



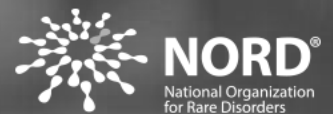
NORD[®]
National Organization
for Rare Disorders

NORD's Project RDAC Initiative

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Region

NORD, an independent nonprofit, is leading the fight to improve the lives of **rare disease patients and families**.

We do this by supporting patients and organizations, accelerating research, providing education, disseminating information and driving public policy.



rarediseases.org



The Problem

- **25-30 million Americans** are living with one of the more than 7,000 unique rare diseases.
- Even though estimated **1 in 10 Americans** have a rare disease, state decision makers often have limited awareness and knowledge of the impact that rare diseases can have on patients, their caregivers, and the overall health care system.





THE SOLUTION: RARE DISEASE ADVISORY COUNCILS (RDACs)

- A diverse body representing the rare disease community to advise state government on their common obstacles
- Opportunity for government officials and the rare disease community to partner to develop resources necessary to prevent and address barriers in a strategic way





Project RDAC

- **Optimize the existing RDACs and to increase the number of RDACs across the country**
- **NORD provides opportunities for the RDACs and the rare disease community to collaborate with each other**
 - Nov 16 @ 2:30 pm ET - RDAC stakeholders meeting
 - All stakeholders in the rare disease community, including members of state RDACs, are invited to attend!
- **Create educational resources to guide RDACs at every step of their journey**
 - Toolkits & webinars
 - Technical assistance to lawmakers and implementers

