

# ADVOCATING FOR A RARE DISEASE ADVISORY COUNCIL IN YOUR STATE



**NORD®**  
National Organization  
for Rare Disorders

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# WELCOME

Dear Fellow Rare Disease Advocate,

Thank you for your continued interest in Rare Disease Advisory Councils (RDACs)! In 2020, the National Organization for Rare Disorders (NORD®) formally launched Project RDAC – an initiative designed to optimize existing RDACs and increase the number of effective councils across the country. As part of this initiative, NORD is developing resources to help RDACs at every step of their journey to ensure all are impactful and high-functioning tools for the rare disease community and their state governments.

This is the second Project RDAC toolkit in a series of three, each curated to guide rare disease advocates through a specific phase in the RDAC lifecycle. NORD's first toolkit, "[Creating a Rare Disease Advisory Council in Your State](#)," focused on building a strong coalition to lay the groundwork for developing and advancing RDACs. This toolkit, "Advocating for a Rare Disease Advisory Council in Your State," is a comprehensive guide to the legislative phase of an RDAC. Presented in this resource are tips on the legislative process, suggestions for engaging with lawmakers, advocacy recommendations for the RDAC coalition and other additional tools.

We hope you will find this toolkit helpful as you work with NORD, its Rare Action Network® (RAN), your state's RDAC coalition, and the rare disease community to establish an RDAC in your state. Before setting out on this path, please reach out to us at [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org) for a status update on the RDAC activities in your state so that we may connect you to any efforts already under way. NORD's policy staff is here to support you throughout this process.

Thank you for all you do!

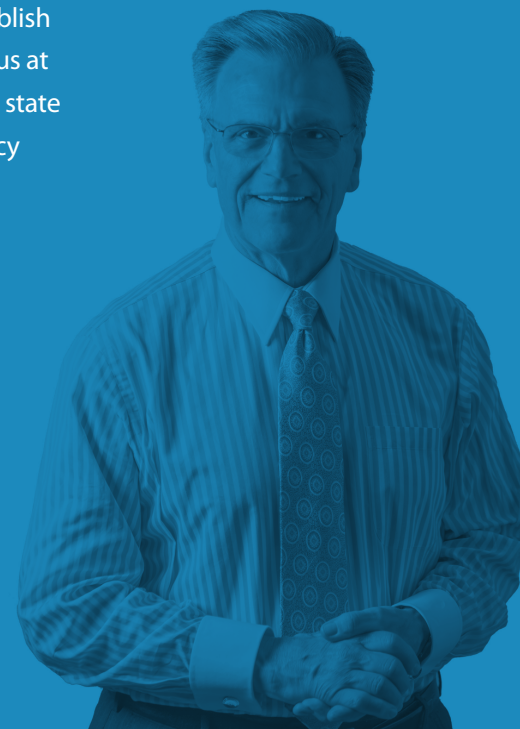
*Alone we are rare. Together we are strong.®*

Sincerely,



**Peter L. Saltonstall**

*President and Chief Executive Officer  
National Organization for Rare Disorders*





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# LIFECYCLE OF AN RDAC FROM START TO FINISH

## START

Coalition Building Phase for a Rare Disease Advocate (covered in the previous Project RDAC toolkit)



Idea to start an RDAC

Build a coalition

Reach out to NORD's policy staff at [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org) for a status update on RDAC efforts in your state (Please note: In states where RDAC development efforts are already underway, NORD can help connect you to existing RDACs or coalitions)



Host initial coalition meeting to provide overview of RDAC

Host second coalition meeting to discuss needs of the rare disease community in your state

Identify your state's needs using NORD's model legislation

## LEGISLATIVE PROCESS

1. RDAC legislation is introduced in state legislature
2. Committee consideration/hearing and vote
3. Report bill out of committee
4. Floor consideration and vote
5. Resolve differences between two chambers
6. Governor's desk for signature
7. RDAC enacted!

