

HOUSE RESOLUTION NO. 44

Rep. Morgan 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

13 Whereas, While more than 800 drugs and biologics have been

1 approved by the Food and Drug Administration (FDA) for the
2 treatment of rare diseases, millions of Americans have rare
3 diseases for which no treatments are available; and

4 Whereas, Individuals and families affected by rare diseases
5 often experience challenges such as diagnostic delay, difficulty
6 finding medical experts, and lack of access to treatments or
7 ancillary services; and

8 Whereas, The rare disease community is often underrepresented
9 in funding, research, clinical trials, and advocacy efforts, with
10 much of the burden to raise public awareness and support placed on
11 those affected; and

12 Whereas, The National Organization for Rare Disorders (NORD)
13 is organizing a nationwide observance of Rare Disease Day on
14 February 28, 2023; and

15 Whereas, Thousands of patients, caregivers, medical
16 professionals, researchers, pharmaceutical companies, and others in
17 Michigan will participate in this observance; now, therefore, be it

18 Resolved by the House of Representatives, That the members of
19 this legislative body declare February 28, 2023, as Rare Disease
20 Day in the state of Michigan.