

SENATE JOINT RESOLUTION

No. 49

STATE OF NEW JERSEY

218th LEGISLATURE

INTRODUCED FEBRUARY 5, 2018

Sponsored by:

Senator ANTHONY M. BUCCO

District 25 (Morris and Somerset)

Senator ANTHONY R. BUCCO

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SYNOPSIS

Designates last full week in October of each year as “Hypophosphatasia Awareness Week.”

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 10/25/2019)

1 **A JOINT RESOLUTION** designating the last full week in October of
2 each year as “Hypophosphatasia Awareness Week.”
3
4 **WHEREAS**, Hypophosphatasia is a rare inherited metabolic disorder
5 that affects the healthy development of bones and teeth by
6 disrupting the body’s production of a critical bone-mineralization
7 enzyme, resulting in the weakening and softening of bones and
8 teeth; and
9 **WHEREAS**, Severe hypophosphatasia affects an estimated one in
10 100,000 infants, with a 50 percent mortality rate during the first six
11 months following birth, and with the most severe cases resulting in
12 stillbirth; and
13 **WHEREAS**, Milder forms of hypophosphatasia can also appear in later
14 childhood or adulthood; and
15 **WHEREAS**, Hypophosphatasia causes painful and potentially life-
16 threatening symptoms such as: skeletal abnormalities, soft skull
17 bones or abnormal skull shape, respiratory problems, high levels of
18 calcium in the blood, poor appetite and weight gain, recurrent
19 vomiting, kidney problems, early loss of primary (baby) teeth, loss
20 of secondary (adult) teeth, abnormally shaped chest, shortened or
21 bowed limbs, enlarged wrist and ankle joints, recurrent foot and
22 thigh bone fractures, and chronic pain and inflammation; and
23 **WHEREAS**, The National Institutes of Health has categorized
24 hypophosphatasia as a “rare disease,” which is any disease or
25 condition that affects fewer than 200,000 persons in the United
26 States; and
27 **WHEREAS**, As with many other rare diseases, hypophosphatasia
28 currently has no cure or proven medical therapy, although treatment
29 approaches, such as enzyme replacement therapy and bone marrow
30 transplantation therapy, are currently being studied; and
31 **WHEREAS**, Research related to rare diseases such as hypophosphatasia
32 is often limited because such small patient populations offer fewer
33 market incentives for developing effective drugs and medical
34 treatments; and
35 **WHEREAS**, Besides struggling with serious medical problems and
36 inadequate or no treatment, patients with hypophosphatasia may be
37 frequently undiagnosed or misdiagnosed as having rickets,
38 osteoporosis, periodontal disease, or other conditions; and
39 **WHEREAS**, Organizations across the world observe “Bone and Joint
40 National Awareness Week” every October to educate patients,
41 families, and health care providers about the many bone and joint
42 disorders, to encourage support for patients and families who are
43 living with these disorders, and to spotlight innovations regarding
44 prevention, management, and treatment; and
45 **WHEREAS**, It is appropriate that New Jersey support the efforts made
46 to combat hypophosphatasia by recognizing the last full week in
47 October as “Hypophosphatasia Awareness Week” to raise
48 awareness of this rare bone disease, to call attention to the

1 challenges associated with diagnosing and treating this disease, to
2 encourage support for patients, families, and caregivers affected by
3 the disease, and to promote further research into the disease and its
4 treatment; now, therefore,

5
6 **BE IT RESOLVED** *by the Senate and General Assembly of the*
7 *State of New Jersey:*

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9 1. The last full week in October of each year shall be
10 designated as “Hypophosphatasia Awareness Week” to raise public
11 awareness of hypophosphatasia and to encourage support for
12 patients, families, and caregivers affected by this rare bone disease.

13
14 2. The Governor is requested to annually issue a proclamation
15 recognizing the last full week in October as "Hypophosphatasia
16 Awareness Week" in New Jersey and to call upon public officials
17 and the citizens of this State to observe the week with appropriate
18 activities and programs.

19
20 3. This joint resolution shall take effect immediately.

21
22
23 STATEMENT

24
25 This resolution would declare the last full week in October as
26 “Hypophosphatasia Awareness Week” in New Jersey to raise public
27 awareness of hypophosphatasia and to encourage support for
28 patients, families, and caregivers affected by this rare bone disease.

29 Hypophosphatasia is an inherited disorder that affects the healthy
30 development of bones and teeth. Hypophosphatasia’s most severe
31 forms affect an estimated one in 100,000 newborns. However, the
32 disease and its milder forms may appear in later childhood or
33 adulthood. Patients with this disease may experience painful and
34 potentially life-threatening symptoms, including skeletal
35 abnormalities, respiratory and kidney problems, loss of teeth,
36 recurrent bone fractures, and chronic pain.

37 Hypophosphatasia, like other rare diseases, currently has no cure
38 or proven medical therapy. Patients with hypophosphatasia may be
39 frequently misdiagnosed or undiagnosed and may need to cope with
40 inadequate or no treatment, due to limited research. Raising public
41 awareness of hypophosphatasia may help patients, families, and
42 caregivers obtain better information about the disease and make
43 better decisions about care. Raising public awareness may also help
44 promote further research into the disease and its treatment.