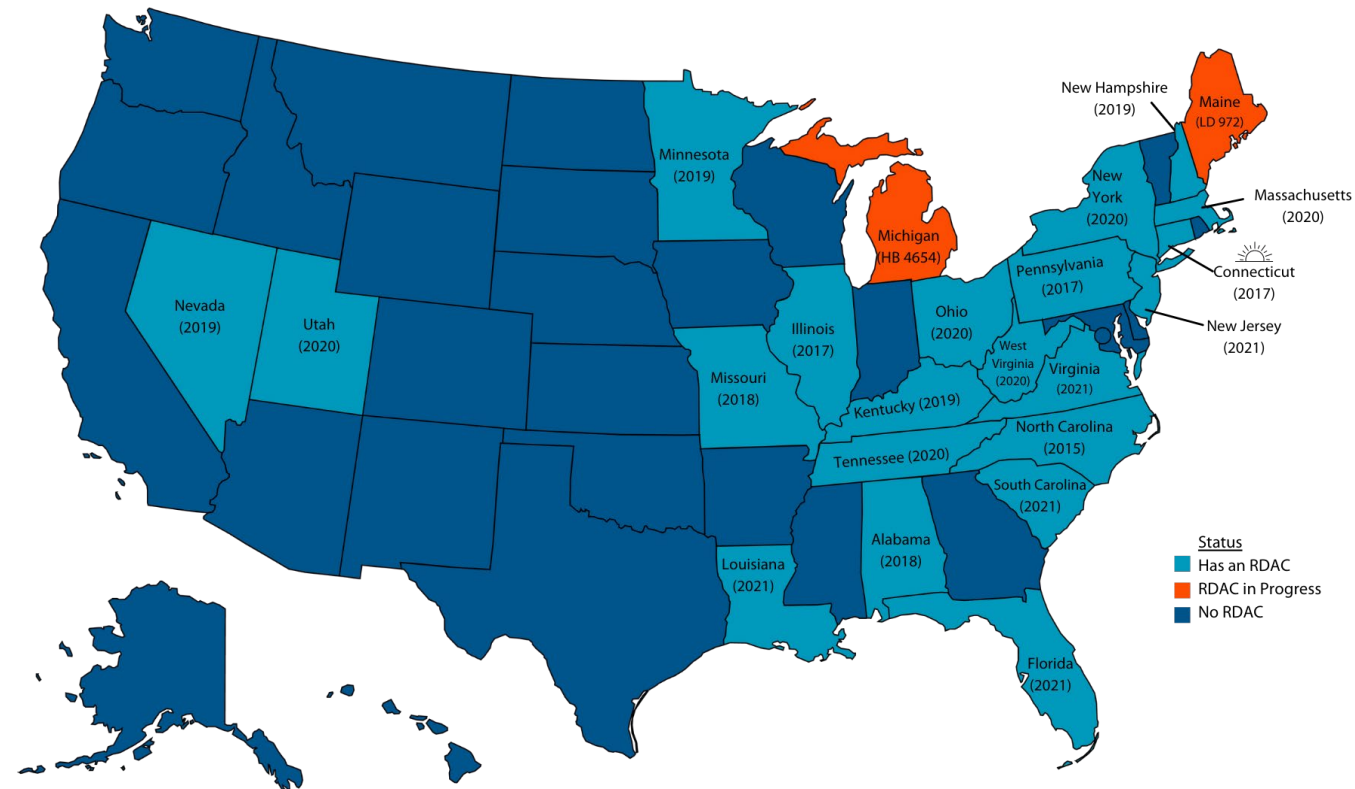




Rare Disease Advisory Councils

Since the launch of Project RDAC:

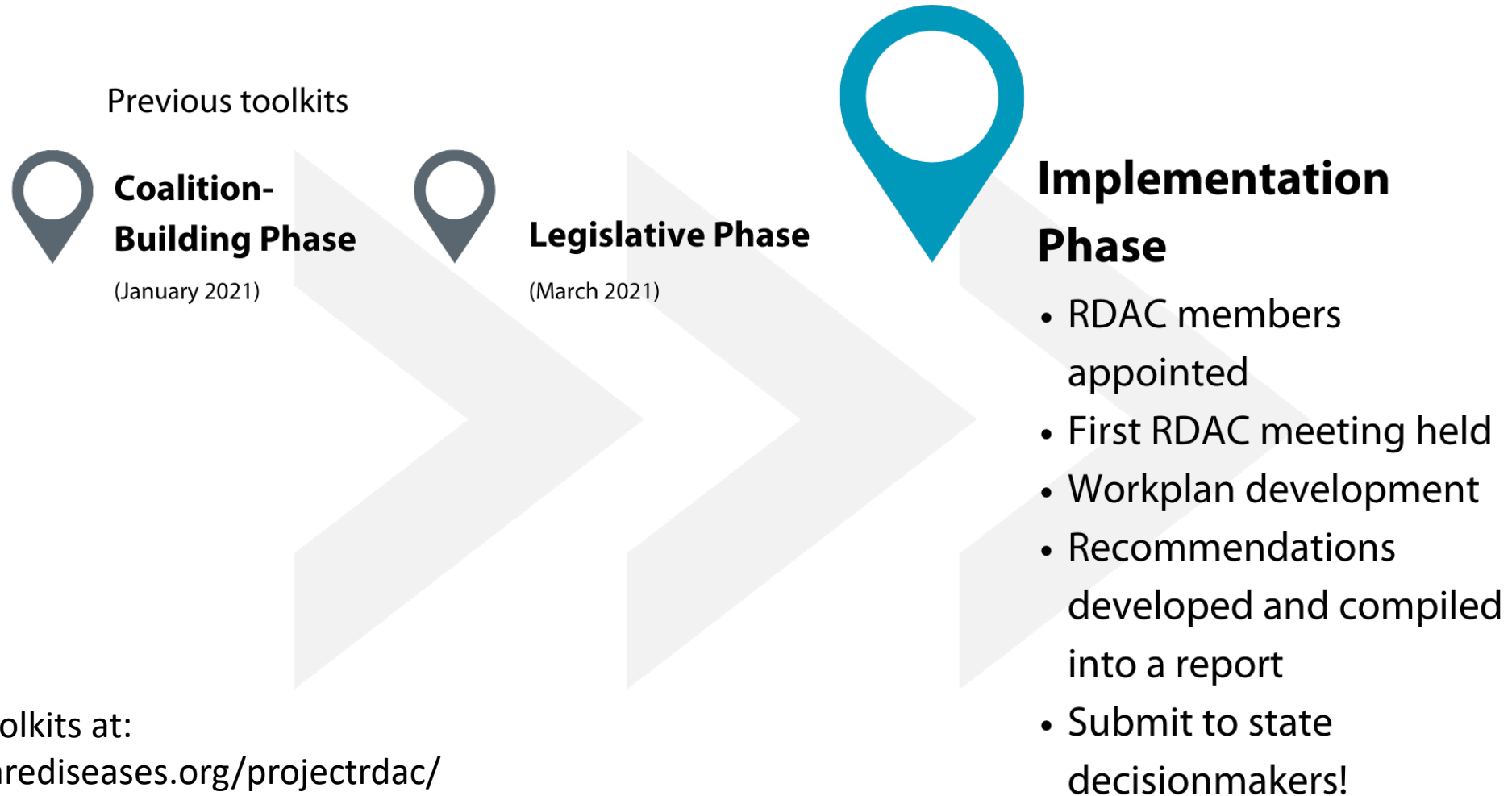
- 7 states have passed RDAC legislation into law (OH, MA, VA, FL, LA, NJ, SC)
- 2 states have pending RDAC legislation (MI and ME)
- 8 states had active RDAC engagement (CA, TX, GA, MD, MS, AR, RI, IN)
- 1 new RDAC bill may still be introduced this year (WI)



