

STATE OF TENNESSEE

PROCLAMATION

BY THE GOVERNOR

WHEREAS, Cystinuria occurs in individuals due to a rare genetic defect that prevents the body from reabsorbing the amino acid cystine, subsequently leading to elevated levels of cystine in the urine and the formation of cystine stones in the kidney, ureter, and bladder; and

WHEREAS, Cystinuria is the most common of the rare kidney stone disorders and affects approximately 1 in 10,000 people; and

WHEREAS, the majority of Cystinuria patients start to suffer from 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; and

WHEREAS, the majority of Cystinuria patients will require numerous stone removal procedures and surgeries; and

WHEREAS, Cystinuria patients may suffer from life threatening complications, such as hypertension, renal insufficiency, end stage renal disease, and the need for 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, there is no cure for Cystinuria, but treatment adherence can significantly reduce the need for surgical interventions, and some patients can live a stone-free life; and

WHEREAS, Cystinuria can be diagnosed from analysis of a 24-hour urine test; and

WHEREAS, 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, early diagnosis is important for the long-term management of a Cystinuria and can potentially limit permanent kidney damage and preserve kidney function; and

NOW, THEREFORE, I, Bill Lee, Governor of the State of Tennessee, do hereby proclaim June 24, 2019 as

<mark>Cystinuria H</mark>wareness Day

in Tennessee and encourage all citizens to join me in this worthy observance.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the official seal of the State of Tennessee to be affixed at Nashville on this fifth day of June, 2019.

Governor

Secretary of State