



## National Lieutenant Governors Association

### 1           **Resolution Recognizing The Last Day of February as *Rare Disease Day***

2   **WHEREAS**, a rare disease or disorder is a disease or disorder that affects a small number of patients,  
and

3   **WHEREAS**, in the United States, a rare disease or disorder affects fewer than 200,000 individuals, and

4   **WHEREAS**, more than 7,000 rare diseases or disorders affect more than 30 million individuals in the  
5   United States<sup>1</sup>, and

6   **WHEREAS**, children with rare diseases or disorders account for a significant portion of the population  
7   affected by rare diseases or disorders in the United States, and

8   **WHEREAS**, many rare diseases and disorders are serious and life-threatening and lack effective  
9   treatments, and

10   **WHEREAS**, although the Food and Drug Administration has approved more than 1,000 orphan  
11   indications for drugs and biological products for the treatment of rare diseases and disorders, 95 percent  
12   of rare diseases do not have an FDA-approved treatment for their condition<sup>2</sup>, and

13   **WHEREAS**, limited treatment options, access barriers, and difficulty obtaining reimbursement for life-  
14   altering and lifesaving treatments can be challenging for individuals with rare diseases or disorders and  
15   their families, and

16   **WHEREAS**, individuals with rare diseases or disorders can experience difficulty in obtaining accurate  
17   diagnoses and finding physicians or treatment centers with expertise in their rare disease or disorder, and

18   **WHEREAS**, “Rare Disease Day” is observed each year on the last day of February, and in 2022, 106  
19   countries recognized Rare Disease Day globally, providing hope and information for rare disease and  
20   disorder patients around the world.

21   **WHEREAS**, states and territories can increase awareness for rare diseases and disorders and support the  
22   families coping with rare diseases by recognizing “Rare Disease Day” annually.

23   **NOW, THEREFORE, BE IT RESOLVED** that the National Lieutenant Governors Association  
24   recognizes the last day of February as “Rare Disease Day” each year.

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<sup>1</sup> Rare Diseases at FDA, <https://www.fda.gov/patients/rare-diseases-fda>

<sup>2</sup> National Organization for Rare Disorders, <https://rarediseases.org/wp-content/uploads/2019/01/RDD-FAQ-2019.pdf>



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25 **BE IT FURTHER RESOLVED** that the NLGA recognizes the importance of increasing awareness of  
26 rare diseases and disorders, encouraging early and accurate diagnoses, and supports national and global  
27 efforts to develop effective treatments, diagnostics, and cures for rare diseases and disorders.

ADOPTED, this day, the 22<sup>nd</sup> of July, 2022.

Sponsors: Lt. Governor Pamela Evette (R – South Carolina), Lt. Governor John Fetterman (D – Pennsylvania),  
Lt. Governor Randy McNally (R – Tennessee), Lt. Governor Billy Nungesser (R – Louisiana)