



NATIONAL POLICY & ADVOCACY TASKFORCE MEETING

May 23, 2023



MEETING AGENDA

- Housekeeping Items
- Introduction to NORD's Policy Team & Our Volunteer Co-Chairs
- Policy Updates & Year-to-Date Highlights
- How to Have an Effective Meeting
- Panel Discussion
- Policy & Advocacy Taskforce Slack

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.

MEET THE NORD POLICY TEAM



Heidi Ross, MPH
Vice President, Policy &
Regulatory Affairs



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



Allison Herrity, MPH
Policy Analyst



Hayley Mason, MPA
Policy Analyst



Annissa Reed, MPH
Associate Director of State
Policy



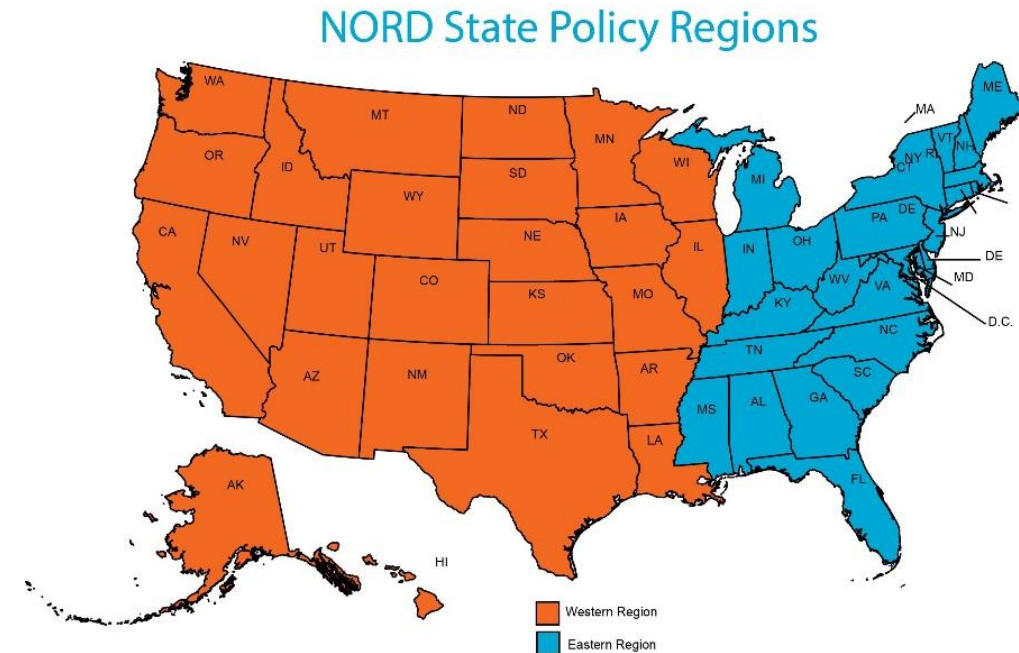
