

1 Our Mission

The Rare & Ready Coalition is a network of rare disease organizations advancing policies to improve outcomes for people living with rare diseases.



2 Our Reach

115

non-profit members

66%

grew in 2025

200+

advocates activated
on important policy issues
throughout the year

3 Our Impact

Coordinated advocacy campaigns to oppose or amend state PDAB proposals that would restrict access to rare disease treatments.

Submitted letters urging passage of legislation to join the Interstate Medical Licensure Compact (IMLC).

Supported RUSP alignment legislation to ensure timely diagnosis for every newborn.

Championed legislation ensuring continuity of treatment by streamlining prior authorization.

4 Our Priorities

Expanding Newborn Screening for Timely Diagnosis



Approving Telehealth Across State Lines



Defeating Prescription Drug Affordability Board (PDAB) Legislation



Supporting Expanded Patient Access to Treatment

