



March 17, 2021

The Honorable Giovanni Capriglione
P.O. Box 12068
Capitol Station
Austin, Texas 78711

Dear Representative Capriglione,

On behalf of the undersigned organizations representing millions of individuals with rare diseases in Texas, we ask for your support to establish a rare disease advisory council (RDAC) within the state by introducing a rider to the budget bill. If enacted, an RDAC would help give a voice to the estimated 1-in-10 individuals living with a rare disease in the state of Texas.

Though we are facing unprecedented times during the COVID-19 pandemic, we write to urge that an RDAC be established this year. 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.¹

Creating an RDAC in Texas will give rare disease patients a unified voice in Texas state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders by developing policy recommendations that identify the needs of rare disease patients, caregivers, and providers in the state to improve patient access to coverage and treatment. It will also be tasked with surveying the community on the quality of care and forecasting the fiscal impact of coverage and treatment for rare disease patients. Opportunities for public engagement will exist through creating and maintaining a website that includes meeting information and reports.

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 expeditiously deliver direct feedback, solutions, and resources to Texas government decisionmakers with one community voice.

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

In creating this council, Texas would join sixteen 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, and West Virginia.

Once again, on behalf of the undersigned organizations, we ask for your support to create an RDAC through the budget process. For any questions, please feel free to 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
Be The Match/National Marrow Donor Program
Chronic Disease Coalition
Cystic Fibrosis Research, Inc.
COPA Syndrome Foundation
Hemophilia Federation of America
Sick Cells