State of Vermont Executive Department A Proclamation

WHEREAS, X-Linked Hypophosphatemia (XLH) is a whole-body, whole-life

rare genetic disorder that affects the person since birth, childhood, adulthood and advanced age affecting the patient's bone, joints,

dental, hearing, muscle and/or nerve systems; and

WHEREAS, XLH affects about one in 20,000 newborns according to the

National Institutes of Health; and

the effects of the disease cause serious and debilitation symptoms WHEREAS,

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 difficulty in obtaining accurate and timely diagnoses, finding effective treatment options, and or 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: and

WHEREAS, the XLH Network Inc (www.xlhnetwork.org) is a non-profit

organization in support of caregivers and patients affected by XLH.

NOW, THEREFORE, I, Philip B. Scott, Governor, hereby proclaim June 2021 as

> X-LINKED HYPOPHOSPHATEMIA (XLH) AWARENESS DAY in Vermont.

> > Given under my hand and the Great Seal of the State of

mont on this 17th day of June, A.D. 2021.

Philip B.

Governor

Secretary of Civil and Military Affairs