

# 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.)

Prepared By: Children and Families Committee

BILL: SB 2226

INTRODUCER: Senator Rich

SUBJECT: Developmental Disabilities

DATE: March 22, 2006

REVISED: 4/03/06

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Goltry	Whiddon	CF	Fav/1 amendment
2.			HC	
3.			HA	
4.				
5.				
6.				

## Please see last section for Summary of Amendments

- Technical amendments were recommended
- Amendments were recommended
- Significant amendments were recommended

### I. Summary:

The bill directs the Agency for Health Care Administration (AHCA or agency) and the Agency for Persons with Disabilities (APD) to expand the Medicaid home and community-based waiver program that serves children diagnosed with Familial Dysautonomia, also known as Riley-Day Syndrome, to serve adults. The bill provides an appropriation for this program for Fiscal Year 2006-07.

This bill substantially amends the following sections of the Florida Statutes: 409.912.

### II. Present Situation:

Familial dysautonomia (FD), also known as Riley-Day Syndrome, is an inherited disorder of the nervous system that affects the development and survival of autonomic and some sensory neurons. Originally reported by Riley et al in 1949, FD is recognized now as one of several hereditary sensory and autonomic neuropathies. Evidence of the disorder may be noted from birth, although neurologic deterioration progresses with age.<sup>1</sup> Familial dysautonomia is one example of a group of disorders known as hereditary sensory and autonomic neuropathies

<sup>1</sup> Robert A D'Amico, MD and Felicia B Axelrod, MD, eMedicine, Familial Dysautonomia, at: <http://www.emedicine.com/oph/topic678.htm>

(HSAN). All HSAN are characterized by widespread sensory dysfunction and variable autonomic dysfunction caused by incomplete development of sensory and autonomic neurons. The disorders are believed to be genetically distinct from each other. Unlike the other HSAN, FD has been noted only in individuals of Ashkenazi Jewish extraction and so it is included as one of the Jewish genetic diseases.<sup>2</sup>

It is estimated that one in 27 individuals of Eastern European Jewish ancestry is a carrier of the gene for FD. All parents of children with FD are carriers of the defective recessive gene that transmits the disease. A parent has no symptoms or warning signs of being a carrier. The first clue for most individuals that they are carriers is the birth of a child with FD.<sup>3</sup> In general, FD is a fatal condition, with approximately 50 percent of individuals reaching the age of thirty. Individuals affected by FD are usually of normal intelligence and can be expected to function independently if treatment is begun early and major disabilities avoided.<sup>4</sup>

Since its original description in 1949, more than 550 patients have been identified and registered with the Dysautonomia Center in New York, an international registry with patient distribution reflecting Jewish dispersion. Of all the patients, 30 percent reside in the New York area and 30 percent reside in Israel.<sup>5</sup>

Affected individuals have difficulty with involuntary actions such as swallowing, breathing, production of tears, and the regulation of blood pressure and body temperature. They also have problems with some sensory functions such as taste and the perception of pain, heat, and cold.<sup>6</sup> The major symptoms seen in FD include difficulty swallowing, delay in developmental milestones, autonomic crisis (episodes of vomiting, high blood pressure and fast heart rate, sweating, abdominal discomfort, and often fever), dizziness, orthostatic hypotension (extreme drop in blood pressure with change in posture), poor weight gain and growth, decreased pain and temperature sensation, no tears when crying, Scoliosis (spinal curvature), and low muscle tone. There is a wide range of symptoms, and individuals vary in their presentation of the disease.<sup>7</sup>

Treatment of FD may include:

- Protection from injury
- Treatment of aspiration pneumonia
- Anticonvulsant therapy if seizures are present
- Liquid tears and bethanechol to prevent drying of eyes
- Anti-emetics to control vomiting
- Increased fluid and salt intake, caffeine, and waist-high elastic stockings for postural hypotension<sup>8</sup>

---

<sup>2</sup> New York University School of Medicine Department of Pediatrics, Dysautonomia Treatment & Evaluation Center, at: <http://www.med.nyu.edu/fd/fdcenter.html>

<sup>3</sup> Dysautonomia Foundation, Inc. at: <http://www.familialdysautonomia.org>

<sup>4</sup> [http://www.mazornet.com/genetics/familial\\_dysautonomia.asp](http://www.mazornet.com/genetics/familial_dysautonomia.asp)

<sup>5</sup> D'Amico, Ibid.

