



April 27, 2021

The Honorable Larry Bagley  
 Chair, House Committee on Health and Welfare  
 900 North 3<sup>rd</sup> Street  
 Baton Rouge, LA 70804

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

Dear Chairman Bagley,

On behalf of the undersigned organizations representing individuals with rare diseases in Louisiana, we thank you for placing House Bill 460 (HB 460) on the Committee on Health and Welfare agenda for consideration. HB 460 establishes a rare disease advisory council (RDAC), 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 Louisiana.

Though we are facing unprecedented times during the COVID-19 pandemic, we urge that HB 460 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.<sup>1</sup>

Creating an RDAC in Louisiana 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 the Governor, the Legislature, and other

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

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 would join seventeen other states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Once again, on behalf of the undersigned organizations, we urge your support for HB 460 by swiftly moving it through your Committee to give a voice to 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](mailto: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  
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  
Neuropathy Action Foundation  
Sick Cells  
The ALS Association  
The ALS Association of Louisiana-Mississippi Chapter  
The Myositis Association  
The Sumaira Foundation for NMO  
wAIHA Warrior