



March 1, 2021

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

Re: Support for Senate Bill 143 – an Act to Create a Rare Disease Advisory Council

Dear Representative Gray,

On behalf of the undersigned organizations representing individuals with rare diseases in Arkansas, we thank you for your work during COVID-19 and willingness to cosponsor Senate Bill 143 (SB 143). SB 143 establishes a rare disease advisory council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in the state of Arkansas.

Though we are facing unprecedented times during the COVID-19 pandemic, we write to urge that SB 143 is passed this session. Rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, across the country, 74% of rare disease patients have had a medical appointment cancelled due to COVID-19 and approximately 70% are concerned about medication and medical supply shortages.¹

Creating an RDAC in Arkansas will give rare disease patients a unified voice in Arkansas state government. Additionally, the RDAC will 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 will 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.

¹ <https://rarediseases.org/new-community-survey-from-nord-reveals-significant-impact-of-covid-19-on-americans-living-with-rare-diseases/>

The RDAC represents enormous value to our organizations and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the 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.

In creating this council, Arkansas would join 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.

Once again, on behalf of the undersigned organizations, we thank you for cosponsoring SB 143 that would enable the creation of a Rare Disease Advisory Council. As a result of your leadership, we are one step closer at giving a voice to Arkansas residents living with rare diseases. For any questions, please feel free to contact Alyss Patel with the National Organization for Rare Disorders via email at apatel@rarediseases.org. Thank you for your consideration.

Sincerely,

American Cancer Society Cancer Action Network

American Kidney Fund

Be The Match

Cystic Fibrosis Research, Inc. (CFRI)

Epilepsy Foundation Arkansas

Hemophilia Federation of America

Immune Deficiency Foundation

Infusion Access Foundation (IAF)

The Leukemia & Lymphoma Society

National Hemophilia Foundation

National Infusion Center (NICA)

National Organization for Rare Disorders (NORD)

Neuropathy Action Foundation

Sick Cells