National Organization for Rare Disorders (NORD)

Tim Boyd, MPH, Director of State Policy

Alone we are rare. Together we are strong.®

NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD®
National Organization
for Rare Disorders

rarediseases.org

1983 Orphan Drug Act

NORD was founded by patients, caregivers and patient organization leaders in 1983 to unify the voice of rare disease patients, caregivers and advocates.

NORD was founded in
1983
along with the Orphan Drug Act

260+
NORD
member
organizations
(& growing each year)

3,000+
RareAction®
advocates
across the country

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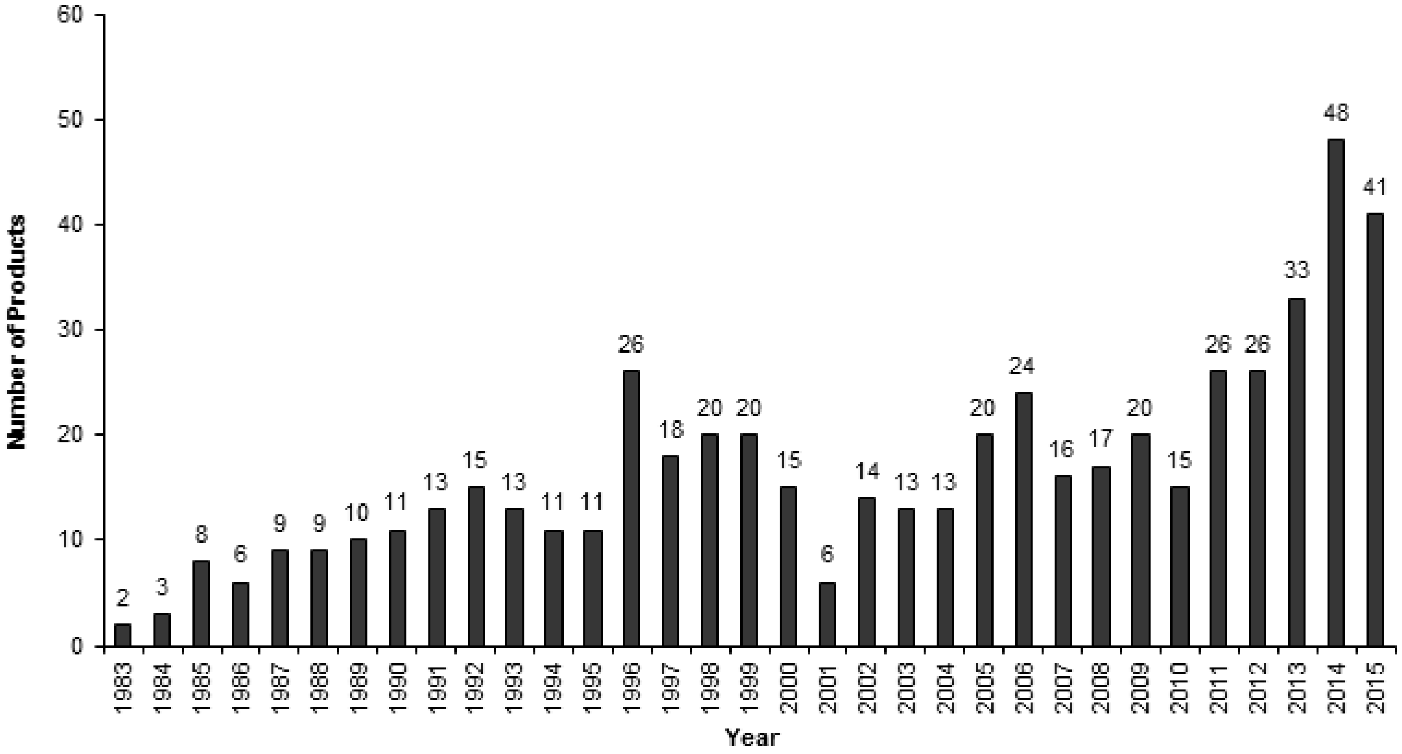
RARE ACTION NETWORK®
powered by NORD®

1983 Orphan Drug Act


Number of Approved Orphan Products by Year

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About NORD

- Leading advocacy organization today; addressing the challenges faced by patients and families at the local, state and federal levels.
- NORD, along with our 250+ disease-specific organizational members, are committed to the identification, treatment, and cure of rare disorders through programs of:

Policy & Advocacy

Research

Education

Patient Assistance

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NORD’s Community Members

250+
patient groups

3,000+
advocates

200+ medical students

90+ corporate council

NORD’s membership spans across more than 700 diseases, all 50 states and over 30 countries.