Meet with legislative sponsors and confirm his or her support



Work with the coalition to fill in the draft model legislation to meet your state's needs



Legislative Phase (covered in this toolkit)

Closely monitor the legislative process and stay in touch with the sponsors throughout to see if there are ways you can help

Assist the legislative sponsors with introduction of the RDAC legislation and work to address any questions/concerns they may have with the draft legislation

Identify members of the state legislature who would be interested in supporting and introducing the legislation (i.e. "sponsoring" the legislation)



Implementation Phase (to be covered in a future Project RDAC toolkit)

RDAC members



First RDAC meeting held



Workplan based on RDAC duties and requirements developed

Recommendations

Recommendations compiled into a report



Recommendations submitted to state government decision makers!



FINISH

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## TIPS FOR THE LEGISLATIVE PHASE OF AN RDAC



*"Having a bill sponsored by as many legislators in both houses of a state legislature at the beginning of the legislative process is advantageous to a bill's progression. While having legislation become law is a multi-step process, enlisting broad support early on can pave a clearer path for a bill's passage."*

REPRESENTATIVE DANIEL BENSON (NJ – 14TH DISTRICT)



*"The Rare Disease Advisory Council legislation would not have been passed in Massachusetts were it not for the strong partnerships we in the Legislature formed with outside advocacy groups - from hosting briefings and organizing social media campaigns to writing letters of testimony to legislative leadership, advocacy groups helped us get this bill over the finish line and are critical to the effort in any state to advance this cause."*

REPRESENTATIVE HANNAH KANE (MA - 11TH DISTRICT)



*"Focusing on legislators with a health care background was key in receiving broad buy-in from other legislators, especially during the early phases of the legislation (introduction, committee agendas, gathering of sponsors). We still had an uphill climb but relying on national statistics, extrapolating them into a state level, and other RDACs bill language and success ensured we were set for a triumphant journey."*

*While the above is all important to the legislative process, it is crucial to not lose sight of the mission and reason why RDACs are important and need to be enacted - patients. Our number one and only priority is to ensure they have their voices heard and improve outcomes for all impacted by a rare condition."*

FERNANDO ANDRZEJEVSKI, EXECUTIVE DIRECTOR, WEST VIRGINIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION



*"Remember that the legislators are very busy people, but they are just people like you and me. There is no need to be nervous. Make sure to go into your meeting on time ready with a clear ask and a short explanation of why that ask is important to you. If you can prepare a leave behind with that information, as well as your email and phone number, it will be easier for them to remember you and contact you if they have any further questions. And always follow-up with a thank you phone call or email!"*

MARY WOOTTEN, NEW YORK RARE ACTION NETWORK VOLUNTEER STATE AMBASSADOR



*"Know your state's legislative calendar! Identify national rare disease organizations that have local chapters or support groups to help advocate for the legislation. Identify rare disease patients and caregivers who may be willing to testify in person before the committee."*

CHARLENE YORK, OHIO RARE ACTION NETWORK VOLUNTEER STATE AMBASSADOR



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# INTRODUCTION TO ADVOCACY AND ENGAGEMENT



### What is Advocacy?

Advocacy is an activity by which an individual or group works to influence the decisions of political or social institutions. Legislative advocacy aims to draw attention to or educate lawmakers on a particular issue to effect change. Some goals of legislative advocacy include:

- Building relationships with lawmakers;
- Influencing policy decisions;
- Creating new programs or initiatives; and
- Altering existing policies.

### Why Engage?

As an individual advocate, getting involved in state government can be overwhelming. The legislative process is complex, and lawmakers work on many different issues in addition to health-related ones. However, it is important to remember that your policymakers were elected to represent YOU. It is essential for them to hear from their constituents, including the rare disease community. Without rare disease advocates, many lawmakers would not know about the challenges faced by rare disease patients and their families. Lawmakers need you to inform them about how the state can best serve your community.

