

A **Rare Disease Advisory Council (RDAC)** is a state-level body that brings together stakeholders from across the rare disease landscape—patients, caregivers, clinicians, researchers, industry leaders, and public health officials—to advise state government on how to improve care, services, and policies for individuals living with rare diseases.

RDACs serve as a critical bridge between the rare disease community and policymakers, ensuring that lived experiences and expert insights inform state-level decisions on healthcare access, insurance coverage, public health planning, emergency preparedness, and more.

Why Every State Should Create, Maintain, and Fund an RDAC

There are more than 10,000 known rare diseases affecting over 30 million Americans—yet most of these conditions are poorly understood, underdiagnosed, and often overlooked in health policy decisions. RDACs are essential because they:

- **Give Patients a Voice in Government:** RDACs ensure that individuals and families affected by rare diseases are represented in state health planning and legislative priorities.
- **Identify Gaps in Care:** From delayed diagnoses to lack of specialists, RDACs surface real-world challenges and propose solutions tailored to each state.
- **Promote Equity:** By including voices from diverse communities and geographies, RDACs help states identify disparities and create more inclusive systems of care.
- **Advise on Key Policies:** RDACs often provide guidance on newborn screening, Medicaid coverage, drug affordability boards, emergency response, and provider education.
- **Strengthen Collaboration:** They bring together cross-sector stakeholders to align efforts and maximize impact in rare disease advocacy and innovation.
- **Bridges Knowledge Gaps:** There are over 10,000 rare diseases affecting 10% of the U.S. population, yet most state policymakers lack direct insight. RDACs close that gap.
- **Improve Patient Outcomes:** By highlighting delays in diagnosis, specialist shortages, high out-of-pocket costs, treatment accessibility—RDACs can shape better-informed policy.
- **Promote Equity:** They foster geographically, demographically, and professionally diverse perspectives so all communities are represented.
- **Legislative and Clinical Impact:** Many states require RDACs to publish findings and recommendations annually, ensuring transparently guiding legislative and regulatory decisions.
- **Disaster & Pandemic Planning:** RDACs ensure the rare-disease perspective is included in emergency preparedness.
- **Public Education & Provider Training:** They build curricula, webinars, and public campaigns to educate both clinicians and families.

How Many RDACs Are There in the U.S.? As of mid-2025:

- 32 states have either established a Rare Disease Advisory Council or passed legislation to create one.
- Additional states are in the process of proposing or organizing RDACs with support from advocates and national organizations.

Summary

What is an RDAC?	A state-level advisory council focused on rare disease issues
Why it matters	Brings patient voices into policy decisions, improves care equity, and identifies barriers
U.S. landscape	32 states have established RDACs; others are advancing similar legislation
Who benefits?	Over 30 million Americans living with 10,000+ rare diseases

Bottom line: RDACs are a proven, cost-effective way to ensure that no rare disease community is left behind. Every state should not only establish one—but also provide the sustained funding and support needed to ensure these councils can meaningfully impact public health policy.

