



January 6, 2011

The Honorable John A. Boehner
Speaker of the House
H-232 U.S. Capitol Building
Washington, DC 20515

The Honorable Nancy Pelosi
House Minority Leader
H-204 U.S. Capitol Building
Washington, DC 20515

Dear Speaker Boehner and Minority Leader Pelosi:

On behalf of the Cystic Fibrosis Foundation, representing nearly 30,000 people with cystic fibrosis (CF), we write to you in support of provisions in the Patient Protection and Affordable Care Act that have the potential to benefit people with chronic, life-threatening diseases and oppose legislation to repeal them in the 112th Congress.

We are making remarkable strides in our fight against cystic fibrosis (CF), but people who live with it face greater obstacles each year, as high medical costs can prevent them from accessing appropriate medical care. Health care for a CF patient costs \$64,000 per year on average, 15 times more than that of the average person. Because of high costs, nearly a quarter of CF patients delay getting medical care or skip treatments their providers recommend to enhance and lengthen their life.

The Foundation sees some promise in a number of provisions in the new health care reform law that increase access to health insurance coverage for those with rare and chronic diseases, a critical tool in decreasing out of pocket costs for patients. These provisions include those allowing children to remain on their parents' insurance until they are 26; prohibiting insurance companies from denying or rescinding coverage based on a pre-existing condition; banning annual and lifetime caps on coverage; and the expansion of Medicaid eligibility.

The new law is not perfect, however, and we are concerned that while the provisions listed above will ensure continuity of coverage and greater access to care for those with CF and other chronic diseases, more must be done to reduce the financial burden so many families face in affording their care, especially in these challenging economic times. We urge you to explore new options to help make care more affordable and reduce shifting costs to patients, while retaining the provisions that have the potential to provide desperately needed relief afforded to people with cystic fibrosis by the law in the new Congress.

We look forward to working with you as we continue our mission to find a cure and control for this life-threatening genetic disease, and as we continue to build hope and add tomorrows every day for those with cystic fibrosis.

Sincerely,



Robert J. Beall, Ph.D.
President and Chief Executive Officer



Mary Dwight
Vice President, Government Affairs

Cc: House Majority Leader Eric Cantor
Committee on Energy and Commerce Chair Fred Upton
Committee on Energy and Commerce Ranking Member Henry A. Waxman
Committee on Ways and Means Chair Dave Camp
Committee on Ways and Means Ranking Member Sander M. Levin
Committee on Education and the Workforce Committee Chair John Kline
Committee on Education and the Workforce Committee Ranking Member George Miller