How To Advocate For Rare Disease-Related Policies

RARE DISEASE NORD® CENTERS OF EXCELLENCE

A Guide for Professionals Involved in Diagnosis, Care, or Research of Rare Diseases

NORD®
National Organization
for Rare Disorders

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NOTE

Utilizing this tool kit developed by the National Organization for Rare Disorders (NORD®) and the NORD® Rare Disease Centers of Excellence does not mean that you must advocate for the same policies as NORD or take the same stance on specific policies as NORD. This is meant to be a tool to help all those responsible for diagnosing, managing, and researching rare diseases, who may also be new to advocacy, learn how to get involved with policy initiatives at different government levels. This guide will also help you determine what institutional rules you need to follow to make sure that everyone engages appropriately. Please use your judgment and expertise to advocate for policies that you believe will positively impact the rare disease community.

This is a product of the National Organization for Rare Disorders (NORD®) Rare Disease Centers of Excellence Policy and Advocacy Working Group. We offer a special thank you to the following members for their contributions toward this resource:

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ABOUT US

The National Organization for Rare Diseases (NORD®) is an independent and nonpartisan nonprofit dedicated to solving the greatest challenges and unmet needs in rare disease patient care, treatment and research. The NORD® Rare Disease Centers of Excellence is the first-of-its-kind network of U.S. medical institutions dedicated to diagnosing, treating and researching all rare diseases.

Introduction to Advocacy

What Is Advocacy?

Advocacy is an activity by which an individual or group works to raise awareness and/or influence the decisions made by lawmakers or social institutions. Advocacy can enable you to effectively serve your community by:

- Raising awareness about key issues
- Building bidirectional relationships with decisionmakers (and their staff) where they look to you for your expertise and value your perspective so they can make better informed decisions
- Urging continued funding for programs or initiatives or support the creation of new programs
- Influencing policy decisions to reflect community interests/needs

Why engage?

Legislators are elected to represent everyone, including those living with a rare disease. Policymakers are responsible for drafting, reviewing, and voting for or against laws and policy. Educating and informing policymakers about how these laws and policies will affect the lives of those living with a rare disease is critical because few policymakers have the necessary knowledge on this topic. These same laws and policies also affect those who dedicate their lives to diagnosing, caring for, and researching rare diseases.

Most legislators really appreciate hearing from their constituents, especially from those with unique perspectives. As clinicians and allied health professionals, you witness the effects of policy changes every day, including the wins and losses with insurance providers, the triumphs and challenges faced by your patients, and the successes and struggles of your clinic. As researchers, you understand the impact of funding changes on government-supported research and how changes to laws, like the Orphan Drug Act, will affect the development of new treatments for rare diseases. As director or staff of a laboratory, you know how changing regulations may affect diagnostic capabilities. Having the nuanced experience of being a clinician, allied health professional, researcher, or lab director puts you in a unique position to advocate for policies on behalf of the rare disease community.

Getting started with engaging lawmakers and/or their staff can seem like a daunting task if you've never done it before. We've compiled a list of tips on how to advocate for rare disease-related policies, covering how to represent yourself to avoid institutional conflict of interest; where to go in your institution to learn about their policies on advocacy; where to find rare disease-related policies at the institutional, local, state, and federal levels; as well as ideas on how to engage with your lawmakers. The tips and guidance in this toolkit are not inclusive, but we hope that we have provided you with the information you will need to get started and become an even better advocate for the rare disease community.

How to Engage in Legislative Advocacy

Who is advocating?

Representing an institution or other affiliation versus advocating as yourself as a private citizen

Understanding the difference between advocating as a private citizen or as a representative of your institution or other professional affiliations (professional organizations, national societies, etc.) is important. It will determine what email or mailing address (personal or work) you use, who your representative may be based on the location from which you are advocating/lobbying, and the actions you choose to pursue. Below are some tips that describe how to advocate as yourself, how to potentially advocate as a representative of your institution/affiliation, or both.

