

**Fifty-ninth Legislative Assembly of North Dakota
In Regular Session Commencing Tuesday, January 4, 2005**

SENATE BILL NO. 2395
(Senators J. Lee, Cook)
(Representatives R. Kelsch, Wrangham)

AN ACT to create and enact a new section to chapter 50-10 of the North Dakota Century Code, relating to a department of human services treatment program for children with Russell-Silver syndrome; to amend and reenact subsection 12 of section 50-10-06 of the North Dakota Century Code, relating to income eligibility for Russell-Silver syndrome treatment and services; to direct the department of human services to apply for a medical waiver; to provide for a legislative council study; to provide for a report to the legislative council; to provide an appropriation; and to declare an emergency.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Subsection 12 of section 50-10-06 of the North Dakota Century Code is amended and reenacted as follows:

12. Establish eligibility criteria for services under this chapter at one hundred eighty-five percent of the poverty line, except for criteria relating to Russell-Silver syndrome, phenylketonuria, or maple syrup urine disease treatment services for which income is not to be considered when determining eligibility. For purposes of this chapter, "poverty line" has the same meaning as defined in section 50-29-01.

SECTION 2. A new section to chapter 50-10 of the North Dakota Century Code is created and enacted as follows:

Russell-Silver syndrome - Services - Definitions.

1. The state agency shall provide payment of a maximum of fifty thousand dollars per child per biennium for medical food and growth hormone treatment at no cost to individuals through age eighteen who have been diagnosed with Russell-Silver syndrome, regardless of income. If the state agency provides an individual with services under this section, the state agency may seek reimbursement from any governmental program that provides coverage to that individual for the services provided by the department. The parent of an individual receiving services under this section shall obtain any health insurance available to the parent on a group basis or through an employer or union, and that insurance must be the primary payer before payment under this program.
2. For purposes of this section:
 - a. "Growth hormone treatment" means a drug prescribed by a physician or other licensed practitioner for the long-term treatment of growth failure, the supplies necessary to administer the drug, one out-of-state physician visit per year to obtain expert consultation for the management of Russell-Silver syndrome, appropriate in-state physician visits, and the travel expenses associated with physician visits for the child and one parent.
 - b. "Medical food" means a formula that is intended for the dietary treatment of a disease or condition for which nutritional requirements are established by medical evaluation and is formulated to be consumed or administered under the direction of a physician as well as any medical procedure and supplies necessary for assimilation of the formula.

SECTION 3. MEDICAID WAIVER - IN-HOME SERVICES. The department shall apply for a medicaid waiver to provide in-home services to children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care. The department may limit the waiver to fifteen participants and may prioritize applicants by degree of need.

SECTION 4. LEGISLATIVE COUNCIL STUDY - HEALTH CARE NEEDS. The legislative council shall consider studying, during the 2005-06 interim, issues relating to medicaid and other public funding for the extraordinary health care needs of children who live in an institution or who are at risk of institutionalization; the comprehensive health association of North Dakota program provided for under chapter 26.1-08, including contracting for a cost-benefit analysis of this program; and the state programs providing services to children with special health care needs to determine whether the programs are effective in meeting these special health care needs, whether there are gaps in the state's system for providing services to children with special health care needs, and whether there are significant unmet special health care needs of children which should be addressed. The legislative council shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixtieth legislative assembly.

SECTION 5. REPORT TO LEGISLATIVE COUNCIL. During the 2005-06 interim, the department shall report to the legislative council regarding the status of the medicaid waiver to provide in-home services under section 3 of this Act, the number of applications the department receives for the in-home services, and the status of the program's appropriation.

SECTION 6. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$150,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing Russell-Silver syndrome services, for the biennium beginning July 1, 2005, and ending June 30, 2007.

SECTION 7. EMERGENCY. This Act is declared to be an emergency measure.

President of the Senate

Speaker of the House

Secretary of the Senate

Chief Clerk of the House

This certifies that the within bill originated in the Senate of the Fifty-ninth Legislative Assembly of North Dakota and is known on the records of that body as Senate Bill No. 2395 and that two-thirds of the members-elect of the Senate voted in favor of said law.

Vote: Yeas 46 Nays 0 Absent 1

President of the Senate

Secretary of the Senate

This certifies that two-thirds of the members-elect of the House of Representatives voted in favor of said law.

Vote: Yeas 90 Nays 3 Absent 1

Speaker of the House

Chief Clerk of the House

Received by the Governor at _____ M. on _____, 2005.

Approved at _____ M. on _____, 2005.

Governor

Filed in this office this _____ day of _____, 2005,

at ___ o'clock _____ M.

Secretary of State