

By: Naishtat

H.R. No. 586

R E S O L U T I O N

1 WHEREAS, There are nearly 7,000 diseases and conditions that
2 are considered rare by medical authorities in the United States,
3 and each year, thousands of Texans are among those whose lives are
4 changed by these diseases; and

5 WHEREAS, A rare disease is defined as one that affects fewer
6 than 200,000 people, but even though a specific disease may afflict
7 only a small number of sufferers, as a group such conditions affect
8 almost 30 million Americans, or nearly one in 10 people in our
9 nation; and

10 WHEREAS, Many rare diseases are serious and debilitating,
11 with a significant impact on the lives of those affected and their
12 families, and more than 15 million Americans have a disease for
13 which there is no specific treatment; and

14 WHEREAS, Individuals and families who face a rare disease
15 often experience a sense of isolation, difficulty in getting an
16 accurate and timely diagnosis, few treatment options, and problems
17 in receiving reimbursement for treatment; moreover, those who are
18 diagnosed with a lesser known disorder often find that they must
19 bear the lion's share of the responsibility for raising awareness
20 as well as for raising funds for research toward a possible
21 treatment or cure; and

22 WHEREAS, The National Organization for Rare Disorders (NORD)
23 is sponsoring a nationwide observance of Rare Disease Day, when
24 patients, medical professionals, researchers, government

1 officials, and companies developing treatments can join together to
2 focus attention on rare diseases as a public health issue; now,
3 therefore, be it

4 RESOLVED, That the House of Representatives of the 83rd Texas
5 Legislature hereby recognize February 28, 2013, as Rare Disease Day
6 and call on all Texans to learn more about this matter of serious
7 concern.