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.

President of the Senate

Speaker of the House

Secretary of the Senate

Chief Clerk of the House

Filed in this office this 7th day of April, 2015,

at 10:08 o'clock A. M.

Secretary of State