

NORD[®]
National Organization
for Rare Disorders

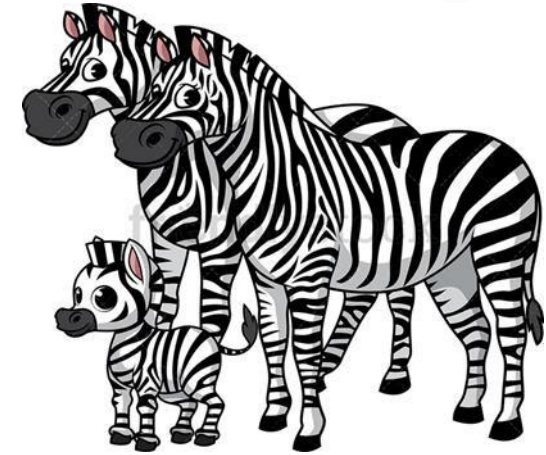
NORD's Rare Disease Advisory Council Work

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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.





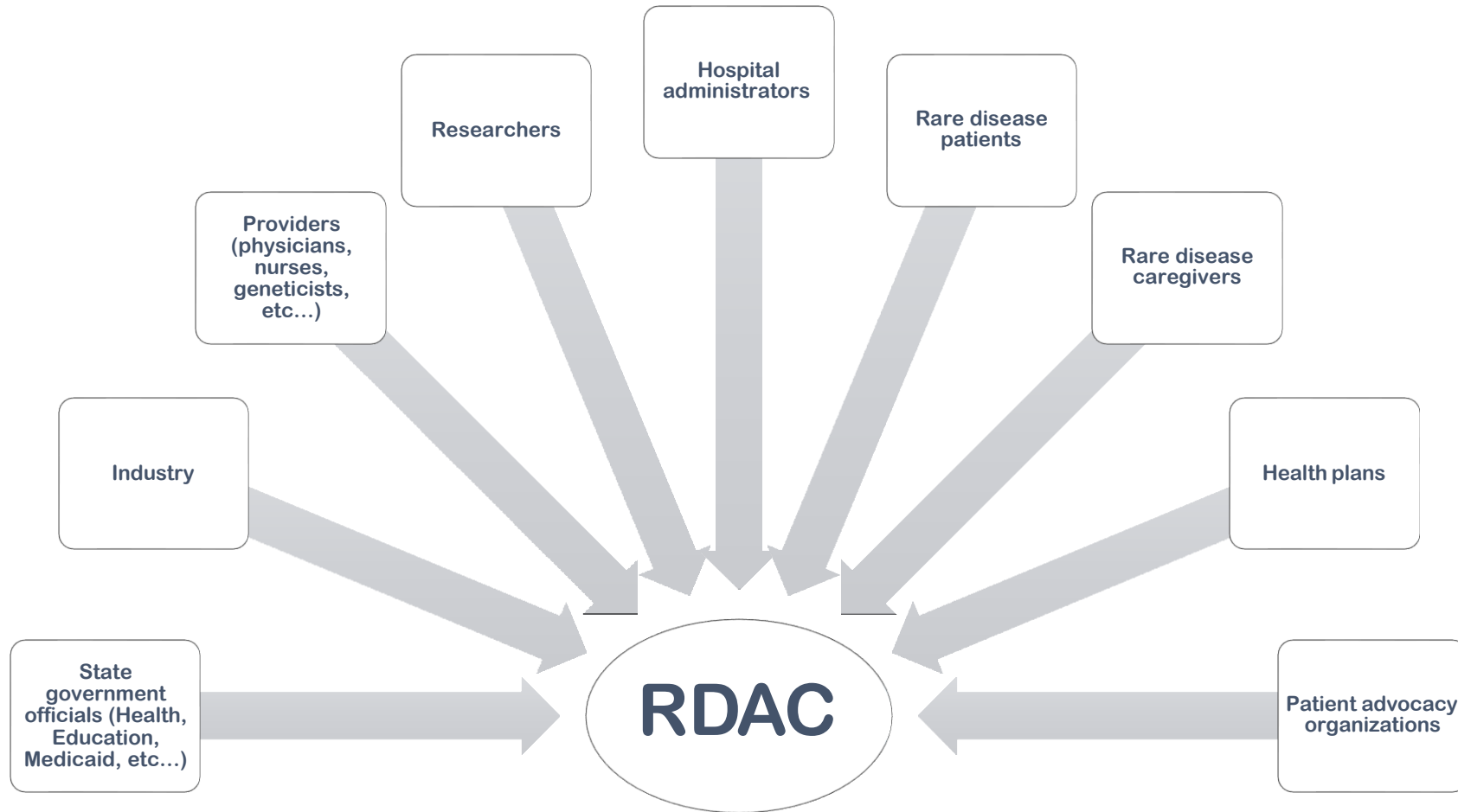
The Solution – Rare Disease Advisory Councils

- Create a diverse body that represents the rare disease community to advise state government on common obstacles
- Enormous opportunity for government officials and the rare disease community to partner together to develop resources necessary to prevent and address barriers in a strategic way





Examples of Membership





Examples of RDAC Duties



- Convene public and solicit comments to help with a first year landscape report



- Consult with rare disease experts to improve access and quality to health insurance, education, and treatment



- Make recommendations to the legislature and state agencies



- Publish a list of resources in the state



- Research and improve the state's newborn screening program



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States That Have Enacted Rare Disease Advisory Council Legislation



States That Have Enacted Rare Disease Advisory Council Legislation

State	Year
Alabama	2018
Connecticut (sunset in 2019)	2017
Illinois (sunset in 2020)	2017
Kentucky	2019
Minnesota	2019
Missouri	2018
New Hampshire	2019
New York	2019
Nevada	2019
North Carolina	2015
Pennsylvania	2017
Tennessee	2020
Utah	2020
West Virginia	2020

14 states!



Differences in RDACs

- Size and membership of council
- Where the council works out of (Department of Health, University, Nonprofit, etc...)
- Funding
- Duties



NORD's Future RDAC Work





Project RDAC: Overview

- Optimize the existing RDACs and to increase the number of RDACs across the country
- NORD will provide opportunities for the RDACs to collaborate with each other
- Create educational resources to guide RDACs at every step of their journey
 - Webinars
 - Toolkits





Inaugural Project RDAC Meeting



Date: December 16, 2020

Time: 2:30 pm - 4:30 pm ET

Where: Via Zoom – register at:

<https://rarediseases.org/rdac-overview/project-rdac-events/>

Thank you.

