
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 295 Session of
2015

INTRODUCED BY COSTA, MARCH 14, 2016

INTRODUCED AND ADOPTED, MARCH 14, 2016

A RESOLUTION

1 Recognizing February 29, 2016, as "Rare Disease Day" in
2 Pennsylvania.

3 WHEREAS, According to the National Institutes of Health,
4 there are approximately 7,000 diseases and conditions considered
5 rare, each affecting fewer than 200,000 Americans, in the United
6 States; and

7 WHEREAS, While each of these diseases may affect small
8 numbers of people, rare diseases as a group affect almost 30
9 million Americans; and

10 WHEREAS, Many rare diseases are serious and debilitating
11 conditions that have a significant impact on the lives of those
12 affected; and

13 WHEREAS, While more than 450 drugs and biologics have been
14 approved for the treatment of rare diseases, according to the
15 Federal Food and Drug Administration, millions of Americans
16 still have rare diseases for which there is no approved
17 treatment; and

18 WHEREAS, Individuals and families affected by rare diseases

1 often experience problems such as diagnosis delay, difficulty
2 finding a medical expert and lack of access to treatments or
3 ancillary services; and

4 WHEREAS, While some rare diseases, such as Amyotrophic
5 Lateral Sclerosis, commonly known as Lou Gehrig's disease, are
6 relatively well known, many others are not known at all by the
7 public, which leaves patients and their families to bear a large
8 share of the burden of funding research and raising public
9 awareness to support the search for treatments; and

10 WHEREAS, Thousands of Pennsylvanians are among those affected
11 by rare diseases since approximately one in ten Americans have
12 rare diseases; and

13 WHEREAS, The National Organization for Rare Disorders
14 organized a nationwide observance of "Rare Disease Day" on
15 February 29, 2016; and

16 WHEREAS, Thousands of patients, caregivers, medical
17 professionals, researchers, government officials, companies
18 developing treatments for rare diseases and others participated
19 in the observance; therefore be it

20 RESOLVED, That the Senate recognize February 29, 2016, as
21 "Rare Disease Day" in Pennsylvania.