
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 135 Session of
2019

INTRODUCED BY J. WARD AND BLAKE, MAY 8, 2019

INTRODUCED AND ADOPTED, MAY 8, 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

18 WHEREAS, Great strides have been made in research and

1 treatment for rare diseases as a result of the Orphan Drug Act;
2 and

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

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

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

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

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

20 RESOLVED, That the Senate designate May 7, 2019, as "Rare
21 Disease Day" in Pennsylvania; and be it further

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