

State of North Carolina

ROY COOPER

GOVERNOR

WORLD SANFILIPPO SYNDROME AWARENESS DAY

2024

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, Sanfilippo Syndrome, also known as MPS III, is a rare and devastating genetic disorder that affects 1 in 70,000 births, primarily affecting children, causing progressive neurological decline, severe cognitive impairment, and a shortened lifespan; and

WHEREAS, the disease initially presents itself with an onset of developmental or speech delay after a period of normal development, followed by severe behavioral problems and hyperactivity; and

WHEREAS, World Sanfilippo Syndrome Awareness Day, observed annually on November 16, aims to raise awareness about this rare disease, support affected families, and encourage research into treatments and cure; and

WHEREAS, it is crucial to educate our communities about Sanfilippo Syndrome to foster understanding, compassion, and support for those living with the condition and their families; and

WHEREAS, it is important to encourage and support efforts to advance research and increase public awareness of the syndrome to improve the quality of life for individuals with Sanfilippo Syndrome and advance effective treatments; and

WHEREAS, on this day, we honor the strength and resilience of individuals and families affected by Sanfilippo Syndrome and recognize the tireless efforts of research, healthcare professionals, and advocates dedicated to making a difference;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim November 16, 2024, as "WORLD SANFILIPPO SYNDROME AWARENESS DAY" in North Carolina, and commend its observance to all citizens.



Roy Cooper

IN WITN SS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this fifteenth day of November in the year of our Lord two thousand and twenty-four and of the Independence of the United States of America the two hundred and forty-ninth.