The Florida Senate BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Education									
BILL:	SB 1286								
INTRODUCER:	Senator Simmons								
SUBJECT:	Gardiner Sc	holarship	•						
DATE:	January 19,	2018	REVISED:						
ANAL	/ST	STAFF	DIRECTOR	REFERENCE	ACTION				
1. Olenick		Graf		ED	Pre-meeting				
2.			_	AED					
3.				AP					

I. Summary:

SB 1286 revises the definition of a rare disease for the purposes of the Gardiner Scholarship Program. Specifically, the bill:

- Specifies that a rare disease is a disorder that affects patient populations of 200,000 individuals or fewer, and
- Conforms the definition of a rare disease to the definition as defined by the Orphan Drug Act of 1983, Pub. L. No. 97-414.

The bill provides an effective date of July 1, 2018.

II. Present Situation:

Gardiner Scholarship Disability Eligibility Requirements

The Gardiner Scholarship Program was established in 2014¹ to provide the option for a parent of an eligible child² to better meet the individual educational needs of his or her child who has a disability.³

A "disability" as defined under the Gardiner Scholarship Program, means for a 3– or 4–year-old child or a student in kindergarten to grade 12, students with disabilities who are documented as having autism spectrum disorder; cerebral palsy; Down syndrome; an intellectual disability; Phelan-McDermid syndrome; Prader-Willi syndrome; spina-bifida; being a high-risk child; muscular dystrophy; Williams syndrome; rare diseases which affect patient populations of fewer than 200,000 individuals in the United States, as defined by the National Organization for Rare Disorders; anaphylaxis; deaf; visually impaired; traumatic brain injury; hospital or homebound;

¹ Section 16, ch. 2014-184, L.O.F.

² Section 1002.385(1) and (3), F.S.

³ Section 1002.385(2)(d), F.S.

BILL: SB 1286 Page 2

or identification as dual sensory impaired, as defined by rules of the State Board of Education and evidenced by reports from local school districts.

During the 2016-2017 school year, 7,593 students qualified for the Gardiner scholarship.⁴

III. Effect of Proposed Changes:

SB 1286 revises the definition of a rare disease for the purposes of the Gardiner Scholarship Program. Specifically, the bill:

- Specifies that a rare disease is a disorder that affects patient populations of 200,000 individuals or fewer, and
- Conforms the definition of a rare disease to the definition as defined by the Orphan Drug Act of 1983, Pub. L. No. 97-414.

In 2017, the Legislature expanded the definition of disability for the purpose s of the Gardiner Scholarship Program to include a child diagnosed with a rare disease or condition, which affects patient populations of fewer than 200,000 individuals in the United States, as defined by the National Organization for Rare Disorders.⁵

The National Organization for Rare Disorders (NORD) provides brief introductions for patients and their families to more than 1200 rare diseases. However, NORD informs that this is not a comprehensive database since there are nearly 7,000 diseases considered rare in the United States. Accordingly, the bill conforms the definition of a rare disease to the federal law.

The bill takes effect July 1, 2018.

IV. Constitutional Issues:

A.	Municipality/County Mandates Restrictions:

B. Public Records/Open Meetings Issues:

None.

None.

C. Trust Funds Restrictions:

None.

⁷ *Id*.

⁴ Florida Department of Education, 2017 Gardiner Scholarship Statistics, (2017), available at http://www.fldoe.org/core/fileparse.php/5606/urlt/Gardiner_Dec_2017.pdf, Step Up for Students, 2016-2017 Step Up For Students Annual Report, (2017), available at https://www.stepupforstudents.org/wp-content/uploads/SU_AR_2017-16 Final Online.pdf.

⁵ Section 1, ch. 2017-166, L.O.F.

⁶ National Organization for Rare Disorders, *Rare Disease Information*, https://rarediseases.org/for-patients-and-families/information-resources/rare-disease-information/ (last visited Jan. 19, 2018).

BILL: SB 1286 Page 3

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A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

None.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Statutes Affected:

This bill substantially amends section 1002.385 of the Florida Statutes:

IX. Additional Information:

A. Committee Substitute – Statement of Changes:

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

B. Amendments:

None.

This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.