

Senate Resolution 106 - Introduced

SENATE RESOLUTION NO. 106

BY BEALL, BOLKCOM, ANDERSON, DVORSKY, DOTZLER, BOWMAN,
PETERSEN, TAYLOR, COURTNEY, GRONSTAL, BERTRAND,
BEHN, BREITBACH, SINCLAIR, JOHNSON, SCHNEIDER,
SEGEBART, GREINER, FEENSTRA, ROZENBOOM, GARRETT,
HOUSER, ZUMBACH, WHITVER, SMITH, ZAUN, MATHIS,
SCHOENJAHN, RAGAN, and BRASE

1 A Resolution recognizing February 28, 2014, as Rare
2 Disease Day in Iowa.

3 WHEREAS, there are nearly 7,000 diseases and
4 conditions that are considered rare in the United
5 States; and

6 WHEREAS, each of these diseases and conditions
7 affect fewer than 200,000 Americans; and

8 WHEREAS, while each of these diseases may affect
9 relatively limited numbers of people, rare diseases as
10 a group affect almost 30 million Americans; and

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

14 WHEREAS, while approximately 340 orphan drugs and
15 biologics have been approved for the treatment of
16 rare diseases affecting between 11 and 14 million
17 people according to the United States Food and Drug
18 Administration, that leaves more than 15 million
19 Americans with rare diseases who have no treatment
20 specific to their disease; and

21 WHEREAS, individuals and families affected by rare
22 diseases often experience problems such as a sense
23 of isolation, difficulty in obtaining an accurate

24 and timely diagnosis, few treatment options, and
25 problems related to accessing or being reimbursed for
26 treatment; and

27 WHEREAS, even though some rare diseases, such as
28 Lou Gehrig's disease and Huntington's disease, are
1 relatively well known, many others are not known at all
2 by the public so that patients and their families must
3 bear a large share of the burden for activities such as
4 raising funds for research; and

5 WHEREAS, thousands of residents of Iowa are among
6 those affected by rare diseases since nearly 1 in 10
7 Americans have rare diseases; and

8 WHEREAS, the National Organization for Rare
9 Disorders, an organization established in 1983,
10 organizes a nationwide observance of Rare Disease
11 Day on the last day in the month of February each
12 year, on which patients, medical professionals,
13 researchers, government officials, and companies
14 developing treatments for rare diseases join together
15 to focus attention on rare diseases as a public health
16 issue; and

17 WHEREAS, Rare Disease Day is anticipated to be
18 observed globally for years to come, providing hope
19 and information for rare disease patients around the
20 world; NOW THEREFORE,

21 BE IT RESOLVED BY THE SENATE, That the Senate
22 recognizes February 28, 2014, as Rare Disease Day in
23 Iowa.