

**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.** The state agency shall provide medical food, as
19 defined in section 25-17-00.1, and coverage for growth hormone at no cost to individuals under
20 age eighteen who have been diagnosed with Russell-Silver syndrome, regardless of income. If
21 the state agency provides an individual with services under this section, the state agency may
22 seek reimbursement from any governmental program that provides coverage to that individual
23 for the services provided by the department. The parent of an individual receiving services

1 under this section shall obtain any readily available employer-based health insurance, and that
2 insurance must be the primary payer before payment under this program.

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

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

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

23 **SECTION 6. APPROPRIATION.** There is appropriated out of any moneys in the
24 general fund in the state treasury, not otherwise appropriated, the sum of \$135,000, or so much
25 of the sum as may be necessary, to the department of human services for the purpose of
26 providing Russell-Silver syndrome services, for the biennium beginning July 1, 2005, and
27 ending June 30, 2007.

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