



SCR-30 Cystinuria Awareness Day. (2021-2022)

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Senate Concurrent Resolution No. 30

CHAPTER 66

Relative to Cystinuria Awareness Day.

[Filed with Secretary of State July 09, 2021.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 30, Dahle. Cystinuria Awareness Day.

This measure would recognize and proclaim June 24, 2021, as Cystinuria Awareness Day to promote awareness of Cystinuria and to show support for California medical research centers that take an active role in the fight against the disease.

Fiscal Committee: no

WHEREAS, Cystinuria occurs in individuals when a rare genetic defect prevents the body from regulating amino acid concentrations, 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; and

WHEREAS, The majority of Cystinuria patients start to suffer from chronic cystine stone formation before 20 years of age; and

WHEREAS, Cystinuria patients often endure episodes of debilitating pain 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, Studies have demonstrated that 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, 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, treatment options significantly reduce medically necessary surgeries, 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 to the long-term management of Cystinuria, which can potentially limit permanent kidney damage and preserve maximal kidney function; and

WHEREAS, One in every 10,000 Americans is believed to be genetically at risk for Cystinuria and there are 42 known cases of Cystinuria in California; and

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

WHEREAS, Kidney stone experts cited the economic burden in the United States due to lost worker productivity, treatment, and the care of individuals of working age with kidney stones to be \$5.3 billion in 2000; and

WHEREAS, Doctors at the University of California, San Francisco, have world-leading expertise on Cystinuria; and

WHEREAS, Well-supported research funding for Cystinuria will lead to improved screening and treatment and improved quality of life, and will expedite the development of a cure; and

WHEREAS, Steps should be taken to promote awareness and research of Cystinuria and to disseminate information on the importance of early diagnosis and management of Cystinuria; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature recognizes and proclaims June 24, 2021, as Cystinuria Awareness Day to promote awareness of Cystinuria and to show support for California medical research centers that take an active role in the fight against this devastating disease; and be it further

Resolved, That the Legislature calls on the people of California, interest groups, and affected persons to observe Cystinuria Awareness Day; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.