

PROJECT RDAC YEAR ONE



OUR MISSION

A Rare Disease Advisory Council (RDAC) provides a platform to strengthen the voice of the rare disease community in state government. Through Project RDAC, the National Organization for Rare Disorders (NORD®) and our partners are working to optimize existing RDACs and increase the number of states with Councils to ensure the needs of the rare disease community are being met.

RESOURCES AND HIGHLIGHTS



3 TOOLKITS AND CORRESPONDING WEBINARS

Topics covered include:
Coalition Building, Legislative Advocacy, and Implementation



2 STAKEHOLDER MEETINGS



4 RDAC LEADER WORKSHOPS



A NORDPOD™ PODCAST EPISODE

Ranked in the top 20% of shows when published with listenership still growing.



There's still more to do to give the rare disease community a strong voice in state policy decision-making. To get involved in NORD's efforts, contact RDAC@rare diseases.org or visit: rare diseases.org/projectrdac.

STATE ACTION AND IMPACT

(Through October 2021)

52	RDAC Coalition Meetings
201	Patient Organizations Engaged
254	Legislators Contacted with Action Alerts
114	Testimonies and Letters of Support
11	RDAC Bills Introduced
7	New RDACs Signed into Law

21 TOTAL RDACS SIGNED INTO LAW TO BENEFIT THE RARE DISEASE COMMUNITY

