



February 5, 2021

The Honorable Missy Irvin
State Capitol Building
500 Woodlane Street, Suite 320
Little Rock, Arkansas 72201

Dear Senator Irvin:

My name is Tammy Jones of Greenwood, Arkansas and I am the Arkansas Rare Action Volunteer State Ambassador for the National Organization for Rare Disorders. NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease.

I am honored to share my story today on behalf of the one in ten Arkansas residents with a rare disease and share my support for SB 143, which would establish a rare disease advisory council in our state.

Rare disease patients in Arkansas 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.

I understand these challenges personally as my immediate family has five people affected by a rare bleeding disorder.

In my work advocating on behalf of rare disease patients, one of the biggest challenges I hear is the need for access to appropriate and affordable treatment. It is not uncommon to hear of stories where people are required to travel extensively to find a medical provider with knowledge of their rare disease. Years ago, when my family members were diagnosed, we were told we would need to drive over three and a half hours for treatment as that was the only care option for individuals with our disorder.

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

To date, sixteen states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) have created a Rare Disease Advisory Council and proven that it is an effective way to ensure better government engagement and action on issues of importance to the rare disease community. I urge you to vote in support of SB 143 and help Arkansas become the 17th state to enact an RDAC.

Thank you,

Tammy Jones

Tammy Jones
Volunteer State Ambassador
Arkansas Rare Action Network