Rare Disease Legislation in the Queue

Healthcare Reform

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Principles for Health Coverage Reform

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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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