



House of Representatives

General Assembly

File No. 459

January Session, 2015

House Bill No. 6100

House of Representatives, April 7, 2015

The Committee on Government Administration and Elections reported through REP. JUTILA of the 37th Dist., Chairperson of the Committee on the part of the House, that the bill ought to pass.

AN ACT DESIGNATING SPINAL MUSCULAR ATROPHY WITH RESPIRATORY DISTRESS AWARENESS DAY.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Subsection (a) of section 10-29a of the general statutes is
2 amended by adding subdivision (69) as follows (*Effective from passage*):

3 (NEW) (69) The Governor shall proclaim February tenth of each
4 year to be Spinal Muscular Atrophy with Respiratory Distress
5 Awareness Day to heighten public awareness of the associated
6 presentation and available treatments for spinal muscular atrophy
7 with respiratory distress. Suitable exercises shall be held in the State
8 Capitol and elsewhere as the Governor designates for the observance
9 of the day.

This act shall take effect as follows and shall amend the following sections:

Section 1	<i>from passage</i>	10-29a(a)
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GAE *Joint Favorable*

The following Fiscal Impact Statement and Bill Analysis are prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and do not represent the intent of the General Assembly or either chamber thereof for any purpose. In general, fiscal impacts are based upon a variety of informational sources, including the analyst's professional knowledge. Whenever applicable, agency data is consulted as part of the analysis, however final products do not necessarily reflect an assessment from any specific department.

OFA Fiscal Note

State Impact:

Agency Affected	Fund-Effect	FY 16 \$	FY 17 \$
Various State Agencies	GF - Potential Cost	See Below	See Below

Municipal Impact:

Municipalities	Effect	FY 16 \$	FY 17 \$
Various Municipalities	Potential Cost	See Below	See Below

Explanation

The bill establishes a Spinal Muscular Atrophy with Respiratory Distress Awareness Day and requires exercises observing the day as designated by the Governor.

Various state agencies and municipalities may incur costs for engaging in the exercises designated by the Governor. The level of costs for affected agencies and municipalities will be dependent upon the location, nature, and size of exercises.

The Out Years

The annualized ongoing fiscal impact identified above would continue into the future subject to inflation.

OLR Bill Analysis**HB 6100*****AN ACT DESIGNATING SPINAL MUSCULAR ATROPHY WITH RESPIRATORY DISTRESS AWARENESS DAY.*****SUMMARY:**

This bill requires the governor to proclaim February 10 of each year as Spinal Muscular Atrophy with Respiratory Distress (SMARD) Awareness Day to heighten awareness about its symptoms and available treatments. It requires that suitable exercises be held in the State Capitol and elsewhere as the governor designates.

SMARD is a rare motor neuron disorder that is referred to as an “orphan disease” because there are so few reported cases. It undermines voluntary muscle function and usually manifests itself during infancy. One of its main symptoms is respiratory failure due to diaphragmatic paralysis.

EFFECTIVE DATE: Upon passage

COMMITTEE ACTION

Government Administration and Elections Committee

Joint Favorable

Yea 15 Nay 0 (03/18/2015)