Advocating as yourself

- Use your personal email address
- Connect with the legislators for your district, town, city, etc. (See pg. 9.)
- When connecting, make sure to explicitly state that you are speaking as a private citizen and not on behalf of an institution nor any government funding source (i.e., a grant)

EXAMPLE: "My name is XXXX. I am a clinical geneticist (genetic counselor, etc.). I work at XXX; however, today I am writing/speaking only on behalf of myself as your constituent."

LOBBYING VS. ADVOCACY:

Lobbying is a form of advocacy, meaning to **advocate specifically for or against a particular piece of legislation.** It is important to consider your institution's rules surrounding lobbying (i.e., many state institutions specifically prohibit lobbying) before taking action on a piece of legislation. You can still advocate for rare disease patients without lobbying by raising awareness about challenges both clinicians and patients face.

Speaking as a representative of the institution

Institutions have different policies regarding acting as an institutional representative. Learn more by connecting with your institution's **government affairs team!**

What is my government affairs team called?

Government affairs teams may be called various names depending on the institution. Some titles to look for can include:

- Government affairs
- Government relations
- Public relations
- Government and community affairs
- Federal and external affairs
- Advocacy and government relations

MORE THAN ONE GOVERNMENT AFFAIRS TEAM

If you work for a multi-institution system (e.g., an adult hospital and a children's hospital), there may be more than one government affairs team for the system.

How do I connect with my government affairs team?

Consider one of these options:

- Search your institution's website or faculty and staff intranet for the government affairs department.
  - Contact information – email or phone numbers – will be located on their website.
  - You might find general, department, or individual contact information.
- Talk to your division chair; they might already have contact in the office to share with you and they may even want to join you when meeting with the team.
- Check your inbox! You may have received an email from the government affairs office at some point along with their contact information.

How do I choose who to contact on the team?

- If you only see specific staffers listed, try reaching out to the director, vice president, or chief of government affairs. You may even come across a manager of government affairs. If you find that they are unable to help you, ask them to refer you to someone who may offer assistance.
- Federal, state, or local government?
  - Your institution's government affairs team may be split into two or three groups: federal, state, and local government. This may add extra confusion when deciding with whom you should speak.
    - If you want to understand your government affairs team in a more general manner, reach out to someone with whom you feel the most comfortable, although there is a chance that they will direct you to someone who may better address your needs.
    - If you are interested in learning about a specific area of policy and advocacy, arrange to meet with someone on that team.

What can I do prior to meeting with my government affairs team?

Before the meeting is scheduled:

- Plan and share what you hope to discuss during the meeting
  - When reaching out to the government affairs team, share your goals for the meeting, such as understanding ways to collaborate and align with your institution's goals and/or how to advocate independently to abide by institutional policies.

Before or after the meeting is scheduled:

- Review their current initiatives, calendars, and outreach items.
    - Look for a list of government and advocacy partners, including federal, state, and local affairs.
    - If you cannot find them, be sure to ask about them when you meet!
- Read up on your institution's strategic plan for different areas of focus.

What do I discuss with my government affairs team when we meet for the first time?

Introductory meetings are most helpful when you have an idea of what you would like to learn from the meeting as well as what you would like to share. First meetings are a good time to:

- Introduce yourself and your role in the institution. Discuss your involvement in the NORD® Rare Disease Center of Excellence (RD CoE) and other relevant advocacy groups, as well as the goals of your individual advocacy and policy interests.
- Learn about the local, state, and/or federal policies, legislation, and regulations your institution is following or actively involved in advocating for or against.
- Ask for tips on how to get involved in the institution's policy goals as an individual vs. a representative of an institution.
    - Ask how to receive support for initiatives you may want to advocate for if they align with the institution's interests.
    - Discuss how to appropriately advocate for or against policies you are passionate about but are not within the institution's goals. Make sure you understand your institution's policies on advocating as an individual citizen.

What information might my government affairs team share?

Below is an example of a set of guidelines a government affairs office may share with you.

Courtesy of Emory University's Office of Government and Community Affairs

Guidelines:

1. When you are speaking with elected officials and policymakers on behalf of yourself or as a representative of a professional organization, please make clear that you are not speaking on behalf of [institution]. We are not restricting employees from identifying their profession and place of employment in the context of their communication with elected officials. This is not intended to restrict the free-exercise rights of employees to petition the government. Rather this reflects our policy that only designated [institution] leaders or representatives are authorized to advocate for [institution] and its official position.

