# [Title Slide]

An Introduction to NORD (National Organization for Rare Disorders)

Massachusetts RDAC (Rare Disease Advisory Council) Meeting

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NORD: National Organization for Rare Disorders: rarediseases.org

[New Slide]: Purpose

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.

NORD: National Organization for Rare Disorders-rarediseases.org

[New Slide]: Our Stakeholders

**NORD**

**Patients and Families**: Undiagnosed, Newly Diagnosed, Caregivers

**Medical Professionals**

**Industry**: Biotechnology, Pharmaceutical, Research Organizations, Service Providers

**Patient Organizations**: Research Foundations, Disease Specific Advocacy Organizations, Support Groups

**Regulators**: Food and Drug Administration (FDA), National Institutes of Health (NIH), Centers for Medicaid and Medicare (CMS), Social Security Administration (SSA)

NORD: National Organization for Rare Disorders-rarediseases.org

[New Slide]: Membership Organizations

**330 Members**

**1,200 PAGs**

**7,000 Rare Diseases**

**Map of states with member organizations:**

**Washington: 3**

**Oregon: 5**

**California: 27**

**Nevada: 2**

**Utah: 3**

**New Mexico: 3**

**Colorado: 4**

**Alaska: 1**

**South Dakota: 1**

**Nebraska: 1**

**Minnesota: 8**

**Iowa: 1**

**Wisconsin: 3**

**Texas: 11**

**Oklahoma: 3**

**Illinois: 20**

**Indiana: 1**

**Ohio: 10**

**Michigan: 7**

**Florida: 14**

**Georgia: 7**

**Tennessee: 4**

**South Carolina: 1**

**North Carolina: 7**

**New York: 26**

**Maine: 4**

**New Hampshire: 1**

**Massachusetts: 16**

**Connecticut: 8**

**New Jersey: 12**

**Pennsylvania: 18**

**Maryland: 16**

**Delaware: 5**

**Mississippi: 1**

**Louisiana: 1**

**Virginia: 11**

**Kentucky: 1**

**Kansas: 1**

**Missouri: 5**

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[New Slide] Rare Diseases Database

https://rarediseases.org/for-patients-and-families/information-resources/rare-disease-information/

Rare Disease Database

* 1,300+ reports
* Integrated videos

In 2021

* Updated reports: 44
* New reports added: 9

NORD: National Organization for Rare Disorders-rarediseases.org

[New Slide} NORD Patient Assistance Programs <https://rarediseases.org> or 800-999-6673

NORD is well-recognized and universally regarded as the expert in navigating the complex rare disease landscape.

**Medication**: Free drug programs for financially eligible uninsured and underinsured patients.

**Premium and Co-Pay**: Branded and disease specific co-payment, co-insurance, and premium funds.

**Medical Service**: Access to durable medical equipment, diagnostics and other services not covered by insurance.

**Travel and Lodging**: Coordination and provision of necessary and temporary housing assistance to facilitate participation in clinical trials.

**Innovative and responsive programs**

**Expanded Access**: Random selection programs when a limited amount of investigational drug is available.

[New Slide] Patient Services Impact

Dedicated Patient Services and Information Services Team

Communication Center:

Mon-Thurs 8:30am-7:00pm

Fri 8:30am-6:00pm EST

$35,642,186 awarded across all NORD assistance programs in 2020

9,951 patients with 265 rare diagnoses assisted

959 patients assisted with medical expenses not covered by health insurance

7636 patients assisted with health insurance premiums and/or copay expenses

68,718 calls answered

65,983 emails answered

Travel and lodging assistance provided for 11 clinical trials

7 new assistance programs opened

Wepage views of NORD’s RareCare programs increased over 155% from 2019

Assistance provided to rare patients and families in 50 states and 5 US territories

[New Slide] Project RDAC

**GOAL: Optimize existing rare disease advisory councils (RDACs) and increase the number of RDACs across the country**

* Organize diverse coalitions of rare disease community stakeholders in support of establishing new RDACs
* Create opportunities for existing RDACs to collaborate with each other
* Develop resources to guide RDACs at every step of the process:
  + Model Language
  + Webinars/Workshops
  + Toolkits
  + Legislator Engagement

[New Slide] 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)
* 3 states have pending RDAC legislation (ME, MI, and WI)
* 8 states had active RDAC engagement (CA, TX, GA, MD, MS, AR, IN, WA)

21 states have passed RDAC legislation!

[New Slide] Lifecycle of an RDAC

Previous Toolkits

Coalition Building Phase: January, 2021

Legislative Phase: March, 2021

Implementation Phase:

* RDAC Members Appointed
* First RDAC Meeting held
* Workplan Development
* Recommendations Compiled and Developed into a report
* Submit to state decision makers!

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

[New slide] Operationalizing the RDAC as the Chair/Vice-Chair

Phase 1: Initial Set Up

Phase 2: Early Meetings and Work

Phase 3: Ongoing Operations, Government Engagement, and Law Compliance

Phase 4: Long-term Success and Thinking Ahead

[New Slide] NORD RDAC Resources

Examples of resources in the RDAC 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

[New Slide] How to request the toolkit

Visit the Project RDAC website: [*rarediseases.org/projectrdac*](http://www.rarediseases.org/projectrdac)