

IMPLEMENTING A RARE DISEASE ADVISORY COUNCIL IN YOUR STATE



NORD[®]
National Organization
for Rare Disorders

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WELCOME

Dear Fellow Rare Disease Advocates,

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 councils across the country. NORD is committed to ensuring all states have RDACs that are impactful and high functioning to benefit the rare disease community and state governments. To facilitate in this process, NORD has developed resources designed to assist RDACs at every step of their journey.

This Project RDAC toolkit is focused on the implementation of your state's RDAC, once legislation creating an RDAC has been signed into law by your Governor. A special thanks to the rare disease advocates and RDAC leaders who are part of an existing council for sharing their wisdom and lessons learned within this toolkit. NORD has additional toolkits on RDACs. "Creating a Rare Disease Advisory Council in Your State" provides a step-by-step guide to building an RDAC coalition and determining the purpose of the council in your state. "Advocating for a Rare Disease Advisory Council in Your State" is a comprehensive guide to the legislative phase of an RDAC and includes resources and tips on the legislative process, suggestions for engaging with lawmakers, and advocacy recommendations for the RDAC coalition. All toolkits, along with additional resources on RDACs, can be found NORD's Project RDAC webpage at rarediseases.org/projectrdac.

We hope you will find this toolkit beneficial as you work with your RDAC coalition, NORD's Rare Action Network of volunteer state ambassadors and the rare disease community to begin the exciting implementation phase. NORD's policy staff stands ready to work with you and help get your state's RDAC off the ground. Please contact us at RDAC@rarediseases.org so that we can connect with you about efforts already underway in your state.

Thank you for all you do!

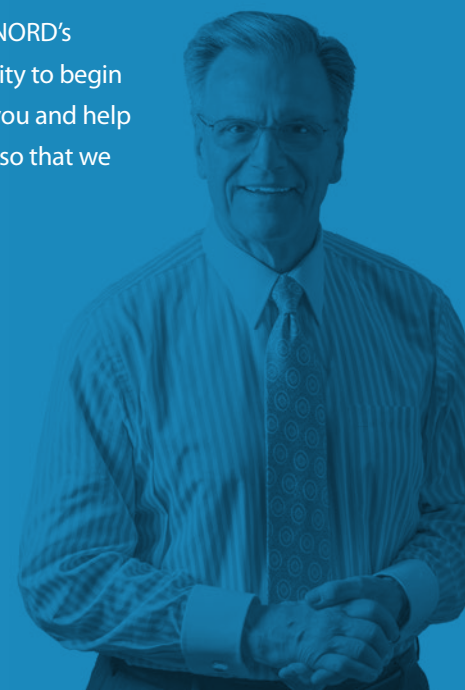
Alone we are rare. Together we are strong.®