Mason Barrett
Policy Analyst



Supraja Sowmiyanarayanan
Program Assistant



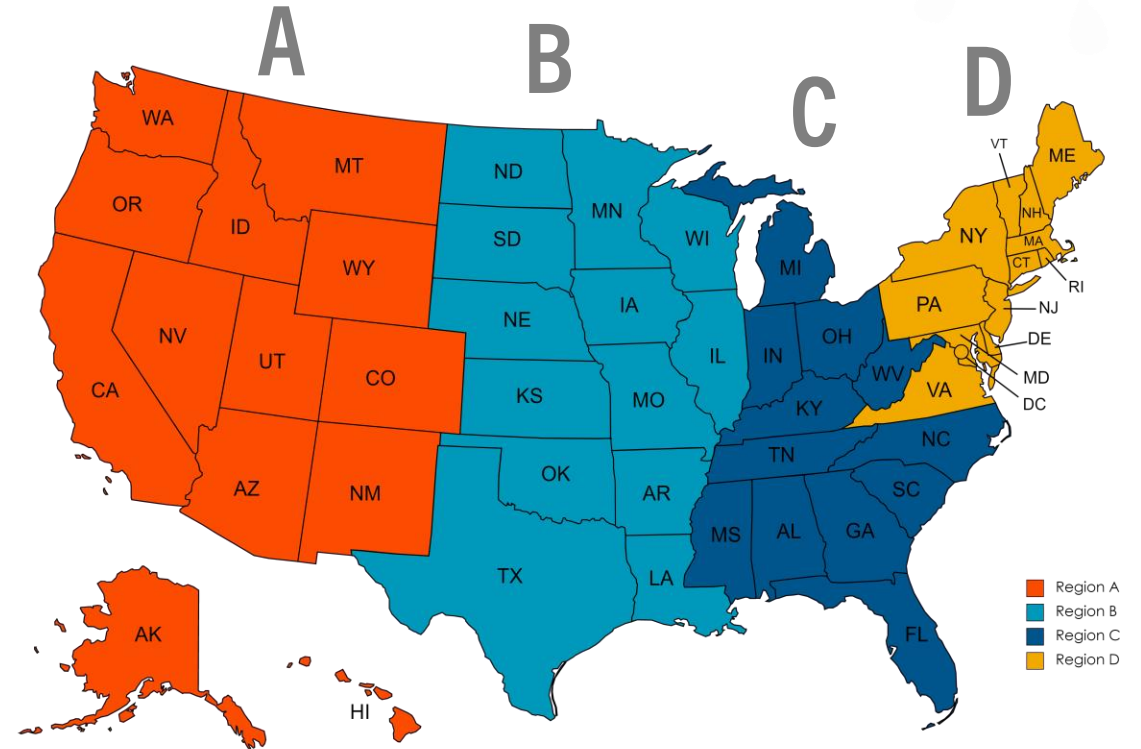
Joining Soon!
State Policy Manager,
Eastern Region



NORD'S POLICY & ADVOCACY TASKFORCES



National Taskforce focused on federal policy



Four Regional Taskforces focused on state and local policy

2023 TASKFORCE MEETING SCHEDULE



REGIONAL MEETINGS

- Week of June 26
- Week of October 9
- Week of December 11

NATIONAL MEETINGS

- September 12
- December 5

JUNE REGIONAL MEETING DATES

REGION A

Wednesday 6/28 at 1 PM MST (12 PM PST)

REGION B

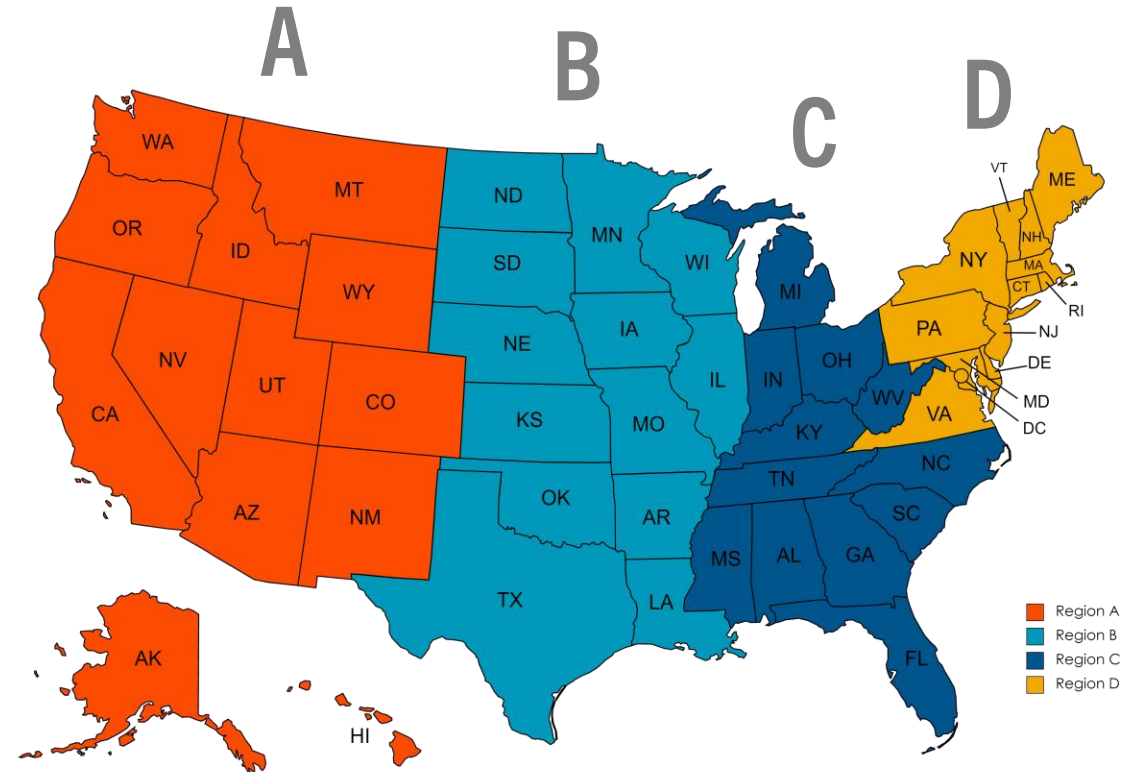
Thursday 6/29 at 2 PM CST (1 PM MST)

