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National Organization for Rare Disorders

RARE ACTION NETWORK
Rareaction.org

MN

May 10, 2018

Senator Julie Rosen
Senator Michelle Benson
Senator Mary Kiffmeyer
Senator Warren Limmer
Senator Scott Newman
75 Rev Dr. Martin Luther King Jr Dr Blvd
St Paul, MN 55155

Representative Jim Knoblach
Representative Jenifer Loon
Representative Paul Torkelson
Representative Pat Garofalo
Representative Gene Pelowski

Re: Support for the Minnesota Rare Disease Advisory Council (HF 2574/ SF 2786)

Dear Conferees:

The Rare Action Network of Minnesota and partner organizations thank the many legislators who have demonstrated a commitment to ensuring that the state of Minnesota continues to be a leader in rare disease research and care by including the creation of the Chloe Barnes Rare Disease Advisory Council in HF3138.

As organizations representing millions of Americans with rare diseases and other severe chronic conditions, we are committed to helping people with rare "orphan" diseases by improving care and increasing public support for these individuals. Any illness, condition, syndrome, disease or disorder affecting fewer than 200,000 Americans is considered rare. With nearly 7,000 rare diseases identified and 30 million Americans affected, it is estimated that nearly 1 in 10 residents of Minnesota is living with a rare disease.

Rare diseases are present across the broad spectrum of medical conditions. For example, all pediatric cancers are considered, as are brain, pancreatic, ovarian, thyroid, and stomach cancers. Other examples of rare diseases include lysosomal storage diseases, Amyotrophic lateral sclerosis (ALS), Ichthyosis, Histiocytosis, Amyloidosis, Rett syndrome, and Huntington's disease. For patients suffering from these or other rare conditions, it can take several years to receive an accurate

diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.

The Chloe Barnes Rare Disease Advisory Council would give rare diseases patients a voice in our state government and provide educational resources for elected leaders on critical issues related to access, coverage, and the diseases themselves. From providing information on the healthcare provider-patient relationship to access issues to vital life-saving medications and therapies, the Council will work as a partner with legislators and other government leaders. Further, by establishing the Council within the University of Minnesota, this legislation ensures that the work of rare disease stakeholders from across the state is supported by the passion and expertise of the Mayo Clinic School of Medicine and the University of Minnesota Medical School.

We hope you consider the incredible support that a Rare Disease Advisory Council could provide for our rare disease community. Please join us in giving a voice to Minnesotans living with rare diseases – many of whom are too young or too sick to speak for themselves.
Sincerely,

ALS Association, MN Chapter
American Cancer Society Cancer Action Network
Chloe's Fight Rare Disease Foundation
Coalition of State Rheumatology Organizations
Colon Cancer Coalition
Epilepsy Foundation of Minnesota
FamilieSCN2A Foundation
Gavin Flying for a Cure
Gillette Children's Specialty Healthcare
Hope Kids
Indian Organization for Rare Diseases
iPFaware Organization
irefuseEB
Joshua Frase Foundation
Legacy of Angels Foundation
Lupus and Allied Diseases Association
Minnesota Consortium for Citizens with Disabilities
Minnesota Genetic Counselors Association
Muscular Dystrophy Association

Organic Acidemia Association
Pediatric Home Services
Pompe Warrior Foundation
Turner Syndrome Society
Wishes and More
Organizations that have sent separate letters of support
Children's Hospitals and Clinics of Minnesota
Medical Alley Association