CFEN
Cystic Fibrosis Engagement Network

February 21, 2017

The Honorable Greg Walden
Chairman, Energy & Commerce Committee
2185 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Frank Pallone
Ranking Member, House Energy & Commerce Committee
237 Cannon House Office Building
Washington, D.C. 20515

The Honorable Kevin Brady
Chairman, House Ways & Means Committee
1011 Longworth House Office Building
Washington, D.C. 20515

The Honorable Richard Neal
Ranking Member, House Ways & Means Committee
341 Cannon House Office Building
Washington, D.C. 20515

Dear Chairmen Walden and Brady and Ranking Members Pallone and Levin:

The Cystic Fibrosis Engagement Network (CFEN) is a diverse coalition of patients, advocates and allies committed to securing access to optimal care for those suffering from cystic fibrosis (CF). The network writes to the committee today on behalf of the 30,000 Americans who suffer from CF, the most common fatal genetic disease in North America.

The patients, families and friends in our network carry the daily burden of this debilitating and systemic disease, which affects the respiratory, digestive, reproductive, and endocrine systems with chronic infections, inflammation, and scarring. But in recent weeks, they've encountered another grave challenge – fear of the changes that may result from the repeal and replacement of the Patient Protection and Affordable Care Act.

As you may know, cystic fibrosis has no cure. The primary cause of death is pulmonary failure, and the median age of death is approximately 29 years old. Thus, patients have a rigorous treatment program, often including multiple rounds of daily respiratory therapy, airway clearance, dozens of oral medications and frequent in-home intravenous medication treatment. They must often be hospitalized for treatment.

When cystic fibrosis was first discovered in 1949, life expectancy was about five years. That statistic has improved with recent breakthrough medications and treatments, yet families continue to lose loved ones with cystic fibrosis patients too early.

Therefore, we ask for your special attention to ensure that patients with this genetic disease can access affordable, quality health coverage, particularly access to specialized providers and to long-awaited medical treatments.

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No matter what final shape new legislation takes, the following principles are essential if cystic fibrosis families are to access approved therapies:

1. **Prohibiting coverage denials based on pre-existing conditions.** Cystic fibrosis is a genetic condition that is passed to children via a recessive allele. Denying individuals coverage based on pre-existing conditions would be devastating to the CF community.
2. **Prohibiting plans from discriminating based on age, expected length of life, present or predicted disability, degree of medical dependency or other medical conditions.** Allowing plans to change benefits based on these criteria could deny CF patients life-saving therapies.
3. **Covering dependents up to age 26.** Polls have shown that 85% of Americans support allowing dependents to stay on their parents' insurance plans until age 26, and CF patients would find it extremely difficult to find affordable health insurance when most young adults with CF are not steady wage earners due to their health condition.
4. **Prohibiting waiting periods that exceed 90 days.** CF patients must access therapies in a timely fashion to mitigate deadly, and costly, medical complications.
5. **Ensuring that coverage is affordable for CF families.** Coverage rules should include annual out-of-pocket maximum on what enrollees must pay for covered services, prohibiting plans from establishing lifetime caps, and ensuring that low-income patients receive premium support.
6. **Providing robust Medicaid coverage.** More than half of children with cystic fibrosis receive their coverage through Medicaid. CF patients who rely on Medicaid need access to specialists and groundbreaking, life-saving treatments.
7. **Requiring that physician networks include CF physicians** so that CF patients have access to the specialists they need.

As the Committee works to build a healthcare system that benefits all Americans, the Cystic Fibrosis Engagement Network asks that each member keep the cystic fibrosis community in mind. With breakthrough therapies that treat, and someday hopefully cure, cystic fibrosis on the horizon, it is vitally important that patients can access the treatments they need.

Sincerely,

Ryan Gough
Executive Director
Cystic Fibrosis Engagement Network

cc: Members of the House Energy and Commerce Committee and Members of the House Ways and Means Committee