NEVADA RDAC FEB 2024

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National Organization for Rare Disorders

NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

National Organization for Rare Disorders ® Mission Statement

We improve the health and well-being of people with rare diseases by driving advances in care, research and policy.

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Our 40-Year History

We are rooted in the advocacy that spurred a movement resulting in the passage of the world's first law incentivizing drug development for rare diseases— the Orphan Drug Act of 1983.

NORD is the only independent and nonpartisan U.S. organization working at the intersection of care, research, policy, and community for all rare diseases.

- We work with national and local decision-makers to advance the following priorities:
- New and Better Therapies
- Access and Affordability of Prescription Drugs
- Comprehensive Health Insurance
- Expanding Telehealth Services
- Strengthening Polices to Support Timely Diagnosis – including newborn screening!

Rare Disease Advisory Councils (RDAC)

A Rare Disease Advisory Council (RDAC) is an advisory body that gives a platform for the rare community to have a stronger voice in state government.

- RDACs address the needs of rare patients and families by giving stakeholders an opportunity to make recommendations to state leaders on critical issues including the need for increased awareness, diagnostic tools and access to affordable treatments and cures.
- NORD's role once an RDAC is established is to provide resources and support as they carry on their work.

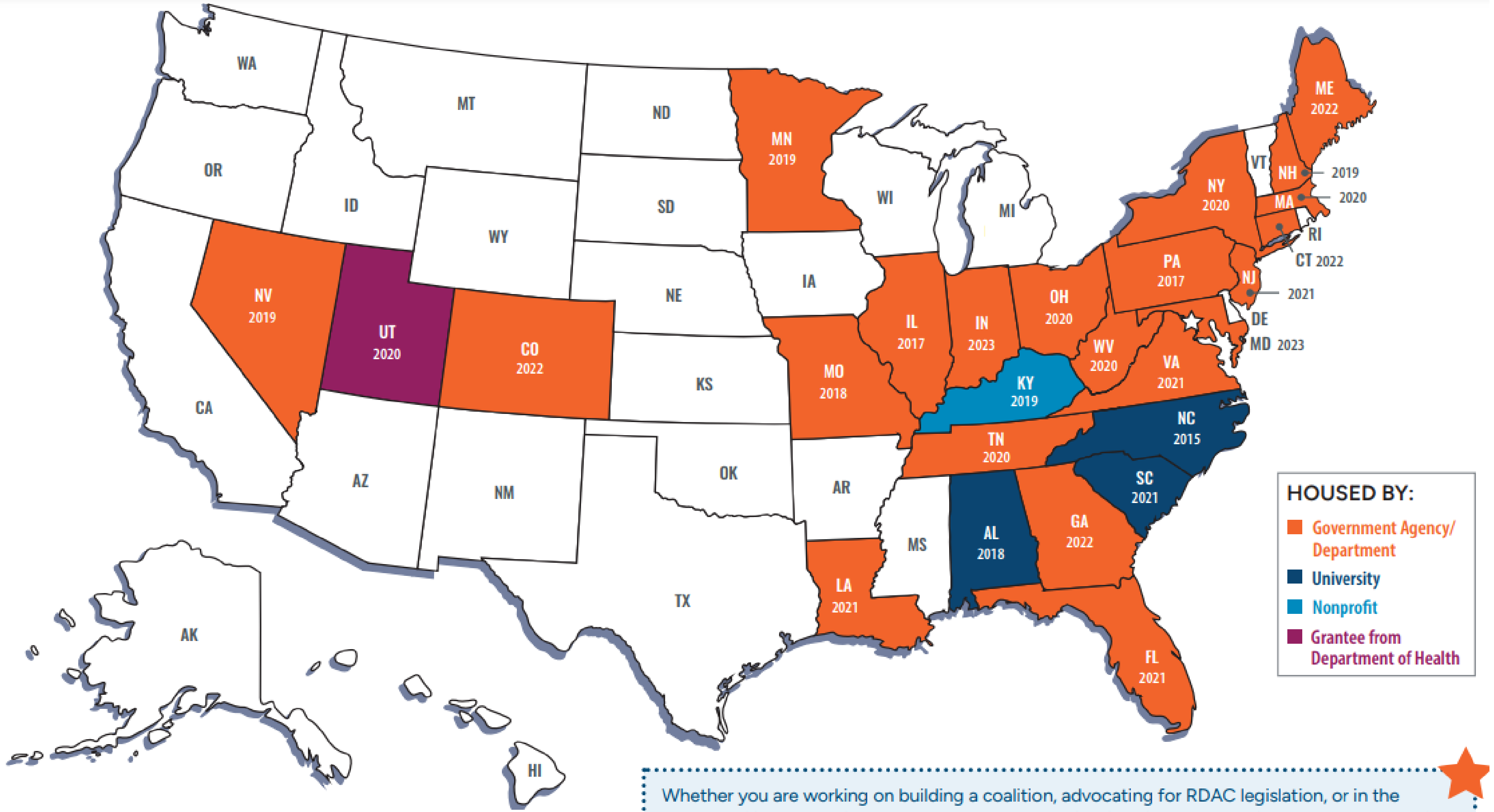
NORD's Project RDAC

GOAL: Optimize existing Rare Disease Advisory Councils (RDACs) and increase the number of RDACs across the country

- Develop resources to guide RDACs at every step of the process:
    - Model Language
    - Webinars and Workshops
    - Toolkits
- Organize diverse coalitions of rare disease community stakeholders in support of establishing new RDACs
- Support existing RDACs in fulfilling their duties
- Create opportunities for existing RDACs to collaborate with each other

Current State of the Union

As of December 2023, there are 27 states with a Rare Disease Advisory Council (RDAC).



Whether you are working on building a coalition, advocating for RDAC legislation, or in the

RDAC In-Person Meeting

In conjunction with Summit in October 2023, NORD® hosted the first in-person gathering of representatives from Rare Disease Advisory Councils across the Country!

- 17 of 27 state RDACs represented
- Robust open discussion period
  - Funding
  - Open Meeting Law
  - Drafting high-quality surveys
- Stakeholder engagement

Newborn Screening and NORD's State Report Card

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NORD’s State Report Card

Latest edition of NORD’s State Report Card is live on our website now! rarediseases.org/driving-policy/nord-state-report-card/

Covers state policies across nine categories:

- Medicaid financial eligibility
- Medical nutrition
- Newborn screening
- Protecting patients in state Medicaid programs