Sincerely,



Peter L. Saltonstall

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



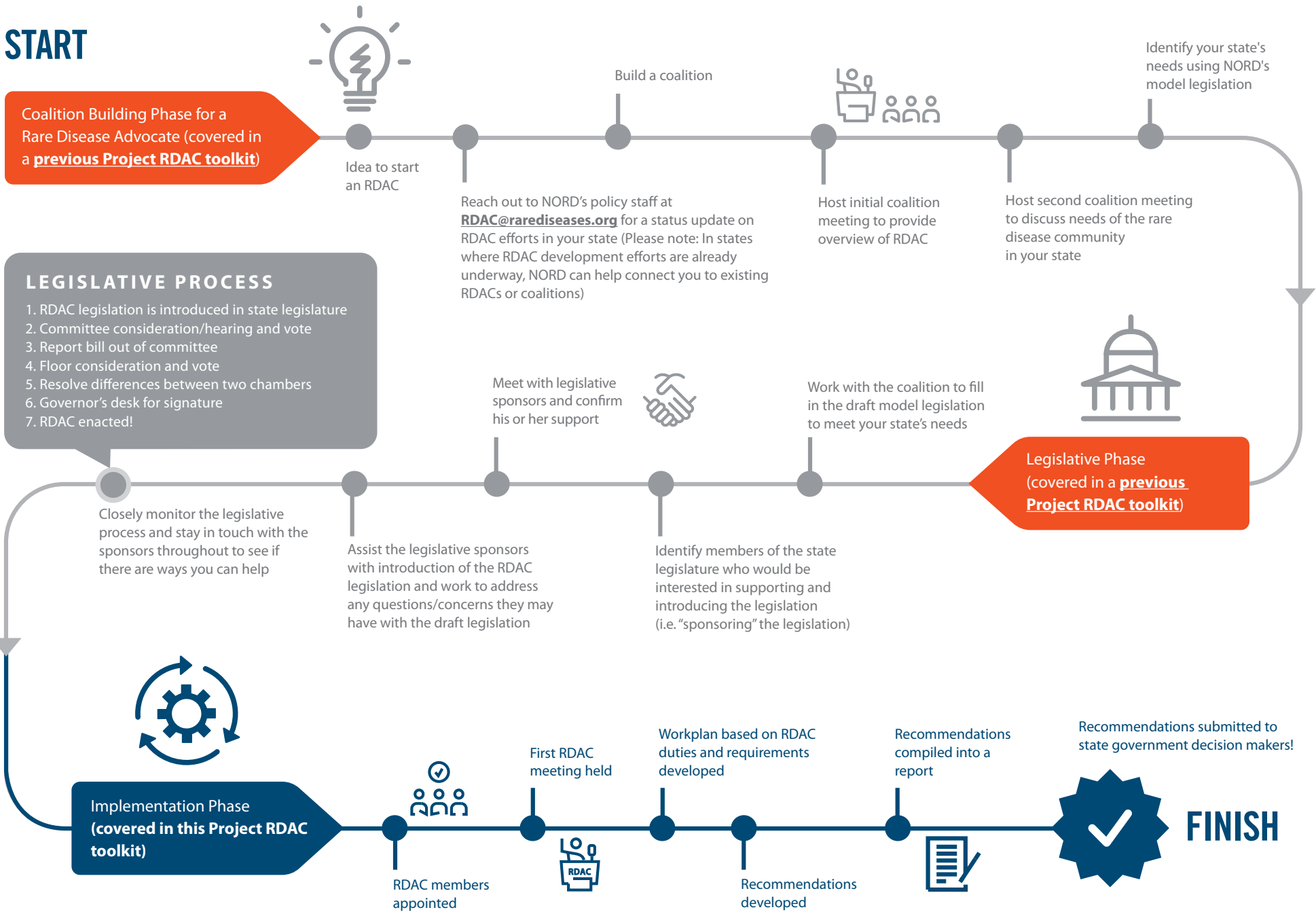
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LIFECYCLE OF AN RDAC FROM START TO FINISH



This is just an example of how an RDAC might be implemented. This process will inevitably vary depending on the state.

START



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GENERAL TIPS FOR THE IMPLEMENTATION PHASE



“Even when rare disease lacks funding, remember that rare disease has partnerships and community. Seek it and more often than not it will be found—a foundation or many foundations to be built from.”

DR. AMBER FEDERIZO, APRN, DIRECTOR OF RESEARCH, THE HEMOSTASIS AND THROMBOSIS CENTER OF NEVADA; AND CHAIR, NEVADA RDAC



“Ensure the RDAC is fully aware and in agreement on where the Council is situated. Whether it is housed within a state agency, institution or independent, having complete endorsement and buy-in from the organization will alleviate hiccups when it comes to future funding sources and requirements.”

PATRICK COLLINS, SENIOR DIRECTOR, HEALTHCARE POLICY AND EXTERNAL AFFAIRS, CSL BEHRING; AND MEMBER, PENNSYLVANIA RDAC



“It is important to decide quickly the scope of work the RDAC would tackle and what it would not. RDACs also need to work closely with the particular state Newborn Genetics Advisory Committees given the obvious overlap of scope of work.”

