

Department of Legislative Services
Maryland General Assembly
2013 Session

FISCAL AND POLICY NOTE

Senate Bill 255 (Senator Montgomery, *et al.*)
Education, Health, and Environmental Affairs

State Government - Commemorative Days - Rare Disease Day

This bill requires the Governor to annually proclaim the last day of February as Rare Disease Day.

Fiscal Summary

State Effect: Commemorating Rare Disease Day does not affect State finances.

Local Effect: None.

Small Business Effect: None.

Analysis

Current Law: Nine official commemorative days and three months are recognized in State law as shown in **Exhibit 1**. The Governor also must issue a proclamation each year encouraging citizens and other individuals to observe a moment of silence at 3 p.m. on Memorial Day to unite in remembrance and commemorate the heroic acts and efforts of Marylanders who have served and died in the U.S. Armed Forces.

Background: A “rare disease or condition” is defined by the federal Orphan Drug Act as a disease or condition which affects less than 200,000 in the United States. According to the National Organization for Rare Disorders (NORD), there are nearly 7,000 such diseases affecting nearly 30 million Americans or about 1 in 10 people.

As noted in the bill’s preamble, people suffering from rare diseases typically experience difficulties in obtaining timely and accurate diagnoses and have limited treatment options

and difficulties in finding health care professionals or treatment centers with knowledge and experience regarding the disease. Even after obtaining a diagnosis, treatments for rare diseases are often expensive and can bring financial hardships to patients and their families.

February 28, 2013, will mark the sixth international Rare Disease Day coordinated by Rare Diseases Europe. Since Rare Disease Day was first launched in 2008, more than 1,000 events have taken place throughout the world. NORD is the U.S. sponsor of the day, and more than 800 patient organizations, government agencies, educational institutions, clinical centers, and companies have signed on as Rare Disease Day Partners in the United States.

Exhibit 1
Official Commemorative Days and Months in Maryland

Asian Lunar New Year Day ¹	January/February
Black History Month	February
Women’s History Month	March
Crime Victim and Advocate Day	April 3
John Hanson’s Birthday ²	April 13
Negro Baseball League Day ³	May
Law Day	May 1
Fire, Rescue, and Emergency Services Workers Day ⁴	June
Maryland Charter Day	June 20
Hispanic Heritage Month ⁵	September/October
Poetry Day	October 15
Annapolis Charter Day	December 17

¹Day designated as new year on the Asian lunar calendar.

²John Hanson served as the first president of the Continental Congress under the Articles of Confederation from 1781 to 1782.

³Commemorated on the second Saturday in May.

⁴Commemorated on the first Sunday in June.

⁵Commemorated from September 15 to October 15.

Source: Department of Legislative Services

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Centers for Disease Control, National Organization for Rare Disorders, Rare Diseases Europe, Department of Legislative Services

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