

April 5, 2013

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

Re: Notice of Proposed Rulemaking
Revised Medical Criteria for Evaluating Respiratory System Disorders
Docket No.SSA-2006-0149

Dear Commissioner Colvin:

We, the undersigned directors of accredited cystic fibrosis (CF) care centers, write to express significant concern with sections 3.04 and 103.04 of the proposed rule, "Revising Medical Criteria for Evaluating Respiratory System Disorders."

The undersigned CF care centers are among a network of more than 110 accredited centers nationwide, providing multidisciplinary care from professionals who specialize in the treatment of this disease. Our experienced physicians evaluate the health of thousands of CF patients every day, and 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.

Among the criteria proposed, we are particularly troubled with revisions to listing 3.04C. This revised listing would designate a patient as disabled if they experience exacerbations or complications requiring three hospitalizations of any length within a 12-month period and at least 30 days apart. It also states that SSA "would no longer consider physician interventions, either as an outpatient or in an emergency department," as qualifying treatment for the aforementioned exacerbations, going on to say, "When these types of complications in CF occur, they are too severe to treat on an outpatient basis."

The proposed criteria are inconsistent with the practice of CF physicians and care centers. There is a movement away from hospitalization for CF complications because of concerns about hospital-acquired infections and due to payment standards discouraging hospitalizations. For this and other reasons, doctors are increasingly treating complicated issues in an outpatient setting, including home intravenous antibiotic therapy, without ever hospitalizing the patient. In all, these proposed eligibility criteria are too narrow and must address the severity of pulmonary exacerbations, an indicator of disease severity in CF, rather than the setting of the treatment.

We urge SSA to recognize exacerbation management through hospitalization, home intravenous antibiotic administration or nebulized therapies for the treatment of the exacerbation.

Thank you for this opportunity to comment on the proposed rule, "Revised Medical Criteria for Evaluating Respiratory System Disorders."

Sincerely,

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