



NATIONAL POLICY & ADVOCACY TASKFORCE MEETING

February 7, 2023



MEETING AGENDA

- Housekeeping Items
- Introduction to NORD's Policy Team
- Policy & Advocacy Taskforces Overview
- NORD's 2023 Advocacy Agenda
- State Report Card Highlights
- Your Role as an Advocate
- Questions & Wrap-Up
- Group Photo

The National Organization for Rare Disorders (NORD) is the leading independent patient advocacy organization representing all individuals and families affected by rare diseases in the United States.

WHO IS NORD?

MISSION

The mission of NORD is to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy.

VISION

Across NORD, we adhere to a shared vision that guides our efforts to help improve the health and wellbeing of people with rare diseases.

VALUES

Compassion, Integrity, Innovation, Inclusion, Collaboration

MEET THE NORD POLICY TEAM



Heidi Ross, MPH
Vice President, Policy &
Regulatory Affairs



Karin Hoelzer, DVM, PhD
Director, Policy &
Regulatory Affairs



Corinne Alberts, MPP
Associate Director,
Policy



Allison Herrity, MPH
Policy Analyst



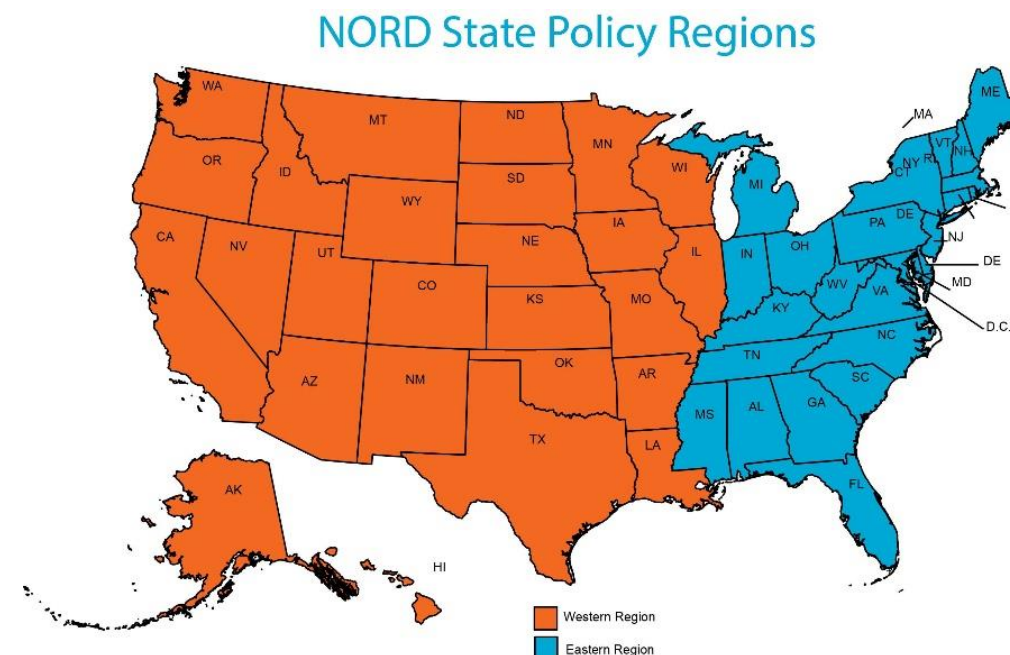
Annissa Reed, MPH
State Policy Manager,
East Coast



