Rare Disease Advisory Councils (RDAC)

NORD®
National Organization
for Rare Disorders

The National Organization for Rare Disorders (NORD®) is working to establish Rare Disease Advisory Councils in every state through Project RDAC.

Learn more below and at ***rarediseases.org/rare-disease-advisory-councils****.*

Currently, there are thirty-two states that have created legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource.

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 is an RDAC?

An RDAC is a state-level advisory body that gives the rare disease community a stronger voice in state government. RDACs address the needs of rare disease patients and families by giving stakeholders an opportunity to share experiences and steer discussions that develop solutions to the issues faced within our community each day.

What is the purpose of an RDAC?

With over 10,000 known unique rare diseases, it is difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness contributes to the obstacles that rare disease patients and their loved ones face. RDACs can use their diverse membership and broad community support to identify barriers and propose solutions to help the rare disease community.

How are RDACs organized?

RDACs are organized differently in each state. Some of the distinguishing features include the type of entity that houses the RDAC, the composition and size of the council, and the duties and accountability requirements of the council.

Who serves on an RDAC?

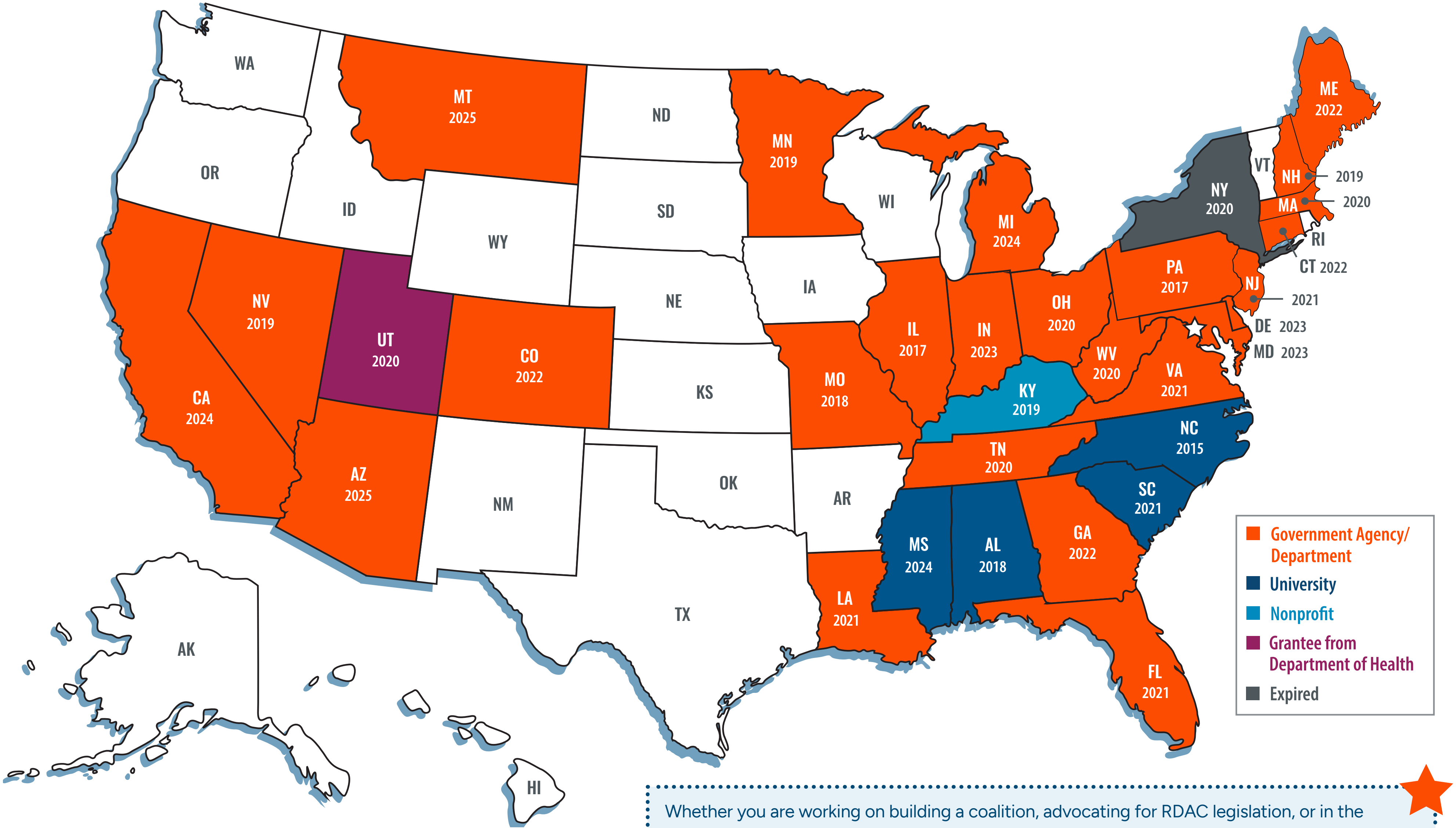
RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials.

How do RDACs help the rare disease community?

RDAC responsibilities vary by state and are tailored to meet state and local needs. In some states, RDACs are conducting surveys to better understand common challenges rare disease patients or caregivers face, consulting with experts to improve access to and quality of care, and/or publishing a list of rare disease resources available in the state on their website.

States That Have Created an RDAC as of May 2025

Currently 32 states have created an RDAC.



Whether you are working on building a coalition, advocating for RDAC legislation, or in the process of implementing a new RDAC law, NORD has helpful tools to guide you every step of the way. Visit **rarediseases.org/rare-disease-advisory-councils** for toolkits, webinars, and more!

For more information on Project RDAC, please contact RDAC@rarediseases.org.

NORD: Fighting for the rare community every day for over 40 years. NORD is improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD is a registered 501(c)(3) charity organization. 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. ©2024 NORD. All rights reserved. NORD®, its icon, tagline, RAN and the Rare Action Network are registered trademarks of the National Organization for Rare Disorders. NRD-2301

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