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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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# SENATE RESOLUTION

No. 29 Session of  
2017

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INTRODUCED BY COSTA, FEBRUARY 8, 2017

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INTRODUCED AND ADOPTED, FEBRUARY 8, 2017

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A RESOLUTION

1 Recognizing February 28, 2017, 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 a small  
8 number of people, rare diseases as a group affect approximately  
9 30 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, According to the United States Food and Drug  
14 Administration, more than 450 drugs and biologics have been  
15 approved for the treatment of rare diseases; and

16 WHEREAS, Millions of Americans have rare diseases for which  
17 there is no approved 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, Some rare diseases, such as amyotrophic lateral  
5 sclerosis, commonly referred to as Lou Gehrig's disease, are  
6 relatively well known; and

7 WHEREAS, Other rare diseases are not publicly known, leaving  
8 patients and their families to bear a large share of the burden  
9 of funding research and raising public awareness to support the  
10 search for treatments; and

11 WHEREAS, Thousands of Pennsylvanians are among those affected  
12 by rare diseases since approximately 1 in 10 Americans have rare  
13 diseases; and

14 WHEREAS, The National Organization for Rare Disorders has  
15 organized a nationwide observance of "Rare Disease Day" on  
16 February 28, 2017; and

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

21 RESOLVED, That the Senate recognize February 28, 2017, as  
22 "Rare Disease Day" in Pennsylvania.