21 states have passed RDAC legislation!



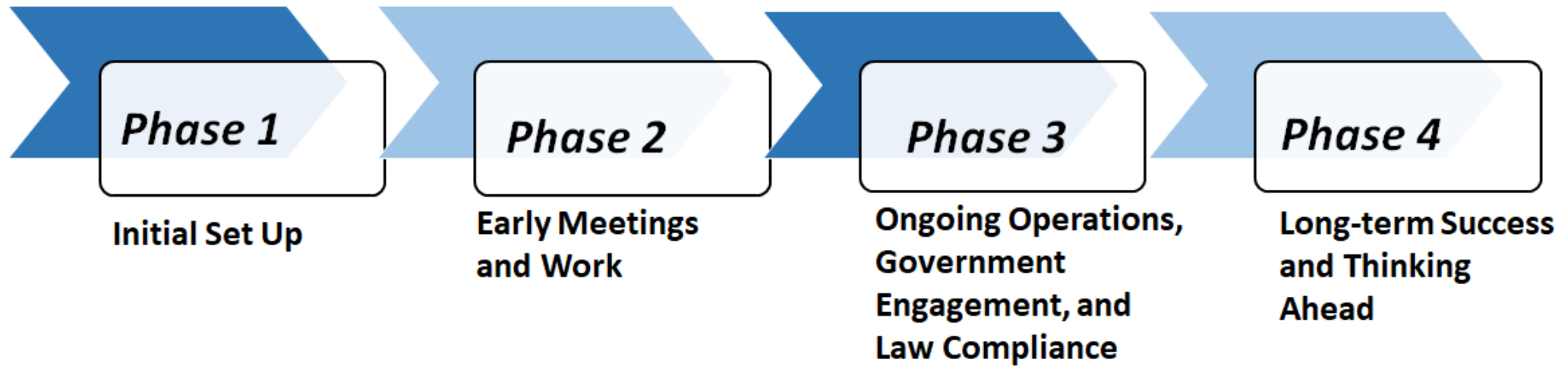
LIFECYCLE OF AN RDAC



Access toolkits at:
<https://rarediseases.org/projectrdac/>



OPERATIONALIZING THE RDAC AS THE CHAIR/VICE-CHAIR





Examples of resources contained in the implementation toolkit:

- Criteria for a strong application process
- Sample email to advertise open RDAC positions
- Sample agenda for first meeting
- Template slides on rare diseases
- Criteria for a strong website
- Template social media posts
- Sample email to invite a guest speaker
- Sample presentation for legislators
- Letter from an RDAC to state agencies





VISIT THE PROJECT RDAC WEBSITE TO REQUEST A TOOLKIT

rarediseases.org/rdac-overview

ADVOCATING FOR A
RARE DISEASE ADVISORY
COUNCIL IN YOUR STATE





FUTURE PROJECT RDAC OPPORTUNITIES



November 16, 2021

RDAC stakeholders meeting

Virtual and open to all!

*For more information on this and
future Project RDAC events visit:
[https://rarediseases.org/projectrdac/
project-rdac-events/](https://rarediseases.org/projectrdac/project-rdac-events/)*



Thank you.

Alone we are rare. Together we are strong.®

rarediseases.org