2. Please do not use your [institutional] e-mail for any advocacy activities, including organizing advocacy efforts or forwarding campaign solicitations. Instead, please use your personal e-mail.
3. Please do not wear your official [institution] ID, your white coat, or other [institution]-provided clothing during your personal advocacy activities.
4. If you receive any media inquiries, please contact the media relations team within Communications and Marketing. They are able to assist with any interviews or can decline on your behalf if you'd rather not participate.
5. Finally, we encourage you to contact [institution government affairs team] to learn more about their work and use their expertise as a resource and sounding board. The staff has decades of experience and they are available to share their guidance on the best way to work with policymakers.
6. For further information, please see [institution]'s lobbying policy.

How do I continue a relationship with my government affairs team?

You've met your government affairs team, you know what policies they are currently supporting or against, you know what bills they are currently following, and you know their policies on lobbying or advocating as an institutional representative.

What do you do when you want to lobby for or against a new bill or regulation?

- Identify the best team member to send the bill or regulation.
  - If your government affairs team is divided into multiple groups, determine to which group you send the bill: federal bill should go to the federal team, state bill should go to the state team.
  - If your government affairs team does not have divisions, you can send the bill to the contact you connected with last time; again, they can redirect you to the best contact if it is not them.
- Send the government affairs team a summary and/or link to the bill.
  - If it is something another organization is supporting or already advocating for or against, be sure to include what they are asking of constituents (e.g., letter of support sign-on, patient or provider stories, etc.).
- Request that the government affairs team confirm whether the legislation aligns with the institution's scope.
  - If they need more information: connect the team with the group organizing the support for the bill (e.g., NORD policy team).
  - If yes: request that they take action as an institution (e.g., sign the letter of support).
  - If no: inquire if you or your clinic/department head can sign for the clinic/department only or as an individual. The government affairs team will provide guidance on what is acceptable for your institution.

Identifying Lawmakers and Laws

For a list of elected officials for where you live or work, visit: usa.gov/elected-officials

- Input your address → Discover the names and contact information for your elected officials at the federal, state, and local levels.

Where you live and where you work may be located in different legislative (voting) districts; as a result, you may have multiple lawmakers you can connect with. Input both your home address and work address to make sure.

LOCAL OFFICIALS

Local officials can be representatives from a village, town or borough, city, or a county. They include: mayors, council members, commissioners, comptrollers, public advocates, clerks, and others.

LOCAL LAWS

At this level, laws are often listed as ordinances, bylaws, or municipal code.

STATE OFFICIALS

State officials include: governors, state senators, state assembly members or representatives, state commissioners, supreme court justices, and others. The U.S. Congress has a tool to look up state government officials. This resource links out to each state's legislature website, where a roster of state lawmakers will be available. Some state websites are also as simple as [state].gov.

STATE LAWS

Visit the respective state legislature website for more information on state bills.

FEDERAL OFFICIALS

Federal officials include the state's two U.S. senators and the U.S. representative for the municipality of interest. The U.S. Congress has a tool to look up federal officials.

FEDERAL LAWS

Visit congress.gov for more information on federal bills.

NORD®
STATE REPORT CARD

REVIEW NORD'S STATE POLICY REPORT CARD®

NORD's State Report Card is a landscape analysis of policies at the state level that impact the rare disease community. It can be a useful tool to help inform you and your coalition where your state stands on key policies. The issues outlined in the report card 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. Report cards for any given year are typically published the January of the following year (i.e. 2023 report cards were published January 2024).

Gaining a deeper understanding of lawmakers and laws

Why do I want to know who my public officials are?

- You want to find out which officials are interested in health and science policy.
- You want those representatives to know that you are available to answer content questions and that you care about certain subjects or specific legislation.

What to know about your public officials when you are considering reaching out to them:

- The committees they sit on
- The party they are part of
    - Is it the majority party?
    - Does is match the governor's?
- If they have previously worked with your institution on other policies; it can be helpful to acknowledge what they have already done for the institution
- The duration of their term in office
- The laws they have not supported or are currently opposed to
- The laws they have supported or currently support and what bills they have sponsored
- Access nonpartisan information on elected officials from Vote Smart.