RIZWAN HAMID, MD, PHD, DOROTHY OVERALL WELLS PROFESSOR; DIRECTOR, DIVISION OF MEDICAL GENETICS AND GENOMIC MEDICINE, DEPARTMENT OF PEDIATRICS, VANDERBILT UNIVERSITY SCHOOL OF MEDICINE; MEMBER OF THE TENNESSEE RDAC



“The Alabama Rare Disease Advisory Council has been a team effort from the very beginning – involving rare disease advocates, health providers, and members of the state legislature. Our work is motivated by a common desire to help ease the journey for those with rare disorders and their caregivers.”

BRUCE KORF, MD, PHD, ASSOCIATE DEAN FOR GENOMIC MEDICINE AND CHIEF GENOMICS OFFICER, UAB MEDICINE; EDITOR, THE AMERICAN JOURNAL OF HUMAN GENETICS; AND CHAIR, ALABAMA RDAC

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A GUIDE FOR GETTING THE RDAC OPERATIONAL

Congratulations to the RDAC coalition and rare disease community in your state on getting RDAC legislation across the finish line! To ensure that your state's RDAC is successfully implemented, it is important to know what happens next and what key areas in the bill on which to focus. Each state's process can look a bit different. In this case, the examples will be based on NORD's model RDAC legislation. However, this can be applied to any version of an RDAC bill.



What happens after the bill is signed into law?

After a bill is signed into law, it is crucial for the RDAC coalition to pay close attention to the key dates and membership appointment process set forth under the law to ensure the RDAC gets off to a good start. See below for helpful tips to guide the coalition.

Key Dates:

The RDAC law will typically include deadlines for member appointment timing and for the first meeting. It is important to review the RDAC law to find these deadlines, pay attention to these dates, and to follow up with the appropriate contact(s) to see if any support is needed to meet the deadlines. The governor or department of health is often tasked with appointing the RDAC's chair within 30 days of enactment, and the first meeting often is required to take place within 90 days enactment. However, this timing can be different for your state.

Membership and Appointment Process:

RDAC membership can vary widely but is typically described in detail within the RDAC statute. NORD's model language recommends 12-15 members from the rare disease community, ranging from patients and caregivers, to providers and researchers, be included on the council. Diverse viewpoints from across the rare disease community are crucial to the overall success of an RDAC.

Please note: RDAC membership is not guaranteed for coalition members.



NORD’s model language recommends that the governor appoint a chair and vice-chair. The chair and vice-chair will then work together to appoint the other members to the council. However, it is also common for the governor or the department of health to make all RDAC appointments.

If the individuals who are tasked with making the appointments have difficulty gathering applications, NORD can engage the state’s **Rare Action Network** to publicize the opportunity and educate those interested on how the application process is being handled in your state. Please feel free to reach out to NORD policy staff if the bill sponsor(s) and/or the governor’s office are encountering difficulty finding individuals who are interested in serving on the council.



How can the coalition engage with the RDAC bill sponsor and government officials?

It is very helpful if the RDAC coalition can continue to offer their assistance and support through the implementation process. This can be accomplished by delegating a coalition member to stay in regular communication with the bill sponsor(s) and those responsible for the appointment of members to the RDAC. NORD policy staff can advise when it makes sense to check in and have created an email guide and **template** to utilize to assist with outreach. It typically takes between three and six months from the time the bill is passed and signed into law until the RDAC has completed its appointments, but the timeline can vary greatly by state.



Does NORD make appointments to the RDAC?

NORD policy staff are more than happy to be an ongoing resource for any questions about a state’s RDAC. In NORD’s model language, the governor makes appointments; however in other states the legislature or department of health also sometimes has that authority. NORD will gladly share how individuals can apply to the council and provide updates on the timeline.

Please note: Sometimes getting the RDAC operational takes longer than anticipated, especially if there are other pressing issues impacting the state. It is essential to remain patient, but persistent, to make sure that the appointment of RDAC leaders/members is prioritized.



How can the RDAC coalition monitor the law post-enactment?

The RDAC coalition is an extremely important part of the implementation process since they have been actively involved in reaching out to lawmakers for support and are familiar with the bill language, the type of members that will be appointed and deadlines that they need to be met.