Alyss Patel
State Policy Manager,
West Coast



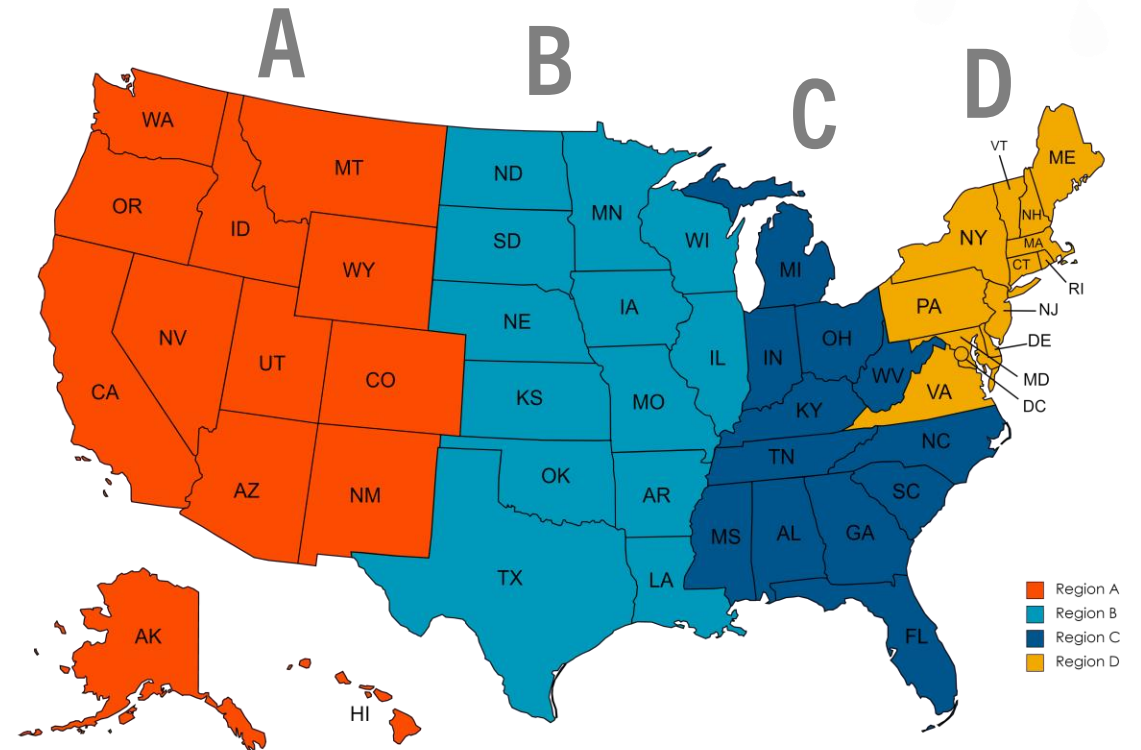
Hayley Mason, MPA
Policy Analyst



NORD'S POLICY & ADVOCACY TASKFORCES



National Taskforce focused on federal policy



Four Regional Taskforces focused on state and local policy

SHORT TERM GOALS

- Grow our movement and engage a greater number of advocates to push for meaningful policy change.
- Help you connect with your elected officials.
- Deliver frequent advocacy opportunities and ways to get involved (we will provide at least one action alert every month).
- Facilitate media opportunities to highlight your advocacy efforts and bring attention to rare disease policy priorities.
- To answer your questions and help you succeed as an advocate.

LONG TERM GOALS

- Drive change and awareness that help make rare diseases a national priority.
- Help you build lasting, productive relationships with your elected officials.
- Prepare and train our community's next generation of advocates.
- Successfully leverage our collective influence and impact to pass legislation that benefits rare patients and families.

REGIONAL POLICY & ADVOCACY TASKFORCES

- Four Regional Taskforces focused on state and local policy
- Five meetings per year
- Aim to facilitate collaboration between states in the same region
- Each Region has two volunteer co-chairs
 - Co-chairs will serve a one-year term
 - Still seeking one co-chair each for Regions A & B!





Washington, Oregon, California, Idaho, Nevada, Utah,
Arizona, Montana, Wyoming, Colorado, New Mexico,
Alaska, Hawaii

REGION A VOLUNTEER CO-CHAIRS



Nick Kirchhof
Colorado



TBD



North Dakota, South Dakota, Nebraska, Kansas,
Oklahoma, Texas, Minnesota, Iowa, Missouri, Arkansas,
Louisiana, Wisconsin, Illinois

REGION B VOLUNTEER CO-CHAIRS



Andrew Larcher
South Dakota



TBD



Michigan, Indiana, Ohio,
Kentucky, West Virginia,
Tennessee, North Carolina,
South Carolina, Mississippi,
Alabama, Georgia, Florida

