



Alone we are rare. Together we are strong.®

January 24, 2024

The Honorable Carri Hicks  
Oklahoma State Senate  
2300 N. Lincoln Blvd Room 515.1  
Oklahoma City, OK 73105

Dear Senator Hicks,

On behalf of the 1-in-10 individuals in Oklahoma with one of the more than 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) commends your leadership and willingness to sponsor legislation to establish a Rare Disease Advisory Council (RDAC) in Oklahoma.

Rare disease patients in Oklahoma face unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. The Oklahoma RDAC would help address these issues by providing a forum for stakeholders across your state knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts the community.

The RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, education, diagnosis, and treatment for the care of those with rare diseases. It will also be tasked with providing a report to the Governor and the Legislature, highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state. The RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Oklahoma government decisionmakers with one community voice.

In creating this council, Oklahoma would join twenty-seven other states (Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.

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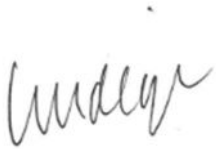
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Senator Hicks, NORD thanks you for introducing SB 1772 and appreciates your support of this important legislation that will help give a voice to Oklahomans living with a rare disease.

Sincerely,

A handwritten signature in blue ink that reads "Lindsey".

Lindsey Viscarra  
State Policy Manager, Western Region  
National Organization for Rare Disorders



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