



June 14, 2021

The Honorable John Bel Edwards
 Governor of Louisiana
 PO Box 94004
 Baton Rouge, LA 70804

Re: Support for House Bill 460 (Hollis): Rare Disease Advisory Council

Dear Governor Edwards:

On behalf of the 29 undersigned organizations representing individuals with rare diseases in Louisiana, we urge you to sign House Bill 460 (HB 460) into law. HB 460 would establish a Rare Disease Advisory Council (RDAC) in the state which would give a voice to the estimated 1-in-10 individuals living with a rare disease in Louisiana. This legislation has passed both chambers of the Louisiana State Legislature unanimously and has broad support from the rare disease community.

The Louisiana Rare Disease Advisory Council will give rare disease patients a unified voice in Louisiana’s state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, education, diagnosis, and treatment for the care of those with rare diseases. It will also be tasked with providing a report to your office, the Legislature, and other relevant agencies highlighting the Council’s findings, activities, and recommendations for addressing the needs of rare disease patients in the state.

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 Louisiana government decisionmakers with one community voice.

In creating this council, Louisiana will join seventeen 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 include Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge you to sign HB 460 into law to support Louisiana residents living with rare diseases. For any questions, please contact Alyss Patel with the National Organization for Rare Disorders via email at apatel@rarediseases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
American Autoimmune Related Diseases Association
American Cancer Society Cancer Action Network
American Kidney Fund
American Partnership for Eosinophilic Disorders
APS Foundation of America, Inc
Be The Match/National Marrow Donor Program
CFC International
Cystic Fibrosis Research Institute (CFRI)
Chronic Disease Coalition
Epilepsy Foundation Louisiana
Hemophilia Federation of America
Immune Deficiency Foundation
Infusion Access Foundation
IGA Nephropathy Foundation of America
International Foundation for Autoimmune & Autoinflammatory Arthritis
International Pemphigus Pemphigoid Foundation
Louisiana Hemophilia Foundation
National Hemophilia Foundation
National Infusion Center Association
National Kidney Foundation of Louisiana
Neuropathy Action Foundation
Sick Cells
The ALS Association
The ALS Association of Louisiana-Mississippi Chapter
The Myositis Association
The Sarcoidosis Awareness Foundation of Louisiana
The Sumaira Foundation for NMO
wAIHA Warrior