rarediseases.org

NORD’s Core Services

Policy & Advocacy

- Advancing Basic and Translational Science
- Strengthening Drug Development
- Ensuring Access to Affordable Treatment
- Ensuring Access to Safe, Effective Medical Care

Research

- Research Grant Program
- *IAmRare* Patient Registries & Natural History Studies
- Clinical Trial Awareness & Education
- Data Collection & Analysis for original research
- White Papers

Education

- Medical Professional Education
- Medical and PharmD Student Education & University Chapter Program
- Patient and Caregiver Education

Patient Services

- Insurance Navigation
- Co-Pay, Premium and Medication Assistance
- Emergency Relief
- Ancillary Services
- Clinical Trial Travel & Lodging

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RareEDU

Multi-front campaign to promote rare disease awareness among medical professionals and students with a goal of helping undiagnosed patients receive an accurate diagnosis, sooner.

Online Resources

- Rare Disease Reports
- Physician Guides
- Publishing Partnerships
    - Frontline Medical Communications
    - Medscape
    - Rare Disease Report
- Disease-State Videos

• Live Events

- CME Activities)
- Rare Diseases & Orphan Products Breakthrough Summit
- Disease-State Roundtables

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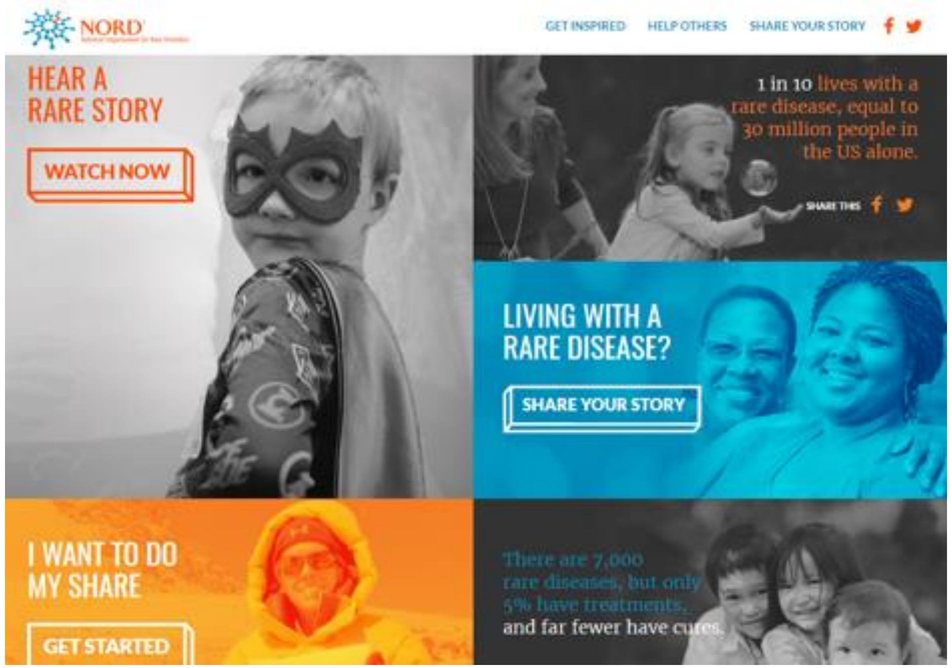
Awareness



NORD

GET INSPIRED HELP OTHERS SHARE YOUR STORY

HEAR A RARE STORY

WATCH NOW

1 in 10 lives with a rare disease, equal to 30 million people in the US alone.

SHARE THIS

LIVING WITH A RARE DISEASE?

SHARE YOUR STORY

I WANT TO DO MY SHARE

GET STARTED

There are 7,000 rare diseases, but only 5% have treatments, and far fewer have cures.

