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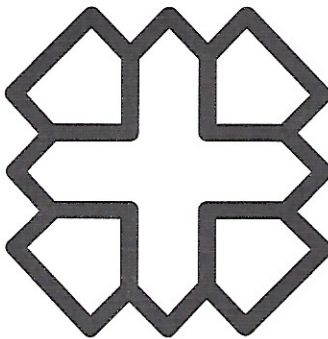
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## AMERICAN PORPHYRIA FOUNDATION

Don Thompson  
Director, Division of Acute Care  
Hospital and Ambulatory Policy Group  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244

**RE: Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals  
MS-DRG 642 – Payment Impact on Porphyria Patients Requiring Inpatient Care  
to Resolve Symptoms and Progression of an Acute Attack**

Dear Mr. Thompson:

Earlier this year, I participated in a discussion with you and your team on the difficulties that patients suffering from acute porphyria attacks have in accessing medically appropriate inpatient care. As you know, the American Porphyria Foundation (APF) has approached CMS multiple times with our concerns that the Medicare inpatient payment for treating acute porphyria attacks is not only grossly inadequate but unfairly impacts patients and the care they receive. We have described the patient impact, worked with industry to present data to support that what we describe is, in fact, our reality, and enlisted the top experts treating porphyria patients to inform CMS on the care we should be receiving.

Although we were disappointed that CMS once again declined to make changes to the inpatient payment for porphyria, I was heartened that you and your staff appear to understand the magnitude of our problem and the need to consider rare diseases like porphyria in future annual payment updates. Over the past weeks, I have met with Congressional staff to reiterate our concerns and have conveyed to them your very clear statement that hospitals do not have the right to avoid administering Panhematin due to its cost. This message came through quite clearly in our discussion with you and was also reflected in the inpatient payment update rule.

In an average week, the APF receives 4-5 calls (and often receives up to 10) from patients who know that they need to be admitted as inpatients and receive Panhematin infusions promptly, yet cannot find a hospital that will administer the treatment. I think we can all agree that it is of little use for a patient to be able to make a complaint after-the-fact; we need the right care in the right setting, at the right time. We need to be able to point to something from CMS – something other than an isolated sentence or two in a lengthy federal register document -- directing hospitals to provide the standard of care and a clear mechanism for reporting violations so that access issues are resolved when they occur.

I have attached a proposed program memorandum based on CMS' statements in the inpatient rule

and in our meeting that can serve as the immediate relief our patients need. The document simply directs hospitals to do what CMS has stated they are required to do for patients experiencing an acute porphyria attack.

If there is another individual or department within CMS or HHS that would ultimately be responsible for taking the action we are requesting, I am happy to discuss this with them in person or by telephone.

I sincerely appreciate your attention and would like to follow up with you once you have had an opportunity to review the attachment. In the interim, I hope that you will not hesitate to call should you need any additional information or have any questions.

Respectfully,

A handwritten signature in cursive script that reads "Desiree Lynn Howe".

Executive Director

cc: Dr. Robert Desnick  
Dr. Karl Anderson