioans with rare disease and their families.

Sincerely,

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