

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 142 Session of 2011

INTRODUCED BY CALTAGIRONE, SANTONI, GILLEN, REICHLEY, MARSICO, BAKER, BEAR, BRADFORD, BRENNAN, BROOKS, BROWNLEE, CLYMER, COHEN, D. COSTA, CREIGHTON, CUTLER, DeLUCA, DIGIROLAMO, DONATUCCI, FLECK, GEIST, GEORGE, GINGRICH, GOODMAN, GRELL, GROVE, HARHART, HENNESSEY, HESS, HORNAMAN, KAVULICH, KORTZ, KOTIK, MAHONEY, MAJOR, MANN, MILLARD, MILNE, MOUL, MURT, MUSTIO, M. O'BRIEN, O'NEILL, PAYNE, QUINN, READSHAW, ROCK, ROSS, SAINATO, SONNEY, STABACK, SWANGER, VEREB, VULAKOVICH AND WHITE, MARCH 17, 2011

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, MARCH 17, 2011

A RESOLUTION

1 Designating the week beginning May 23, 2011, as "Duchenne
2 Muscular Dystrophy Awareness Week" in Pennsylvania.

3 WHEREAS, Duchenne Muscular Dystrophy is the most common and
4 devastating form of Muscular Dystrophy that affects about one in
5 3,600 male infants; and

6 WHEREAS, Duchenne Muscular Dystrophy appears between the ages
7 of two and six years and as early as infancy, affecting
8 approximately 400 to 600 young boys born with this condition
9 each year, each of which being deprived of the opportunity of a
10 full and vibrant life; and

11 WHEREAS, The Duchenne Muscular Dystrophy gene provides the
12 blueprints for the protein Dystrophin, a protein found in the
13 muscles, which functions in keeping the muscles intact and
14 strong as they contract and relax; and

1 WHEREAS, The Dystrophin gene is found in every muscle of the
2 body but more prominently seen in the skeletal and cardiac
3 muscles which, respectively, are primarily used for bodily
4 movement and heart functions leading to rapidly worsening muscle
5 weakness and heart conditions; and

6 WHEREAS, As this disease worsens, the afflicted child
7 experiences chronic fatigue, falling, difficulty with motor
8 skills such as running, jumping and hopping and rapidly
9 worsening weakness, particularly in the legs, pelvis, arms and
10 neck; and

11 WHEREAS, Between the ages of nine and 13 years, most boys
12 require a motorized wheelchair to get around because they have
13 lost all ability and strength to move and function on their own;
14 and

15 WHEREAS, Duchenne Muscular Dystrophy is 100% fatal, with life
16 expectancy in the mid 20's, due to lung or heart complications;
17 and

18 WHEREAS, No cure has been found for Duchenne Muscular
19 Dystrophy; and

20 WHEREAS, To control symptoms and slow the progression of
21 muscle weakness, the typical drug is corticosteroid, which helps
22 the muscle but has a number of negative side effects on
23 patients; and

24 WHEREAS, Drug companies will not sponsor corticosteroid for
25 trial; and

26 WHEREAS, Devices such as leg braces are used to maximize
27 quality of life; and

28 WHEREAS, "Duchenne Muscular Dystrophy Awareness Week"
29 provides an opportunity for families and young boys whose lives
30 have been significantly altered to celebrate life and an

1 opportunity for everyone to honor them as they deal with the
2 daily struggles that are encountered, to honor those health
3 professionals dedicated to helping those who are suffering and
4 to let them all be aware that they are not alone in this
5 challenge; and

6 WHEREAS, Establishing "Duchenne Muscular Dystrophy Awareness
7 Week" will also provide the opportunities for families to share
8 in their experience with the public and to raise public
9 awareness that Duchenne Muscular Dystrophy should receive the
10 public and medical attention that is deserved; therefore be it

11 RESOLVED, That the House of Representatives designate the
12 week beginning May 23, 2011, as "Duchenne Muscular Dystrophy
13 Awareness Week" in Pennsylvania; and be it further

14 RESOLVED, That the House of Representatives encourage all
15 citizens to increase awareness, education and services for
16 Duchenne Muscular Dystrophy, which each year affects thousands
17 of young boys and their families.