NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

NORD CEO Statement: Navigating Proposed Policy Changes and Their Impact on Rare Disease Advocacy

There are several proposed policy changes occurring across government entities, many of which have the potential to impact the rare disease community. At the National Organization for Rare Disorders (NORD®), we remain steadfast in our commitment to advancing the needs of the more than 30 million Americans with rare diseases. As the leading independent, nonpartisan, nonprofit organization dedicated to rare disease advocacy, we recognize the importance of working with all stakeholders — government agencies, policymakers, researchers, industry leaders, and patient advocates — to ensure that individuals with rare diseases can access the necessary medical care, treatments, and innovations they deserve.

In times of change, the rare disease community's voice must remain at the forefront of discussions that shape policies impacting medical and scientific research and discovery as well as access to medical care and treatments. NORD is uniquely positioned to be the bridge between decision-makers and the real-world needs of individuals with rare diseases. Our role is to ensure that contemplated policy solutions prioritize continued progress in rare disease research and treatment development while upholding the principles of access, affordability, and innovation.

We will continue to advocate for the rights and needs of the rare disease community, and we welcome opportunities to engage with federal agencies, Congress, and the broader healthcare ecosystem to provide our expertise and insights. As a trusted thought leader in the rare disease space, we stand ready to collaborate, inform, and drive solutions that uphold our shared commitment to improving lives.

For more information on how NORD advocates for the rare disease community, visit NORD's Policy & Advocacy Page.

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