## STATE OF NORTH DAKOTA

## PROCLAMATION ====

## TARLOV CYST DISEASE AWARENESS DAY

MAY 16, 2024

WHEREAS, Tarlov Cyst Disease is classified as a rare disease where cerebrospinal fluid-filled sacs form in the nerve roots near the base of the spine, however these cysts can be present along any part of the spine; and

WHEREAS, Tarlov cysts may be known to be asymptomatic, but due to nerve compression and inflation, many cysts may cause bone erosion, radicular pain, weakness and neurologic dysfunction including bowel or bladder changes; and when symptomatic, Tarlov cysts can be progressive, extremely painful and debilitating, and can often limit the patient's ability to walk, sit or stand; and

WHEREAS, more women are diagnosed with Tarlov Cyst Disease than men; and

WHEREAS, Tarlov Cyst Disease symptoms include, but are not limited to, varying levels of intractable pain that are usually defined by cyst location and associated nerve distribution; and progressive nerve compression can lead to neurological damage; and pain often mimics other conditions, making this rare disease difficult to diagnose; and

WHEREAS, treatment for Tarlov Cyst Disease generally focuses on controlling symptoms, with some patients finding long-term relief through surgical intervention; and

WHEREAS, some patients with Tarlov Cyst Disease may also present with additional co-morbid conditions such as connective tissue disorders; and patients often remain at an increased risk of developing other conditions and diseases due to the limited invasive medical treatments to provide relief of pain and symptoms; and this disease and its symptoms vary widely depending on the severity of each case; and

WHEREAS, the need for research on the origins of the disease, non-invasive treatments and the continued support of neurosurgical procedures is imperative; and insurance companies often deny patients necessary treatments and surgery under misinformed pretenses that they are experimental, unnecessary or ineffective.

NOW, THEREFORE, as Governor of the State of North Dakota, I do hereby proclaim May 16, 2024, TARLOV CYST DISEASE AWARENESS DAY in the State of North Dakota.



Doug Burgum

GOVERNOR

ATTEST:

Michael Howe SECRETARY OF STATE