HOUSE RESOLUTION NO.44

Reps. Morgan, Alexander, Arbit, Bierlein, Fitzgerald, Glanville, Morse, Weiss, Wilson and Young offered the following resolution:

- 1 A resolution to declare February 28, 2023, as Rare Disease Day 2 in the state of Michigan.
- 3 Whereas, There are approximately 7,000 diseases and conditions
- 4 considered rare (each affecting fewer than 200,000 Americans in the
- 5 United States), according to the National Institutes of Health
- **6** (NIH); and
- 7 Whereas, While each of these diseases may affect small numbers
- 8 of people, rare diseases as a group affect almost 30 million
- 9 Americans and thousands of Michigan residents; and
- 10 Whereas, Many rare diseases are chronic, progressive, and
- 11 debilitating, significantly impacting the lives of those affected;
- **12** and

Whereas, While more than 800 drugs and biologics have been 1 2 approved by the Food and Drug Administration (FDA) for the treatment of rare diseases, millions of Americans have rare 3 diseases for which no treatments are available; and 4 5 Whereas, Individuals and families affected by rare diseases 6 often experience challenges such as diagnostic delay, difficulty 7 finding medical experts, and lack of access to treatments or 8 ancillary services; and 9 Whereas, The rare disease community is often underrepresented 10 in funding, research, clinical trials, and advocacy efforts, with much of the burden to raise public awareness and support placed on 11 12 those affected; and Whereas, The National Organization for Rare Disorders (NORD) 13 14 is organizing a nationwide observance of Rare Disease Day on 15 February 28, 2023; and 16 Whereas, Thousands of patients, caregivers, medical professionals, researchers, pharmaceutical companies, and others in 17 18 Michigan will participate in this observance; now, therefore, be it Resolved by the House of Representatives, That the members of 19

this legislative body declare February 28, 2023, as Rare Disease

Day in the state of Michigan.

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