



State of North Carolina

ROY COOPER
GOVERNOR

LEUKODYSTROPHY AWARENESS MONTH

2023

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, leukodystrophies are a group of rare, genetic disorders that affect the white matter of the brain and nervous system; and

WHEREAS, metachromatic leukodystrophy, or MLD, is a rare and fatal genetic disorder in which an accumulation of fats in the brain, called sulfatides, result in progressive destruction of white matter of the brain and nervous system; and

WHEREAS, patients suffering from MLD, primarily young children, experience progressive destruction of their motor, behavioral, and cognitive functions; and

WHEREAS, in its most severe and common form, MLD causes children to lose the ability to walk, talk, and interact with the world around them; 50 percent of children who experience the most severe form of the disease will not live past five years of disease onset; and

WHEREAS, in the United States, the incidences for these disorders are estimated to be 1 in 100,000 births for MLD, 1 in 100,000 births for Krabbe, and 1 in 21,000 male births for ALD; 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 of the importance of newborn screenings;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September, 2023, as “**LEUKODYSTROPHY AWARENESS MONTH**” in North Carolina, and commend its observance to all citizens.



Roy Cooper
Governor

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this thirty-first day of August in the year of our Lord two thousand and twenty-three and of the Independence of the United States of America the two hundred and forty-eighth.