

SENATE JOINT RESOLUTION

No. 24

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED JANUARY 27, 2020

Sponsored by:

Senator SAMUEL D. THOMPSON

District 12 (Burlington, Middlesex, Monmouth and Ocean)

Senator THOMAS H. KEAN, JR.

District 21 (Morris, Somerset and Union)

SYNOPSIS

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

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 3/5/2020)

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 can be carried
22 by females, who normally do not show any symptoms of the
23 disease, but can pass it along to their children; and
24 **WHEREAS**, Genetic counseling is advised for people with a family
25 history of this disease, and genetic testing can detect the gene that
26 causes Duchenne muscular dystrophy in approximately 95 percent
27 of cases; and
28 **WHEREAS**, Scientists and donors around the world are conducting
29 intense research to develop new treatments for Duchenne muscular
30 dystrophy, including research into new drug treatments, gene
31 therapy, muscle regeneration, stem cell transplantation, and more;
32 and
33 **WHEREAS**, A worldwide coalition of Duchenne patient and parent
34 organizations, United Parent Projects Muscular Dystrophy,
35 recognizes World Duchenne Day on September 7 of each year in
36 countries all over the world; and
37 **WHEREAS**, A New Jersey charity focused on Duchenne muscular
38 dystrophy, JAR of Hope, was founded after Jim and Karen Raffone
39 learned of their son’s diagnosis on September 13, 2013; and
40 **WHEREAS**, The State of New Jersey can support these efforts to raise
41 awareness of Duchenne Muscular Dystrophy and to raise funding to
42 support research into treatments and an eventual cure for the
43 disease by annually honoring and joining in their work; now,
44 therefore,
45
46 **BE IT RESOLVED** *by the Senate and General Assembly of the*
47 *State of New Jersey:*

3. This joint resolution shall take effect immediately.

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