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LRB-5751/1 CMH:skw

2021 ASSEMBLY RESOLUTION 24

January 21, 2022 - Introduced by Representatives Dittrich, Mursau, Sinicki, Shankland, Magnafici, Cabrera, L. Myers, Shelton, Subeck, Hintz, Loudenbeck, Cabral-Guevara and Duchow. Referred to Committee on Rules.

1 **Relating to:** observing February 28, 2022, as Rare Disease Day in Wisconsin. 2 Whereas, there are nearly 7,000 diseases and conditions considered rare (each 3 affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH); and 4 5 Whereas, while each of these diseases may affect small numbers of people, rare 6 diseases as a group affect approximately 25 to 30 million Americans; and 7 Whereas, many rare diseases are serious and debilitating conditions that have 8 a significant impact on the lives of those affected; and 9 Whereas, while more than 800 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), 10 11 millions of Americans still have rare diseases for which there is no approved 12 treatment; and Whereas, individuals and families affected by rare diseases often experience 13

problems such as diagnosis delay, difficulty finding a medical expert, and lack of

access to treatments or ancillary services; and

Whereas, while the public is familiar with some rare diseases, many patients
and families affected by less widely known rare diseases bear a large share of the
burden of funding research and raising public awareness to support the search for
treatments; and
Whereas, residents of Wisconsin are among those affected by rare diseases
because nearly one in 10 Americans have rare diseases; and
Whereas, the National Organization for Rare Disorders (NORD) is organizing
a nationwide observance of Rare Disease Day on February 28, 2022; now, therefore,
be it
Resolved by the assembly, That February 28, 2022, will be observed as Rare
Disease Day in Wisconsin.

(END)