
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 84 Session of
2013

INTRODUCED BY HAHN, BAKER, BARRAR, CALTAGIRONE, CAUSER, CLYMER,
SCHLEGEL CULVER, DELUCA, DIGIROLAMO, FLECK, GINGRICH, GROVE,
HARHART, HENNESSEY, HESS, KORTZ, MACKENZIE, MAHONEY, MAJOR,
MICOZZIE, MILLARD, MILNE, O'BRIEN, PICKETT, READSHAW, ROCK,
ROSS, SONNEY, GILLEN, MARSICO AND MURT, FEBRUARY 11, 2013

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
FEBRUARY 11, 2013

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,

1 difficulty in obtaining an accurate and timely diagnosis, few
2 treatment options and problems related to accessing or being
3 reimbursed for treatment; and

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

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

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

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