### How to Engage and Recruit New Advocates in Your Community

In addition to your coalition, it can be helpful to engage rare disease advocates from outside the coalition. The following tactics are a good place to start:

- **Review previous event registration(s).** If members of your coalition have hosted events for the rare disease community in the past, reviewing registration information from those events can provide you with contact information for those who have been active participants in the community previously. These people may be more likely to get involved in the RDAC effort.
- **Reach out to patient organizations in your state.** There are state-based rare disease organizations as well as many national organizations with state or regional chapters that may be interested in getting involved in the effort to establish an RDAC. Reach out to those groups to ask them to join a sign-on letter in support of the legislation and share opportunities to take action with their community. An example of an organizational letter of support can be found in Section 8.

### What is an op-ed?

An opinion piece, or op-ed, is a great way to spread awareness of RDAC legislation in your local community. See Section 8 for additional information.

- **Utilize NORD's Rare Action Network.** NORD has volunteer RAN Ambassadors and Community Engagement Liaisons in states across the country. These volunteers are familiar with rare disease advocates in their state and can send out action items via email and on social media. NORD can also help send out emails to RAN members in your state. Reach out to the NORD policy staff via email at [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org) for more information.
- **Engage your local community.** Educate members of your local community about rare diseases and the need for an RDAC in your state, encouraging them to take action by asking their representatives to support the RDAC legislation.

### How to Use Your Coalition

The RDAC coalition should continue to work together throughout the legislative process; it is important to work with your coalition to come up with a plan outlining how you will stay in contact and how often you will meet. This may vary from state to state, as the legislative process does not move at a uniform pace. In addition, NORD policy staff recommend creating an information-sharing system to send out legislative updates to the coalition and assist with coordinating lawmaker outreach.

Finally, the coalition should consider how to share information with the broader rare disease community in its state. For some states, an email list may make the most sense, while social media might be a better fit for others. The NORD policy team can offer its advocacy email system to the coalition to ensure advocates stay up-to-date and know the appropriate time to engage. A sample social media toolkit can be found in Section 8.

