



Alone we are rare. Together we are strong.®

July 6, 2026

The Honorable Josh Stein  
Governor of North Carolina  
1 Edenton St  
Raleigh, NC 27601

**Re: Support for Senate Bill 257 (Jackson) – North Carolina Rare Disease Advisory Council**

Dear Governor Stein,

The National Organization for Rare Disorders ([NORD](#)) writes today on behalf of the 1-in-10 North Carolinians living with a rare disease to support the provisions of Senate Bill 257 relating to the North Carolina Rare Disease Advisory Council (RDAC). The changes in this bill will increase the powers and responsibilities of the Council and ultimately strengthen its ability to represent the rare disease community in the state. We ask you to sign this bill into law so that the Council can be best positioned to serve patients and families in North Carolina.

With over 10,000 known rare diseases, the rare disease community is incredibly diverse and faces a complex and multifaceted set of challenges. Unfortunately, a widespread lack of understanding of rare diseases often exacerbates these challenges due to policies that do not account for the needs of the community. RDACs are critical to closing the awareness gap in state governments because they create collaboration between patients, families, and other stakeholders, with lawmakers and government officials.

In 2015, North Carolina made history by being the first state to establish a Rare Disease Advisory Council, setting a standard that has led to the creation of councils in 33 states across the country. The provisions in Senate Bill 257, if enacted, will continue North Carolina's legacy of innovation in rare disease policy by expanding and strengthening the Council. The bill moves the advisory council to be housed within the Department of Health and Human Resources, giving the Council more direct access to policymakers and the Department's resources. It also grants the Council the ability to advise the Governor, Secretary, and General Assembly on issues facing the rare disease community and increases the representation of rare disease patients and caregivers among the Council's membership.

NORD deeply appreciates North Carolina's commitment to uplifting the voices of those affected by rare diseases and we are hopeful that you will continue this legacy with your signature on Senate Bill 257. If you have any questions, please contact Carolyn Sheridan at [csheridan@rarediseases.org](mailto:csheridan@rarediseases.org).

Thank you for your service to North Carolina.

Sincerely,

**Carolyn G Sheridan, MPH**  
Associate Director of State Policy

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