May 28, 2021

The Honorable Ron DeSantis  
Governor of Florida  
The Capitol  
400 South Monroe Street  
Tallahassee, FL 32399

Re: Support for House Bill 1373/Senate Bill 272 - Florida Rare Disease Advisory Council

Dear Governor DeSantis:

On behalf of the 10 undersigned organizations representing individuals with rare diseases in Florida, we urge you to sign House Bill 1373 (HB 1373)/Senate Bill 272 (SB 272) into law. HB 1373/SB 272 would establish a Rare Disease Advisory Council (RDAC) to give a voice to the estimated 1-in-10 individuals living with a rare disease in Florida. This legislation has passed both chambers of the Florida Legislature unanimously and has broad support from the rare disease patient community.

The Florida Rare Disease Advisory Council will give rare disease patients a unified voice in the state government by providing them with a forum to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on the provider-patient relationship to identifying best practices, the council will coordinate with legislators and other government leaders to improve public policy for the state’s rare disease community.

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 challenges that Florida’s rare disease community faces. In addition, the RDAC will 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 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

On behalf of the undersigned organizations, we urge you to sign HB 1373/SB 272 into law to support 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
Alpha-1 Foundation
Be The Match/National Marrow Donor Program
Cystic Fibrosis Research Institute
Epilepsy Foundation Florida
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
The Joshua Frase Foundation
NTM Info & Research
Phelan-McDermid Syndrome Foundation
Sick Cells