DoYourShare.com **233.7k+ People Reached**

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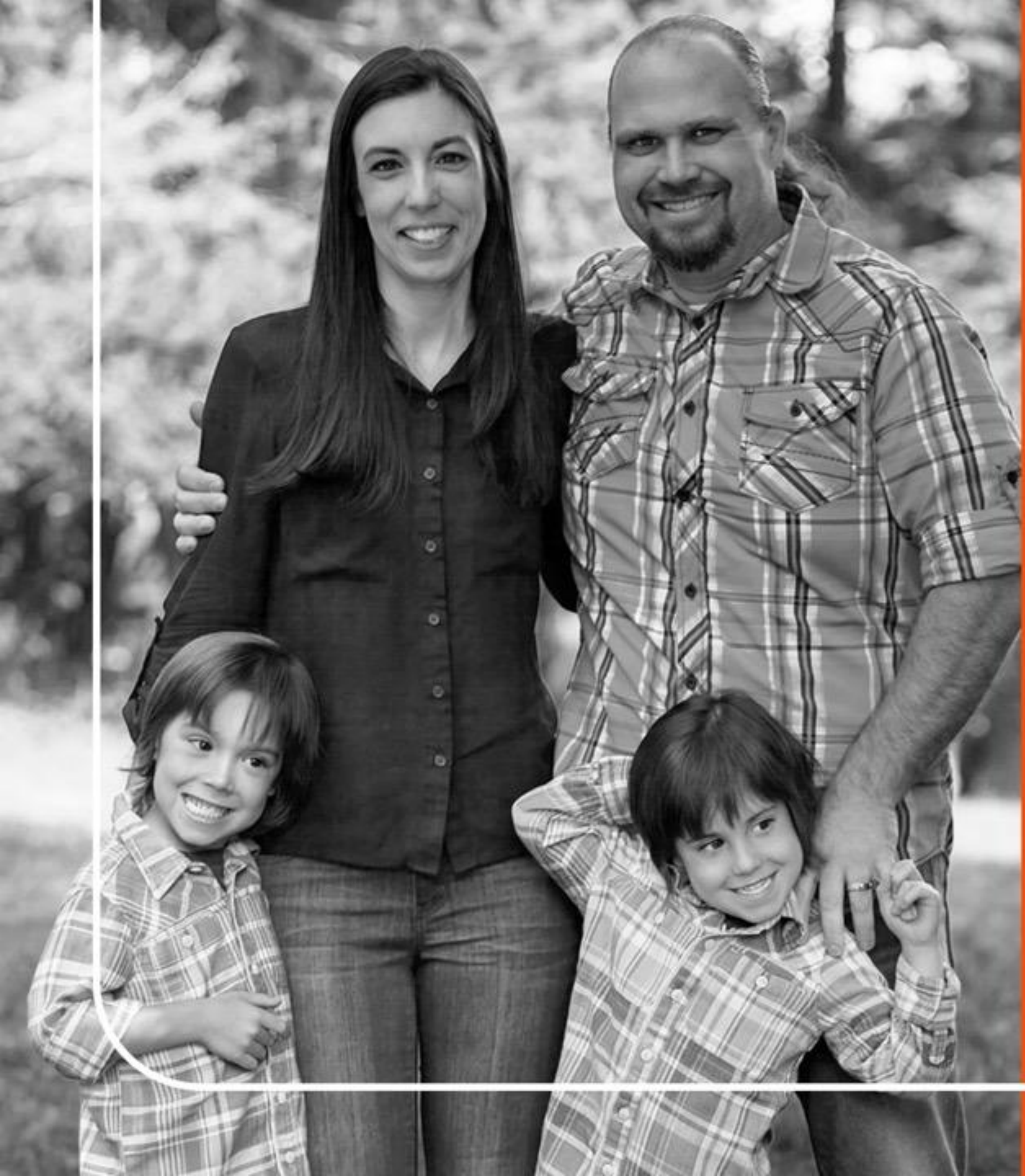

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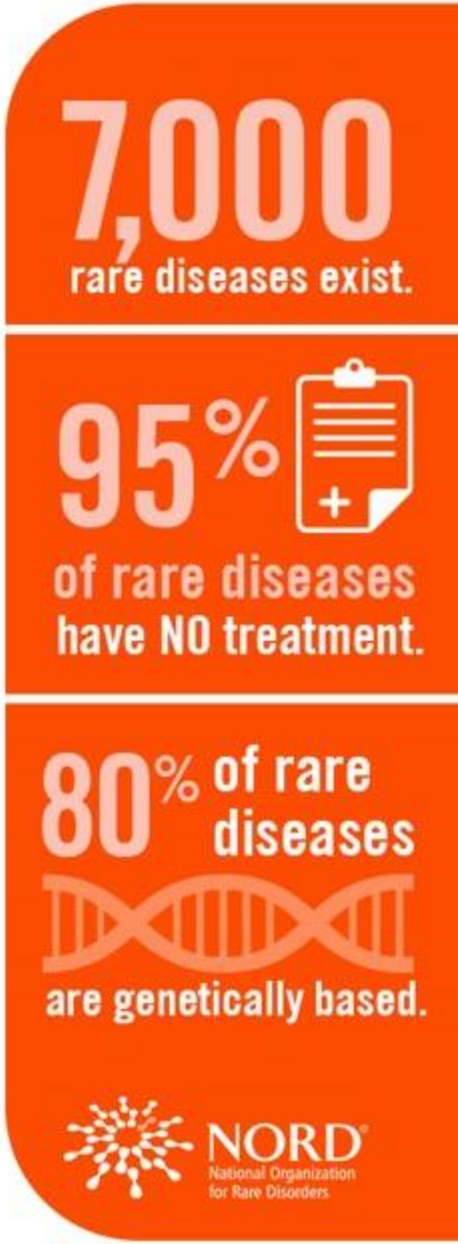
Rare Action Network (RAN)

Features:

- Rareaction.org
- Policy education
- Legislative days
- Rare Disease Day



7,000 rare diseases exist.

