



March 17, 2021

The Honorable Michelle Gray  
State Capitol Building  
500 Woodlane Street, Suite 320  
Little Rock, Arkansas 72201

Dear Representative Gray,

On behalf of the 1-in-10 individuals in Arkansas with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) appreciates your willingness to cosponsor legislation to establish a Rare Disease Advisory Council (RDAC) within the state. We write today to express our deep concern with the recent amendment to SB 143 that, if enacted, would remove the RDAC in its entirety from this legislation.

NORD along with several other patient organizations in Arkansas were pleased to see SB 143, as introduced, pass quickly through the Senate unanimously on February 9<sup>th</sup>. The originally introduced version of this bill included critical provisions that would establish a robust Rare Disease Advisory Council in the state of Arkansas. Unfortunately, the recently proposed amendments would gut these critical pieces of the bill and instead would make minimal changes to the Arkansas Medicaid Drug Utilization Review Board to add two rare disease experts to this entity. While the inclusion of the input of rare disease experts in the Medicaid drug review process is helpful, amending the bill to eliminate the RDAC portion will significantly reduce the benefits of SB 143 to the Arkansas rare disease community.

Rare disease patients in Arkansas face unique challenges every day of their lives, 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. It is estimated that of the 7,000 known rare diseases, approximately 90% have no FDA-approved treatment, so the benefit of amending the legislation to be entirely focused on Medicaid prescription drug access is quite limited to the rare disease community.

The Arkansas Rare Disease Advisory Council, as passed by the Senate, would help address these broader issues faced by the rare disease community 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. Additionally, the RDAC would be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for the care of those with rare diseases. It would also be tasked with creating a rare disease plan for the state and developing methods to publicize the profile



of the social and economic burden of rare diseases to ensure health care providers are informed.

Currently sixteen other states that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states include: Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia.

The RDAC provisions of SB 143 represent enormous value to the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing rare disease-related challenges. In addition, an RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Arkansas government decisionmakers with one community voice. We urge you to support your originally introduced version of SB 143, which has already been passed unanimously by the Senate.

Representative Gray, we respectfully ask you to reconsider your amendment to SB 143.

Sincerely,

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

Tammy Jones  
Volunteer State Ambassador  
Arkansas Rare Action Network