

Fifty-ninth
Legislative Assembly
of North Dakota

ENGROSSED 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; and to declare an emergency.

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

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

10 12. Establish eligibility criteria for services under this chapter at one hundred
11 eighty-five percent of the poverty line, except for criteria relating to Russell Silver
12 syndrome, phenylketonuria₁, or maple syrup urine disease treatment services for
13 which income is not to be considered when determining eligibility. For purposes of
14 this chapter, "poverty line" has the same meaning as defined in section 50-29-01.

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

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

1 insurance must be the primary payer before payment under this program. There may be no
2 recipient liability connected with 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 shall
6 require an applicant to demonstrate a chronic physical condition that results in prolonged
7 dependency on medical care for which daily skilled nursing intervention is medically necessary.
8 The department shall require an applicant to demonstrate a condition that is life-threatening,
9 requires frequent administration of time-consuming medically necessary daily treatments, or
10 requires the use of complex medical equipment or services such as a ventilator, dialysis
11 machine, enteral or parenteral nutrition support, or continuous oxygen. The department may
12 limit the waiver to fifteen participants and may prioritize applicants by degree of need.

13 **SECTION 4. LEGISLATIVE COUNCIL STUDY - CHILD HEALTH CARE NEEDS.** The
14 legislative council shall consider studying, during the 2005-06 interim, issues relating to
15 medicaid and other public funding for the extraordinary health care needs of children who live in
16 an institution or who are at risk of institutionalization. The legislative council may assign
17 portions of this study to appropriate interim committees. The legislative council shall report its
18 findings and recommendations, together with any legislation required to implement the
19 recommendations, to the sixtieth legislative assembly.

20 **SECTION 5. EMERGENCY.** This Act is declared to be an emergency measure.