

1 HR81
2 205993-1
3 By Representatives Lee and Clouse
4 RFD: Rules
5 First Read: 03-MAR-20

2
3
4
5
6
7
8 RECOGNIZING JUNE 24, 2020, AS CYSTINURIA AWARENESS
9 DAY IN ALABAMA.

10
11 WHEREAS, Cystinuria occurs in individuals in which a
12 rare genetic defect prevents the body from regulating amino
13 acid concentrations, subsequently leading to elevated levels
14 of cystine and the formation of cystine stones in the kidney,
15 ureter, and bladder; and

16 WHEREAS, Cystinuria has been documented as a leading
17 risk factor for one of the most common forms of kidney stones;
18 and

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

22 WHEREAS, the majority of Cystinuria patients start
23 to suffer from chronic cystine stone formation before the age
24 of 20; and

25 WHEREAS, Cystinuria patients endure episodes of
26 debilitating pain (typically known as renal colic), nausea,
27 vomiting, and recurrent urinary track infections; and

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

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

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

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

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

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

21 WHEREAS, one in every 10,000 Americans are believed
22 to be genetically at risk for Cystinuria; and

23 WHEREAS, detection may be improved by increased
24 education and screening, as many patients do not receive a
25 diagnosis until after enduring one or more stone episodes; and

26 WHEREAS, early diagnosis is important to the
27 long-term management of Cystinuria, which can potentially

1 limit permanent kidney damage and preserve maximal kidney
2 function; and

3 WHEREAS, kidney stone experts cite the economic
4 burden in the United States for providing care for individuals
5 of working age with kidney stones to be 5.3 billion dollars in
6 the year 2000, which is the equivalent of 8 billion dollars in
7 2020; now therefore,

8 BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF
9 THE LEGISLATURE OF ALABAMA, That this body recognizes June 24,
10 2020, as "Cystinuria Awareness Day" in Alabama, and encourages
11 efforts that raise awareness of and increase public knowledge
12 about Cystinuria, to inform all people of the State of Alabama
13 about the risk factors and long-term health consequences of
14 Cystinuria, and disseminate information on the importance of
15 early diagnosis and management of Cystinuria patients; and
16 supports research to improve the screening and treatment for
17 Cystinuria, identify ways to enhance the quality of life for
18 Cystinuria patients and develop a cure for Cystinuria.

19 BE IT FURTHER RESOLVED, That we call on the people
20 of Alabama, interest groups, and affected persons to promote
21 awareness of Cystinuria, take an active role in the fight
22 against this devastating disease, and observe Cystinuria
23 Awareness Day with appropriate activities and educational
24 programs.