<sup>6</sup> New York University School of Medicine Department of Pediatrics, Dysautonomia Treatment & Evaluation Center, at: <http://www.med.nyu.edu/fd/fdcenter.html>

<sup>7</sup> Familial Dysautonomia Hope Foundation at: <http://www.fdhope.org/FamilialDysautonomia/AboutFD.htm>

<sup>8</sup> National Library of Medicine, National Institutes of Health, Medline Plus, at: <http://www.nlm.nih.gov/medlineplus/ency/article/001387.htm#Treatment>

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 (19), and California (15). New York is the only state that includes FD as a chronic developmental disability.

Persons with FD are not currently served by the Agency for Persons with Disabilities (APD). However, s. 409.912 (51), F.S., was created by ch. 2005-115, L.O.F., and directed AHCA to develop a model home and community-based waiver for Florida children diagnosed with FD. The agency has identified ten children and eight adults diagnosed with FD in the state of Florida. The FD Model Home and Community-Based Services Waiver application has been sent to the Federal Centers for Medicaid and Medicare Services for review and approval. According to AHCA staff, the waiver application includes adults, so that, pending approval by CMS and the Legislature, they will be able to serve adults with FD as well as children.

In 1981, Congress authorized states to apply for the waiver of certain federal requirements for the Medicaid program. There were three types of waivers authorized:

- Section 1115 Research & Demonstration Projects: This section provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program.
- Section 1915(b) Managed Care/Freedom of Choice Waivers: This section provides the Secretary authority to grant waivers that allow states to implement managed care delivery systems or otherwise limit individuals' choice of provider under Medicaid.
- Section 1915(c) Home and Community-Based Services Waivers: The 1915(c) waiver enables a state to receive Medicaid reimbursement to provide home and community services (other than room and board) to individuals who would otherwise require Medicaid-funded institutional care. Under 1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized.

The Model waiver (originally known as a “Katie Beckett” waiver) is a provision in the Tax Equity and Fiscal Responsibility Act (TEFRA 134), was added to the Medicaid program in 1982, and gives states the option to cover non-institutionalized children with disabilities. Before TEFRA 134 was enacted, if a child with disabilities lived at home, the parents’ income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child’s own income and resources were counted in determining financial eligibility. Since TEFRA, states have the option to waive or disregard the deeming of parental income and resources for children under 18 years old who are living at home but who would otherwise be eligible for Medicaid-funded institutional care.

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

Senate Bill 2226 amends s. 409.912(5), F.S., relating to cost effective purchasing of health care and Medicaid waivers removing the word “model” in describing the type of waiver to be

developed. The bill also adds adults to the Familial Dysautonomia home and community-based waiver and deletes language that makes the waiver services subject to the availability of funds and limitations provided by the General Appropriations Act.

The bill provides an appropriation of \$171,840 from General Revenue and \$246,160 from the Medical Care Trust Fund, for a total of \$418,000 to implement the FD Waiver for Fiscal Year 2006-2007.

#### **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:

Children and adults with FD will have access to enhanced services funded by Medicaid, thus reducing the financial burden on families for providing health care for a severe and chronic condition.

C. Government Sector Impact:

A benefit of the implementation of a federal waiver program is the federal Medicaid reimbursement of 58.89 percent for each state dollar spent.

During the 2005 legislative session, the agency was appropriated recurring funding in the amount of \$171,840 from the General Revenue Fund and \$246,160 from the Medical Care Trust Fund for the purpose of implementing ch. 2005-115, L.O.F., during Fiscal Year 2005-06. This bill appropriates an additional amount of \$171,840 from the General Revenue Fund and \$246,160 from the Medical Care Trust Fund to the Agency for the purpose of implementing this legislation during the Fiscal Year 2006-07.

According to AHCA, the FD Waiver application requested a cap on the total dollar amount for services per beneficiary of \$20,900 per beneficiary (\$418,000 / 20

beneficiaries). Limited services are available on the FD Waiver, and \$20,900 per beneficiary should adequately cover expenditures for services for both children and adults. No additional funding for Fiscal Year 2006-07 is required.<sup>9</sup>

**VI. Technical Deficiencies:**

If additional funding for this waiver is not required, the appropriation should be deleted from the bill.

**VII. Related Issues:**

None.

---

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

---

---

<sup>9</sup> Agency for Health Care Administration, SB 2226 Bill Analysis, March 21, 2006.



---

## **VIII. Summary of Amendments:**

Barcode 741402 by Children and Families

Deletes an appropriation to the Agency for Health Care Administration.

WITH TITLE AMENDMENT

---

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

---