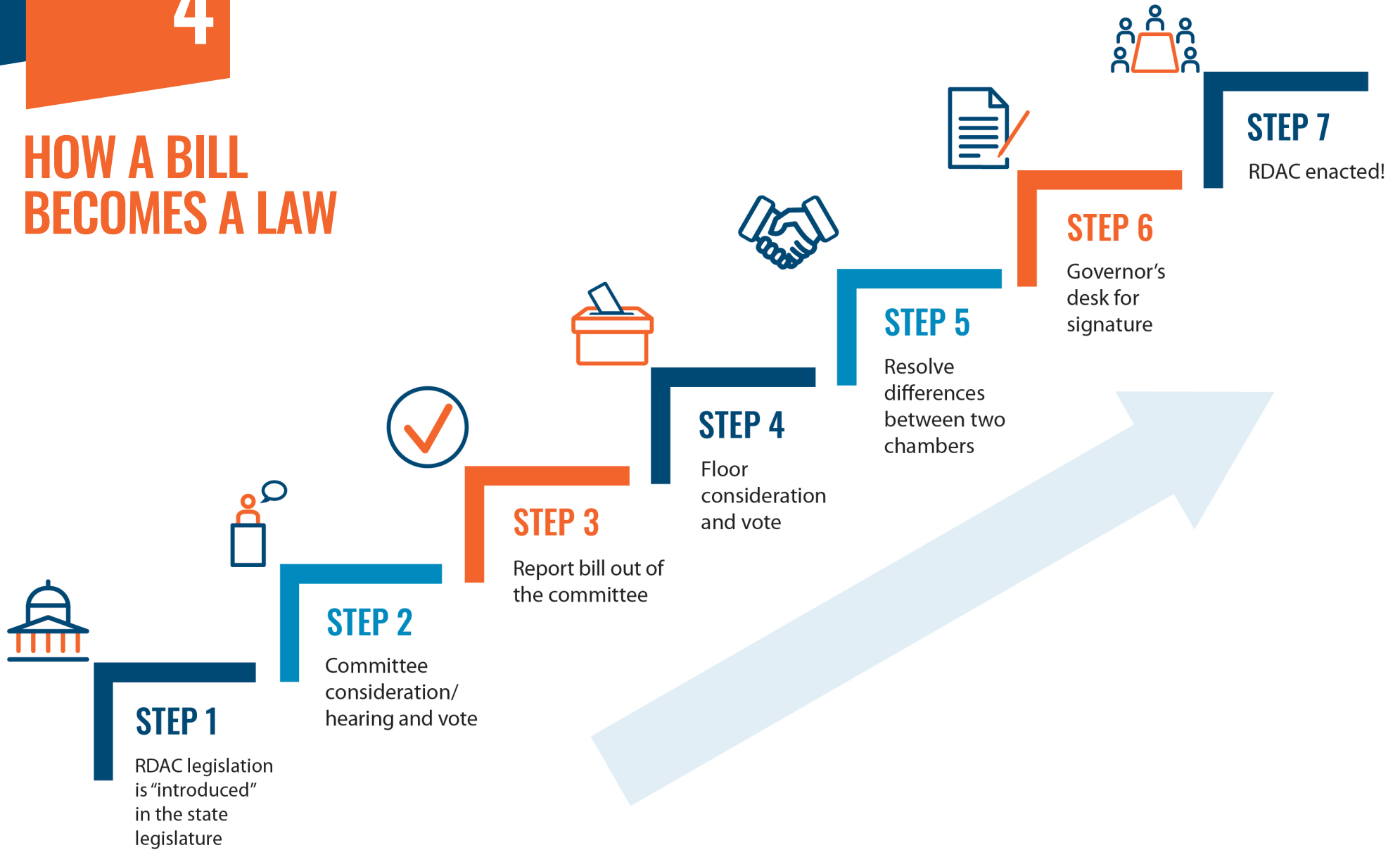


Please share your progress with NORD so we can promote it on our social media channels!

Email us: [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org)

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## HOW A BILL BECOMES A LAW



## 5

# A GUIDE FOR THE RARE DISEASE ADVOCATE ON THE LEGISLATIVE PROCESS

Each state legislature is unique. There is no uniform way a bill becomes a law, and the process can vary depending on the state. This section is intended to provide a general overview of the steps an RDAC bill will go through before becoming a law and what you can do at each step in the process.



## 1. RDAC legislation is introduced in the state legislature

**WHAT HAPPENS:** The first step in the process of a bill becoming a law is the introduction of the bill. While anyone can have an idea for a bill and draft potential bill language, only members of the legislature are able to introduce the bill.

**WHAT YOU CAN DO:** Thank your sponsor(s) for introducing the legislation. Write them a letter ([see example](#)), send them an email or call their office. You can also thank the RDAC sponsor(s) on social media. This shows the sponsors that you appreciate what they are doing and spreads the word about the new legislation. See Section 8 for a social media toolkit containing sample posts for each step in the legislative process.



## 2. Committee consideration/hearing and vote

**WHAT HAPPENS:** After a bill is introduced, it is referred to a committee for further consideration. Committees are smaller groups of legislators that focus on specific subject areas (e.g., health, education, appropriations, etc.). A committee holds hearings on the bill where legislators debate the merits of the bill and can propose amendments to the bill language, as appropriate. Supporters and opponents of the bill can testify to sway committee members to vote for or against it.

**WHAT YOU CAN DO:** Contact members of the committee ahead of the hearing and encourage them to vote in favor of the bill.

*If your state's RDAC bill has been referred to a committee but hasn't received a hearing yet, there are steps you can take to encourage the committee to hold a hearing. See Section 8 to learn more about what steps you can take during this part of the advocacy process.*

*State legislatures generally have members' contact information available on their website. If you're not sure who your representative is, or if they are on the committee, NORD has a tool that you can use to find out. See Section 8 for more information.*



**YOU CAN ALSO PROVIDE TESTIMONY FOR THE PUBLIC HEARING.** Providing testimony is a meaningful way to share your story with members of the committee and explain your personal connection to the legislation. There are different ways to submit testimony: **written or orally** (both in-person and virtually). Check your state legislature's website to learn more about the requirements and deadlines for submitting testimony in your state.

