NORD
amda Acid Maltase Deficiency Association
AGSAA
The Akari Foundation www.theakarifoundation.org Conexión En Español Para Las Enfermedades Raras
ABDA American Behcet's Disease Association
APS Foundation of America, Inc Celebrating 15 years of service
BDSRA foundation
CACNA1A FOUNDATION
CHRIS "CJ" JOHNSON FOUNDATION
CFRI Cystic Fibrosis Research Institute RESEARCH · EDUCATION · ADVOCACY · SUPPORT
GFPD GLOBAL FOUNDATION FOR PEROXISOMAL DISORDERS
HCU NETWORK AMERICA
Houston's Sickle Cell Association Sickle Cell Association of Houston sicklecellhouston.org
Immune Deficiency Foundation
Infusion Access Foundation
AiARTHRITIS INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS
ippf International Pemphigus & Pemphigoid Foundation
LGS FOUNDATION LENNOX GASTAUT SYNDROME
LUPUS and ALLIED DISEASES Association, Inc.
LYMPHEDEMA ADVOCACY GROUP
Myositis Support & Understanding
NAF National Ataxia Foundation
nnpdf NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.
National PKU Alliance
National Scleroderma Foundation Texas Bluebonnet 25th Anniversary National Scleroderma Foundation
Neuropathy Action Foundation Awareness • Education • Empowerment
PHELAN-McDERMID SYNDROME FOUNDATION
SICK CELLS
HOUSTON SICKLE CELL COLLABORATIVE
MTF 1997 25 2022 SICKLE CELL ASSOCIATION OF TEXAS MARC THOMAS FOUNDATION www.sicklecelltx.org
SRNA connect. care. cure. Siegel Rare Neuroimmune Association
SLC6A1 Connect
STXBP1 disorders
SYNGAP1 FOUNDATION RESEARCH EDUCATION ADVOCACY
SynGAP Research Fund Collaboration. Transparency. Urgency.
T.E.A.M. 4 Travis Together Ending Asplenia Mortality
TEXAS PRADER-WILLI ASSOCIATION
TX RARE

April 19, 2023

The Honorable Lois Kolkhorst
Chair
Senate Health and Human Services Committee
P.O. Box 12068
Capitol Station
Austin, TX 78711

Re: Support for Senate Bill 1408: Texas Rare Disease Advisory Council

Dear Chair Kolkhorst and Members of the Senate Health and Human Services Committee:

On behalf of the 39 undersigned organizations representing individuals with rare diseases in Texas, we urge you to add Senate Bill 1408 (SB 1408) to the Senate Health and Human Services Committee's next meeting agenda. SB 1408 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 Texas. Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they provide a forum for patients, families, and experts across the state to analyze the needs of the community and make recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, or publish and compile resources related to rare diseases.

In creating this council, Texas will join twenty-four other states that have already enacted similar legislation in support of their rare disease community and have proven that an RDAC can be an invaluable resource. Those states are Alabama, Colorado, Connecticut, Florida, Georgia, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, we urge you to add SB 1408 to the Senate Health and Human Services Committee's next meeting agenda and help give a voice to all Texas residents living with rare diseases. For more information, please 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
Acid Maltase Deficiency Association (AMDA)
Aicardi Goutieres Syndrome Advocacy Association
The Akari Foundation
American Behcet's Disease Association
APS Foundation of America, Inc
BDSRA Foundation
CACNA1A Foundation, Inc.
Chris "CJ" Johnson Foundation Inc
Cystic Fibrosis Research Institute
Gene Giraffe Project
The Global Foundation for Peroxisomal Disorders
HCU Network America
Houston Sickle Cell Collaborative
Immune Deficiency Foundation
Infusion Access Foundation
International Foundation for Autoimmune & Autoinflammatory Arthritis
International Pemphigus Pemphigoid Foundation
Lennox-Gastaut Syndrome (LGS) Foundation

Lupus and Allied Diseases Association, Inc.
Lymphedema Advocacy Group
Myositis Support and Understanding
National Ataxia Foundation
National Niemann-Pick Disease Foundation
National Scleroderma Foundation, Texas Bluebonnet Chapter
National PKU Alliance
Neuropathy Action Foundation
Phelan-McDermid Syndrome Foundation
Sick Cells
Sickle Cell Association of Houston
Sickle Cell Association of Texas Marc Thomas Foundation
Siegel Rare Neuroimmune Association
SLC6A1 Connect
STXBP1 Foundation
SYNGAP1 Foundation
SynGAP Research Fund
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)
Texas Prader-Willi Association
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