Support for SB207 (Woods)
Establishing the Oklahoma Rare Disease Advisory Council

On behalf of the undersigned organizations representing individuals with rare diseases in Oklahoma, we urge your support of Senate Bill 207 (Woods). SB207 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.

Rare diseases are present across a broad spectrum of medical conditions. For patients living with one of the over 10,000 known 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. This lack of awareness often contributes to the obstacles to timely treatment and care faced by many rare disease patients.

Creating an RDAC in Oklahoma will give rare disease patients a unified voice in state government by serving as the advisory body on rare diseases to the Legislature and state departments. Additionally, the RDAC will be tasked with:

1. Convening public hearings and soliciting comments from the general public to gain an understanding of the rare disease landscape in Oklahoma;
2. Providing testimony and comments on pending legislation and regulations before the Legislature and other state agencies;
3. Consulting with experts on rare disease to develop policy recommendations to improve patient access to, and quality of, rare disease specialists and other needed services;
4. Establishing best practices and protocols to include in state planning related to natural disasters and public health emergencies;

5. Identifying areas of unmet need for research that can inform future studies and work done by the Council; and
6. Researching and identifying best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare disease in Oklahoma.

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 that Oklahoma's rare disease community faces. In addition, the RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Oklahoma government decisionmakers with one community voice.

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

Once again, on behalf of the undersigned organizations, we urge your support for SB207 and swift passage of the bill. For any questions, please feel free to contact Carolyn Sheridan with the National Organization for Rare Disorders via email at csheridan@rarediseases.org . Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
Adrenal Insufficiency United
AiArthritis
ALS Association
American Cancer Society Cancer Action Network
APS Type 1 Foundation, Inc.
Cystic Fibrosis Research Institute
Cystic Fibrosis United
Congenital Hyperinsulinism International
Dravet Syndrome Foundation
Epilepsy Foundation of Oklahoma
Fanconi Cancer Foundation
Friedreich's Ataxia Research Alliance
The Global Foundation for Peroxisomal Disorders
HCU Network America
International Pemphigus & Pemphigoid Foundation
KAT6 Foundation
Lupus and Allied Diseases Association
Lymphadema Advocacy Group
Mellie J Foundation
MLD Foundation
Myasthenia Gravis Association
National Fragile X Foundation
NEC Society

Oklahoma Hemophilia Foundation
Oklahoma Rare
Project Alive
Supporters of Families with Sickle Cell, Inc.
The Bonnell Foundation
The Ehlers-Danlos Society
The National Neimann-Pick Disease Foundation
United MSD Foundation