

1 HJR95
2 149432-1
3 By Representative Rich
4 RFD: Rules
5 First Read: 26-FEB-13

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8 DESIGNATING FEBRUARY 28, 2013, AS ALABAMA RARE
9 DISEASE AWARENESS DAY AND DESIGNATING MAY 15, 2013, AS MPS
10 AWARENESS DAY.
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12 WHEREAS, patients of rare diseases and their
13 families suffer in isolation because of the rareness of their
14 disease; and

15 WHEREAS, there are more than 6,000 rare diseases
16 affecting more than 60 million people in Europe and the United
17 States alone; most of these diseases are genetic, serious,
18 chronic, and debilitating; and

19 WHEREAS, advances in rare disease research have more
20 chances of succeeding when multiple national and international
21 teams of researchers work together to understand rare diseases
22 and find treatment therapies; and

23 WHEREAS, public policies in health care and social
24 services that have proven beneficial to certain people living
25 with rare diseases could become more standardized and
26 replicated nationally and internationally; this is the idea

1 behind the European Union's call for countries to develop
2 national plans for rare diseases in all member states by the
3 end of 2013; and

4 WHEREAS, Mucopolysaccharidosis, also known as MPS I,
5 is a particularly devastating and heartbreaking rare genetic
6 disease which leads to cell, tissue, and organ damage; and

7 WHEREAS, a greater public awareness of MPS and other
8 rare diseases and a coordinated effort is needed to better
9 study and treat those diseases successfully; now therefore,

10 BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH
11 HOUSES THEREOF CONCURRING, That in order to raise awareness of
12 rare diseases, and particularly MPS, February 28, 2013, is
13 hereby designated as Rare Disease Awareness Day in Alabama;
14 and May 15, 2013, is hereby designated MPS I awareness Day in
15 Alabama.