

NAME: Erica Barnes

TOPIC: Testimony in support of HF988, Human Services Finance Committee

DATE: February 9<sup>th</sup>, 2023

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Chair Noor and Human Services Finance Committee members, thank you for allowing me to speak to you today. My name is Erica Barnes. I am Executive Director of the MN Rare Disease Advisory Council and mother to Chloe Sophia Barnes who passed away in 2010 from a rare disease. For the past 12 years I have worked in the advocacy and non-profit space on behalf of my community and it is an honor to represent them as well as the Council today. I am here to speak in support of HF988 that establishes a base operational budget for the Council as an executive branch state agency.

When people hear the term “rare disease” they often assume that that disease affects only a small portion of society. And while this is true when each rare disease population is considered individually, when the over 7,000 different rare diseases are considered collectively, they affect 1 in 10 of the population. Individuals can be affected in a myriad of ways by their rare disease. They might be born with skin so thin like my friend and University of MN student Mohamed that they are referred to as “butterfly children” and live in constant pain. Or they may, like the community RDAC Council member Rae Blaylark represents, have a disease that affects the biochemistry of sickle cells that can lead to organ damage, swelling, stroke and (again) chronic pain. Still others, like my daughter Chloe, may be born apparently happy and healthy but eventually lose the ability to walk, talk, swallow, or breath on their own. In spite of these varying symptoms there is one thing nearly all individuals with rare diseases have in common: a strikingly similar set of barriers above those encountered if diagnosed with a more common disease when seeking to access care in the health system. These barriers include extreme delay in diagnosis (average time is 7-8 years), difficulties identifying a clinician with expertise locally which leads to the need to travel for hours just to receive care or possibly relocation to a new city or state, and significant disparities in treatment options (only 5% of the 7,000 rare disease populations have an FDA approved treatment).

It was the recognition of the lack of equitable care for the rare disease patient population that motivated a 42-member coalition to call for the creation of the MN Rare Disease Advisory Council in 2019. The Council’s vision statement is this: we envision a world where every Minnesota citizen living with a rare disease has access to a timely diagnosis, comprehensive care, and an effective treatment. I have here with me Council member and workgroup lead Dr. Sheldon Berkowitz who will give you a brief overview of some of the work we have done to execute on this vision and what we hope to do in the future.

In closing I want to leave you with this quote from Abbey Meyers, founder of the National Organization for Rare Disorders (NORD) and mother of a son with a rare disease. “Families affected by rare diseases represent a medically disenfranchised population that falls through the cracks of every healthcare system in the world.” The MN Rare Disease Advisory Council exists

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to fill those cracks so that these families stop falling through them. Thank you and please fund this urgent work.