

2023 Assembly Joint Resolution 111

## **ENROLLED JOINT RESOLUTION**

Relating to: observing February 29, 2024, as Rare Disease Day in Wisconsin.

Whereas, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH); and

Whereas, while each of these diseases may affect small numbers of people, rare diseases as a group affect approximately 25 to 30 million Americans; and

Whereas, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

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), millions of Americans still have rare diseases for which there is no approved treatment; and

Whereas, individuals and families affected by rare diseases often experience 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 29, 2024; now, therefore, be it

*Resolved by the assembly, the senate concurring, That* February 29, 2024, will be observed as Rare Disease Day in Wisconsin.

Senator Chris Kapenga President of the Senate Representative Robin J. Vos Speaker of the Assembly

Edward A. Blazel Assembly Chief Clerk

Date