

Rare Disease Legislation in the Queue

Healthcare Reform

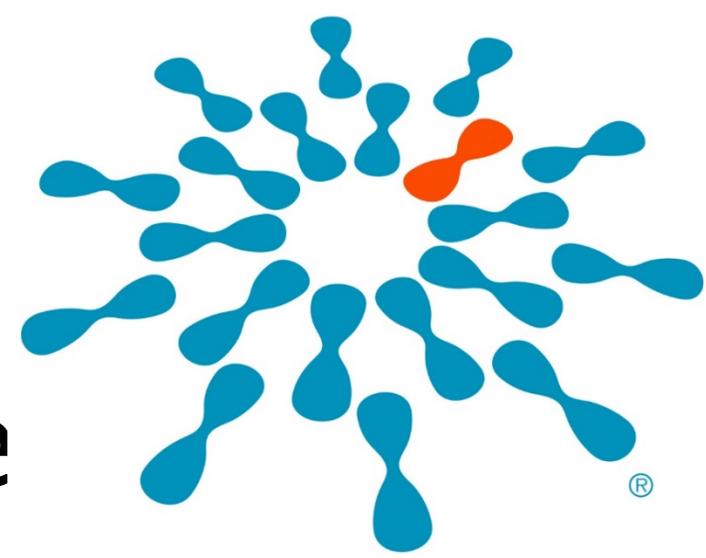


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National Organization for Rare Disorders

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.

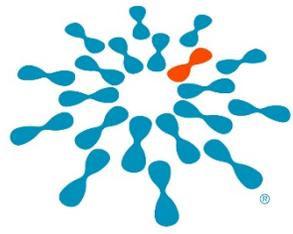
A social, political, and financial culture of innovation that supports both the basic and translational research necessary to create diagnostic tests and therapies for all rare disorders.

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

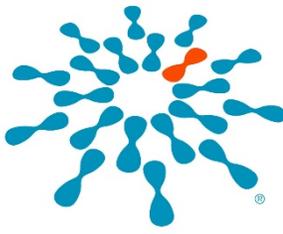


- Policy and regulatory advocacy
- State advocacy and alliance partnerships
- Patient representation (FDA, NIH, SSA)
- Education (patients, professionals, public)
- Mentoring (patient organizations)
- Patient assistance programs
- Patient Networking (disease specific meetings, online communities, creation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

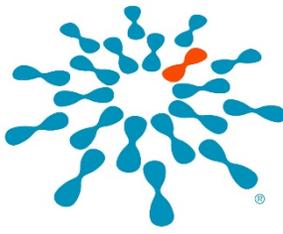


The Affordable Care Act





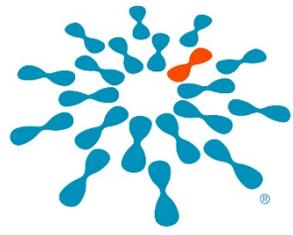
Principles for Health Coverage Reform



Protect Patients with Pre-existing Conditions

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



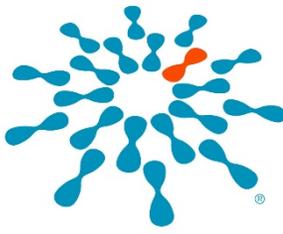


Protect Patients against Exorbitant Costs



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

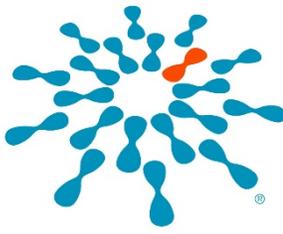




Prohibit High-Risk Pools from including:

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

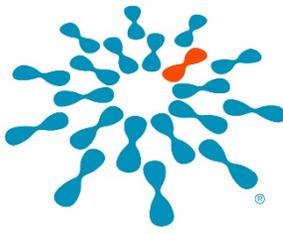




Oppose the weakening of State Medicaid programs

- 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



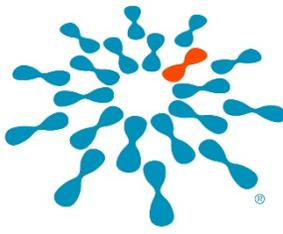


Additional Key Protections:



- 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



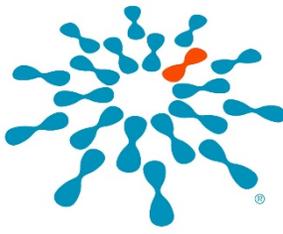


Additional Key Protections:



- 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



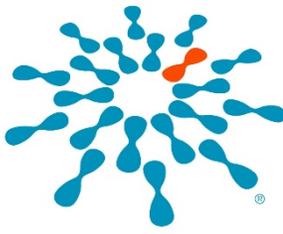
Somewhat likely:

- 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?

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