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1 SENATE RESOLUTION

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WHEREAS, Cystinuria occurs in individuals in which a rare 2 3 genetic defect prevents the body from regulating amino acid 4 concentrations, subsequently leading to elevated levels of cystine and the formation of cystine stones in the kidney, 5 6 ureter, and bladder; and 7 WHEREAS, The American Urological Association recognizes 8 Cystinuria as the most common monogenic kidney stone disorder; 9 and 10 WHEREAS, The majority of Cystinuria patients start to suffer from chronic cystine stone formation before the age of 11 12 20; and 13 WHEREAS, Cystinuria patients often endure episodes of debilitating pain (typically known as renal colic), nausea, 14 vomiting, and recurrent urinary tract infections; and 15 16 WHEREAS, The majority of Cystinuria patients will require 17 numerous stone removal procedures and surgeries; and 18 WHEREAS, Studies have demonstrated Cystinuria patients 19 have worse health related quality of life than the general

population, specifically in areas of general health, bodily

- 1 pain, and mental health; and
- 2 WHEREAS, Cystinuria patients may suffer from life
- 3 threatening complications, such as hypertension, renal
- 4 insufficiency, end stage renal disease, and the need for a
- 5 kidney transplant; and
- 6 WHEREAS, The majority of Cystinuria patients forming
- 7 recurrent stones will develop some form of chronic kidney
- 8 disease in their lifetime; and
- 9 WHEREAS, There is no cure for Cystinuria, treatment options
- 10 significantly reduce medically necessary surgeries and some
- 11 patients can live a stone-free life; and
- 12 WHEREAS, Cystinuria can be diagnosed from analysis of a
- 13 24-hour urine test; and
- 14 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
- 17 WHEREAS, Early diagnosis is important to the long-term
- 18 management of a Cystinuria, which can potentially limit
- 19 permanent kidney damage and persevere maximal kidney function;
- 20 and

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- 1 WHEREAS, One in every 10,000 Americans are believed to be
- 2 genetically at risk for Cystinuria; and
- 3 WHEREAS, Cystinuria has been documented as a leading risk
- 4 factor for one of the top most common forms of kidney stones;
- 5 and
- 6 WHEREAS, Kidney stone experts cite the economic burden in
- 7 the United States for providing care for individuals, of
- 8 working age, with kidney stones to be \$5.3 billion dollars in
- 9 the year 2000; and
- 10 WHEREAS, Doctors at Southern Illinois University's School
- 11 of Medicine have world-leading expertise on Cystinuria;
- 12 therefore, be it
- 13 RESOLVED, BY THE SENATE OF THE ONE HUNDREDTH GENERAL
- 14 ASSEMBLY OF THE STATE OF ILLINOIS, that we recognize June 24,
- 2017 as "National Cystinuria Awareness Day"; and be it further
- 16 RESOLVED, That we encourage steps be taken to raise
- awareness of and increase public knowledge about Cystinuria, to
- inform all people in Illinois about the dangers of Cystinuria;
- 19 to disseminate information on the importance of early diagnosis
- and management of Cystinuria patients; and to support research

- 1 funding of Cystinuria at Illinois medical research centers to
- 2 improve screening and treatment for Cystinuria, to support
- 3 efforts that may improve the quality of life for Cystinuria
- 4 patients, and to develop a cure for Cystinuria; and be it
- 5 further
- 6 RESOLVED, That we call on the people of Illinois, interest
- 7 groups, and affected persons to promote awareness of
- 8 Cystinuria, to take an active role in the fight against this
- 9 devastating disease, and to observe National Cystinuria
- 10 Awareness Day with appropriate ceremonies and activities.