

STATE OF NORTH DAKOTA

PROCLAMATION

MSD WORLD DAY JULY 30, 2024

WHEREAS, whereas, more than 300 million people around the world, and more than 25 million Americans, are affected by over 7,000 rare diseases, with approximately two-thirds of those affected being children; and

WHEREAS, Multiple Sulfatase Deficiency (MSD) is a rare disease that impacts 1 in 500,000 individuals, and its limited impact has resulted in minimal research because of the lack of commercial viability for treatment; and

WHEREAS, MSD impacts 750 children in the United States and more than 15,000 children worldwide; and children with MSD typically do not live past their 13th birthday; and

WHEREAS, in 2021, families affected by MSD came together from around the world to create the first MSD World Day, picking July 30 to honor Professor Thomas Dierks, one of the researchers who first described the biological cause of MSD, identifying that the SUMF1 gene which encodes for the formylglycine generating enzyme, was deficient in MSD children; and

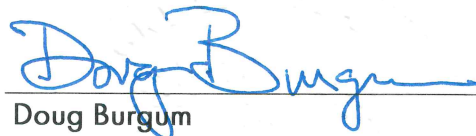
WHEREAS, Jill Anseth, a former North Dakota resident, child of Thomas and Linda Anseth, lived with MSD until it claimed her life at the age of 14 in 1991; and

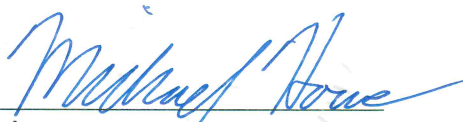
WHEREAS, Max Anseth, a former North Dakota resident, child of Thomas and Linda Anseth, lived with MSD until it claimed his life at the age of 16 in 2000; and

WHEREAS, all North Dakotans are called to recognize the existence of MSD and its impact on the lives of North Dakotans and bring honor and awareness of those affected by MSD and other rare diseases in North Dakota and the world.

NOW, THEREFORE, as Governor of the State of North Dakota, I do hereby proclaim
July 30, 2024, **MSD WORLD DAY** in the State of North Dakota.




Doug Burgum
GOVERNOR

ATTEST: 
Michael Howe
SECRETARY OF STATE