

RARE DISEASE ADVISORY COUNCILS (RDAC)



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 NEW JERSEY'S RDAC EFFORT:

Assembly Bill 4016 /Senate Bill 2682 has been introduced by Senator Vin Gopal, Senator Tom Kean Jr., Assemblyman Ronald Dancer, Assemblyman Daniel Benson, and Assemblyman Anthony Verrelli.

A4016/S2682 will require the RDAC to:

- Conduct a study on issues relating to the quality of and access to treatment services for rare disease patients.
- Establish best practice standards to share with health care providers to inform them of effective ways to recognize and treat rare diseases.
- Develop strategies to raise public awareness of rare diseases in the state.

Email us at RDAC@rarediseases.org to get involved in the effort to get **A4016/S2682** signed into law!

It's estimated that

25-30
MILLION AMERICANS

(almost 1 in 10) have rare diseases



More than

90%

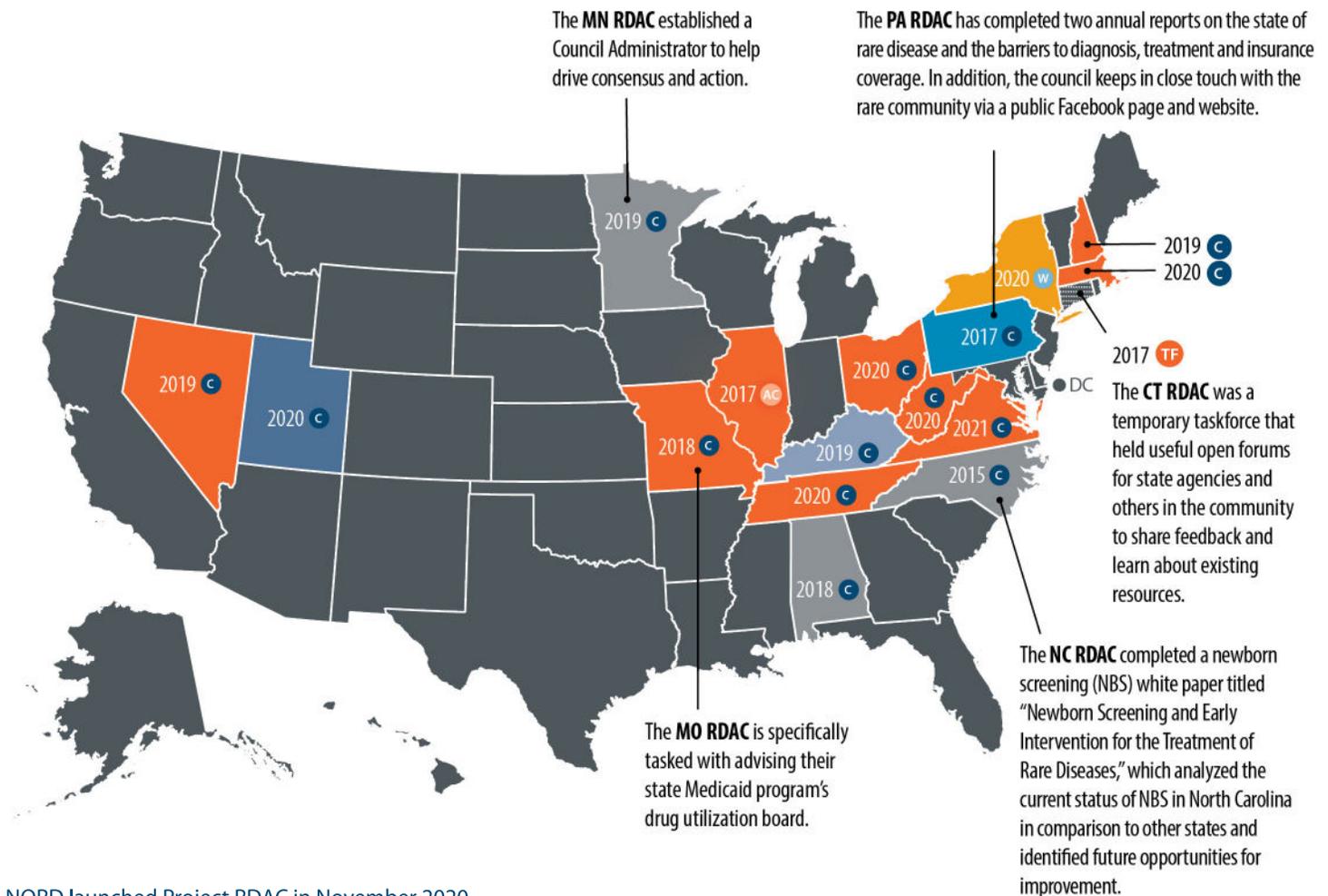
of rare diseases are without an FDA-approved treatment.



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

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STATES THAT HAVE ENACTED RDACS (AS OF APRIL 2021)



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

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.