NORTH DAKOTA

PROCLAMATION ===

XLH AWARENESS MONTH JUNE 2024

WHEREAS, X-Linked Hypophosphatemia (XLH) is a whole-body, whole-life rare genetic disorder that affects the person since birth and through childhood, adulthood and advanced age, damaging the patient's bone, joints, dental, hearing, muscle and/or nervous systems;

WHEREAS, XLH affects about 1 in 20,000 newborns according to the National Institutes of Health (NIH); and

WHEREAS, the effects of the disease cause serious and debilitating symptoms that have a major impact on the lives of those people who suffer from XLH and their families; and

WHEREAS, patients affected by XLH and their families often encounter a variety of problems outside the illness itself, such as difficulty in obtaining accurate and timely diagnoses, finding effective treatment options, and being able to afford the appropriate treatment; and

WHEREAS, XLH is not a curable disease, however dedicated researchers around the world continue their efforts to understand how genetic mutations work with the hope that a cure will be found one day; and

WHEREAS, educational programs must be public and constant so that new parents and health providers can be exposed to the most up-to-date information;

WHEREAS, the state of North Dakota encourages people to gain awareness of XLH and those working to help the people affected, including the XLH Network Inc., a nonprofit organization in support of caregivers and patients affected by XLH.

NOW, THEREFORE, as Governor of the State of North Dakota, I do hereby proclaim June 2024, XLH AWARNESS MONTH in the State of North Dakota.

OF NORTH Y

Doug Burgum GOVERNOR

Michael Howe SECRETARY OF STATE