

2014 -- S 2402

=====
LC004919
=====

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2014

SENATE RESOLUTION

PROCLAIMING FEBRUARY 28TH, 2014 TO BE "RARE DISEASE DAY" IN THE STATE
OF RHODE ISLAND

Introduced By: Senators Doyle, Nesselbush, Paiva Weed, Lombardi, and Crowley

Date Introduced: February 26, 2014

Referred To: Recommended for Immediate Consideration

1 WHEREAS, In 2008, the first annual Rare Disease Day was organized to raise awareness
2 and draw attention to rare diseases as an important public health issue. By 2013, more than 70
3 countries participated in the observance of this day; and

4 WHEREAS, A rare disease, also referred to as an orphan disease, is any disorder that
5 affects a small percentage of the population. There are nearly 7,000 diseases that are considered
6 rare, with each one affecting fewer than 200,000 Americans; and

7 WHEREAS, Nearly 30 million Americans currently live with and are affected by a rare
8 disease; and

9 WHEREAS; About 80 percent of rare diseases are genetic in origin and it is estimated
10 that about half of all rare diseases affect children; and

11 WHEREAS, While some rare diseases, such as Lou Gehrig's disease (ALS), are fairly
12 well known, many others are not. Many of these orphan diseases are almost completely
13 unknown, have virtually no treatments available, and are not even being studied by any medical
14 researchers; and

15 WHEREAS, Many rare diseases are serious, chronic, and debilitating. Many are life-
16 threatening and many are deadly; and

17 WHEREAS, By supporting policies and practices that promote innovative research and
18 the development of new treatments, we can reduce mortality, provide access to higher standards
19 of care, help break the isolation of the people living with rare diseases, and give more survivors

1 the ability to live independently and have a better quality of life and; now, therefore be it

2 RESOLVED, That this Senate of the State of Rhode Island and Providence Plantations
3 hereby commemorates "Rare Disease Day" on February 28, 2014. We furthermore urge patients,
4 patient organizations, health professionals, researchers, drug developers, public health authorities
5 and the citizens of the state to join together to focus on finding treatments, offering hope, and
6 "show you care about rare"; and be it further

7 RESOLVED, That the Secretary of State be and hereby is authorized and directed to
8 transmit a duly certified copy of this resolution to the Rhode Island Rare Disease Foundation.

=====
LC004919
=====