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May 28, 2010

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Susan McCutchen  
Senior Program Associate  
Committee of Medical Experts to Assist Social Security on Disability Issues  
Institute of Medicine  
500 Fifth Street, NW, Keck 778  
Washington, DC 20001

**RE: Disability in Patients with Pulmonary Hypertension**

Dear Ms. McCutchen and members of the Pulmonary Hypertension Working Group:

In response to our request to develop more specific disability criteria for patients with pulmonary hypertension (PH), the Scientific Leadership Council of the Pulmonary Hypertension Association (PHA) recommends the following approach:

1. In the SSA Listings, under *Respiratory System – Adult, 3.00 “Respiratory System”, G: Chronic cor pulmonale and pulmonary vascular disease\**, we believe that the term “cor pulmonale” should not be used for the following reasons:
  - a. Cor pulmonale is not a standardized term, and it is subject to wide variations in clinical interpretation.
  - b. Cor pulmonale is not typically used in the medical records of patients with PH.

Thus, our recommendation is to delete section 3.00, part G from the Listing documentation.

2. In the SSA Listings, under *Respiratory System – Adult*, we would like to suggest that section 3.09 be changed from:

**3.09 Cor pulmonale secondary to chronic pulmonary vascular hypertension.**

*Clinical evidence of cor pulmonale (documented according to 3.00G) with:*

- A. *Mean pulmonary artery pressure greater than 40 mm Hg;*  
*or*
- B. *Arterial hypoxemia. Evaluate under the criteria in 3.02C2.*

to

**Liaisons:**

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*PH Resource Network Chair*  
Harry R. Rozakis, *Patient*

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### **3.09 Pulmonary hypertension.**

Disability according to one or more of the screening criteria below due to clinically documented pulmonary hypertension:

<b>Criterion</b>	<b>Rationale</b>
1. Syncope	Compromised cardiac output due to right ventricular failure results in decreased cerebral blood flow
2. NYHA/WHO class IV symptoms	Severely limited exercise capacity due to inability of the right ventricle to meet the demands of normal activities or daily living in the face of high pulmonary vascular resistance
3. Systemic arterial oxygen saturation <88% at rest or with exercise, with or without supplement oxygen	Chronic impairment of gas exchange due to clinically documented pulmonary hypertension
4. Severely reduced exercise capacity a. 6-minute walk test <300 m b. Peak Oxygen consumption <10 ml/kg/min	Severely limited exercise capacity due to inability of the right ventricle to meet the demands of exercise in the face of high pulmonary vascular resistance

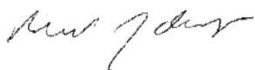
Based on the feedback from last month's webinar, we believe the above disability criteria for patients with pulmonary hypertension are simpler and more specific to patients with severe pulmonary hypertension. Any patient with pulmonary hypertension that meets one or more of these criteria should be considered impaired enough to automatically mean that they are disabled.

3. In the Compassionate Allowances Listings<sup>+</sup>, we would like to suggest that the following condition be added:

*Pulmonary Arterial Hypertension (PAH) – with NYHA/WHO class IV symptoms and/or severely reduced exercise capacity.*

Thank you for allowing PHA to provide these recommendations.

Sincerely,



Ronald J. Oudiz, MD

On behalf of Pulmonary Hypertension Association

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\* [www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm](http://www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm)

<sup>+</sup> [www.ssa.gov/compassionateallowances/conditions.htm](http://www.ssa.gov/compassionateallowances/conditions.htm)