

RARE DISEASE ADVISORY COUNCILS (RDAC)



The National Organization for Rare Disorders (NORD®) is working to establish high-functioning Rare Disease Advisory Councils in every state through Project RDAC. Learn more below and at rarediseases.org/projectrdac.

Currently, there are twenty-one states that have enacted 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 an advisory body that gives the rare community a stronger voice in state government. RDACs address the needs of rare disease patients and families by giving stakeholders an opportunity to raise awareness and make formal recommendations to state leaders on the most important issues they face.



What is the purpose of an RDAC?

With over 7,000 known unique rare diseases, it is difficult for state government officials to have an in-depth understanding of the rare disease communities 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.



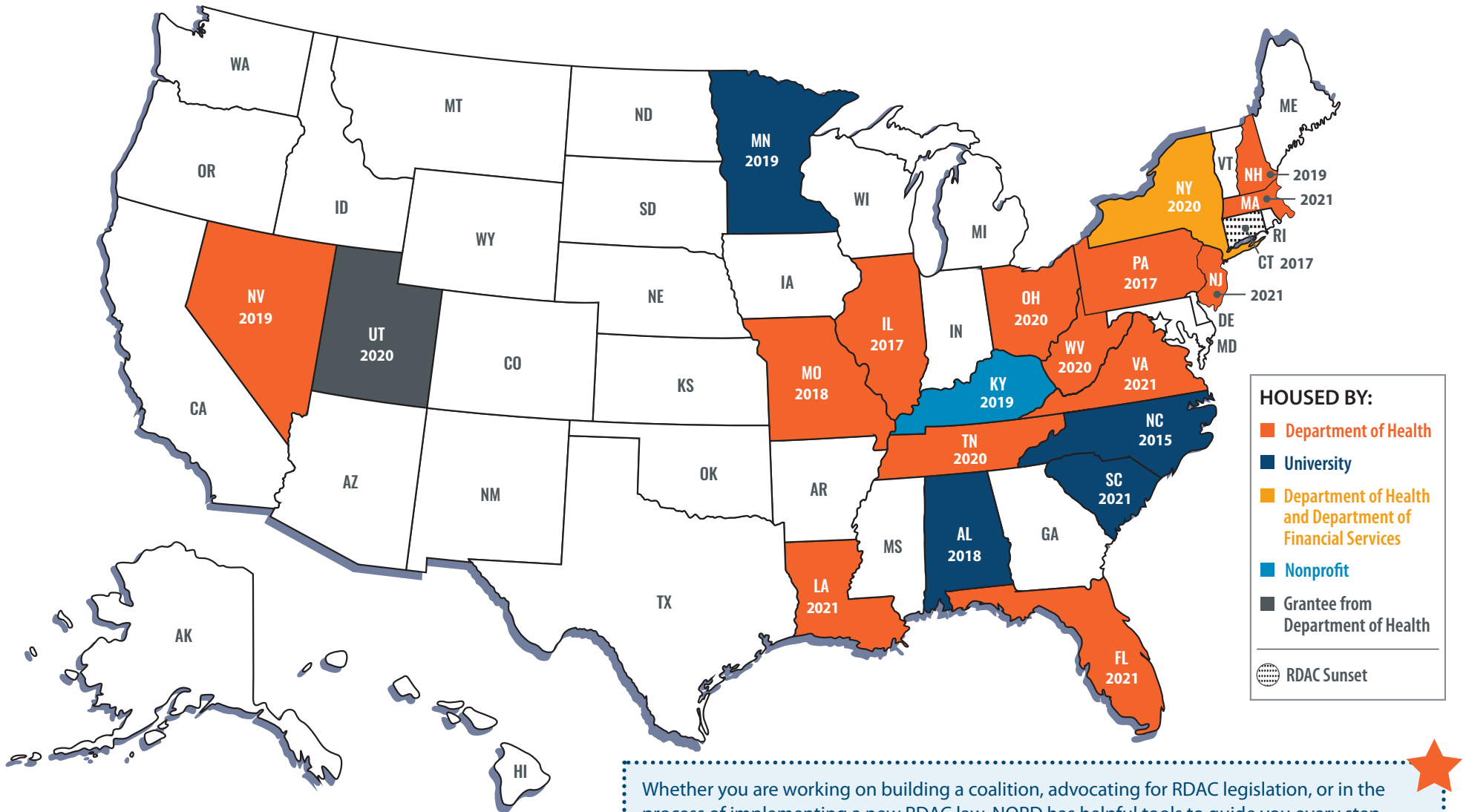
How do RDACs help the rare disease community?

RDAC responsibilities vary by state and should be tailored to meet state needs. RDACs help their local rare disease community in a variety of ways, including by 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 publishing a list of rare disease resources available in the state on their website.

Alone we are **rare**. Together we are strong.®

rareaction.org
rarediseases.org

STATES THAT HAVE ENACTED RDACS (AS OF SEPTEMBER 2021)



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/project-rdac-resources 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 nearly 40 years. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient support services. NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. 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. ©2021 NORD. All rights reserved. NORD®, its icon, tagline and the Rare Action Network are registered trademarks of The National Organization for Rare Disorders. NRD-2200