Why is it important to know when my public officials meet?

- Most preparation work is done before the legislative session, which can be brief (three months of the year). The legislative session is packed and you need to know when bills will be discussed to organize testimony.

Where you can go to find out when your lawmakers meet:

- State or Federal legislature website (see previous page)
    - Legislature websites will often have calendars posted for when committees meet, houses are in session, etc.
    - "In session" may be procedural; Check calendars on the legislature's website to see if the meeting is actually happening as calendars are updated at different times and can change without notice
- The National Conference of State Legislatures (NCSL) also shares each state's session dates: State Legislative Session Calendar

Why is it important to know what bills are in progress at local, state, and federal levels?

- There could be a bill on a topic that you or your colleagues have experience with
- There could be a bill on a topic that supports or opposes a position that is important to your institution
- If there is strong opposition or support for a bill, you can plan to organize information to support your (or your institution's) stance on the bill

When reading bills:

- Do not just read the title – read over the whole summary, if available; If possible, read through the portion of bill that is available to you
- Check to see if the bill is adding new language, repealing language, or amending existing language
- Check to see who is sponsoring the bill
- Check to see where in the legislative process the bill is
- Check the effective date (usually located at the end of the bill)

On some legislative websites, you may be able to track bills:

- For congressional bills in progress, you can elect to "Get Alerts" – selecting this option will allow you to receive emails on any updates to that bill
- Some state legislatures allow you to set tracking notifications or join a free bill subscription service
- This option will give you the most timely updates on bills
- You can sign up for alerts on bills or elected officials here: legiscan.com or fastdemocracy.com

Inviting lawmakers to your institution

WHY: You are providing them with an opportunity to interact with the constituents – patients, caregivers, providers, laboratory staff, and/or researchers – that a particular piece of legislation may impact, negatively or positively.

HOW:

- Have them visit your clinic(s), research lab, diagnostic or other labs.
- Invite them to attend a genetics or rare disease event: Rare Disease Day or other awareness day celebration, a Grand Rounds, or another type of institutional event related to a cause you are advocating for or against.

Meet with lawmakers or attend hearings

WHY: Elected officials are busy. If they are unable to visit you, you can visit them!

HOW TO PREPARE:

- Know the bill number that you are advocating for or against and share it at the beginning of the meeting.
- Share:
  - Stories from patients/families in community and from across your institution: Tip Guide
  - Stories directly from patients or families willing to testify during a hearing
  - Publications related to hearing topic
  - An aligned force made of individuals in otherwise competing roles or institutions
  - Personal and scientific pieces of evidence to support your stance on a bill
    - Why is this topic important and what facts do you have to show that?
- How to share:
  - Create a pitch – outline what you want to say.
  - Create reference materials – provide them with a summary of the information and stories you presented, as well as additional resources for them to reference.

