

STATE OF ALASKA



Executive Proclamation by Governor Mike Dunleavy

WHEREAS, a rare disease or disorder is a physical condition that affects fewer than 200,000 people. Approximately 25 million people in the United States and 400 million worldwide are affected by Rare Diseases and Disorders; and

WHEREAS, there are many different causes of rare diseases and disorders, the majority are thought to be genetic – caused by changes in genes or chromosomes; however, the exact cause of many rare diseases remains unknown, making research, diagnosis, and treatment difficult; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected. Individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, some rare diseases and disorders, such as Multiple Sclerosis, also known as MS, are relatively well known because of successful awareness campaigns, many are not, such as Narcolepsy, a neurological sleep disorder, which causes the sufferer to experience extreme and uncontrollable bouts of drowsiness during the day; and

WHEREAS, Sudden Unexplained Death in Childhood (SUDC) is when a sudden and unexplained death of a child 12 months or older occurs. These deaths elude scientific understanding, despite thorough investigations, and consequently cannot be predicted nor prevented. According to the CDC, there are approximately 400 cases of SUDC in the United States each year. SUDC is the fifth leading cause of death among children ages one to four in the United States; and

WHEREAS, with approximately 7,000 conditions designated as rare diseases, and limited research and treatment options, the process of diagnoses can be extremely challenging; and

WHEREAS, Rare Disease and Disorder Day provides an opportunity to raise awareness of the many rare diseases and disorders affecting the lives of countless Alaskans, which can lead to more research, quicker diagnoses, and better treatment options for our neighbors and friends.

NOW THEREFORE, I, Mike Dunleavy, GOVERNOR OF THE STATE OF ALASKA, do hereby proclaim February 28, 2021 as:

Rare Disease and Disorder Day

in Alaska, and encourage all Alaskans to support those with rare diseases and disorders, promote and raise awareness within their communities, and celebrate the progress being made by medical professionals and researchers worldwide.

Dated: February 28, 2021



A blue ink signature of Mike Dunleavy.

*Mike Dunleavy, Governor
who has also authorized the
seal of the State of Alaska to
be affixed to this proclamation.*