August 16, 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, Minority Leader
United States House of Representatives
H-204, The Capitol
Washington, D.C. 20515

Re: Potential Reforms and Fixes to the Private Insurance Markets

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

On behalf of the 30 million men, women, and children in the United States 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 write today to continue our correspondence on health coverage reform. On February 28, 2017, NORD submitted to Congressional leadership our "Principles for Health Coverage Reform."[1] These principles outlined various provisions necessary within any health reform package to protect rare disease patients.

We have used these principles to evaluate the various proposals put forth to repeal and replace the Affordable Care Act (ACA), including the various iterations of the American Health Care Act, the Better Care Reconciliation Act, the Obamacare Repeal Reconciliation Act, and the Health Care Freedom Act. These proposed bills did not adhere to several of our principles as they would have dramatically weakened the quality and affordability of health coverage available to rare disease patients.

While we did not support these bills, we agree that improvements to the stability and viability of the ACA marketplaces are needed. In particular, some of the marketplaces require immediate attention: premiums and deductibles for exchange plans in these areas are increasing unsustainably, cost-sharing and coinsurance are unaffordable, and provider networks and formularies are too narrow. Short-term stabilization provisions must be enacted to address these problems.

[1] "Protecting Rare Disease Patients: Principles for Health Coverage Reform." National Organization for Rare Disorders. February 28, 2017. https://rarediseases.org/wp-content/uploads/2014/11/NORDs-Principles-for-Health-Coverage-Reform-Final.pdf.

We also believe there are various long-term improvements to the private insurance markets that can be enacted in order to expand patient access to quality coverage.

For these reasons, we are eager to work with Congress to craft bipartisan policy solutions. The proposals below adhere to our Principles for Health Coverage Reform and will help individuals with rare diseases and their families purchase more affordable, quality health coverage on the ACA exchanges.

Short-Term Stabilization Proposals:

- **Ensure Cost-Sharing Reductions (CSR)**: The CSRs are integral to allowing individuals who fall between 100% and 250% of the Federal Poverty Line (FPL) to purchase insurance on the private marketplaces. This assistance is critical to individuals with rare diseases purchasing insurance on the exchanges for several reasons.

  First, rare diseases are often incredibly expensive and require many specialists, hospital stays, and prescription drugs. These expenses often drive individuals with rare diseases and their families into financial distress. Thus, the CSRs become a vital part of ensuring low-income families with rare diseases maintain their coverage.

  Second, the CSRs also encourage low-income individuals who are healthy, but may not be able to purchase insurance otherwise, to participate in the marketplaces. Their inclusion in the plans contribute to a downward force on premiums, thus helping to stabilize the market.

  Finally, without the CSRs, it is our understanding that premiums would raise substantially across the country. In California, for example, it was recently estimated that premiums would rise by 12.4% percent if the CSRs went unfunded.[2] This premium increase and similar premium increases across the country may make insurance for individuals with rare diseases simply unaffordable.

  Consequently, the CSRs should be appropriated by Congress to safeguard the coverage of low-income individuals with rare diseases.

- **Create and Encourage Stability Funds**: We believe a state innovation waiver recently requested by the state of Alaska, and approved by the Administration, can serve as a model for stabilizing insurance markets across the country. The program offers re-insurance to insurers for beneficiaries with particularly costly conditions, oftentimes rare diseases. Similar proposals were explored as part of the American Health Care Act and the Better Care Reconciliation Act.

[2] "Covered California Releases 2018 Rates: Continued Stability and Competition in the Face of National Uncertainty." Covered California Daily News. Accessed August 16, 2017. http://news.coveredca.com/2017/08/covered-california-releases-2018-rates.html.

We believe these reinsurance proposals have the promise of stabilizing premiums while maintaining, perhaps even improving, quality insurance options for individuals with rare diseases.

- **Expand Awareness and Outreach**: Empirical evidence shows that the more robust the outreach is from the state exchanges and the Administration, the more robust the following enrollment will be. One of the core problems of the ACA has been the overestimation of the number of young and/or healthy individuals that would sign up in the marketplaces. This left the marketplaces with a higher proportion of individuals with expensive conditions than expected, resulting in higher premiums and deductibles.

  With greater outreach, additional healthy individuals may sign up, contributing to stabilization of the markets and lowered premiums and deductibles.

- **Enforce the Individual Mandate:** In order to further offset the costs of individuals with expensive conditions and bring down premiums, Congress should consider policies that either strengthen the individual mandate through greater enforcement or penalties, or alternatively incentivize healthy individuals to sign up for health insurance.

  Risk pools currently have a disproportionate number of individuals with expensive conditions, leading to higher premiums. One of the most effective methods Congress can pursue to bring down premiums and deductibles is to encourage young and healthy individuals to sign up.

- **Explore State Flexibility with 1332 Waivers:** We understand there is growing interest in affording states greater flexibility in obtaining 1332 waivers to reform their private insurance market. We acknowledge that under prior interpretation of the 1332 waiver requirements, states faced a very high bar to successfully obtaining a waiver.

  Consequently, we support exploring ways to offer states greater flexibility and autonomy in obtaining 1332 waivers to structure their insurance markets. But this flexibility and autonomy absolutely cannot come at the expense of patients with pre-existing conditions. In order for us to not oppose proposals that loosen 1332 waiver requirements, key protections such as guaranteed issue, community rating, non-discriminatory benefit designs, prohibition on annual and lifetime caps, annual out-of-pocket maximums, and EHB requirements must remain in place. Any proposal that would repeal these protections in the name of state flexibility would harm individuals with rare diseases across the country and should not be enacted.

