

Proclamation

by Governor Jim Justice

- Whereas,** Leukodystrophies are a group of rare genetic disorders that affect the white matter of the brain and nervous system affecting an estimated 1 in 7,000 people; and
- Whereas,** Metachromatic Leukodystrophy (MLD) is a rare genetic disorder where the accumulation of fats called sulfatides in the brain result in progressive destruction of white matter of the brain and nervous system; and
- Whereas,** for MLD, the incidence is estimated to be 1 in 100,000 births in the United States; and
- Whereas,** some rare diseases, or diseases that affect fewer than 200,000 people in the United States are often severely debilitating and many have no effective treatments; and
- Whereas,** there are over 40 types of leukodystrophies, the process of disruption in the proper functioning of the nervous system causes loss of normal function ultimately leading to severe multiple impairments and 100% dependence on caretakers; and
- Whereas,** for Krabbe, the incidence is estimated to be 1 in 100,000 births in the United States; and
- Whereas,** for ALD, the incidence is estimated to be 1 in 21,000 male births in the United States; and
- Whereas,** institutions of stature continue researching many forms of leukodystrophy, looking for breakthroughs that may lead to a cure; and
- Whereas,** there is a lot that can be done to make life more positive for a person with leukodystrophy and their family, and having a network of support helps tremendously to get through the hard times; and
- Whereas,** newborn screening and early diagnostic measures are important to ensure that leukodystrophy families have an opportunity for timely diagnosis and guidance from a healthcare professional; and
- Whereas,** improved awareness and education around Leukodystrophies will increase parental awareness.

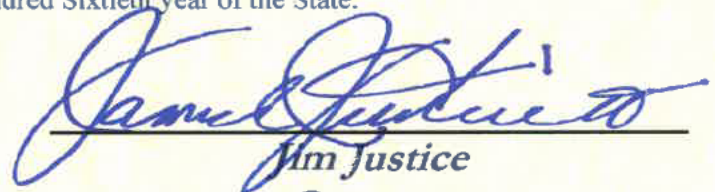
Now, Therefore, Be it Resolved that I, Jim Justice, Governor of the Great State of West Virginia, do hereby proclaim *September 2022* as:

Leukodystrophy Awareness Month

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 Second day of August, in the year of our Lord, Two Thousand Twenty-Two, and in the One Hundred Sixtieth year of the State.



Jim Justice
Governor

By the Governor:



Mac Warner
Secretary of State

