

**Congress of the United States**  
**Washington, DC 20515**

May 3, 2013

Acting Commissioner Carolyn W. Colvin  
Social Security Administration  
6401 Security Boulevard  
Baltimore, MD 21235

Dear Commissioner Colvin:

As members concerned with the health and well-being of those with cystic fibrosis (CF), we write today with concerns about the recently proposed rule, "Revised Medical Criteria for Evaluating Respiratory System Disorders" as they pertain to CF. We urge you to reconsider these planned changes and ensure that those with CF are treated fairly as they manage this progressive, complex disease.

CF is a fatal genetic disease that affects 30,000 children and adults in the United States. CF is primarily a lung disease, caused by a defective gene that makes the body produce thick mucus that clogs the lungs and leads to life-threatening infections. This mucus also obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food. Although advances have been made in CF treatment and care, the lives of young people with CF are still cut far too short by this progressive - and ultimately fatal - disease. The predicted median age of survival for a person with CF is in the late-30s.

Under the Social Security Administration's (SSA) proposed rule, a patient would need to show three hospitalization admissions for exacerbations or complications of CF in the year prior to applying for benefits. In a major departure from current rules, outpatient or emergency department visits for CF complications will no longer count as a medical intervention making the person eligible for disability. This proposed change in listing 3.04C (regarding treatment for complications or exacerbations that stem from CF) does not reflect current medical practices, under which providers are treating a rising number of patients through home intravenous antibiotics or inhaled nebulized therapies due to concerns about hospital-acquired infection. Insurance providers are also increasingly discouraging inpatient hospital treatment through increased cost sharing, creating a serious financial burden for CF patients who are admitted to the hospital. We are concerned that the changes proposed by SSA would deny many CF patients critical disability benefits, even though they are unable to work.

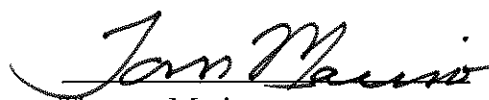
Patients seek care for exacerbations in outpatient settings whenever possible, and it is important that this is reflected in SSA's criteria for disability benefits. We therefore respectfully request that the SSA revise section 3.04C to permit designation of a patient as disabled if the patient is treated not only through hospitalization, but also through as an outpatient using treatments such as home IV antibiotic administration or nebulized therapies.

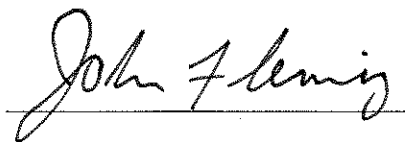
We are also concerned with section 3.04D, a list of acute and chronic CF complications that in combination would reflect a listing-level impairment qualifying CF patients for disability benefits. Under the proposed change, a patient would need to show two of the six criteria in a 12 month period in order to meet the listing. However, any one of the first four complications on the list alone would indicate a very serious complication and would render someone with CF unable to work. For example, one of the complications - respiratory failure requiring continuous assisted (mechanical) ventilization for at least 48 hours, or for at least 72 hours if postoperatively – should render someone eligible for disability benefits regardless of whether the patient has other complications. We urge reconsideration and revision of this list to more accurately reflect the progression of CF and current treatment practices.

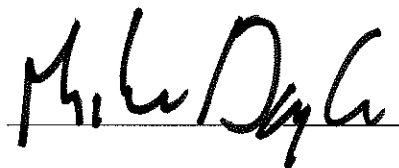
As 128 physicians who specialize in CF stated in their letter to SSA about these proposed changes, “we believe that many provisions in the proposed regulation do not serve as accurate measurements of the disability of children and adults with cystic fibrosis.” We believe that these proposed changes could negatively impact CF patients, and we thank you for your attention to this request. If you have any questions, please contact Sara Schaumburg with Congressman Markey’s office at [sara.schaumburg@mail.house.gov](mailto:sara.schaumburg@mail.house.gov) or Drew Kent with Congressman Marino’s office at [drew.kent@mail.house.gov](mailto:drew.kent@mail.house.gov).

Sincerely,

  
Edward J. Markey  
Co-chair, Cystic Fibrosis Caucus

  
Thomas Marino  
Co-chair, Cystic Fibrosis Caucus

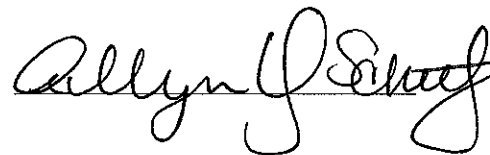












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Bill [Signature]

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Corine Brown

Tim [Signature] (AR-02)

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**List of Signers:**

1. Edward J. Markey
2. Tom Marino
3. Lou Barletta
4. Corrine Brown
5. Chris Collins
6. Jim Cooper
7. Mike Doyle
8. John Fleming
9. Jim Gerlach
10. Tim Griffin
11. Alcee L. Hastings
12. John B. Larson
13. Stephen F. Lynch
14. Jim McGovern
15. Richard E. Neal
16. Randy Neugebauer
17. Bill Pascrell, Jr.
18. Donald M. Payne, Jr.
19. Chellie Pingree
20. Tom Reed
21. Charles B. Rangel
22. Peter Roskam
23. Allyson Y. Schwartz
24. Pat Tiberi