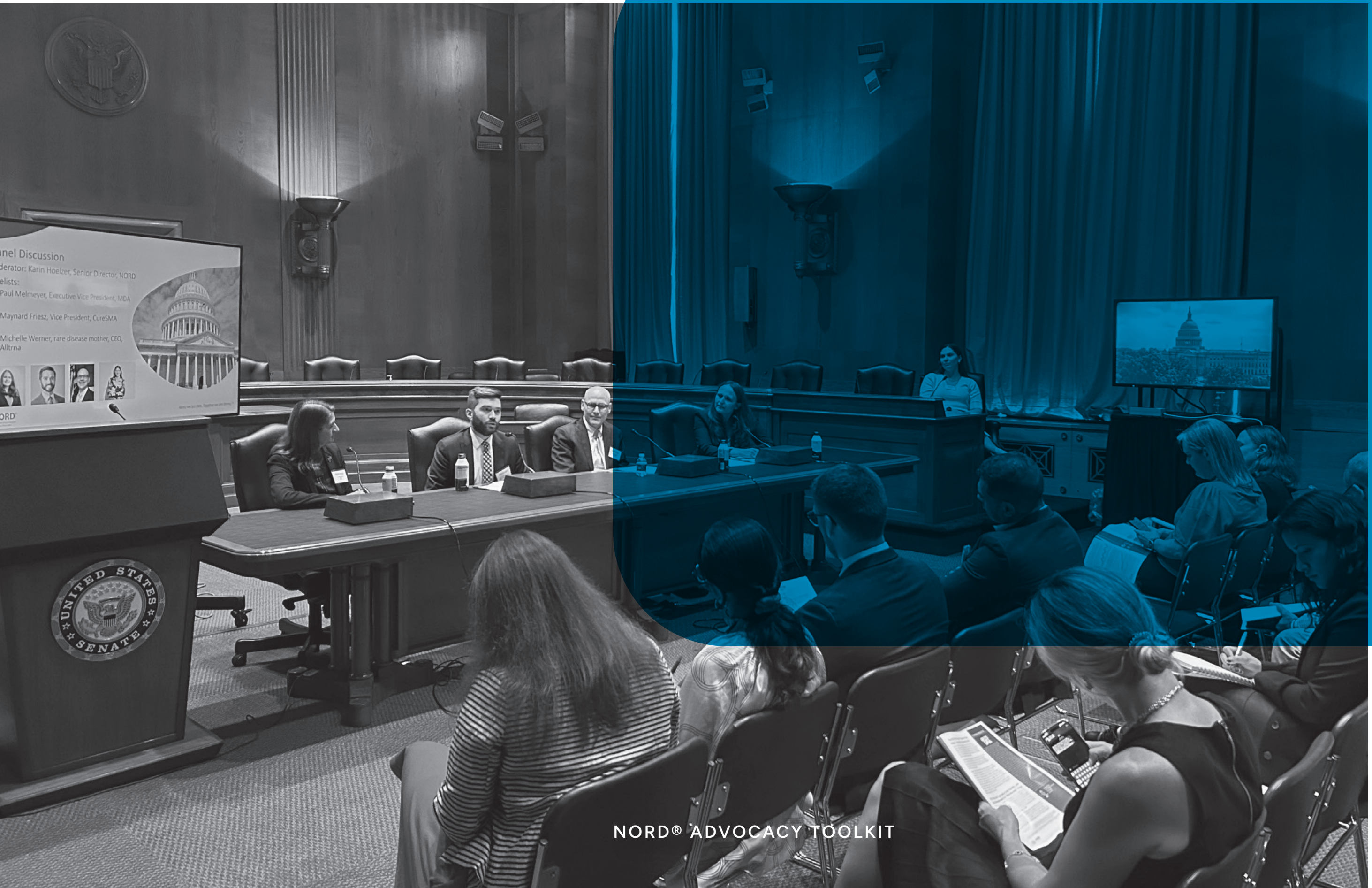
IMPORTANT CONSIDERATION

If someone asks you a question that you don't know the answer to, you can let them know that you will get back to them; be sure to follow through! If you neglect to do so, you may lose your credibility, affecting the power of your argument.

- For more information, refer to the following resources:
    - **What to expect when you meet with a legislator:** How to prepare for meetings and what to talk about
    - **How to prepare to meet with your legislator:** How to identify who to talk to, how to meet with them, and how to prepare for the meeting

What can I do if I am unable to meet with my lawmaker? Meet with a staff member instead!

Meeting with a staff member can be just as, or sometimes more, valuable than meeting with a lawmaker. The staff member is an individual who is passionate about learning about the issue, so this person will likely take the time to learn from you and the resources you share.



Next Steps: Organizing Around a Specific Topic

The guidance we have introduced above is a summary of general tips, actions, and activities to introduce you to the many ways to engage in advocacy and policy. However, advocacy and policy actions are not general; they are typically centered around a specific problem, issue, or topic. Therefore, the actions you take will need to be specific to best address the problem, issue, or topic.