Although some RDAC coalition members are likely to be appointed to the council, being a part of the RDAC coalition does not guarantee a spot on the council. The application process will be shared with the coalition, and members will be encouraged to apply if they are interested.

If a coalition member is not appointed to the state's RDAC, they will still have opportunities to be involved. Most RDACs have public meetings, allowing for participation from state residents. Participating in RDAC meetings and engaging with the RDAC through their website and/or social media are all ways for coalition members to continue using their voices to make an impact.

While some RDAC coalitions decide to disband once the bill is signed into law, other coalitions choose to regularly touch base on how they can provide support to the state's RDAC. Choose what is best for your coalition to help ensure the RDAC is successfully implemented and supporting the rare disease community.



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A GUIDE FOR GETTING THE RDAC OPERATIONAL

Have you been appointed as the RDAC chair or vice-chair in your state? The below sections outline the four main phases of beginning an RDAC and making it a high-impact, functional resource for the state. These insights are based on the experiences of other councils that have already gone through this process. It is also important to note that each state implements councils or advisory bodies in different ways, and that there is no uniform way to do it. The goal of this section is to provide some guidance to make the process smoother. As always, please feel free to reach out to the NORD policy staff at RDAC@rarediseases.org with any questions.



PHASE 1

INITIAL SET UP

- *Understand and begin the appointment process*
- *Ensure all appointments are made and set up first meeting*

PHASE 2

EARLY MEETINGS AND WORK

- *Host a second meeting*
- *Identify initial priorities*
- *Establish a robust strategy and opportunities for public engagement moving forward*

PHASE 3

ONGOING OPERATIONS, GOVERNMENT ENGAGEMENT AND LAW COMPLIANCE

- *Continue to meet as necessary*
- *Set up a mechanism to weigh in on ongoing policy, stay updated, and introduce the RDAC to relevant agencies/legislature*
- *Ensure you are complying with the statute*

PHASE 4

LONG TERM SUCCESS AND THINKING AHEAD

- *Continue to monitor the appointments and term limits*
- *Continue to evaluate the council and map out next steps*
- *Return to the legislature as necessary to seek public funding or adjust the law to help address identified challenges or barriers to success*

PHASE 1

Initial Set Up

Understand and begin the appointment process

- ❑ Secure a government contact (if the council is tied to a state government health agency or department) and learn how the appointment process will be handled.
- ❑ After you have a contact, reach out and work to ensure all the RDAC membership positions are filled in accordance with the law. It can be really useful to engage with the coalition that helped push for the RDAC initially to help publicize the opportunity to apply to be a member.
- ❑ Spread the word about open positions with your contacts, including NORD policy staff, patient organizations operating in the state and health care providers. NORD is happy to send an email out to the state Rare Action Network and spread the word on social media. Email the NORD policy team at RDAC@rarediseases.org to get that process started.
- ❑ The process and forms can vary state to state but check out some examples of [criteria](#) to consider for a strong application and process, and a [sample email](#) to help spread the word about open positions.

Tips for success:

- Often the bill's sponsor can help connect you with the right person working on the RDAC within state government.
- Some RDACs plan out their entire year of meetings to give members ample time to prepare and ensure stronger attendance numbers. Often it is helpful at the start of an RDAC's implementation to meet monthly, but at minimum, ensure meetings are organized in accordance with the law's requirements, usually at least once a quarter.

Ensure all appointments are made and set up first meeting

- ❑ Once the appointments have been made, it is recommended that council leadership cross reference the law's membership requirements with the appointments made to ensure all roles have been filled appropriately.
- ❑ In NORD's model language, the chair is required to set up first meeting; however that could differ depending on the state. Please try to include a virtual component to the meeting as these are state-wide councils and council members may not always be able to travel to the meeting location.
- ❑ Check out NORD's [sample agenda](#) and examples from [Minnesota](#), [Pennsylvania](#) and [Tennessee](#) for examples of strong meetings.
- ❑ After the first meeting concludes, send out a recap, minutes and date of the next meeting to all council members (more advance notice the better).



