

SENATE BILL 255

P1

3lr1037

By: **Senators Montgomery, Benson, Forehand, Frosh, King, Madaleno, Manno, Peters, Ramirez, Raskin, and Robey**

Introduced and read first time: January 18, 2013

Assigned to: Education, Health, and Environmental Affairs

A BILL ENTITLED

1 AN ACT concerning

2 **State Government – Commemorative Days – Rare Disease Day**

3 FOR the purpose of requiring the Governor annually to proclaim a certain day as Rare
4 Disease Day; and generally relating to commemorative days.

5 BY adding to

6 Article – State Government

7 Section 13–411

8 Annotated Code of Maryland

9 (2009 Replacement Volume and 2012 Supplement)

10 Preamble

11 WHEREAS, Rare diseases are chronic, disabling, severe, life–altering, and often
12 fatal disorders; and

13 WHEREAS, There are approximately 7,000 known rare diseases that each
14 affect fewer than 200,000 individuals in the United States and jointly affect
15 approximately 25,000,000 to 30,000,000 individuals, as well as their families, in the
16 United States; and

17 WHEREAS, Most residents of Maryland know a family member, neighbor, or
18 friend who has a rare disease; and

19 WHEREAS, People suffering from rare diseases typically experience difficulties
20 in obtaining timely and accurate diagnoses and have limited treatment options and
21 difficulties in finding health care professionals or treatment centers with knowledge
22 and experience regarding the disease; and

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 WHEREAS, Treatments for rare diseases are often expensive and bring great
2 financial hardships to patients and their families; and

3 WHEREAS, Research on rare diseases is important because it gives hope to
4 people with rare diseases and because it often adds significantly to the general
5 understanding of common, as well as rare, diseases; and

6 WHEREAS, Thousands of Maryland residents are affected by rare disease as
7 patients, families, friends, caregivers, and health care providers; and

8 WHEREAS, The State of Maryland joins in support of a nationwide and
9 international observance of Rare Disease Day with patients and their families,
10 government officials, patient advocacy groups, researchers, and companies developing
11 treatments for rare disease to focus attention on rare disease as a public health issue;
12 now, therefore,

13 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF
14 MARYLAND, That the Laws of Maryland read as follows:

15 **Article – State Government**

16 **13-411.**

17 **THE GOVERNOR ANNUALLY SHALL PROCLAIM THE LAST DAY OF**
18 **FEBRUARY AS RARE DISEASE DAY.**

19 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
20 October 1, 2013.