You'll need to know:

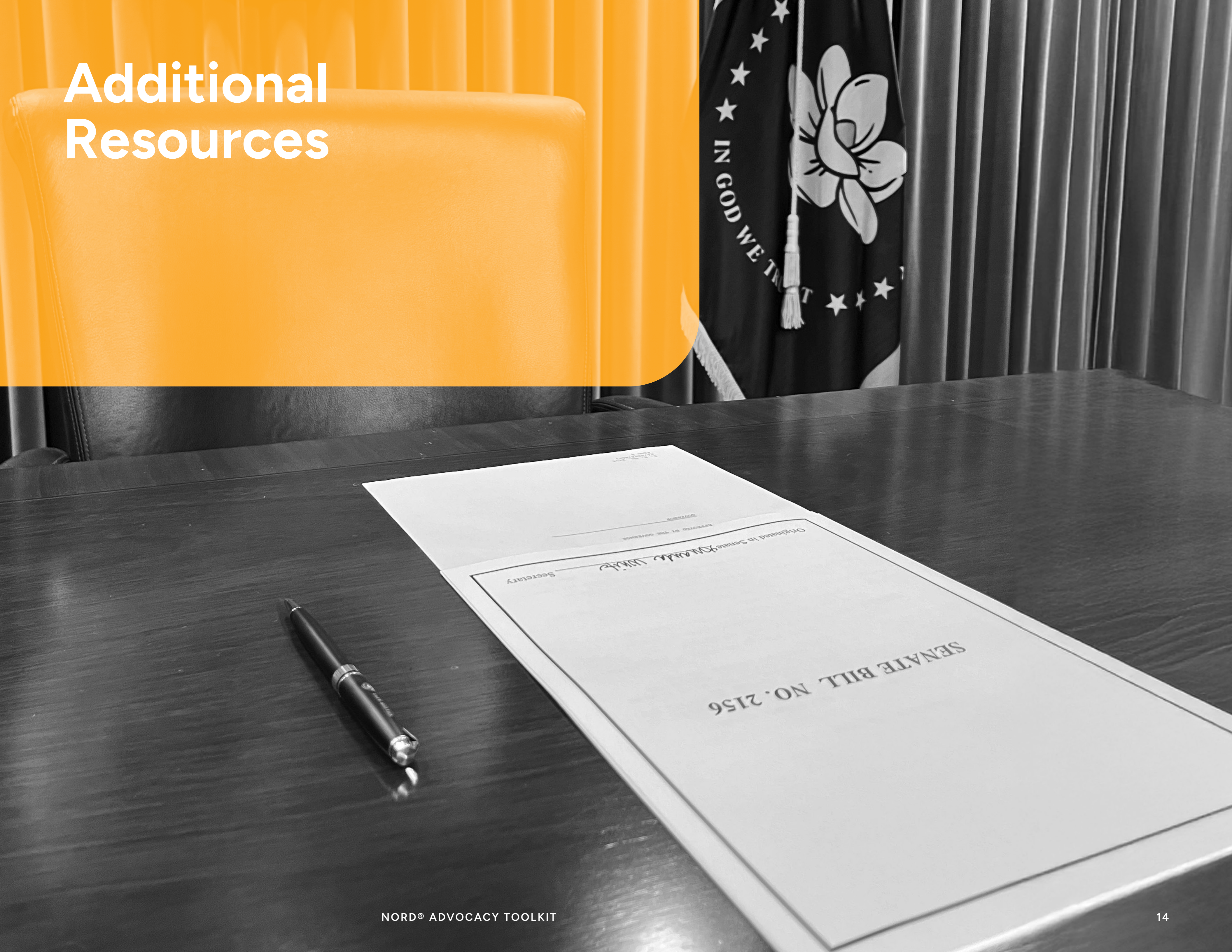
- What efforts are already taking place across your state, across the nation, within your institution, or within the professional organizations you are part of related to the topic or issue
- When the bill of interest is going to be discussed in a legislative capacity, if there is a bill
- What specific information, stories, research, and other related items will be needed to support your view and when you will need it ready

Tackling a specific issue by yourself can be tough, but you will likely never engage in advocacy or policy alone. Taking action is a team effort! This is particularly key as you are a busy individual and those you want to connect with are also busy. Working with others toward your collective advocacy goals will mean sharing responsibilities. This is also be a great time to learn from others as well as share your knowledge.

