

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

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ENROLLED, House Joint Resolution,
DESIGNATING FEBRUARY 28, 2013, AS ALABAMA RARE
DISEASE AWARENESS DAY AND DESIGNATING MAY 15, 2013, AS MPS
AWARENESS DAY.

WHEREAS, patients of rare diseases and their
families suffer in isolation because of the rareness of their
disease; and

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

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

WHEREAS, public policies in health care and social
services that have proven beneficial to certain people living
with rare diseases could become more standardized and
replicated nationally and internationally; this is the idea
behind the European Union's call for countries to develop
national plans for rare diseases in all member states by the
end of 2013; and

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

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

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

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Speaker of the House of Representatives

President and Presiding Officer of the Senate

House of Representatives

I hereby certify that the within Act originated in
and was adopted by the House 28-FEB-13.

Jeff Woodard
Clerk

Senate

02-MAY-13

Adopted