NORD®
National Organization
for Rare Disorders

RARE
FL

May 6, 2021

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

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

Dear Governor DeSantis,

On behalf of the 1-in-10 individuals in Florida with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to sign Senate Bill 272 / House Bill 1373 into law. This legislation would establish a Rare Disease Advisory Council and help give a voice to the rare disease community in Florida. It passed both chambers of the Florida Legislature unanimously and has broad support from the patient community.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research.

The Florida Rare Disease Advisory Council will give rare disease patients a unified voice in the state government by providing them 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 entire state.

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 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, we urge you to swiftly sign Senate Bill 272 / House Bill 1373 into law and help improve the lives of Florida residents living with rare diseases. We look forward to working with your office to successfully enact the Florida Rare Disease Advisory Council and stand ready to assist with this effort in any way. For further questions, please feel free to contact us at areed@rarediseases.org.

Sincerely,

Heidi Ross

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