
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 831 Session of
2018

INTRODUCED BY TOEPEL, LONGIETTI, BIZZARRO, R. BROWN, BURNS,
CALTAGIRONE, CORBIN, SCHLEGEL CULVER, DALEY, DIGIROLAMO,
DONATUCCI, DRISCOLL, DUSH, HAHN, PHILLIPS-HILL, JAMES,
KINSEY, MARSICO, McCLINTON, MILLARD, NEILSON, OBERLANDER,
PASHINSKI, PICKETT, READSHAW, RYAN, SCHLOSSBERG, SCHWEYER,
SONNEY, STAATS, TOOHL, WARD, WARREN, WATSON AND GILLEN,
APRIL 16, 2018

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
APRIL 16, 2018

A RESOLUTION

1 Designating June 19, 2018, as "Rare Disease Day" in
2 Pennsylvania.

3 WHEREAS, There are approximately 1.2 million Pennsylvanians
4 who suffer from rare diseases and there are approximately 7,000
5 rare diseases afflicting nearly 30 million people in the United
6 States; and

7 WHEREAS, Children with rare genetic diseases account for more
8 than half of the population affected by rare diseases in the
9 United States; and

10 WHEREAS, Many rare diseases are serious and life-threatening
11 and lack an effective treatment; and

12 WHEREAS, Rare diseases include epidermolysis bullosa,
13 progeria, sickle cell anemia, Tay-Sachs, cystic fibrosis, many
14 childhood cancers and fibrodysplasia ossificans progressiva; and

15 WHEREAS, Individuals with rare diseases experience challenges

1 that include difficulty in obtaining an accurate diagnosis,
2 limited treatment options and difficulty finding physicians or
3 treatment centers with expertise in their disease; and

4 WHEREAS, Great strides have been made in research and
5 treatment for rare diseases as a result of the Orphan Drug Act;
6 and

7 WHEREAS, The United States Food and Drug Administration and
8 the National Institutes of Health have established special
9 offices to advocate for rare disease research and treatments;
10 and

11 WHEREAS, The National Organization for Rare Disorders is an
12 organization established in 1983 to provide services to patients
13 with rare diseases and advocate on behalf of patients with rare
14 diseases; and

15 WHEREAS, The National Organization for Rare Disorders was a
16 primary force behind the enactment of the Orphan Drug Act and
17 remains a critical public voice for people with rare diseases;
18 and

19 WHEREAS, The National Organization for Rare Disorders
20 sponsors "Rare Disease Day" in the United States to increase
21 public awareness of rare diseases; and

22 WHEREAS, "Rare Disease Day" has become a global event
23 occurring annually on the last day of February; therefore be it

24 RESOLVED, That the House of Representatives designate June
25 19, 2018 as "Rare Disease Day" in Pennsylvania; and be it
26 further

27 RESOLVED, That the House of Representatives join millions of
28 people around the world in observing "Rare Disease Day" and
29 finding ways to work together to provide the different kinds of
30 care that people living with a rare disease need.