

MOTION BY SUPERVISOR JANICE HAHN

February 27, 2024

Proclaim February 29, 2024 as “Rare Disease Day” in Los Angeles County

A disease or disorder is defined as rare in the United States when it affects fewer than 200,000 people. According to the National Institutes of Health, there may be as many as 7,000 diseases and conditions that are considered rare in the United States, affecting an estimated 25-30 million Americans. Some diseases that fall into this category include Sickie Cell Anemia, Behcet’s Disease, and Duchenne Muscular Dystrophy. Many rare diseases can result in the premature death of infants or can be fatal in early childhood. All pediatric cancers are considered rare diseases.

For people of all ages, common symptoms of these types of conditions can often hide underlying rare diseases leading to misdiagnosis and delayed treatment. According to the American Behcet’s Association, “This delay in diagnosis can significantly impact treatment outcomes for patients. Research and development for rare diseases do not receive as much attention or funding as more common conditions, in turn, individuals with rare diseases and their families feel isolated due to the rarity of their condition.” There is often no effective cure for or understanding of the exact cause of rare diseases, which

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adds to the high level of pain and suffering endured by patients and their families. Additionally, these patients and their families bear a large share of the burden to fund research and raise public awareness for these rare diseases. In an effort to increase awareness, the National Organization for Rare Disorders is organizing a nationwide observance of Rare Disease Day on the last day of February, the most-rare day on the calendar.

I, THEREFORE, MOVE that the Board of Supervisors:

- 1) Proclaim February 29, 2024 as “Rare Disease Day” in Los Angeles County to help raise awareness and improve knowledge of rare diseases amongst the general public;
- 2) Encourage all Los Angeles County employees and residents to learn more about Rare Disease Day by visiting <https://www.rarediseaseday.org/>.

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