

1 A RESOLUTION declaring February 27, 2020, to be Kentucky Rare Disease Day.

2 WHEREAS, a rare disease, sometimes called an orphan disease, is defined in the  
3 United States as a disease that affects fewer than 200,000 people; and

4 WHEREAS, there are over 6,000 known rare diseases affecting approximately 30  
5 million men, women, and children in the United States; and

6 WHEREAS, 1 in 20 will live with a rare disease at some point in his or her life,  
7 with 70 percent of genetic rare diseases beginning in childhood; and

8 WHEREAS, while the exact cause for many rare diseases remains unknown, 72  
9 percent of rare diseases are genetic in origin and can be linked to mutations in a single  
10 gene or in multiple genes which can be passed down from generation to generation; and

11 WHEREAS, challenges for a person who has a rare disease include delays in  
12 obtaining a diagnosis, misdiagnosis, shortages of medical specialists who can provide  
13 treatment, increased medical expenses, and lack of access to therapies and medication  
14 used to treat rare diseases that are not approved by the Federal Food and Drug  
15 Administration for that purpose; and

16 WHEREAS, researchers have made considerable progress in developing diagnostic  
17 tools and treatment protocols and in discovering methods of prevention, but much more  
18 remains to be accomplished in the search and development of new therapeutics; and

19 WHEREAS, the Kentucky Rare Disease Advisory Council was established by the  
20 General Assembly in 2019 to act as the advisory body on rare diseases to the General  
21 Assembly, the Governor, and to all relevant state and private agencies that provide  
22 services to, or are charged with the care of, individuals with rare diseases and to secure  
23 funding for research for the development of new treatments for rare diseases;

24 NOW, THEREFORE,

25 ***Be it resolved by the Senate of the General Assembly of the Commonwealth of***  
26 ***Kentucky:***

27 ➔Section 1. This honorable body declares February 27, 2020, to be Kentucky

- 1 Rare Disease Day.
- 2       ➔Section 2. The Clerk of the Senate is directed to transmit a copy of this
- 3 Resolution to Senator Denise Harper Angel.