- Protecting patients in state-regulated insurance
- Rare Disease Advisory Councils
- Step therapy
- Telehealth
- Prescription drug out-of-pocket costs

NORD’s State Report Card®

Since 1983, NORD has worked to ensure that the voice of the rare disease patient has been front and center when important policy and regulatory decisions have been made at both the federal and state levels. NORD began when a group of parents of children with rare diseases came together to advocate for the passage of the Orphan Drug Act of 1983 (ODA).

In 2015, NORD launched its State Report Card project with a goal of evaluating how effectively states are serving people with rare diseases. It is important to note, however, that these issues are not exhaustive. The issues contained herein touch on several critical and relevant policy areas at the state level, but with each issue included, there are still many others that are capable of impacting the lives of rare disease patients.

The Issues

Click to learn more:

The State Report Card is updated each year and was published this week. This coincides with the start of many state legislative sessions!

Click Nevada’s box to be brought to the State’s specific report.

On this page:

- Detailed report card, including the grades for each sub-category that contributes to the overall issue-area grade.
- Links to additional resources.

Click the NORD Report Card box to be brought to the Report Card landing page.

On this page:

- Overview of the NORD Report Card
- Links to the dedicated page for each issue area states are graded on.
- Within each issue area, a nationwide view of the grades for each state, evaluation criteria, and NORD’s position.

NORD supports robust, well-funded newborn screening programs in every state

- Newborn screening (NBS) traces its origins to the 1960s, when Dr. Robert Guthrie developed a blood test to screen newborns for phenylketonuria (PKU) shortly after birth and before showing any symptoms
- Since the 1960s, NBS programs have been established in every state and territory throughout the United States
- Currently, approximately four million babies are screened annually for at least 31 serious disorders that can be detected at birth.
- Of those four million newborns screened, over 12,000 are found to have a disorder that, if left undiagnosed and untreated, would cause severe developmental disability or death

Nevada’s NBS Program

- Currently, Nevada scores a B grade on Newborn Screening on NORD’s State Report Card
    - States are graded on 4 categories related to NBS and the grades are averaged for an overall grade
- 58 Conditions are screened in Nevada, and the state tests for 32 of the 37 conditions on the Recommended Uniform Screening Panel (RUSP)
- The Newborn Screening Program is supported entirely with fees generated by birth registrations
- States with A grades screen more (or all) RUSP conditions, add RUSP conditions with an effective and efficient process, control funding streams for the NBS program, and/or have an effective NBS advisory committee.

Thank You!

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