

SENATE JOINT RESOLUTION

No. 69

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED MARCH 16, 2020

Sponsored by:

Senator JOSEPH F. VITALE

District 19 (Middlesex)

SYNOPSIS

Designates July 20 of each year as “Emma’s Day” to raise awareness of lysosomal storage disorders.

CURRENT VERSION OF TEXT

As introduced.



- 1 **A JOINT RESOLUTION** designating July 20 of each year as “Emma’s
2 Day” to raise awareness of lysosomal storage disorders.
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- 4 **WHEREAS**, Lysosomes are minute bodies within cells that convert lipids,
5 sugars, and proteins into smaller components to provide energy for
6 the body, and lysosomal storage disorders result from material
7 accumulating within cells; and
- 8 **WHEREAS**, There are more than 40 types of lysosomal storage
9 disorders, including Krabbe disease, Tay-Sachs disease, Gaucher
10 disease, and Pompe disease; and
- 11 **WHEREAS**, Lysosomal storage disorders are rare, inherited, and
12 primarily affect children; and
- 13 **WHEREAS**, Many children with lysosomal storage disorders die within
14 a few months or years of birth, after suffering from symptoms
15 which include (depending on the particular disorder) developmental
16 delays, movement disorders, seizures, dementia, deafness,
17 blindness, enlarged livers or spleens, bones that grow abnormally,
18 and pulmonary and cardiac problems; and
- 19 **WHEREAS**, Emma Daniels, was born in New Jersey in 2009 and
20 diagnosed with Krabbe disease, a lysosomal storage disorder which
21 most often affects infants before six months of age, and for which
22 no cure yet exists; and
- 23 **WHEREAS**, Research is underway to find reliable cures and treatments
24 for lysosomal storage disorders, and it is appropriate to raise
25 awareness of these disorders and of the need for newborn screening
26 and effective treatments; now, therefore,
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- 28 **BE IT RESOLVED** *by the Senate and General Assembly of the*
29 *State of New Jersey:*
30
- 31 1. July 20 of each year is designated as “Emma’s Day” in the
32 State of New Jersey.
33
- 34 2. The Department of Health and all other public and private
35 entities entrusted with the health of the citizens of this State are
36 urged to observe this day with appropriate activities to increase
37 public awareness of lysosomal storage disorders.
38
- 39 3. This joint resolution shall take effect immediately.
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41

42 **STATEMENT**
43

44 This joint resolution designates July 20 of each year as “Emma’s
45 Day” in the State of New Jersey in order to raise awareness of
46 lysosomal storage disorders and acknowledge the importance of
47 newborn screening in diagnosing these disorders. Emma Daniels

SJR69 VITALE

3

1 was born in New Jersey in 2009 and diagnosed with Krabbe
2 disease, a lysosomal storage disorder.

3 Lysosomal storage disorders are inherited, and affect primarily
4 children, many of whom die within a few months or years of birth
5 after much suffering. There are more than 40 of these disorders,
6 including Krabbe disease, Tay-Sachs disease, Gaucher disease, and
7 Pompe disease. Currently no cure or reliable treatments exist.

8 This joint resolution urges the Department of Health and all
9 other public and private entities entrusted with the health of the
10 citizens of this State to observe “Emma’s Day” with appropriate
11 activities to increase public awareness of lysosomal storage
12 disorders.