



April 16, 2021

The Honorable Chris Sprowls
Speaker of the House
Florida House of Representatives
402 South Monroe Street
Tallahassee, FL 32399

Re: Support for House Bill 1373

Dear Speaker Sprowls,

On behalf of the undersigned organizations representing individuals with rare diseases in Florida, we urge you to allow swift floor consideration of House Bill 1373 (HB 1373). HB 1373 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 Florida. On

March 18th, the Florida Senate unanimously passed Senate Bill 272 (SB 272), which is companion legislation to HB 1373.

Creating an RDAC in Florida will give rare disease patients a unified voice in Florida 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.

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 Florida government decisionmakers with one community voice.

In creating this council, Florida would join seventeen 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, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge you to allow swift House floor consideration of HB 1373 to help give a voice to Florida residents living with rare diseases. For any questions, please feel free to contact Annissa 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

Be The Match/National Marrow Donor Program

Cauda Equina Foundation, Inc.

Epilepsy Foundation Florida

Global Healthy Living Foundation

Hemophilia Federation of America

Immune Deficiency Foundation

International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)

The Leukemia & Lymphoma Society

NTM Info & Research

Phelan-McDermid Syndrome Foundation

Sick Cells