
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 316 Session of
2019

INTRODUCED BY TOEPEL, LONGIETTI, SCHMITT, HOHENSTEIN, ISAACSON
AND WARREN, MAY 6, 2019

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
MAY 6, 2019

A RESOLUTION

1 Designating May 7, 2019, as "Rare Disease Day" in Pennsylvania.

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

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

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

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

14 WHEREAS, Individuals with rare diseases experience challenges
15 that include difficulty in obtaining an accurate diagnosis,
16 limited treatment options and difficulty finding physicians or
17 treatment centers with expertise in their disease; and

1 WHEREAS, Great strides have been made in research and
2 treatment for rare diseases as a result of the Orphan Drug Act;
3 and

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

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

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

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

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

21 RESOLVED, That the House of Representatives designate May 7,
22 2019, as "Rare Disease Day" in Pennsylvania; and be it further

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