

**Sixty-fourth Legislative Assembly of North Dakota  
In Regular Session Commencing Tuesday, January 6, 2015**

SENATE CONCURRENT RESOLUTION NO. 4016  
(Senators Heckaman, Wanzek)  
(Representatives Devlin, Headland, Pollert, Vigesaa)

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

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

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

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

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

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

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

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

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

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

**BE IT FURTHER RESOLVED**, that the Secretary of State forward copies of this resolution, via certified mail return receipt requested, to the Surgeon General of the United States, the Commissioner of the federal Food and Drug Administration, and each member of the North Dakota Congressional Delegation; and

**BE IT FURTHER RESOLVED**, that the Sixty-fourth Legislative Assembly urges Congress and the President of the United States to direct the federal Food and Drug Administration to review and update the Compassionate Care application process so a greater number of terminally ill patients may benefit.

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President of the Senate

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Speaker of the House

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Secretary of the Senate

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Chief Clerk of the House

Filed in this office this \_\_\_\_\_ day of \_\_\_\_\_, 2015,  
at \_\_\_\_\_ o'clock \_\_\_\_\_ M.

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Secretary of State