- For a strong first council meeting, ensure there is time to do a round of introductions, then review the RDAC statute and history of rare diseases and common challenges. Check out these [template slides](#) that can help provide a background on rare diseases and the common challenges the community faces. After introductions and the overview are completed, work through operation issues including: meeting frequency, virtual component, notetaking, funding allocations as appropriate.

PHASE 2

Early Meetings and Work

Host a second meeting

- ❑ At the second meeting, start to strategize on initial work priorities and develop an associated work plan. These early meetings where you develop a strategy and workplan are critical to the overall success of the RDAC.

Identify initial priorities

- ❑ Review the RDAC law to understand key duties and responsibilities.
- ❑ Develop a survey for the state's rare disease community to assess and prioritize issues for the state's RDAC to focus on. Please reach out to NORD's policy staff at RDAC@rarediseases.org to get connected with other state councils that have completed surveys. Here are examples of surveys that [New Hampshire](#) and [Pennsylvania](#) conducted.
- ❑ Consult with the state's RDAC coalition to discuss what policy issues they'd like the council to prioritize.

Establish a robust strategy and opportunities for public engagement moving forward

- ❑ Ongoing public engagement is important to ensure diverse voices from across the state are heard and the RDAC remains a voice for all. Please see tips at the right to help achieve that goal:

Tip 1 - Maintain a public website: A public website is a great resource to keep all your information for meetings, membership, the law, reports, contacts and other important information all in one space. Please see this resource as a [guide](#) for criteria to include on a strong RDAC website and examples from other states including: [Alabama](#), [Minnesota](#), [North Carolina](#), [Pennsylvania](#) and [Tennessee](#).

Tip 2 - Engage via social media: Social media is not for everyone, but some councils are finding success with engaging with their state's rare disease population via Facebook. Check out Pennsylvania's [Facebook page](#) as an example. Also, here are some [template posts](#) to help promote the work of the council on social media.

Tip 3 - Have open meetings: Due to the membership limitations often included in the law, not everyone will be able to serve on an RDAC or attend in person. NORD recommends RDAC meetings be open to the public and have a virtual component to ensure strong participation from community members and increased public engagement. It is also suggested to share upcoming meetings and meeting minutes on your RDAC website and via social media.

Tip 4 - Include a guest speaker at each meeting: In order to hear from different voices across the state, it is recommended that a guest speaker from the state's rare disease community kick off each meeting. This will help tie the work of the council back to the mission and vision of improving the lives of all rare disease patients and families in your state. Here is a [sample email](#) to invite a guest speaker.

Tip 5 - Consider hosting listening sessions: Listening sessions or open forums held in different locations or regions across the state are a good opportunity to hear from different perspectives and members of the rare disease community. This can be done either virtually or in-person. NORD policy staff are happy to help promote these opportunities through NORD social media channels.

Tip 6 - Set up a mechanism for public comment: On the state's RDAC website, create a portal or establish a public email address to accept and receive public comment or feedback. This will help the council communicate directly with the public and hear different perspectives.

Tip 7 - Develop a listserv: A listserv for email communications is important. This is a good way to update your state about future opportunities with the council including general announcements, clinical trial opportunities, etc.

PHASE 3

Ongoing Operations, Government Engagement and Law Compliance

Continue to meet as necessary

- ❑ Start to brainstorm a mission and vision statement. Here is [resource by Mind Tools](#) to help guide developing a mission and vision statement.
- ❑ Review appropriations (if any) against the statute to determine if there are any reporting requirements and how to best utilize funding.
- ❑ Develop and begin to implement the RDAC's work plan. Expect this work to take up multiple early meetings.
- ❑ Start to discuss external funding opportunities and ways to support the council's work. Other councils have found external grants helpful to support their overall goals. Unfortunately, funding takes time to secure, so it is recommended that a council start to work early on this.

Set up a mechanism to weigh in on ongoing policy, stay updated and introduce the RDAC to relevant agencies/ legislature

- ❑ Keep up to date and research the status of policy for the rare disease community in your state. [NORD's state policy report card](#) is a good place to start.
- ❑ Introduce the council to the state's legislators on the relevant health committees and ask to schedule a presentation. In the presentation, provide background on the council, an overview of rare diseases, and policy areas you would like them to pursue. Here is a [sample presentation](#).

