



HR0614

LRB098 14430 GRL 49116 r

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HOUSE RESOLUTION

2 WHEREAS, In the United States, a disease is considered rare
3 if it is believed to affect fewer than 200,000 Americans;
4 according to the National Institutes of Health, there are
5 approximately 6,800 diseases classified as rare; while each
6 disease is rare, when considered together, they affect nearly
7 30 million Americans or almost 1 in 10 people; there are
8 certain challenges that all patients and families affected by
9 rare diseases share; and

10 WHEREAS, Hypophosphatasia, or HPP, is a rare, inherited
11 disease known for its impact on bones and teeth; with almost
12 all forms of hypophosphatasia, bones become soft because they
13 cannot absorb important minerals like calcium and phosphorous;
14 in some people, this can cause problems with bone growth and
15 strength and lead to broken bones and bone pain; and

16 WHEREAS, An estimated 1 in 100,000 newborns have
17 hypophosphatasia; milder cases may be more common in children
18 and adults; it is currently unknown how many people have
19 hypophosphatasia and have not been diagnosed with the disease;
20 and

21 WHEREAS, The genes for hypophosphatasia are passed from
22 parents to their children; one or both parents may pass along

1 the abnormal gene that causes hypophosphatasia; a person can
2 inherit the disease by receiving 1 abnormal gene that causes
3 hypophosphatasia from only one parent; when a person receives
4 an abnormal gene from each parent, the disease may be more
5 severe; hypophosphatasia rarely occurs in a person if neither
6 parent has the abnormal gene that causes the disease; and

7 WHEREAS, Research suggests that some people with
8 hypophosphatasia may experience worse symptoms over time;
9 these symptoms can affect parts of the body beyond the bones
10 and teeth, including the brain, kidneys, and muscles;
11 hypophosphatasia can appear anytime throughout a person's
12 life; and

13 WHEREAS, Every person afflicted with hypophosphatasia
14 experiences symptoms differently; the signs and symptoms of
15 hypophosphatasia vary from one person to another, with bones
16 and teeth most often affected; bones can be weakened, which may
17 result in fractures; baby teeth can fall out earlier than
18 normal and adult teeth can be affected as well; in a recent
19 combined review of two studies of people who have
20 hypophosphatasia, 1 in 8 people had severe bone pain, 1 in 8
21 had joint pain, and more than 1 in 5 people had muscle pain;
22 and

23 WHEREAS, Hypophosphatasia is a rare disease that doctors

1 may not even know about; by raising awareness and educating the
2 public on this rare disease, diagnosis and treatments may be
3 prescribed earlier in the process; therefore, be it

4 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
5 NINETY-EIGHTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that
6 we designate October 30, 2013 as Illinois Hypophosphatasia
7 Awareness Day in conjunction with HPP Awareness Week on October
8 20-26, 2013 to raise awareness, support, and recognition of
9 people with hypophosphatasia across the State.