REGION C

Monday 6/26 at 12 PM EST (11 AM CST)

REGION D

Thursday 6/29 at 11 AM EST



REGION A

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



Nick Kirchhof
Colorado



Kellie Herbert
Colorado



Melanie Flood
California

REGION B

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



Andrew Larcher
South Dakota



Breana Bagley
Illinois



Nicole Ivelic
Illinois

REGION C

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



Pam Judge
Ohio



Jeron Hill
North Carolina



Aaron Blocker
Mississippi

REGION D

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



Julie Raskin
New Jersey



Barbie Ann Stephen
Maryland



Tai Pasquini
Massachusetts

RARE DISEASE POLICY UPDATES

TELEHEALTH

- Hawaii passed Interstate Medical Licensure Compact legislation earlier this month
- Active IMLC legislation in Missouri, North Carolina, Massachusetts, and New York
- Looking to expand our engagement on telehealth legislation beyond the IMLC
- DEA remote prescribing proposed rule



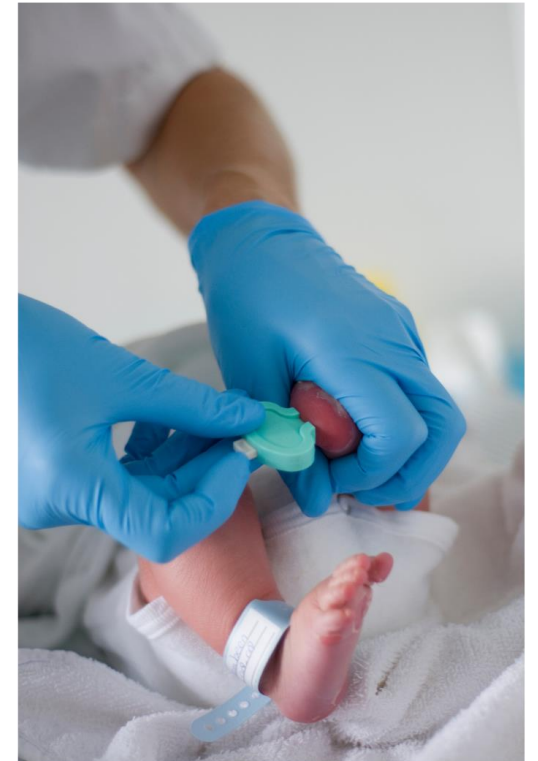
STEP THERAPY

- House and Senate versions of the Safe Step Act have been reintroduced in Congress (H.R. 2630/S.652)
- Language from the Safe Step Act was included in legislation that advanced out of the Senate Health, Education, Labor, and Pensions Committee on May 11