- ❑ **Write a letter** to the relevant agencies (Department of Health and Insurance, Medicaid Agency, etc.) to introduce the council and set up introductory meetings as necessary.
- ❑ Develop a mechanism that all council members are comfortable with to weigh in on active policy discussions. Some councils do this more informally through one-on-one conversations, while others formally weigh in via letters of support for specific policies or state decisions on their RDACs letterhead.

Ensure you are complying with the statute

- ❑ Work on necessary reports and submit on timely basis. Be sure to start the reports early as they can be time intensive. However, they are a great way to demonstrate value to the legislature. See examples from [Alabama](#), [North Carolina](#) and [Pennsylvania](#).
- ❑ Once the report or other public reporting is complete, be sure to submit to relevant agencies or legislators as necessary and add to your RDAC website.
- ❑ Develop a mechanism that all council members are comfortable with to weigh in on active policy discussions. Some councils do this more informally through one-on-one conversations, while others formally weigh in via letters of support for specific policies or state decisions on their RDACs letterhead.

NORD staff or other RDACs are happy to come speak at meetings and provide guidance as needed. Reach out at RDAC@rarediseases.org for more information. Please note: NORD is unable to provide funding to individual RDACs.

PHASE 4

Long Term Success and Thinking Ahead

Continue to monitor the appointments and term limits

- ❑ Set up a process for when there is a vacancy on the council. It is recommended to confirm with the RDAC's housing entity or the law to ensure the RDAC is meeting the requirements. Be sure to not let a seat go vacant for long.

Continue to evaluate the council and map out next steps

- ❑ Evaluate the RDAC's early successes and challenges.
- ❑ Update the council's website and other resources as needed.

Return to the legislature as necessary to seek public funding or adjust the law to help address identified challenges or barriers to success



QUICK RESOURCE GUIDE

Section 3 Resources: A Guide For Getting the RDAC Operational - For the RDAC Coalition Members

1. [Sample email](#) to sponsor or government official (to encourage support for starting the council after it has been signed into law)

Section 4 Resources: A Guide For Getting the RDAC Operational - For the Appointed RDAC Chair/Vice-Chair

Phase 1 - Initial Set Up

1. [Examples of criteria](#) to consider for a strong RDAC application and process
2. [Sample email](#) to help spread the word about open RDAC positions
3. [Sample agenda](#) for first RDAC meeting
 - Examples from states: [Minnesota](#), [Pennsylvania](#) and [Tennessee](#)
4. [Template background slides](#) on rare diseases and common challenges

Phase 2 - Early Meetings and Work

1. Examples of state RDAC surveys from [New Hampshire](#) and [Pennsylvania](#)
2. [Guide](#) for creating a strong RDAC website
 - Examples of websites from other state RDACs: [Alabama](#), [Minnesota](#), [North Carolina](#), [Pennsylvania](#) and [Tennessee](#)
3. [Template](#) social media posts
 - Example of social media pages from the [Pennsylvania RDAC](#)
4. [Sample email](#) to invite a guest speaker to an RDAC meeting

Phase 3 - Ongoing Operations, Government Engagement and Law Compliance

1. Mission and vision [resource](#) by MindTools
2. NORD's state policy report card [website](#)
3. [Sample presentation](#) for state legislators
4. [Letter](#) from RDAC to state agencies
5. Examples of reports from state RDACs: [Alabama](#), [North Carolina](#) and [Pennsylvania](#)

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CONCLUSION

Implementing a well-functioning, impactful RDAC in your state will benefit the entire rare disease community by raising awareness and educating state government decisionmakers on the challenges patients and families face every day. NORD wishes you the best of luck implementing your state's RDAC. Please stay tuned for future Project RDAC opportunities by checking out the website rarediseases.org/projectrdac regularly.

Thank you for your continued advocacy on RDACs!

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-2173