
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 127 Session of
2015

INTRODUCED BY FARINA, KAVULICH, FLYNN, MURT, READSHAW, BISHOP,
SCHREIBER, SCHLEGEL CULVER, V. BROWN, ROZZI, HELM, KIRKLAND,
MILLARD, COHEN, HARHART, WHEELAND, O'NEILL, McNEILL, MAJOR,
DIGIROLAMO, LONGIETTI, HENNESSEY, FRANKEL, CALTAGIRONE,
BROWNLEE, THOMAS, YOUNGBLOOD, WATSON, ROSS, GINGRICH,
MARSICO, KINSEY, J. HARRIS, SCHWEYER AND SCHLOSSBERG,
FEBRUARY 26, 2015

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
FEBRUARY 26, 2015

A RESOLUTION

1 Designating February 28, 2015, 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

1 often experience problems such as a sense of isolation,
2 difficulty in obtaining an accurate and timely diagnosis, few
3 treatment options and problems related to accessing or being
4 reimbursed for treatment; and

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

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

13 WHEREAS, The National Organization for Rare Disorders is
14 organizing a nationwide observance of "Rare Disease Day" on
15 February 28, 2015, and patients, medical professionals,
16 researchers, government officials and companies developing
17 treatments for rare diseases are joining together to focus
18 attention on rare diseases as a public health issue on that day;
19 therefore be it

20 RESOLVED, That the House of Representatives designate
21 February 28, 2015, as "Rare Disease Day" in Pennsylvania.