95% of rare diseases have NO treatment.

80% of rare diseases are genetically based.

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Rare CT

RARE CT

RARE DISEASE DAY®

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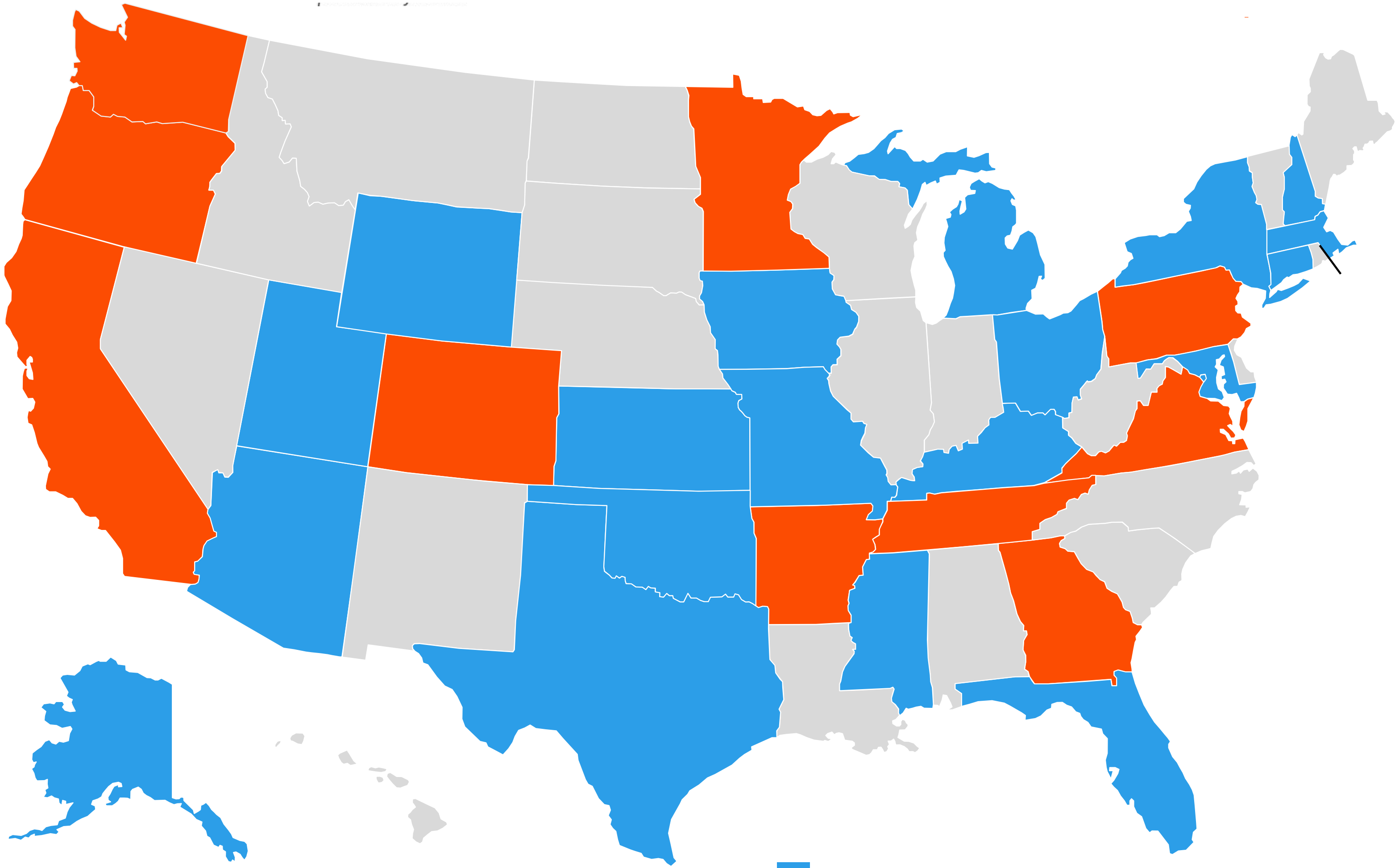
State Ambassador Program