NEWBORN SCREENING

- Working with NBS Braintrust on strategy around federal newborn screening legislation
- Currently monitoring legislation at the state level
 - Law enforcement access to NBS dried bloodspots
 - Consent for use of dried bloodspots for research purposes
- Evaluating our current position on written and informed consent for DBS retention and use



RARE DISEASE ADVISORY COUNCILS

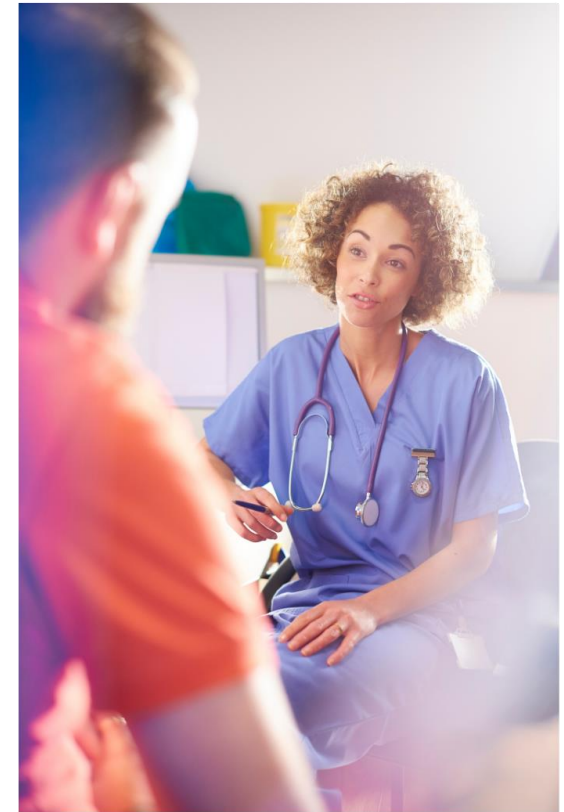
- Maryland and Indiana RDACs were signed into law in early May!
- Active legislation in Michigan, Washington, and Delaware
- Legislation in Texas and Oregon is unlikely to advance
- Mississippi, Arkansas, California, and Iowa legislation did not advance this year, but coalitions in these states plan to regroup for next year's session



Maryland Governor Wes Moore signed RDAC legislation into law on May 3, 2023.

HEALTH COVERAGE

- NORD continues to support policies that expand access to and strengthen state Medicaid programs & oppose those that seek to restrict eligibility or benefits (ex: work requirements)
- Joined other patient organizations in urging the Administration to protect patient's access to health coverage as the Public Health Emergency ends
- Submitted comments to CMS regarding the Medicare Drug Price Negotiation Program
- Supporting biomarker coverage legislation in several states



FOOD AND DRUG ADMINISTRATION

- The Retaining Access and Restoring Exclusivity (RARE) Act passed through the Senate HELP Committee on May 11
 - This legislation clarifies the scope of the market exclusivity period for orphan drugs
- Have submitted comments on FDA regulatory issues including:
 - The design and conduct of externally controlled trials for drugs and biologics
 - Gaps in educational materials on rare disease drug development
 - Other issues such as cell and gene therapy
- Joined other patient organizations in Amicus Brief supporting FDA's authority to oversee the safety and effectiveness of drugs (Texas mifepristone case)

HAVING AN EFFECTIVE MEETING WITH YOUR ELECTED OFFICIALS

WHY MEET WITH YOUR ELECTED OFFICIALS?

- Your voice is an informative way for your legislators to understand what the rare disease community needs!
- Without hearing from advocates like you, your elected officials won't know how to help the rare disease community.
- Many elected officials are unaware of just how common rare disease is! While our individual patient populations are small, approximately one in ten Americans is affected by a rare condition.



HOW DO YOU MEET WITH YOUR ELECTED OFFICIALS?

- Many advocates meet with their elected officials as part of a lobby day organized by a patient group, but you can also meet with your elected officials independently.
- While meeting with elected officials in Washington, DC is a cool experience, it is not necessary to travel to DC to meet with your elected officials. Every member of Congress has one or more offices in their district/state, and some offices also offer virtual meetings.



