



Alone we are rare. Together we are strong.®



March 25, 2024

The Honorable Jason White
Speaker of the House
Mississippi House of Representatives
State Capitol, Room 302
Jackson, MS 39201

The Honorable Dean Kirby
Senate President Pro Tempore
Mississippi State Senate
State Capitol, Room 307
Jackson, MS 39201

**RE: Support and Recommendations Regarding House Bill 616 (McKnight)/Senate Bill 2156 (Blackwell)
– Establishes a Rare Disease Advisory Council in the State of Mississippi**

Dear Mr. Speaker and Mr. President,

The 23 undersigned organizations representing individuals with rare diseases in Mississippi, write in support of House Bill 616 (McKnight) and Senate Bill 2156 (Blackwell), which would establish a Rare Disease Advisory Council (RDAC) in the state, giving a voice to the estimated 1-in-10 individuals living with a rare disease in Mississippi. Additionally, we want to provide **our recommendation to resolve differences between the two bills as part of the Conference Committee process.**

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As defined by the Orphan Drug Act, any condition that affects fewer than 200,000 Americans¹ is considered rare. Overall, there are more than 10,000 known rare diseases, affecting an estimated 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 complex needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

With diverse membership and broad community support, a Mississippi RDAC will serve as a valuable resource as our health care system evolves. A strong RDAC can help relieve burdens on the state by expeditiously delivering direct feedback, solutions, and resources to Mississippi government decision makers with one community voice. Without an RDAC, Mississippi laws and regulations that affect the rare community will be developed without the consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

Each chamber has passed a bill creating an RDAC, but the bills propose different Council membership. House Bill 616 (McKnight) passed with unanimous support on March 8th and proposes a 20-member Council. Senate Bill 2156 (Blackwell) passed similarly on March 14th and proposes a 10-member Council. **The 22 undersigned organizations and the National Organization for Rare Disorders (NORD) support a 12-member Council and ask the final bill use the membership proposed in SB 2156 with the following additions as included in HB616:**

- ✦ Increase the number of rare disease patient members by one, for a total of two.
- ✦ Add one Registered Nurse (RN) or Advanced Practice Nurse (APN) with experience treating rare disease patients.

In the 27 other Councils across the country the rare patient voice is routinely cited as one of the most valuable. After all, rare disease patients are experts in their conditions, putting them in a well-placed position to identify gaps and necessary improvements in the healthcare system to benefit the broader community. Additionally, RNs and APNs also would bring a unique perspective to the Council given their unique position in the healthcare system being so close to patients and the everyday operations of healthcare facilities.

Both bills propose to house the RDAC within the University of Mississippi Medical Center and propose the Council fulfill the same 11 duties including: creating and disseminating a first-year landscape or survey of the rare disease population to help identify unmet needs of the rare disease patients, caregivers, and providers in the state and developing recommendations to improve patient access to and quality of rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services.

Our 23 organizations and Mississippi's rare disease community are eager to welcome Mississippi to the community of 27 states that have given their rare disease patients a stronger voice in state government by creating a Rare Disease Advisory Council (RDAC). Those states include most of Mississippi's neighbors, Alabama, Louisiana, and Tennessee, as well as Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada, North

¹ [United States Food & Drug Administration, Rare Diseases at FDA](#)

Carolina, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, South Carolina, Utah, Virginia, and West Virginia.

On behalf of the undersigned organizations, **we thank you for seeing these critical pieces of legislation through your respective chambers and ask the final bill include membership that increases the voice of individuals with lived experience and those uniquely positioned in our healthcare system.** For any questions, please feel free to contact Carolyn Sheridan with the National Organization for Rare Disorders via email at csheridan@raredisases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders®
AiArthritis
The ALS Association
American Cancer Society Cancer Action Network (ACSCAN)
American Partnership for Eosinophilic Disorders
APS Foundation of America
Cystic Fibrosis Research Institute (CFRI)
Dravet Syndrome Foundation
Epilepsy Foundation
Epilepsy Foundation Mississippi
HCU Network America
International Pemphigus & Pemphigoid Foundation
The Leukemia & Lymphoma Society
Lymphedema Advocacy Group
Mellie J Foundation
Mississippi Metabolics Foundation
The Myositis Association (TMP)
National Marrow Donor Program (NMDP)
National MPS Society
National Niemann-Pick Disease Foundation
NephCure
Neuropathy Action Foundation (NAF)
United MSD Foundation

CC:

Senator Kevin Blackwell, Sponsor SB2156
Representative Jay McKnight, Sponsor HB616
Kendra Hawkins, Legislative Assistant for Senate President Pro Tempore Kirby



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