

## A RESOLUTION

1 Designating February 28, 2013, as "Rare Disease Day" in  
2 Pennsylvania.

3 WHEREAS, There are nearly 7,000 diseases and conditions  
4 considered rare, each affecting fewer than 200,000 Americans, in  
5 the United States; and

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

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

12 WHEREAS, Of the nearly 7,000 rare diseases identified by the  
13 National Institutes of Health, only about 200 rare diseases have  
14 Food and Drug Administration-approved treatments; and

15 WHEREAS, Individuals and families affected by rare diseases  
16 often experience problems such as a sense of isolation,  
17 difficulty in obtaining an accurate and timely diagnosis, few

1 treatment options and problems related to accessing or being  
2 reimbursed for treatment; and

3 WHEREAS, While some rare diseases, such as Lou Gehrig's  
4 disease and Huntington's disease, are relatively well known,  
5 many others are not known at all by the public, which leaves  
6 patients and their families to bear a large share of the burden  
7 for things such as raising funds for research; and

8 WHEREAS, Thousands of Pennsylvanians are among those affected  
9 by rare diseases since nearly one in ten Americans have rare  
10 diseases; and

11 WHEREAS, The National Organization for Rare Disorders is  
12 organizing a nationwide observance of "Rare Disease Day" on  
13 February 28, 2013, and patients, medical professionals,  
14 researchers, government officials and companies developing  
15 treatments for rare diseases are joining together to focus  
16 attention on rare diseases as a public health issue on that day;  
17 therefore be it

18 RESOLVED, That the House of Representatives designate  
19 February 28, 2013, as "Rare Disease Day" in Pennsylvania.