REGION C VOLUNTEER CO-CHAIRS



Pam Judge
Ohio



Aaron Blocker
Mississippi

REGIONAL POLICY & ADVOCACY TASKFORCES

Virginia, District of Columbia,
Maryland, Delaware, New Jersey,
Pennsylvania, New York, Connecticut,
Rhode Island, Massachusetts,
Vermont, New Hampshire, Maine



REGION D VOLUNTEER CO-CHAIRS



Julie Raskin
New Jersey



Tai Pasquini
Massachusetts

2023 TASKFORCE MEETING SCHEDULE



REGIONAL MEETINGS

- Week of February 20
- Week of April 3
- Week of June 26
- Week of October 9
- Week of December 11

NATIONAL MEETINGS

- February 7
- May 23
- September 12
- December 5

FEBRUARY REGIONAL MEETING DATES

REGION A

Tuesday 2/21 at 12 PM MST (11 AM PST)

REGION B

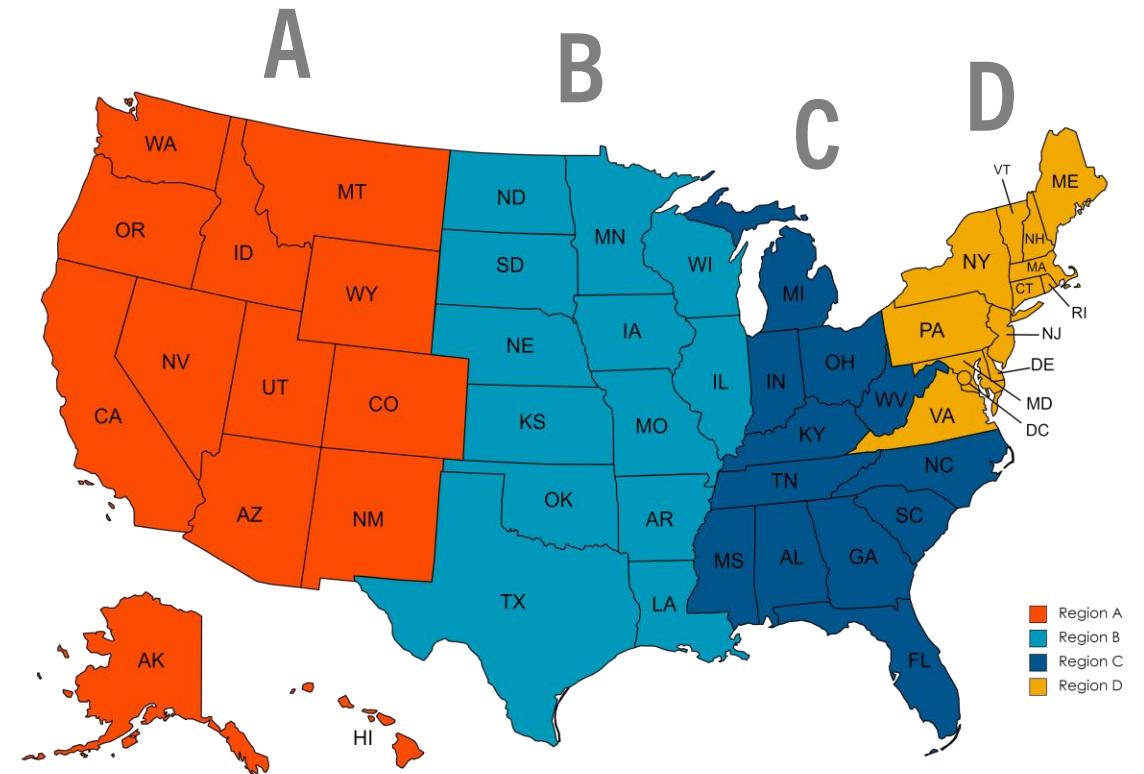
Thursday 2/23 at 12 PM CST (11 AM MST)

REGION C

Wednesday 2/22 at 9 AM EST (8 AM CST)

REGION D

Wednesday 2/22 at 12 PM EST





TELEHEALTH

- Interstate Medical Licensure Compact
- Federal telehealth legislation



STEP THERAPY

- Step therapy protections in target states
- Safe Step Act



GENETIC TESTING

- Expand access to genetic testing
- Grow the genetics workforce



MEDICAID

- Medicaid expansion in target states
- Accelerating Kids' Access to Care Act



NEWBORN SCREENING

- Protecting newborn screening programs at the state level



RARE DISEASE ADVISORY COUNCILS

- Give the rare disease community a voice in state government

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 STATE REPORT CARD

How does your state measure up?

