



January 24, 2022

The Honorable Sam C. Mims, V
 Chair
 House Public Health and Human Services Committee
 Room: 104-B
 P. O. Box 1018
 Jackson, MS 39215

Re: Support for House Bill 458: Rare Disease Advisory Council

Dear Chair Mims and Members of the House Public Health and Human Services Committee:

On behalf of the 18 undersigned organizations representing individuals with rare diseases in Mississippi, we urge you to add House Bill 458 (HB 458) to the House Public Health and Human Services Committee’s agenda. HB 458 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 Mississippi.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many 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. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community’s needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they provide a forum for patients, families, and experts across the state to analyze the needs of the community and make recommendations on how to improve public policy related to rare diseases. RDAC members typically include a

variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, or publish and compile resources related to rare diseases.

In creating this council, Mississippi will join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource. Those states are Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge you to add HB 458 to the House Public Health and Human Services Committee's agenda and push for its swift passage. For any questions, please feel free to contact Anniisa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders

ALS Association

American Behcet's Disease Association (ABDA)

American Cancer Society Cancer Action Network

APS Foundation of America, Inc.

Be The Match/National Marrow Donor Program

CFC International

IGA Nephropathy Foundation

International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)

International Pemphigus Pempqioid Foundation

Leukemia and Lymphoma Society

Lymphedema Advocacy Group

National Niemann-Pick Disease Foundation

Neuropathy Action Foundation

Sick Cells

Soft Bones

The Myositis Association

United MSD Foundation