

ASSEMBLY JOINT RESOLUTION

No. 122

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED FEBRUARY 25, 2020

Sponsored by:

Assemblyman RONALD S. DANCER

District 12 (Burlington, Middlesex, Monmouth and Ocean)

SYNOPSIS

Designates September 7 through 13 of each year as “Duchenne Muscular Dystrophy Awareness Week” in New Jersey.

CURRENT VERSION OF TEXT

As introduced.



1 **A JOINT RESOLUTION** permanently designating September 7
2 through 13 as “Duchenne Muscular Dystrophy Awareness
3 Week” in New Jersey.
4
5 **WHEREAS**, Duchenne muscular dystrophy is a genetic disorder caused
6 by a mutation in the gene that encodes for dystrophin, a protein that
7 helps maintain the structure of muscle cells; and
8 **WHEREAS**, Duchenne muscular dystrophy is the most common fatal
9 genetic disorder diagnosed in childhood, affecting approximately
10 one in 3,500 boys globally; and
11 **WHEREAS**, Duchenne muscular dystrophy is characterized by
12 progressive muscle degeneration and weakness, with symptoms
13 often beginning as early as three years of age; and
14 **WHEREAS**, This muscle weakness normally begins to affect critical
15 organs like the heart and lungs by early teenage years; and
16 **WHEREAS**, Until recently, boys with Duchenne muscular dystrophy
17 often did not survive into adulthood, but advances in cardiac and
18 respiratory care are allowing many to live into their 30s or later;
19 and
20 **WHEREAS**, The mutated gene that causes Duchenne muscular
21 dystrophy is located on the X chromosome, and thus cannot be
22 transmitted can be carried by females, who normally do not show
23 any symptoms of the disease, but can pass it along to their children;
24 and
25 **WHEREAS**, Genetic counseling is advised for people with a family
26 history of this disease, and genetic testing can detect the gene that
27 causes Duchenne muscular dystrophy in approximately 95 percent
28 of cases; and
29 **WHEREAS**, Scientists and donors around the world are conducting
30 intense research to develop new treatments for Duchenne muscular
31 dystrophy, including research into new drug treatments, gene
32 therapy, muscle regeneration, stem cell transplantation, and more;
33 and
34 **WHEREAS**, A worldwide coalition of Duchenne patient and parent
35 organizations, United Parent Projects Muscular Dystrophy,
36 recognizes World Duchenne Day on September 7 of each year in
37 countries all over the world; and
38 **WHEREAS**, A New Jersey charity focused on Duchenne muscular
39 dystrophy, JAR of Hope, was founded after Jim and Karen Raffone
40 learned of their son’s diagnosis on September 13, 2013; and
41 **WHEREAS**, The State of New Jersey can support these efforts to raise
42 awareness of Duchenne Muscular Dystrophy and to raise funding to
43 support research into treatments and an eventual cure for the
44 disease by annually honoring and joining in their work; now,
45 therefore,
46
47 **BE IT RESOLVED** *by the Senate and General Assembly of the*
48 *State of New Jersey:*

AJR122 DANCER

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1 1. The week beginning September 7 and ending September 13
2 of each year is designated as “Duchenne Muscular Dystrophy
3 Awareness Week” to raise public awareness of Duchenne Muscular
4 Dystrophy, to educate health care professionals and parents about
5 the condition, help improve early diagnosis and treatment for the
6 disease, to improve the quality of life of all people affected by
7 Duchenne Muscular Dystrophy, and to encourage further research
8 into treatments for the disease.

2. The Governor is respectfully requested to issue a proclamation recognizing “Duchenne Muscular Dystrophy Awareness Week” in New Jersey, and calling upon public officials and the citizens of this State to observe the week with appropriate activities and programs.

16 3. This joint resolution shall take effect immediately.

STATEMENT

21 This joint resolution designates September 7 through 13 of each
22 year as “Duchenne Muscular Dystrophy Awareness Week,” to raise
23 public awareness of Duchenne Muscular Dystrophy, to educate
24 health care professionals and parents about the condition, help
25 improve early diagnosis and treatment for the disease, to improve
26 the quality of life of all people affected by Duchenne Muscular
27 Dystrophy, and to encourage further research into treatments for the
28 disease. This week includes two significant dates: World Duchenne
29 Day on September 7, and the date on which Jamesy Raffone was
30 diagnosed with Duchenne muscular dystrophy, leading his parents
31 to found JAR of Hope, a New Jersey charity focused on Duchenne
32 muscular dystrophy.