

# SENATE STAFF ANALYSIS AND ECONOMIC IMPACT STATEMENT

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

BILL: SB 1544  
 SPONSOR: Senator Wasserman Schultz  
 SUBJECT: Developmental Disabilities  
 DATE: February 4, 2002      REVISED: 02/13/02 \_\_\_\_\_

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Barnes</u>	<u>Whiddon</u>	<u>CF</u>	<u>Fav/ 1 Amendment</u>
2.	_____	_____	<u>HC</u>	_____
3.	_____	_____	<u>AHS</u>	_____
4.	_____	_____	<u>AP</u>	_____
5.	_____	_____	_____	_____
6.	_____	_____	_____	_____

## I. Summary:

SB 1544 adds “familial dysautonomia” to the list of disorders included in the definition of “developmental disability” in ch. 393, F.S. The bill defines the condition as a genetic neurological condition characterized by decreased pain and temperature sensation, absence of overflow tearing, pernicious vomiting, spine curvature, and blood pressure lability.

This bill amends section 393.063, of the Florida Statutes.

## II. Present Situation:

*Familial Dysautonomia, Manual of Comprehensive Care* by Dr. Felicia B. Axelrod, Physician-Director, Dysautonomia Treatment and Evaluation Center, New York University Medical Center in New York and Hadassah Hospital-Mt. Scopus in Jerusalem, defines familial dysautonomia (FD) as a genetic disease which is present from birth which results in incomplete development of the nervous system causing a decreased number of nerve cells. The affected nerve cells are those which control certain sensations and autonomic functions. The sensory nerve cells which are most severely affected are those responsible for pain, heat perception, and taste. The autonomic nerve cells control bodily functions such as sweating, swallowing, regulation of blood pressure and body temperature, and the ability to cry tears. Dr. Axelrod reports that all children with FD have the same basic problem—incomplete development of nerve cells. Some children also have secondary problems, such as feeding problems, vomiting, poor growth, spinal curvature and lung problems.

Familial dysautonomia is a recessive genetic disease meaning that both parents carry the gene despite a lack of outward signs. The recessive gene causing FD occurs with a remarkable high carrier frequency in individuals of Eastern European Jewish ancestry (Ashkenazi Jewish

extraction). It is estimated that one in 30 persons with Eastern European Jewish ancestry is a carrier of the FD gene. Affected individuals usually are of normal intelligence. Familial dysautonomia patients can be expected to function independently if treatment is begun early and major disabilities are avoided.

The FD Foundation in New York reports that based on the FD world-wide registry, there are currently 331 surviving persons with FD and 178 of those persons reside in the United States. Seventy percent of these persons reside in New York (68), New Jersey (24), Florida (17), and California (15).

Section 393.063(12), F.S., defines “developmental disability” as a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely. The Department of Children and Family Services (department) estimates that their current client population by disorder is as follows: retardation, 30,608 (82.5 percent); cerebral palsy, 3,457 (9.32 percent), autism, 2,045 (5.51 percent); spina bifida, 939 (2.53 percent), and Prader-Willi syndrome, 45 (.12 percent).

Persons with FD are not currently served by the Developmental Disability program of the department. According to the department, FD has not been approved by the Centers for Medicaid and Medicare Services, (formally HCFA) as a developmental disability for which medical services may be reimbursed under the Developmental Services Home and Community-Based Services (DS/HCBS) waiver program. Seventy-three percent of the persons served by the Developmental Disability program live in the community and are served under the Developmental Services Home and Community-Based Services (DS/HCBS) waiver, which results in the federal government matching state expenditures for services at a 45 percent state, 55 percent federal expenditure ratio.

### **III. Effect of Proposed Changes:**

SB 1544 amends s. 393.063(21), F.S., to specify that “familial dysautonomia” is a developmental disability and defines the term in s. 393.063(21), F.S., to mean a genetic neurological condition characterized by decreased pain and temperature sensation, absence of overflow tearing, pernicious vomiting, spine curvature, and blood pressure lability. The bill specifies that the incidence of the disease within the Ashkenazi Jewish population is one in 3,600, based on an estimated carrier frequency of one in 32.

### **IV. Constitutional Issues:**

#### **A. Municipality/County Mandates Restrictions:**

None.

#### **B. Public Records/Open Meetings Issues:**

None.

C. Trust Funds Restrictions:

None.

**V. Economic Impact and Fiscal Note:**

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

Families with children who suffer with FD currently receive no financial assistance from the publicly funded Developmental Disability Program unless it is combined with a covered developmental disability. This bill through appropriated state general revenue funds could provide some assistance to these persons and their families.

C. Government Sector Impact:

This bill would have an impact on the Developmental Disability Program but the extent of the fiscal impact is not known. The department states that the financial needs to serve this group are uncertain as there is no historical cost data, although average costs in the program currently exceed \$1500 per person per month.

Regarding the life expectancy of those with FD which would affect the fiscal impact of serving this population, Dr. Berish Rubin, a researcher at Fordham University, states that only 50 percent of those affected with FD live to be 30 years of age.

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

**VIII. Amendments:**

#1 by Children and Families:

Removes language from the bill that is not directly related to the definition of “familial dysautonomia” such as the incidence rate of the disease.