

ASSEMBLY JOINT RESOLUTION

No. 92

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED FEBRUARY 13, 2020

Sponsored by:

Assemblywoman NANCY J. PINKIN

District 18 (Middlesex)

SYNOPSIS

Designates July of each year as “Cockayne Syndrome Awareness Month” in New Jersey.

CURRENT VERSION OF TEXT

As introduced.



1 **A JOINT RESOLUTION** permanently designating the month of July
2 as “Cockayne Syndrome Awareness Month” in New Jersey.
3
4 **WHEREAS**, Cockayne Syndrome is a rare genetic disorder
5 characterized by short stature and an appearance of premature
6 aging; and
7 **WHEREAS**, Edward Alfred Cockayne (1880 – 1956), after whom this
8 disease is named, was a London physician who concentrated
9 primarily on hereditary diseases of children; and
10 **WHEREAS**, Cockayne Syndrome occurs in approximately two out of
11 every one million babies born in the United States and Europe
12 combined and there are currently three families in New Jersey with
13 children who are afflicted with Cockayne Syndrome; and
14 **WHEREAS**, Children afflicted with Cockayne Syndrome can exhibit
15 the following symptoms of this disorder: poor growth,
16 microcephaly (smallness of the head), progeria (premature aging),
17 sensitivity to sunlight, moderate to profound developmental and
18 neurological delays, and a shortened lifespan; and
19 **WHEREAS**, There are three subtypes of Cockayne Syndrome, which
20 are distinguished by the severity and age of onset of symptoms.
21 Classical or Type I is the onset of symptoms in early childhood,
22 usually after age one. Type II has much more severe symptoms that
23 are apparent at birth. Type III has the mildest symptoms of the three
24 types and appears later in childhood; and
25 **WHEREAS**, Research indicates that Cockayne Syndrome is the result
26 of mutations in genes which provide instructions for making
27 proteins that are involved in repairing damaged DNA; and
28 **WHEREAS**, Cockayne Syndrome is inherited in an autosomal recessive
29 pattern; therefore, in order for a child to be affected, he or she must
30 inherit a mutation in the same gene from both parents; and
31 **WHEREAS**, There is no specific treatment for Cockayne Syndrome,
32 but the symptoms of the disease may be treated through a number
33 of different therapies, including: physical, occupational, speech,
34 vision, and hearing therapies; and
35 **WHEREAS**, There is ongoing research to study the causes, progression,
36 and biological effect of Cockayne Syndrome, with the hope of
37 creating a treatment that could help to slow or end this debilitating
38 and deadly disease; and
39 **WHEREAS**, Due to the relatively small number of cases each year, it is
40 important to raise awareness of Cockayne Syndrome because it has
41 an extremely significant impact both emotionally and economically
42 on affected families and their extended communities; and
43 **WHEREAS**, Increased awareness of Cockayne Syndrome will assist
44 those families affected by the disease in locating social and medical
45 support more easily through entities such as the Share and Care
46 Cockayne Syndrome Network, which holds an annual meeting each
47 year for families; now, therefore,

1 **BE IT RESOLVED** *by the Senate and General Assembly of the*
2 *State of New Jersey:*

3

4 1. The month of July of each year is designated as “Cockayne
5 Syndrome Awareness Month” in the State of New Jersey to foster
6 an awareness and understanding of Cockayne Syndrome.

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8 2. The Governor is requested to annually issue a proclamation
9 calling upon public officials and citizens of this State to observe
10 “Cockayne Syndrome Awareness Month” with appropriate
11 activities and programs.

12

13 3. This joint resolution shall take effect immediately.

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STATEMENT

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18 This joint resolution designates the month of July of each year as
19 “Cockayne Syndrome Awareness Month” in New Jersey.

20 Cockayne Syndrome (CS) is a rare genetic disorder which occurs
21 in approximately two out of every one million newborns each year
22 in the United States and Europe combined. Symptoms of CS
23 include poor growth, microcephaly (smallness of the head), progeria
24 (premature aging), sensitivity to sunlight, moderate to profound
25 developmental and neurological delays, and a shortened lifespan.

26 It is important for those families affected by CS to raise
27 awareness of this disease. Increased awareness of CS will assist
28 those families with finding social and medical support more easily
29 through entities such as the Share and Care Cockayne Syndrome
30 Network, which holds an annual meeting each year for families.