RARE DISEASE ADVISORY COUNCILS (RDAC)

NORD®
National Organization for Rare Disorders

NORD is working to establish well-organized, high-functioning Rare Disease Advisory Councils in every state to support the needs of the rare disease community.

An estimated 25-30 million Americans are living with a rare disease; that is close to one in ten people. Yet, with over 7,000 known unique rare diseases, it is difficult for state policymakers and government officials to have an in-depth understanding of the entire rare disease community. This lack of awareness contributes to common obstacles that rare disease patients face, such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs and limited access to medical specialists.

Rare Disease Advisory Councils (RDACs) demonstrate enormous promise to address these barriers for the rare disease community. With diverse membership and broad community support, RDACs can be a valuable resource for state governments as our health care system continues to advance. Without RDACs in place, state laws and regulations that affect the rare community will continue to be developed without the consultation of rare disease stakeholders, often leaving this vulnerable population at greater risk for poor health and economic outcomes. With strong RDACs, government officials and the rare disease community can partner together to develop the resources necessary to prevent and address barriers in a strategic way that allows states and their citizens to thrive.

In 2015, the first RDAC was created in North Carolina by patients, caregivers, families, and providers. Since then, rare disease advocates and stakeholders have sought councils in other states to help better represent their communities.

WHAT SHOULD YOU KNOW ABOUT CALIFORNIA'S RDAC EFFORT:

Senate Bill 247 has been introduced by Senator Susan Eggman.

SB 247 will require the RDAC to:

- **Coordinate statewide efforts to study the incidence of rare diseases;**
- **Act as the advisory body on rare diseases to the Legislature, and state departments, that provide service to, or that are charged with the care of, persons with rare diseases; and**
- **Serve as an expert advisory committee to the Medi-Cal Drug Use Review Board.**

Email us at RDACs@rarediseases.org to get involved in the effort to get SB 247 signed into law!

It's estimated that
25-30
MILLION AMERICANS
(almost 1 in 10) have rare diseases

More than
90%
of rare diseases are without an FDA-approved treatment.

Alone we are rare. Together we are strong.®

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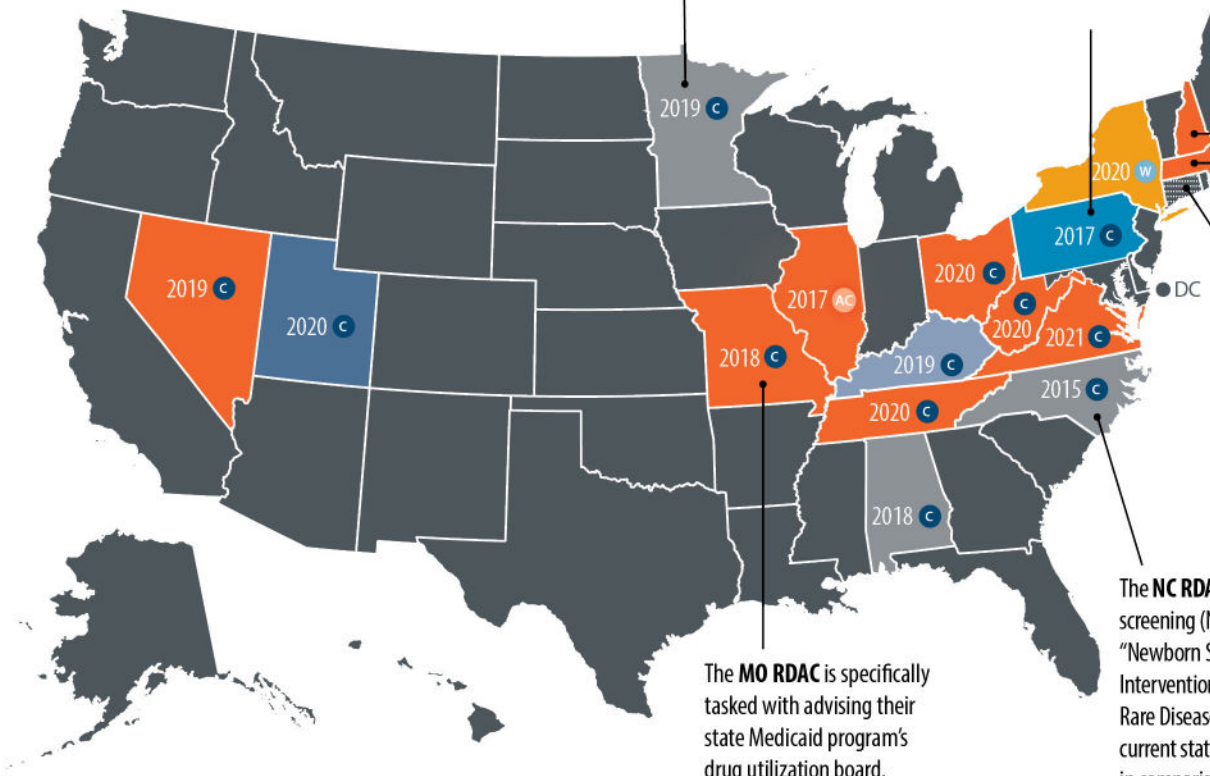
STATES THAT HAVE ENACTED RDACS (AS OF APRIL 2021)

The **MN RDAC** established a Council Administrator to help drive consensus and action.

The **PA RDAC** has completed two annual reports on the state of rare disease and the barriers to diagnosis, treatment and insurance coverage. In addition, the council keeps in close touch with the rare community via a public Facebook page and website.



The **CT RDAC** was a temporary taskforce that held useful open forums for state agencies and others in the community to share feedback and learn about existing resources.

The **NC RDAC** completed a newborn screening (NBS) white paper titled "Newborn Screening and Early Intervention for the Treatment of Rare Diseases," which analyzed the current status of NBS in North Carolina in comparison to other states and identified future opportunities for improvement.

The **MO RDAC** is specifically tasked with advising their state Medicaid program's drug utilization board.

NORD launched Project RDAC in November 2020 to optimize existing RDACs and help more states enact RDAC legislation. Through this work, NORD will develop tools and resources to help RDACs at every step of their journey based on feedback from the existing RDACs and rare disease community. Please check back here for additional information and updates on the project. For more, visit: **rarediseases.org/rdac-overview**

HOUSED BY:

- Department of Health
- University
- Grantee from Department of Health
- Outside Nonprofit
- Department/Caucus
- Department of Health and Department of Financial Services

TYPE:

- C Council
- AC Advisory Commission
- CB Committee to DUR Board
- TF Task Force
- W Work Group
- RDAC Sunset

NORD: Fighting for the rare community every day for more than 38 years.

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

The mission of NORD's Rare Action Network® (RAN) is to connect and empower a unified network of individuals and organizations with the tools, training, and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. To join RAN, go to **rareaction.org.**

For more information on Rare Disease Advisory Councils or NORD, please contact RDAC@rarediseases.org.

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