Finding your team:

- Continue engaging with your government affairs team
    - They may be working on taking action toward something you want to support – ask how you can help.
    - Or, ask if they know of others at your institution interested or involved in areas where you share the same concerns.
        - Often, they can connect you with a more experienced member at your institution who can help you further understand the landscape in which you are working as well as what resources and support are available.
- If your state has a Rare Disease Advisory Council (RDAC), connect to find out what issues they are focusing on and how you can help.
- Connect with other clinicians, researchers, lab directors, and physicians in your state.
    - Stay connected to learn and share information, stories, actions, and news about the issues that are important to you.

Additional Resources



General Resources

- **Congressional Bills Vocabulary:** This webpage explains different vocabulary associated with different types of congressional bills and types of legislation.
- **Explore a Bill on Congress.gov:** An overview of a legislation page on Congress.gov which demonstrates what you will find under each tab.
- **A Citizen's Guide to Participation in the Legislative Process:** A guide created by the California State Senate that educates individuals on how to get involved with the legislative process as a citizen. You will find details on how to connect with legislators and how to prepare for your interactions, some details on how bills are written and passed, and definitions of common words and phrases used in policy and government.
- **How to Read a Bill:** A guide created by the California State Senate to help constituents read bills online. Although created for California residents, tips can be applied to other state and federal bills.
- **Advocacy Education for Rare Diseases:** A Rare Disease Learning Center – you will be exposed to content on what is a rare disease, why you should advocate, and basics on the legislative process and meeting with a legislator.
- **Sharing Your Story:** A guide for clinicians to share with patients (or use themselves) to prepare a story to share with legislators.
- **Tips on Meeting with a Legislator:** See pages 3-6 for a deep dive into details on preparing to meet with your elected officials.
- **Rare Disease Advisory Councils (RDACs):** An RDAC acts as an advisory body that gives the rare disease community a stronger voice in state government. With the support of NORD, other patient organizations, and stakeholders in the rare disease community, RDACs are enabling states to strategically identify and address barriers that prevent individuals living with rare diseases from obtaining proper treatment and care for their condition
- **National Conference of State Legislatures (NCSL)** is home to the most comprehensive information available on legislatures in U.S. states, territories, and commonwealths.

State resources: Legislative guides (not inclusive)

