

Steve Sisolak
Governor

Richard Whitley, MS
Director



**DEPARTMENT OF
HEALTH AND HUMAN SERVICES**
DIVISION OF PUBLIC AND BEHAVIORAL HEALTH
Helping people. It's who we are and what we do.



Lisa Sherych
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical Officer

May 19, 2021

Senator Dina Neal

Dina.Neal@sen.state.nv.us

Re: Senate Bill 175

Proposed amendment: Addition of the term rare disease diagnoses as determined by the Rare Disease Advisory Council of Nevada to all instances of the word Lupus.

The Nevada Rare Disease Advisory Council supports Senate Bill 175 and is most appreciative of Senator Neal for highlighting the need for improved Nevada data for improved Nevada outcomes. The infrastructure and data created by this bill is critically needed to support populations in Nevada who have not been well counted nor well researched in terms of prevalence and incidence and therefore have not received the benefit of focus such that any level of standard of care has been valued or outcomes improved in the state. Without such data, Nevadans with Lupus and Rare Disease and the struggles they faced cannot be known. As you know, the state's tracking of COVID 19 allowed for informed decisions county by county to be made in almost real-time. It is time similar tracking allows Nevada to be ahead and document and address the deficiencies that allow our mortality and morbidity to be higher than similarly populated states. If similar tracking can be made for diagnoses notoriously difficult to find, Nevada can be ahead instead of maintaining solely survival. Rare disease and lupus require extra focus if they are to have any chance at better outcomes.

A handwritten signature in black ink, appearing to read "Amber Federizo".

Dr. Amber Federizo, APRN, FNP-BC

Chair, Nevada Rare Disease Advisory Council (RDAC)

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**Patient Protection Commission
Sara Chalhagian, Executive Director**

sarachalhagian@gov.nv.gov

Re: SB40

The Nevada Rare Disease Advisory Council supports Senate Bill 40 and is most appreciative of the Patient Protection Committee for highlighting the need for improved Nevada data for improved Nevada outcomes. The infrastructure and data created by this bill is critically needed to support populations in Nevada who have not been well counted nor well researched in terms of cost and quality and therefore have not received the benefit of focus such that any level of standard of care has been valued or outcomes improved in the state. Without such data, Nevadans and the struggles and costs they face cannot be known. As you know, the state's tracking of COVID 19 allowed for informed decisions county by county to be made in almost real-time. It is time similar tracking allows Nevada to be ahead and document and address the deficiencies that allow our mortality and morbidity to be higher than similarly populated states. If similar tracking can be made for diagnoses notoriously difficult to find, Nevada can be ahead of cost increases. Rare disease and lupus require extra focus if they are to have any chance at better outcomes while reducing cost and preserving outcomes.

A handwritten signature in black ink, appearing to read "Amber Federizo", written over a horizontal line.

Dr. Amber Federizo, APRN, FNP-BC

Chair, Nevada Rare Disease Advisory Council (RDAC)