June 4, 2021

The Honorable Phil Murphy
Governor of New Jersey
Office of the Governor
P.O. Box 001
Trenton, NJ 08625

Re: Support for Assembly Bill 4016/Senate Bill 2682 - New Jersey Rare Disease Advisory Council

Dear Governor Murphy:

On behalf of the 28 undersigned organizations representing individuals with rare diseases in New Jersey, we urge you to sign Assembly Bill 4016 (A4016)/Senate Bill 2682
(S2682) into law. A4016/S2682 would establish a Rare Disease Advisory Council (RDAC) in the state which would give a voice to the estimated 1-in-10 individuals living with a rare disease in New Jersey. This legislation has passed both chambers of the New Jersey Legislature unanimously and has broad support from the rare disease patient community.

The New Jersey 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 New Jersey’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 New Jersey government decisionmakers with one community voice.

In creating this council, New Jersey 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 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.

On behalf of the undersigned organizations, we urge you to sign A4016/S2682 into law to support New Jersey 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
AliveAndKickn
Alliance for Patient Access
American Kidney Fund
APS Foundation of America, Inc
Children's Cardiomyopathy Foundation
Congenital Hyperinsulinism International
Consortium if MS Centers
Epilepsy Foundation New Jersey
Fabry Support & Information Group
Fighting H.A.R.D. Foundation
Global Healthy Living Foundation
Hemophilia Federation of America
Histiocytosis Association
Hypertrophic Cardiomyopathy Association
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
The Life Raft Group
Malan Syndrome Foundation
Movement Disorders Policy Coalition
National Coalition for Infant Health
National PKU News
New Jersey Association of Mental Health and Addiction Agencies, Inc.
Parent Project Muscular Dystrophy
Pink Oracle, A New Jersey Nonprofit Fighting for "ADA Access for All!"
Scleroderma Foundation
Sick Cells
The Sickle Cell Association of New Jersey
Vision Health Advocacy Coalition