

Introduced by

Senators Heckaman, Wanzek

Representatives Devlin, Headland, Pollert, Vigesaa

1 A concurrent resolution urging Congress and the President of the United States to direct the
2 federal Food and Drug Administration to allow the use of experimental medications to treat
3 Pantothenate kinase-associated neurodegeneration (PKAN) for the benefit of the three children
4 of the Kulsrud family living in Grace City, North Dakota.

5 **WHEREAS**, the three children of the Kulsrud family have been diagnosed with PKAN and
6 are unlikely to enjoy a full life as adults; and

7 **WHEREAS**, the oldest of the Kulsrud children has reached the average age of expected
8 survival; and

9 **WHEREAS**, the other two Kulsrud children are rapidly progressing into the later stages of
10 the disease; and

11 **WHEREAS**, experimental treatments are available that could prolong the lives of the
12 Kulsrud children; and

13 **WHEREAS**, these experimental treatments may also provide significant improvements in
14 the Kulsrud children's overall quality of life; and

15 **WHEREAS**, the federal Food and Drug Administration has the authority to allow the use of
16 experimental drugs for the treatment of rare diseases and disorders, such as PKAN; and

17 **WHEREAS**, there are experimental medical options available that the federal Food and
18 Drug Administration have not allowed the Kulsrud family to access;

19 **NOW, THEREFORE, BE IT RESOLVED BY THE SENATE OF NORTH DAKOTA, THE**
20 **HOUSE OF REPRESENTATIVES CONCURRING THEREIN:**

21 That the Sixty-fourth Legislative Assembly urges Congress and the President of the United
22 States to direct the federal Food and Drug Administration to allow the use of experimental
23 medications to treat Pantothenate kinase-associated neurodegeneration (PKAN) for the benefit
24 of the three children of the Kulsrud family living in Grace City, North Dakota.

1 **BE IT FURTHER RESOLVED**, that the Secretary of State forward copies of this resolution,
2 via certified mail return receipt requested, to the Surgeon General of the United States, the
3 Commissioner of the federal Food and Drug Administration, and each member of the North
4 Dakota Congressional Delegation; and
5 **BE IT FURTHER RESOLVED**, that the Sixty-fourth Legislative Assembly urges Congress
6 and the President of the United States to direct the federal Food and Drug Administration to
7 review and update the Compassionate Care application process so a greater number of
8 terminally ill patients may benefit.