NORD®
National Organization
for Rare Disorders

RARE NJ

May 23, 2023

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

Dear Governor Murphy:

On behalf of the 1-in-10 individuals in New Jersey living with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for signing Assembly Bill 4016 (A4016)/Senate Bill 2682 (S2682), legislation to establish a Rare Disease Advisory Council (RDAC), into law on June 30, 2021. The passage of this legislation demonstrates the strong commitment from the state of New Jersey to address the unique challenges faced by the rare disease community. However, we are concerned about the significant delay in establishing the RDAC due to the appointments that have not yet been made.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting more than 25 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 large 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.

The establishment of the RDAC is crucial to ensure that New Jersey remains at the forefront of rare disease advocacy, research, and healthcare. By bringing together experts from various fields, including patients, healthcare professionals, and researchers, the RDAC will provide valuable insights and recommendations to address the unmet needs of rare disease patients. Moreover, the council will enhance the coordination of efforts among different stakeholders, leading to more efficient use of resources and improved outcomes.

We understand that your office has the responsibility of appointing 20 members of the RDAC, and we respectfully request that you prioritize this process without further delay. By promptly appointing individuals with diverse perspectives and expertise, you will be taking a significant step towards fulfilling the vision set forth by the RDAC law. Moreover, it will demonstrate your commitment to the rare disease community and its urgent need for attention and action.

NORD stands ready to support your office in any way necessary to facilitate the appointment process. We have a vast network of individuals and organizations with extensive knowledge and experience in rare diseases who are eager to contribute their expertise to the RDAC. Together, we can make a meaningful difference in the lives of those affected by rare diseases in New Jersey.

In implementing this council, New Jersey would join twenty-five 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, Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

We kindly request a meeting with you or a representative from your office to discuss the importance of the RDAC and explore how we can collaborate to expedite the appointment process. We believe that by working together, we can ensure that the RDAC becomes an invaluable resource for the rare disease community in New Jersey.

Thank you for your attention to this urgent matter. We look forward to the opportunity to collaborate towards the establishment of the New Jersey Rare Disease Advisory Council. For further information and to follow up on meeting request, please contact me at HRoss@rarediseases.org

Sincerely,

Heidi Ross

Heidi Ross
Vice President, Policy and Regulatory Affairs
National Organization for Rare Disorders