Long-Term Improvement Proposals:

- **Limit Specialty Tier Cost-Sharing**: The Patients' Access to Treatments Act (H.R.2999), introduced by Congressmen McKinley and Butterfield, would curb the increasing use of unaffordable co-insurance in specialty tiers within a growing number of exchange plans.

Currently, exchange plans are increasingly moving medically-necessary orphan therapies without any therapeutic alternative to the specialty tier on the formulary. Once on the specialty tier, patients are often asked to contribute anywhere from 30 to 50 percent of the drug's cost, often resulting in the patient reaching their yearly maximum out-of-pocket (MOOP) within a matter of weeks.

The Patients' Access to Treatments Act would curb this practice by limiting cost-sharing in specialty tiers to that of the non-preferred brand drug tier. This would greatly increase accessibility and affordability of many orphan drugs in exchange plans. Additionally, this policy change would have a negligible result on premiums, as evidenced by similar policies implemented in Colorado and Montana.[3]

This bipartisan legislation holds the promise of making healthcare more affordable for thousands of individuals with rare diseases on exchange plans and we encourage Congress to include it in any ACA repair package.

- **Ensure Access to Third-Party Assistance**: The Access to Marketplace Insurance Act (H.R.3742 in the 114th Congress) would ensure that low-income individuals have access to third-party assistance for paying premiums. Over the past several years, opaque and even contradictory guidances from the Administration have resulted in qualified health plans (QHPs) on the exchanges rejecting third-party premium assistance.

  This is particularly concerning for individuals with rare diseases as they often cannot afford to pay the premiums of the more comprehensive plans they require. By codifying the ability of third-party charitable organizations to help these patients in need, Congress would again further increase access to insurance for those who need it.

- **Reorient Yearly Maximum Out-of-Pocket Limits to Monthly Limits**: The ACA created a yearly maximum out-of-pocket limit (MOOP) that is currently set at $7,150 for an individual plan and $14,300 for a family plan. These out-of-pocket limits have proved to be critical for patients with expensive conditions. Patients avoid medical bankruptcies, and are no longer required to choose between medical care and basic necessities.

  While this patient protection has improved the health and wellbeing of our patients dramatically, it can be improved by reorienting the maximums from a yearly cap to a monthly cap. Individuals with rare diseases who require particularly expensive care can hit their MOOP within the first month, requiring the individual to pay the full deductible and the $7,150 (or $14,300) in required cost-sharing all within the first 30 days. Knowing this, many individuals with rare diseases will save up for January or take out loans due to the substantial immediate costs.

  By dividing the yearly MOOP into monthly MOOPs, the payments can be spread out over the year. The MOOP level can remain the same ($595.83 each month) and still have a substantial, positive impact on patient lives.

[3] "Initial Findings from Colorado Insurance Landscape Analysis 2016." The Moran Company. August 2016. http://phrma-docs.phrma.org/sites/default/files/pdf/colorado-exchange-deliverable-highlights.pdf.

- **Strengthen Oversight on Benefit Design, Provider Networks, and Utilization Management Techniques**: While the ACA successfully ended several insurance practices that discriminated against individuals with pre-existing conditions, such as health status rating, total benefit exclusions, and denial of coverage, there are still certain insurance practices that are tantamount to discrimination and should be addressed.

  Most notably, insurers are increasingly structuring their provider networks and formularies to discourage high-cost individuals from signing up for their plans. For example, treatments for rare diseases require the most substantial cost-sharing or go uncovered. Similarly, plans on the exchanges find creative ways to exclude the specialists and specialty hospitals that individuals with rare diseases need.

  For these reasons, we hope that stronger oversight, either at the state or Federal level, can be implemented to ensure our patients are not discriminated against.

- **Expand Coverage of Medically Necessary Medical Nutrition:** Each year, thousands of children and adults in our country are diagnosed with digestive, and inherited metabolic disorders, requiring them to pursue access to life-saving medical foods and other forms of medical nutrition. These conditions, most of which are rare, require medical nutrition just like a diabetic requires insulin or an individual with end stage renal disease requires dialysis.

  Unfortunately, this medically necessary nutrition is often very expensive (upwards of $60 per can for individuals with metabolic conditions), and is often not covered by insurance. Instead of recognizing medical nutrition as the medically-necessary treatments that they are, insurers often consider these treatments as elective or purely dietary in nature. This is simply not the case. Lack of access to medical nutrition can cause irreparable mental and physical harm. Families continue to struggle with the tremendous financial burden associated with lack of coverage for these medically necessary foods. By accessing medical nutrition, individuals with these serious conditions may also avoid requiring more expensive and specialized care, such as biologics for inflammatory conditions.

  The 114th Congress recognized this disparity in the National Defense Authorization Act by expanding access to life-saving medical nutrition for military families in the TRICARE program. The Medical Nutrition Equity Act (S.1194 and H.R. 2587) takes the next step by requiring coverage of these treatments in private insurance plans, as well as Medicaid, Medicare, and the Federal Employee Health Benefit Program (FEHBP). If this legislation is enacted, families who purchase private insurance will no longer face financial ruin and mental and physical harm due to lack of access to medical nutrition.

- **Expand Coverage of Genetic Testing:** Coverage of genetic testing is critical to ensuring that individuals with rare diseases are accurately diagnosed and appropriately cared for. Not only will this result in better health outcomes for our patients, we believe this will also reduce costs by reducing the amount of unnecessary care given to undiagnosed patients.

Unfortunately, genetic testing is widely uncovered by plans in the health insurance marketplaces, a gap Congress can address through long-term improvements to the ACA.

These are just a handful of the ways in which Congress can strengthen the ACA for individuals with rare diseases. We are eager to work with both houses and both parties to craft patient-friendly reforms to expand access to quality and affordable health insurance on the private insurance market.

We appreciate your time and attention to this important matter. 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, Director of Federal Policy, at 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