



February 9, 2017

The Honorable Mitch McConnell, Majority Leader  
United States Senate  
S-230, The Capitol  
Washington, D.C. 20510

The Honorable Chuck Schumer, Minority Leader  
United States Senate  
S-221, The Capitol  
Washington, D.C. 20510

The Honorable Paul Ryan, Speaker  
United States House of Representatives  
H-232, The Capitol  
Washington, D.C. 20515

The Honorable Nancy Pelosi  
United States House of Representatives  
H-204, The Capitol  
Washington, D.C. 20515

**Re: Insurance Coverage Protections for Individuals with Pre-existing Conditions**

Dear Leader McConnell, Speaker Ryan, Leader Schumer and Leader Pelosi:

On behalf of the 30 million men, women, and children affected by one of the 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your continuing support of the rare disease community.

We are heartened by the vocal commitment expressed throughout Congress for individuals with pre-existing conditions. We are also appreciative of the collaborative, collegial outreach offered, and we are ready and willing to work together with Congress to improve the lives of the rare disease patient population. And NORD looks forward to working with Congress in order to ensure that many ACA provisions are either kept intact, or replaced with equivalent if not improved provisions without delay or interruption.

In addition to participating in congressional meetings, we want to further contribute to the conversation through several rounds of correspondence to Congress. This letter, our first, focuses on insurance protections for individuals with pre-existing conditions to shield them from medical underwriting. Other protections and provisions, will be addressed in subsequent correspondence.

Over 80 percent of the 7,000 known rare disorders are genetic. Insurers regard individuals who are born with their disease (two thirds of rare diseases affect children) as having a pre-existing condition from the moment they are born, sometimes even earlier.

Prior to the ACA, rare disease patients were often offered unaffordable or entirely inadequate insurance, or denied health insurance altogether.

The ACA successfully addressed these problems by codifying the following insurance protections against medical underwriting for individuals in the small and large-group markets:

- **Guaranteed Issue:** Requires insurers to offer insurance to all patients, regardless of health status, during annual open enrollment periods, special enrollment periods, and renewal periods.
- **Prohibition on Benefit Exclusions:** Ensures discriminatory benefit exclusions or limitations aimed at individuals or groups of individuals with expensive pre-existing conditions are banned.
- **Community Rating:** Guarantees that patients are not charged higher premiums because of their health status, including if they have a gap in coverage.

Without all three of these protections in place, insurers will once again be able to push rare disease patients out of the health insurance system. The exclusion of any one of these protections will render the other two ineffective. Without guaranteed issue, insurers could comply with community rating and benefit inclusion principles, but deny coverage to rare disease patients. Without community rating, insurers could offer quality insurance to rare disease patients, but charge prohibitively expensive premiums.

It is critical that any replacement or repair to the ACA includes these fundamental protections for rare disease patients. As you continue to deliberate on ACA replace or repair plans, we again stand committed to work with you to guarantee that some of the most vulnerable and neglected Americans, rare disease patients, are not forgotten.

We appreciate your time and attention to this important matter, and please do not hesitate to reach out to us to continue the conversation. For questions regarding NORD or the above comments, please contact Paul Melmeyer, Associate Director of Public Policy, at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org), or 202-545-3828.

Sincerely,



Peter L. Saltonstall  
President and CEO

CC: The Honorable Lamar Alexander, Chairman, Senate Committee on Health, Education, Labor, and Pensions  
The Honorable Orrin Hatch, Chairman, Senate Committee on Finance  
The Honorable Patty Murray, Ranking Member, Senate Committee on Health, Education, Labor, and Pensions  
The Honorable Ron Wyden, Ranking Member, Senate Committee on Finance  
The Honorable Greg Walden, Chairman, House Committee on Energy and Commerce  
The Honorable Kevin Brady, Chairman, House Committee on Ways and Means  
The Honorable Frank Pallone, Ranking Member, House Committee on Energy and Commerce  
The Honorable Richard Neal, Ranking Member, House Committee on Ways and Means