Select your state to learn more:

SELECT A STATE

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:

 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 (Fail First)	 Telehealth	 Prescription Drug Out-of-Pocket Costs

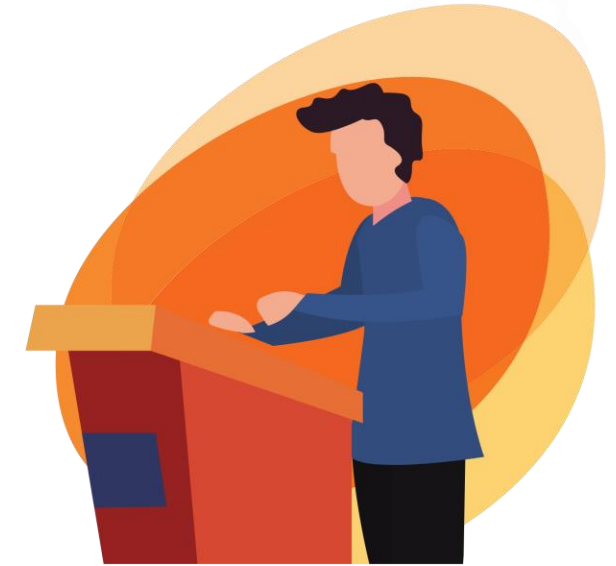
Patient Stories

2022 - HIGHLIGHTS

- Four states signed step therapy reform legislation into law
- Four states enacted legislation to create a RDAC, bringing the total number of states up to 24
- All 50 states and the District of Columbia screen for at least 31/37 conditions on the Recommended Uniform Screening Panel
- Four new states joined the Interstate Medical Licensure Compact, a step toward expanding telehealth access across state lines
- Twelve states expanded Medicaid eligibility for low-income residents
- Several states saw their grade improve for prescription drug out-of-pocket costs by passing copay accumulator legislation or adopting standard benefit design

HOW YOU CAN GET INVOLVED

- Action alerts
- Providing testimony during a hearing
- Submitting written testimony
- Sharing your story with NORD and your elected officials
- Meeting with your elected officials
- Speaking with media outlets or writing an opinion piece
- Sharing your ideas for advocacy opportunities and policy with NORD
- Helping to engage other advocates



SHARE YOUR STORY WITH YOUR ELECTED OFFICIALS

- The first step in developing a working relationship with your elected officials is **sharing your story**
- Introduce yourself and tell them **why you care** about rare disease policy
- NORD has created action alerts to help you easily contact your members of Congress



EXAMPLE:

“Shortly after birth I was diagnosed with a rare condition called isovaleric acidemia through newborn screening. My body can’t break down the amino acid leucine, so I get most of my nutrition through specialized formula. Without access to appropriate medical nutrition products, I could face brain damage or worse. I care about rare disease policy because newborn screening saved my life and medical nutrition legislation has the potential to eliminate a significant financial burden for me and my family.”

NEXT STEPS

- You will receive a follow up email in the next 48 hours with:
 - A Zoom recording of this meeting
 - An action alert to introduce yourself to and share your story with your elected officials
 - A sign-up form for the first set of Regional Taskforce meetings
- If you have unanswered questions, know of any bills we should be tracking, or have advocacy opportunities you'd like to share, email the NORD policy team at policy@rarediseases.org
- Thank you for joining! We know that by working together we can accomplish great things. We are looking forward to working with you all to improve the lives of rare patients and their families

FEBRUARY 28TH IS RARE DISEASE DAY!

There are several ways you can celebrate Rare Disease Day:

- Find an event near you
- Light it up for rare
- Share your support on social media
- Show your stripes
- Share your story with NORD



RARE DISEASE DAY®

[www.rarediseases.org/
rare-disease-day/](http://www.rarediseases.org/rare-disease-day/)



QUESTIONS?

Thank you.

