

**SECOND ENGROSSMENT
with House Amendments**Fifty-ninth
Legislative Assembly
of North Dakota**REENGROSSED SENATE BILL NO. 2395**

Introduced by

Senators J. Lee, Cook

Representatives R. Kelsch, Wrangham

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

8 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

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

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

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

18 **Russell-Silver syndrome - Services - Definitions.**

19 1. The state agency shall provide payment of a maximum of fifty thousand dollars per
20 child per biennium for medical food and growth hormone treatment at no cost to
21 individuals through age eighteen who have been diagnosed with Russell-Silver
22 syndrome, regardless of income. If the state agency provides an individual with
23 services under this section, the state agency may seek reimbursement from any
24 governmental program that provides coverage to that individual for the services

1 provided by the department. The parent of an individual receiving services under
2 this section shall obtain any health insurance available to the parent on a group
3 basis or through an employer or union, and that insurance must be the primary
4 payer before payment under this program.

5 2. For purposes of this section:

6 a. "Growth hormone treatment" means a drug prescribed by a physician or other
7 licensed practitioner for the long-term treatment of growth failure, the supplies
8 necessary to administer the drug, one out-of-state physician visit per year to
9 obtain expert consultation for the management of Russell-Silver syndrome,
10 appropriate in-state physician visits, and the travel expenses associated with
11 physician visits for the child and one parent.

12 b. "Medical food" means a formula that is intended for the dietary treatment of a
13 disease or condition for which nutritional requirements are established by
14 medical evaluation and is formulated to be consumed or administered under
15 the direction of a physician as well as any medical procedure and supplies
16 necessary for assimilation of the formula.

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

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

1 its findings and recommendations, together with any legislation required to implement the
2 recommendations, to the sixtieth legislative assembly.

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

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

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