*If you are presented with the opportunity to provide **oral testimony**, you will want to prepare your remarks ahead of time. NORD policy staff are available to work with advocates who plan to testify during a public hearing.*

*Any person or organization can submit **written testimony**, an easy way for advocates to make their voices heard. Written testimony should detail your personal connection and stance on the legislation. An example of written testimony can be found in Section 8.*



### 3. Report bill out of the committee

**WHAT HAPPENS:** The committee will vote on whether to “report” the bill out of committee and advance it to the floor of the full legislative body for consideration and a final vote. The committee may also vote to report the bill to another committee where the committee consideration process is repeated.

**WHAT YOU CAN DO:** If enough members of the committee vote in support of a bill, it will move out of the committee to either another committee or the full legislative body for consideration. If a committee approves the RDAC bill, you can thank its members and chair for their support.

*Refer to the social media toolkit located in Section 8 for sample posts to thank a committee member.*



#### 4. Floor consideration and vote

**WHAT HAPPENS:** When the committee reports the bill out, it heads to the floor for consideration by the full chamber. Once again, legislators debate the merits of the bill and may propose amendments. When the debate is complete, legislators vote on the bill and any proposed amendments. If the bill passes, it is sent to the other chamber where it goes through a similar process.

*Most state legislatures are bicameral, meaning they have two chambers. The smaller chamber is called the Senate, while the larger chamber is called the House of Representatives/Delegates or Assembly.*

**WHAT YOU CAN DO:** Encourage lawmakers to vote in favor of the RDAC bill by emailing their offices, reaching out to them on social media, and scheduling meetings to share your support for the legislation.

One way to make it easier for people to contact their legislators is by using action alerts. An action alert is a message that advocates can send to elected officials to encourage them to act on a specific policy issue. Section 8 provides an example of an action alert and explains how NORD can help create and distribute them for you.

*A good way to prepare for a meeting with a legislative office is to practice telling your story. Check out Section 8 for a step-by-step guide to effectively sharing your story.*



#### 5. Resolve differences between the two chambers

**WHAT HAPPENS:** If each chamber passes a different version of the bill, the two chambers must resolve the differences between the versions they passed. States may form a “conference committee” to work out the variations. Once the differences are worked out, both chambers must vote in favor of the final version.

**WHAT YOU CAN DO:** If you prefer one version of the RDAC over the other, you should contact lawmakers and urge them to adopt the preferable bill.

Once the legislature has resolved the differences between the bill versions, they can officially pass the legislation. This is a great accomplishment, and you will want to thank the legislature and your RDAC sponsors for supporting the rare disease community in your state.

*Be sure to provide your lawmaker's office with your reasoning for preferring one version over the other. They may be able to use this information to advocate for adopting that version of the legislation.*



## 6. Governor's desk for signature

**WHAT HAPPENS:** After the two chambers reconcile the differences between versions of the bill and each passes the final version, it is sent to the Governor's desk for their signature. The Governor can sign the bill or veto it.

**WHAT YOU CAN DO:** Contact the Governor's office and encourage them to sign the RDAC legislation into law.

*Remember to thank the Governor if the RDAC is signed into law! The social media toolkit in Section 8 provides sample posts you can use.*

*Vetoes of RDAC legislation are uncommon. However, if the RDAC is vetoed, the veto can be overridden by a vote of the state legislature. If no override occurs, the legislative process must start over. NORD policy staff can work with you if this unlikely situation occurs.*



## 7. RDAC enacted!

**WHAT HAPPENS:** Once the Governor signs the bill, the RDAC becomes law!

**WHAT YOU CAN DO:** Spread the word and thank all the lawmakers and advocates involved.

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## WHAT TO EXPECT DURING THE LEGISLATIVE PROCESS

### ***How do I target the right member for sponsorship?***

A sponsor of a bill is the lead member who introduces the legislation and helps with the overall strategy. NORD recommends targeting members of all political parties to serve as the lead sponsors of the RDAC bill. Work to identify sponsors that are on committees of jurisdiction; i.e., committees where the RDAC would often be referred to for further consideration before becoming law. States have different names for their committees, but the RDAC legislation typically goes through the health and appropriations committees in each legislative chamber.

