

SENATE JOINT RESOLUTION

No. 50

STATE OF NEW JERSEY

218th LEGISLATURE

INTRODUCED FEBRUARY 5, 2018

Sponsored by:

Senator ANTHONY R. BUCCO

District 25 (Morris and Somerset)

SYNOPSIS

Designates last full week of May of each year as “Osteopetrosis Awareness Week” and last Saturday of May of each year as “Osteopetrosis Awareness Day.”

CURRENT VERSION OF TEXT

As introduced.



1 **A JOINT RESOLUTION** designating the last full week of May of each
2 year as “Osteopetrosis Awareness Week” and the last Saturday
3 of May of each year as “Osteopetrosis Awareness Day.”
4

5 **WHEREAS**, Osteopetrosis is a rare, congenital bone disorder that
6 causes bones to be overly dense and prone to breaking due to an
7 imbalance in the bone remodeling process that allows for new bone
8 to be created but not for old bone to be removed; and

9 **WHEREAS**, Osteopetrosis is categorized into three forms: malignant
10 infantile osteopetrosis (MIOP), the most severe form of the disorder
11 with the lowest life expectancy rates and often identified shortly
12 after birth; adult osteopetrosis, far milder than MIOP and diagnosed
13 from adolescence through adulthood; and intermediate
14 osteopetrosis, often considered a severe case of the adult form of
15 the disorder and found in children younger than 10; and

16 **WHEREAS**, Mild cases of osteopetrosis may cause no symptoms or
17 problems, while severe cases of the disorder are life threatening and
18 can impact the entire body; and

19 **WHEREAS**, In severe cases, osteopetrosis can lead to stunted growth,
20 painful deformity, and increased risk of fractures due to the creation
21 of dense, brittle bones; vision loss, hearing loss, and paralysis of
22 facial muscles due to compression of the nerves in the skull; and
23 anemia and lowered immunity due to crowding of bone marrow and
24 the inefficient production of blood cells and platelets; and

25 **WHEREAS**, The adult form of osteopetrosis affects approximately
26 1,250 people in the United States, while only eight to 40 children
27 are born in the country with MIOP each year; and

28 **WHEREAS**, As with many rare diseases, there is much to understand
29 about osteopetrosis and how to treat those affected, yet research is
30 limited because such a small patient population offers fewer market
31 incentives for developing effective drugs and medical treatments;
32 and

33 **WHEREAS**, The United States Food and Drug Administration has
34 approved only one drug, interferon gamma-1b, designed
35 specifically to delay the progression of osteopetrosis; and

36 **WHEREAS**, For cases of MIOP, a bone marrow transplant is currently
37 the only treatment to completely stop bone and bone marrow
38 abnormalities and to prolong survival; however, an appropriately
39 matched donor is usually available for only 50 percent of those
40 affected and engraftment is successful in about 45 percent of
41 transplants; and

42 **WHEREAS**, Franklin Township, New Jersey is honored to be the
43 headquarters of The OsteoPETrosis Society, a non-profit
44 organization that provides education and support to patients,
45 caregivers, and medical professionals who are dealing with
46 osteopetrosis, while also supporting research aimed at identifying
47 additional treatment and a cure for the disorder; and

1 **WHEREAS**, It is appropriate that New Jersey encourages public
2 awareness of this rare bone disorder and recognizes the last full
3 week of May of each year as “Osteopetrosis Awareness Week”
4 and the last Saturday of May of each year as “Osteopetrosis
5 Awareness Day” in order to call attention to the challenges of
6 treating this disorder; to encourage support for patients, families,
7 and caregivers affected by this disorder; and to promote further
8 research into this disorder and its treatment; now, therefore,

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10 **BE IT RESOLVED** *by the Senate and General Assembly of the*
11 *State of New Jersey:*

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13 1. The last full week of May of each year shall be designated as
14 “Osteopetrosis Awareness Week” and the last Saturday of May of
15 each year shall be designated “Osteopetrosis Awareness Day” to
16 raise public awareness of osteopetrosis, to encourage support for
17 patients and families affected by osteopetrosis, and to promote
18 further research into osteopetrosis and its treatment.

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20 2. The Governor is requested to annually issue a proclamation
21 calling upon public officials and citizens of this State to observe
22 “Osteopetrosis Awareness Week” and “Osteopetrosis Awareness
23 Day” with appropriate activities and programs.

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25 3. This resolution shall take effect immediately.

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STATEMENT

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30 This resolution would designate the last full week of May of
31 each year as “Osteopetrosis Awareness Week” and the last Saturday
32 of May of each year as “Osteopetrosis Awareness Day” to raise
33 public awareness of this rare bone disorder; to call attention to the
34 challenges of treating this disorder; to encourage support for
35 patients, families, and caregivers affected by this disorder; and to
36 promote further research into this disorder and its treatment.

37 Osteopetrosis is a rare, congenital bone disorder that causes
38 bones to be overly dense and prone to breaking. The disorder is
39 caused by an imbalance in the bone remodeling process that allows
40 for new bone to be created but not for old bone to be removed.
41 Osteopetrosis ranges from a mild, symptom free adult form to a
42 severe, life threatening infant form known as Malignant Infant
43 Osteopetrosis, or MIOP.

44 In severe cases, symptoms can lead to stunted growth, painful
45 deformity, and bone fractures due to the presence of dense, brittle
46 bones. Vision loss, hearing loss, and paralysis of facial muscles
47 may also occur as the dense bone compresses nerves in the skull. In
48 addition, dense bone can crowd bone marrow and cause the

1 inefficient production of blood cells and platelets, leading to anemia
2 and lowered immunity.

3 There is much to understand about osteopetrosis and how to treat
4 those affected. The United States Food and Drug Administration
5 has approved only one drug, interferon gamma-1b, designed
6 specifically to delay the progression of osteopetrosis. Currently, for
7 cases of MIOP, a bone marrow transplant is the only treatment to
8 completely stop bone and bone marrow abnormalities and to
9 prolong survival; however, there are several challenges to this
10 treatment. First, finding an appropriately matched donor is usually
11 available for only 50 percent of those affected. With a donor found,
12 engraftment is successful in about 45 percent of transplants. In
13 addition, a bone marrow transplant cannot reverse any existing
14 damage caused by the disorder.

15 The efforts of The OsteoPETrosis Society, located in Asbury,
16 New Jersey, provide education and support to patients, caregivers,
17 and medical professionals who are dealing with osteopetrosis, while
18 also supporting research aimed at identifying additional treatment
19 and a cure for the disorder. Increasing public awareness will
20 contribute to The OsteoPETrosis Society's mission and may
21 promote further research into the disorder and its treatment.