1. Alabama
2. Alaska
3. Arizona
4. Arkansas
5. California
6. Colorado
7. Connecticut
8. Delaware
9. Florida
10. Georgia
11. Hawaii
12. Idaho
13. Illinois
14. Indiana
15. Iowa
16. Kansas
17. Kentucky
18. Louisiana
19. Maine
20. Maryland
21. Massachusetts
22. Michigan
23. Minnesota
24. Mississippi
25. Missouri
26. Montana
27. Nebraska
28. Nevada
29. New Hampshire
30. New Jersey
31. New Mexico
32. New York
33. North Carolina
34. North Dakota
35. Ohio
36. Oklahoma
37. Oregon
38. Pennsylvania
39. Rhode Island
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42. Tennessee
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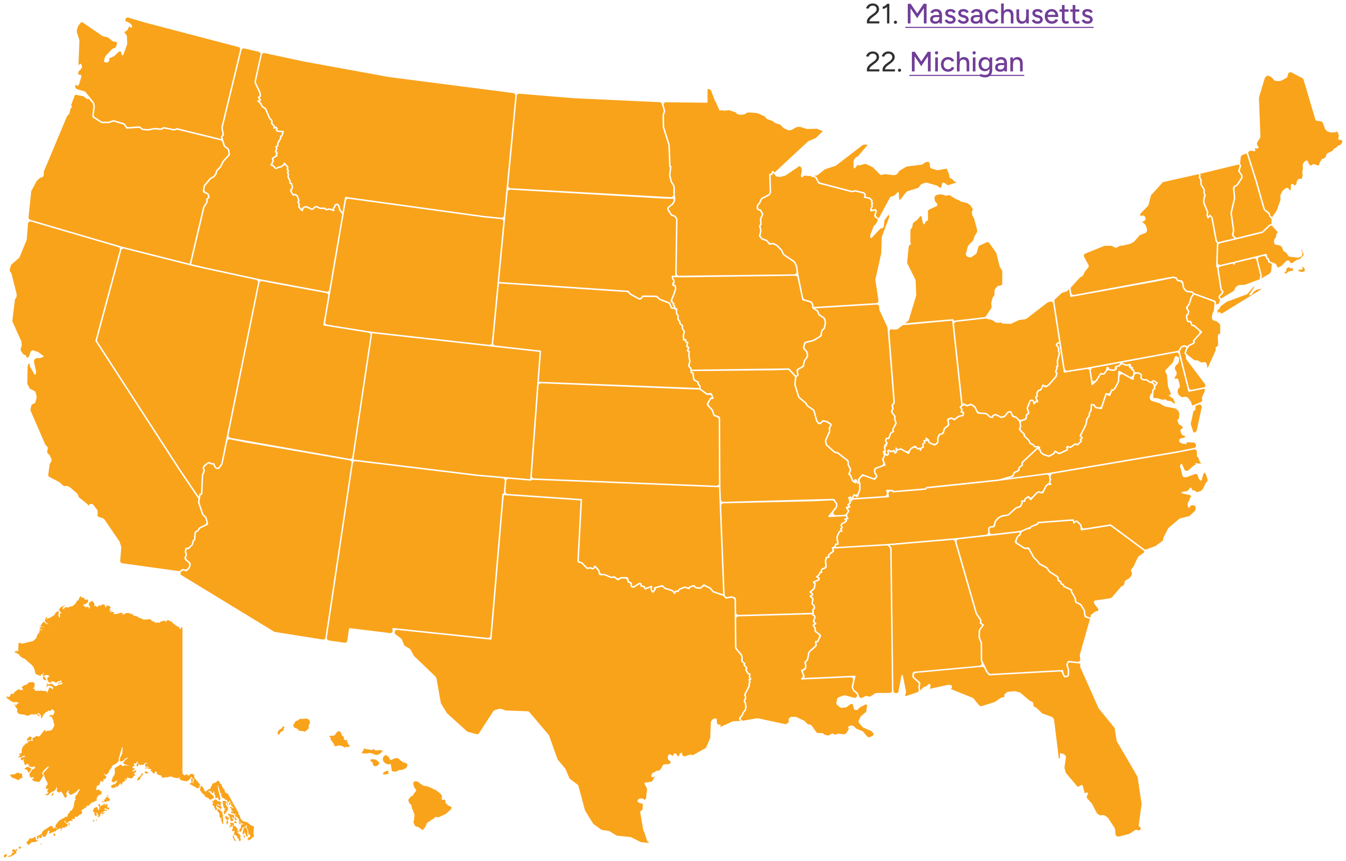
44. Utah
45. Vermont
46. Virginia
47. Washington
48. West Virginia
49. Wisconsin
50. Wyoming



Professional organizations' policy corners – genetics, medicine, and rare disease (not inclusive)

In this section, you find links to the "Policy Corners" of various professional organizations that may be of importance to you. Professional organization policy teams often highlight various bills that could positively or negatively impact professionals or the patients and family they serve, as well as share organizational stances or comments about bills. In addition, they can also promote policy actions, like organization sign-on letters. NORD does not endorse any one professional organization and is providing this list as a starting point for your reference.

- **The National Society of Genetic Counselors:** Federal advocacy initiatives of the NSGC. You can also visit the "policy" tab on their website for more information
- **The American College of Medical and Genetics and Genomics:** A list of policy areas that the ACMG follows; ACMG-authored or -supported policy statements also available
- **American Academy of Pediatrics:** AAP-authored policy statements and list of endorsed statements
- **American Society of Human Genetics:** The ASHG policy statements on genetics research, genetics in healthcare, and genetics in society
- **American College of Obstetricians and Gynecologists:** Statements of policy and position statements from ACOG
- **Association of Public Health Laboratories:** APHL regulatory and advocacy initiatives, advocacy priorities, and position statements
- **American Medical Association (AMA):** Current policies of the American Medical Association
- **American Public Health Association Policies:** A database of previous policy statements produced by the APHA
- **Society of Inherited Metabolic Disorders:** A list of policy issues and statements that are the focus of SIMD

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