## Proclamation by Governor Jim Justice

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 worldwide according to the National Institutes of Health (NIH); and

Whereas, the effects of the disease cause serious and debilitation 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 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 researches 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, is a non-profit organization in support of caregivers and patients affected by XLH.

**Now, Therefore,** Be it Resolved that I, Jim Justice, Governor of the Great State of West Virginia, do hereby proclaim *June 2024* as:

## XLH Awareness Month

hereby proclaim June 23, 2024 as:

## XLH Awareness Day

in the Mountain State and encourage all citizens to join me in this observance.

In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of West Virginia to be affixed.

**Done** at the Capitol, City of Charleston, State of West Virginia, this the First day of June, in the year of our Lord, Two Thousand Twenty-Four, and in the One Hundred Sixty-First year of the State.

SEMPER LINE

Jim Justice Governor

By the Governor:

Mac Warner Secretary of State