NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

April 3, 2025

The Honorable Representative Paul Tuss
Montana House of Representatives
State Capitol
Helena, MT 59601

RE: Support for House Bill 943 (Tuss) -- Establishes the Montana Rare Disease Advisory Council

Dear Representative Tuss,

The National Organization for Rare Disorders (NORD) writes today in strong support of House Bill 943, legislation that would establish a Rare Disease Advisory Council (RDAC) in Montana.

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the estimated 1-in-10 Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

As defined by the Orphan Drug Act, a rare disease is any disease or condition that affects fewer than 200,000 people in the United States. It is estimated that more than 30 million Americans are living with one of the over 10,000 known rare diseases. Through Project RDAC, NORD is working to establish an effective RDAC in every state in the country to help address the complex needs of the rare community at the state level. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

We are particularly impressed with several key strengths of HB943:

The council's composition of 17 members includes three positions (two individuals with rare diseases and one caregiver) specifically designated for patients and caregivers, ensuring that those directly affected by rare diseases have a strong voice. Montana would be the first state to explicitly include a representative of the state's public health laboratory, which runs critical newborn screening programs that are often the first line of defense in identifying rare diseases early in life.

The bill outlines five essential duties for the council, including developing policy recommendations to improve patient access to specialists, affordable healthcare coverage, diagnostics, and treatments. The council will also conduct a needs assessment of the rare disease population in Montana—a cornerstone activity that has proven invaluable in other states with established councils.

Additionally, the ongoing base appropriation of $16,000 will provide critical support for the council's work from the outset. Nationwide, councils are funded at various levels and in many cases had to return to the legislature to request financial support once their work had already begun. By including this appropriation at the council's establishment, Montana is addressing funding needs proactively, setting the RDAC up for a successful implementation period.

NORD is eager to welcome Montana to the community of 30 states that have given their rare disease patients a stronger voice in state government by creating a Rare Disease Advisory Council. By establishing this council, Montana would become a leader in the Northwest region, as neighboring states like Idaho, Wyoming, and North Dakota have yet to establish similar councils. States with councils include Alabama, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Thank you for sponsoring this important legislation. We hope you consider NORD a resource as this bill moves through the legislative process, and we look forward to working with you and your staff to improve the lives of rare disease patients and their families living in Montana. If you have any questions or need further assistance, please do not hesitate to contact us.

Sincerely,

C Sheridan

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CC:
Leah Barber, Director of Grassroots Advocacy, National Organization for Rare Disorders®