
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 173 Session of
2019

INTRODUCED BY J. WARD, DINNIMAN, FARNESE, FONTANA, BARTOLOTTA,
LANGERHOLC, BREWSTER, MARTIN, BROWNE, PHILLIPS-HILL, KILLION,
SCAVELLO, BLAKE, MENSCH, TARTAGLIONE, HUGHES AND COSTA,
JUNE 18, 2019

INTRODUCED AND ADOPTED, JUNE 18, 2019

A RESOLUTION

1 Recognizing June 24, 2019, as "Cystinuria Awareness Day" in
2 Pennsylvania.

3 WHEREAS, Cystinuria occurs in individuals in which a rare
4 genetic defect prevents the body from regulating amino acid
5 concentrations, subsequently leading to elevated levels of
6 cystine and the formation of cystine stones in the kidney,
7 ureter and bladder; and

8 WHEREAS, The American Urological Association recognizes
9 cystinuria as the most common monogenic kidney stone disorder;
10 and

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

13 WHEREAS, Cystinuria patients often endure episodes of
14 debilitating pain (typically known as renal colic), nausea,
15 vomiting and recurrent urinary tract infections; and

16 WHEREAS, The majority of cystinuria patients will require
17 numerous stone removal procedures and surgeries; and

1 WHEREAS, Studies have demonstrated cystinuria patients have
2 worse health-related quality of life than the general
3 population, specifically in areas of general health, bodily pain
4 and mental health; and

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

8 WHEREAS, The majority of cystinuria patients forming
9 recurrent stones develop some form of chronic kidney disease in
10 their lifetime; and

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

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

16 WHEREAS, Detection may be improved by increased education and
17 screening, as many patients do not receive a diagnosis until
18 after enduring one or more stone episodes; and

19 WHEREAS, Early diagnosis is important to the long-term
20 management of a cystinuria, which can potentially limit
21 permanent kidney damage and preserve maximal kidney function;
22 and

23 WHEREAS, One in every 10,000 Americans are believed to be
24 genetically at risk for cystinuria and there are 30 known cases
25 of cystinuria in Pennsylvania; and

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

29 WHEREAS, Kidney stone experts cite the economic burden in the
30 United States for providing care for individuals of working age

1 with kidney stones to be \$5.3 billion in 2000; and

2 WHEREAS, Doctors at the University of Pennsylvania have
3 world-leading expertise on cystinuria; and

4 WHEREAS, Well-supported research funding for cystinuria will
5 lead to improved screening and treatment, improved quality of
6 life and expedite the development of a cure; therefore be it

7 RESOLVED, That the Senate recognize June 24, 2019, as
8 "Cystinuria Awareness Day" in Pennsylvania to promote awareness
9 of cystinuria and to show support for research at the
10 Pennsylvania medical research centers that take an active role
11 in the fight against cystinuria.