



May 18, 2021

The Honorable Sharon Hewitt  
Louisiana State Senate  
900 North 3<sup>rd</sup> Street  
Baton Rouge, LA 70804

Dear Senator Hewitt,

On behalf of the 1-in-10 individuals in Louisiana with one of the approximately 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 Louisiana.

Rare disease patients in Louisiana 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 Louisiana Rare Disease Advisory Council would help address these issues by providing a forum for stakeholders across the state to analyze the needs of the rare community and make recommendations on how to improve public policy.

The RDAC represents enormous value to our organization and the rare disease community we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. Additionally, 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, the Legislature, and other relevant agencies 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 Louisiana government decisionmakers with one community voice.

In creating this council, Louisiana would join seventeen other states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia, and West Virginia) that have enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.



Senator Hewitt, we thank you for sponsoring HB 460 and appreciate your support for this important legislation that will give a voice to Louisiana residents living with a rare disease.

Sincerely,

Alyss Patel  
State Policy Manager, Western Region  
National Organization for Rare Disorders

Libby Airhart  
Volunteer State Ambassador  
Louisiana Rare Action Network