SCHEDULING A MEETING

- You can request a meeting with your elected official in writing or over the phone. Many offices also have a "Request a Meeting" option on their official Congressional webpage (see next two slides).
- When you schedule your meeting, let the office know what policy issue and legislation (i.e. bill number, if applicable) you want to discuss.
- Make sure to identify yourself as a constituent!



MEETING WITH YOUR ELECTED OFFICIALS

The screenshot shows the official website of Congressman Greg Landsman, Ohio's First District. The header includes the congressman's name and district, navigation links for 'ABOUT', 'ISSUES', and 'HOW CAN WE HELP?', a search icon, and a 'GET ASSISTANCE' button. A dropdown menu is open under 'HOW CAN WE HELP?', listing several options: 'GET ASSISTANCE', 'SCHEDULE A D.C. TOUR', 'REQUEST A MEETING' (which is circled in red), 'SHARE AN OPINION', 'ORDER A FLAG', 'INTERNSHIPS', and 'COMMUNITY PROJECT FUNDING'. The main content area features a large blue banner with a photo of Congressman Landsman and the text 'I'm Congressman Greg Landsman.' Above this banner is a location pin icon and the text 'Today, I'm in Washington, DC'. Below the banner is a row of five buttons: 'GET ASSISTANCE', 'SCHEDULE A D.C. TOUR', 'REQUEST A MEETING', and 'SHARE AN OPINION', each accompanied by a small icon.

MEETING WITH YOUR ELECTED OFFICIALS

The screenshot shows the website for Brad Wenstrup, representing Ohio's 2nd District. The navigation bar includes links for HOME, BRAD, UPDATES, SERVICES, PRIORITIES, and CONTACT & CONNECT. A 'SIGN UP' button and social media icons are also present. The main content area is titled 'CONTACT & CONNECT' and features a large 'X' icon. The primary call to action is 'Voice Your Opinion', followed by 'Let Us Help' and 'Invite Me' (which is circled in red). Below this is 'Sign Up For My Newsletter' and 'Telephone Townhall'. A section titled 'STOP BY' lists four locations: Union Township, Peebles, Chillicothe, and Washington, DC Office. A 'SHARE' sidebar on the left contains icons for Facebook, Twitter, Email, and Print.

BRAD WENSTRUP
Representing Ohio's 2nd District

HOME BRAD UPDATES SERVICES PRIORITIES CONTACT & CONNECT SIGN UP

CONTACT & CONNECT

Voice Your Opinion

Let Us Help

Invite Me

Sign Up For My Newsletter

Telephone Townhall

STOP BY

UNION TOWNSHIP
4350 Aicholtz Road

PEEBLES
170 North Main St.

CHILLICOTHE
475 Western Avenue

WASHINGTON, DC OFFICE
2335 Rayburn H.O.B.

SHARE

f t e p

PREPARING FOR THE MEETING

Plan out what you're going to say! We recommend the formula below:

1. **Introduce yourself:** it's good to include your name, where you're from, and your condition of interest and how it impacts you.
2. **Introduce the problem:** explain the challenge you or your loved one is experiencing. Be specific about how this problem impacts you or your loved one.
3. **Introduce your ask:** tell the person what you're asking them or their boss to do. Do you want them to vote in favor/opposition of a specific bill? Cosponsor a bill? Introduce a new piece of legislation?
4. **Connect the problem directly to the ask:** bring it back around and explain how your ask would help you or your loved one.

BREAKING IT DOWN

Introduce yourself:

Ex: Hi, my name is Allison Herrity and I'm a constituent of Representative Landsman living in Cincinnati. I have a rare connective tissue disorder that makes my tissue a bit stretchier than it's supposed to be. One result of that is that my stomach doesn't empty like it's supposed to.

BREAKING IT DOWN

Introduce the Problem:

Before moving to Cincinnati, I was stable on a medication for my stomach for two years, but when I moved here my insurance forced me to go off my medication and try a different, less expensive medication before they would cover the medication I had been on. This process is called step therapy because you have to go through one or more "steps" to access the medication your doctor prescribed. In my case, the other medication didn't work well for me, and my symptoms got significantly worse. For me this meant constant nausea, difficulty keeping food down, and unintentional rapid weight loss.

