



State of North Carolina

ROY COOPER
GOVERNOR

CYSTINURIA AWARENESS DAY

2021

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, cystinuria is a rare genetic defect that prevents the body from regulating amino acid concentrations, subsequently leading to elevated levels of cystine and the formation of cystine stones in the kidney, ureter, and bladder; and

WHEREAS, The American Urological Association recognizes cystinuria as the most common monogenic kidney stone disorder; 1 in every 10,000 Americans are believed to be genetically at risk for cystinuria and there are an estimated 38 known cases of cystinuria in North Carolina; and

WHEREAS, the majority of cystinuria patients start to suffer from chronic cystine stone formation before the age of 20; and

WHEREAS, cystinuria patients often endure episodes of debilitating pain (typically known as renal colic), nausea, vomiting, and recurrent urinary tract infections, at times requiring numerous stone removal procedures and surgeries; and

WHEREAS, cystinuria patients may suffer from life threatening complications, such as hypertension, renal insufficiency, and end stage renal disease, sometimes requiring a kidney transplant; and

WHEREAS, the majority of cystinuria patients forming recurrent stones will develop some form of chronic kidney disease in their lifetime; and

WHEREAS, while there is no cure for cystinuria, treatment options significantly reduce medically necessary surgeries, and some patients can live without developing kidney stones; and

WHEREAS, early diagnosis of cystinuria is important to its long-term management, as cystinuria can be diagnosed from analysis of a 24-hour urine test; however, detection may be improved by increased education and screening, as many patients do not receive a diagnosis until after enduring one or more stone episodes; and

WHEREAS, medical professionals across the nation, including at The University of North Carolina at Chapel Hill, are lending their expertise on cystinuria to help better understand and treat this disease; and

WHEREAS, well-supported research funding for cystinuria will lead to improved screening and treatment, improved quality of life, and expedited development of a cure;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim June 24, 2021, as “**CYSTINURIA AWARENESS DAY**” 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 sixteenth day of June in the year of our Lord two thousand and twenty-one and of the Independence of the United States of America the two hundred and forty-fifth.