### ***How long does it typically take for an RDAC to pass in a state's legislature?***

Each RDAC effort looks different. Some states have passed an RDAC bill in one legislative session, while others have taken several years to pass an RDAC. During the 2020 state session, six states signed RDAC legislation into law. NORD policy staff is available to guide you throughout the process.

### ***What has worked well in other states?***

In other states, it has been helpful to have a strong coalition supporting the RDAC throughout the legislative process. The coalition can help put pressure on certain members or committees, as needed, to help move the bill towards the finish line. This can look different in every state, but NORD has found that when advocates contact

their legislators to share their stories, it can make a big difference. Sharing impactful personal stories allows legislators to become passionate about helping their rare constituents, who they now know in a deeper, meaningful way.

### ***What challenges have advocates faced in other states when trying to pass an RDAC?***

In states that have enacted RDAC legislation, the legislation is typically non-controversial and non-partisan and many legislators have been happy to support the effort. However, some challenges have arisen in the past including disputes regarding where to best “house” the RDAC, funding for the RDAC, and what issue areas should be the focus of the RDAC. Ideally, these challenges can be addressed during the coalition phase, but occasionally may come up again during the legislative process. NORD policy staff are here to help strategize how to best handle issues as they emerge.

### ***How can advocates be helpful to bill sponsors during the legislative process?***

During the legislative process, it is important for advocates and NORD policy staff to have an open line of communication with the bill sponsor's office. It is useful to have a good staff contact in the sponsor's office and check in on a regular basis to see how you can be supportive. NORD policy staff can advise when it makes the most sense to check in.

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## WHAT TO EXPECT NEXT IN THE RDAC PROCESS

**Congratulations on getting an RDAC signed into law! Now it is time for the implementation phase. Please reach out to NORD policy staff at [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org) to request the implementation phase toolkit.**

Below you will find an overview of how the implementation phase has worked in other states, but it can look different depending on the state.

1. RDAC signed into law
2. Thank the legislative sponsors and Governor
3. Work with Governor (or whomever was identified as head of appointments) to make the necessary appointments in a timely manner
4. Monitor the appointments progress; if it is not going as planned, consider engaging the coalition to put pressure on the process by circulating a letter or making calls
5. Ensure all RDAC members are appointed
6. Plan the first RDAC meeting
7. Conduct the first RDAC meeting
8. Create a workplan based on RDAC duties and requirements
9. Develop recommendations
10. Compile recommendations into a report
11. Submit recommendations to state government decision makers



# 8

## RESOURCES

**NORD policy staff has created a variety of resources to help at every step of the RDAC legislative process. Please see below for tools to help get an RDAC enacted in your state. All resources are available upon request to [RDAC@rarediseases.org](mailto:RDAC@rarediseases.org).**

1. NORD's Model Bill Language
2. [How to Identify Your Lawmakers Tool](#)
3. How to Share Your Story with a Lawmaker
4. Action Alerts
5. Sample Written Testimony for Public Hearings
6. Opinion Piece (Op-Ed)
7. Organizational Letter of Support
8. Social Media Toolkit



# 9

## CONCLUSION

Advocating for an RDAC in your state will benefit the entire rare disease community and can help raise the profile of the challenges rare disease patients and families face every day. RDACs provide a forum for making recommendations on how to improve policies that impact the rare disease community, while also reducing the burden on government. When the rare disease community works together on solutions in a strategic and collaborative way, we can be more effective and create lasting change.

Thank you for your continued advocacy on RDACs with NORD!

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

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NORD: Fighting for the rare community every day for nearly 40 years. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient support services. NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. NORD is a registered 501(c)(3) charity organization. NRD-2140

