

## Proclamation

## By the Governor of Alabama

WHEREAS, the American Urological Association recognizes Cystinuria as the most common monogenic kidney stone disorder; 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; and

WHEREAS, the majority of Cystinuria patients will require numerous stone removal procedures and surgeries which cause physical, emotional and financial strain on patients and their families; and

WHEREAS, Cystinuria patient may suffer from life threatening complications such as hypertension, renal insufficiency, end-stage renal disease, and the need for a kidney transplant; and

WHEREAS, studies have demonstrated Cystinuria patients have worse health related quality of life than the general population, specifically in areas of general health, bodily pain, and mental health; and

WHEREAS, there is no cure for Cystinuria, treatment options significantly reduce medically necessary surgeries and some patients can live a stone-free life; and

WHEREAS, Alabama has taken a leadership role to better understand and address the needs of patients with rare diseases through the creation of the Rare Disease Advisory Council in 2018 which brings together clinicians and patients to focus on this important issue;

NOW, THEREFORE, I, Kay Ivey, Governor of Alabama, do hereby proclaim June 24, 2020, as

## Cystinuria Awareness Day

in the state of Alabama.



Given Under My Hand and the Great Seal of the Office of the Governor at the State Capitol in the City of Montgomery on the 15<sup>th</sup> day of June 2019.

Kay Ivey, Governor