

# Rare Disease Legislation in the Queue

## Healthcare Reform



**Paul Melmeyer**

**Associate Director of Public Policy**

**National Organization for Rare Disorders**

# Principles for Health Coverage Reform



February 28, 2017

Paul Melmeyer, Associate Director of Public Policy, NORD

# Our Vision



**NORD's vision and guiding principles on which our advocacy initiatives are based:**

A national awareness and recognition of the challenges faced by people living with rare diseases and the associated costs to society.

A nation where people with rare diseases can secure access to diagnostics and therapies that extend and improve their lives.

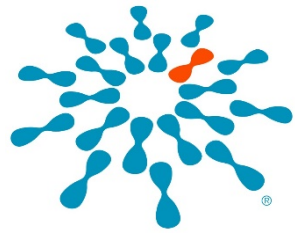
A social, political, and financial culture of innovation that supports both the basic and translational research necessary to create diagnostic tests and therapies for all rare disorders.

A regulatory environment that encourages development and timely approval of safe and effective diagnostics and treatments for patients with rare diseases.

# Major NORD Programs and Initiatives

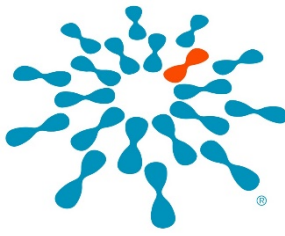


- Policy and regulatory advocacy
- State advocacy and alliance partnerships
- Patient representation (FDA, NIH, SSA)
- Education (patients, professionals, public)
- Mentoring (patient organizations)
- Patient assistance programs
- Patient Networking (disease specific meetings, online communities, creation of new patient organizations)
- Increase disease understanding (Research grants, patient registries)
- International Partnerships
- US Sponsor of International Rare Disease Day

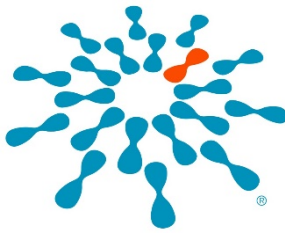


# The Affordable Care Act





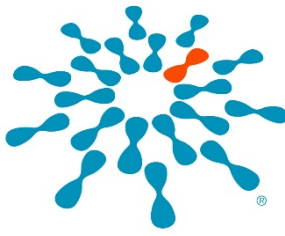
# ***Principles for Health Coverage Reform***



# Protect Patients with Pre-existing Conditions

- Guaranteed issue and renewal of insurance
- Prohibition on benefit exclusions
- Community rating





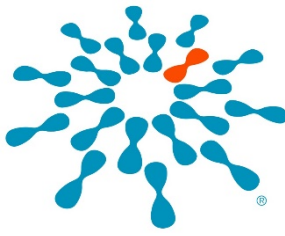
# Protect Patients against Exorbitant Costs



- Cap out-of-pocket costs
- Ban annual and lifetime limits



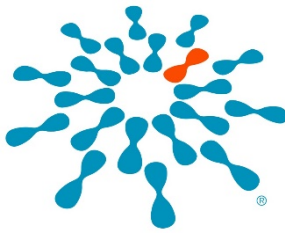




# Prohibit High-Risk Pools from including:

- Eligibility based upon diagnosis
- Waiting periods
- Enrollment caps
- Benefit caps or medical underwriting
- Inadequate funding
- Burdensome plan structure

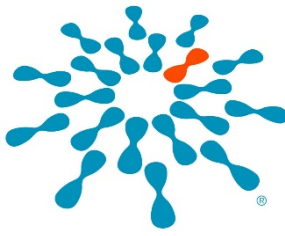




# Oppose the weakening of State Medicaid programs

- Block grants and per-capita caps could:
  - Cap Federal assistance for sickest patients
  - Not accommodate financial hardship
  - Not cover new orphan therapies
  - Not cover particularly expensive care



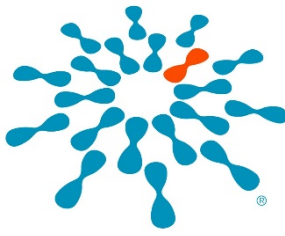


# Additional Key Protections:



- Allow children to stay on their parents plan until age 26
- Sustain coverage for individuals in the Medicaid expansion population
- Close the Medicare Part D donut hole
- Ensure quality insurance:
  - Essential health benefits
  - Adequate provider networks





# Additional Key Protections:



- Keep vital care options:
  - Community First Choice 1915(k) program
  - Concurrent Care for Children
- Adequate and equitable financial assistance
- Incentives for purchasing insurance
- Prohibition on discrimination due to disability





# What will stay and what will go?

## NORD's Perspective

### Most likely to be included:

- Insurance Protections for Individuals with pre-existing conditions
- No annual and lifetime limits
- Children stay on plan until 26
- Prohibition on discrimination based upon disability



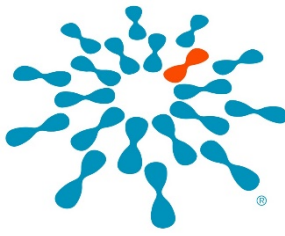
### Somewhat likely:

- Out of pocket maximums
- Close the Medicare Part D donut hole
- Quality insurance standards
- Vital Care Options
- Incentives for purchasing insurance



### Vulnerable:

- Adequate high-risk pools
- Weakening of Medicaid
- Sustained coverage of Medicaid Expansion population
- Adequate and equitable financial assistance



Questions?

[pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org)