BREAKING IT DOWN

Introduce your Ask:

I'm here today to ask Representative Landsman to cosponsor H.R. 2630, the Safe Step Act. The Safe Step Act would establish a step therapy exemption process and mandate certain circumstances where a patient cannot be forced to go through the step therapy process. Over half of states have already taken action to curtail inappropriate use of step therapy in state-regulated health plans, but these state laws don't help people insured through most employer-based health plans or Medicare.

BREAKING IT DOWN

Connect the Problem Directly to the Ask:

One of the circumstances where patients would be granted an exemption under the Safe Step Act is when a patient is stable on a medication and that medication has been previously covered by any health plan. With the Safe Step Act in place, patients like me would be able to stay on their prescribed medication and avoid unnecessary disruptions in care. I hope I can count on Representative Landsman to support this important legislation!

ATTENDING THE MEETING

- It's a good idea to call or email to confirm the meeting a few days beforehand
- Arrive on time and prepared for your meeting
- Thank the legislator or staffer for taking the time to meet with you at the beginning and end of the meeting
- Record the contact information of the person you met with so you can follow up on your ask!



PANEL DISCUSSION – HOW TO HAVE AN EFFECTIVE MEETING WITH YOUR ELECTED OFFICIALS



Moderated by
Allison Herrity
Policy Analyst: National
Organization for Rare
Disorders



**Delegate Emily
Shetty**
Maryland House of
Delegates member (D-
18), Maryland RDAC Bill
Sponsor



Melanie Flood
Region A Co-Chair, Rare
Disease patient,
Communications Director:
First 5 Association of
California



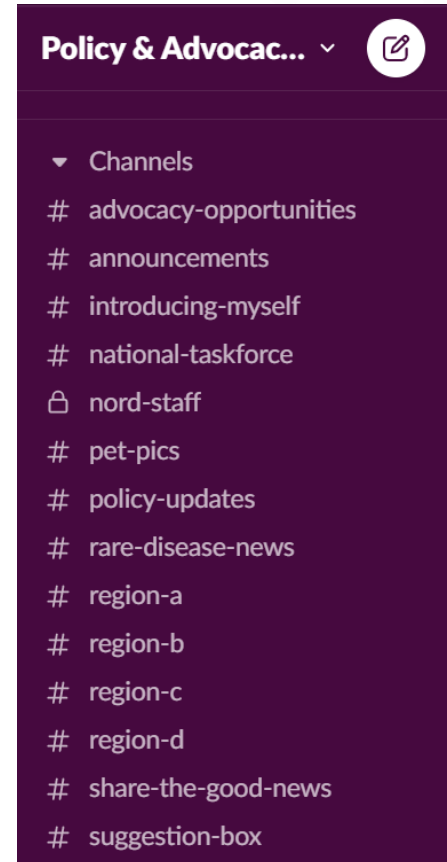
Julie Raskin
Region D Co-Chair, Rare
Disease parent, Executive
Director: Congenital
Hyperinsulinism
International

- We have created a Slack workspace for the Policy & Advocacy Taskforce!
- Slack is an instant messaging platform where Taskforce members will be able to more easily communicate with the NORD team, regional co-chairs, and each other
- The NORD team will use the Slack to give more regular updates on movement of legislation and other policy updates
- We hope the platform will help foster a community and encourage collaboration



POLICY & ADVOCACY TASKFORCE SLACK

- The follow-up email that will go out after this meeting will contain an invite link to join the Slack
- You can also join by going to **bit.ly/NORDTaskforceSlack**
- The Slack has several channels with various topics! Browse the channels and join the ones that interest you
- Once you've joined the Slack, take a minute to update your profile and introduce yourself in the introducing-myself channel!
- If you have any questions or difficulty joining the Slack, reach out to the NORD team at taskforce@rarediseases.org!



QUESTIONS?

Thank you.