🟦 **State Ambassador**

🟧 **State Ambassador also part of Member Organization**

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Policy Focus

- Average of 5-7 years for diagnosis
- Only 5% have an FDA approved treatment or therapy
- Extensive, life-long medical needs
- High cost of care and treatment

- Few medical experts
- Little research or known about diseases
- Social Isolation
- Small, scattered patient populations

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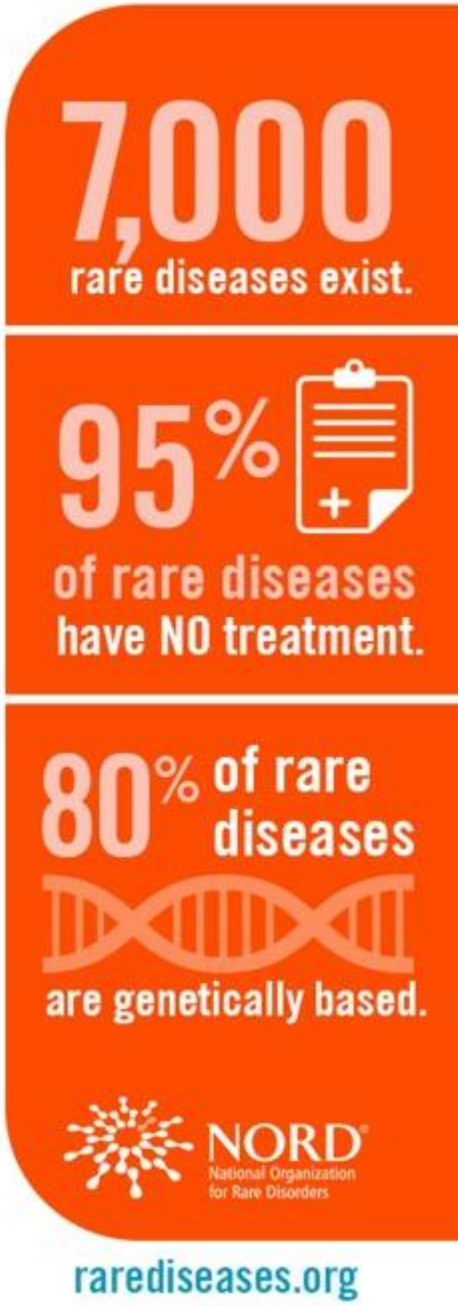

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Policy Focus

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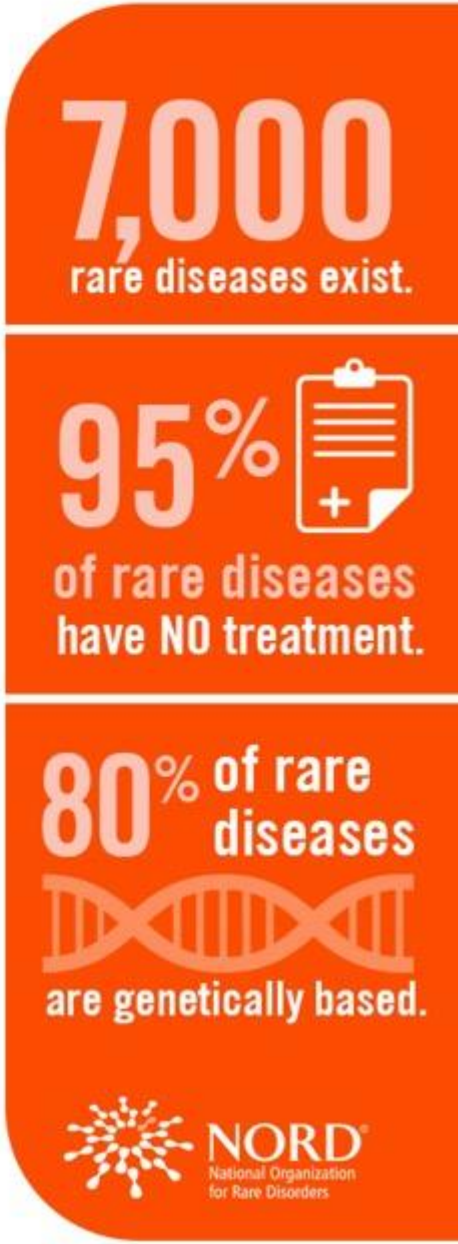
- Rx OOP Protections (CT SB 22)
- Biosimilar Prescriber Communication (CT H 7118)
- Rare Disease Advisory Councils
- EMS protocols
- ACA



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