# Are payors ready for transparent prices yet?

*Jasmin Barman-Aksözen*

International Porphyria Patient Network, Hegarstrasse 3, 8032, Zurich, Switzerland

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Katrina Perehudoff argues that transparency norms and aligned medicines pricing policies lead to a more equitable access to medicinces.[1] However, one key question is whether payors and Health Technology Assessment (HTA) bodies are ready for this type of transparency yet. I am a patient suffering from erythropoietic protoporphyria (EPP), an ultra-rare inborn error of metabolism. Fortunately, EPP can be addressed by treating patients with afamelanotide, a drug approved by the EMA in 2014. The drug's manufacturer applied an unconventional uniform pricing policy.[2] Today, I sometimes wish they had rather adopted the more conventional approach, i.e., high list prices followed by confidential price reductions as this might have facilitated patient access to the treatment. Although the drug's price is considerably lower than the average list price of other ultra-orphan drugs, patients in several countries still have no access to this life-changing treatment - eight years after its regulatory approval.[3,4] Instead, the patient community is faced with unreasonable interpretations of the evidence for the benefit the treatment provides and unfair and discriminatory assessments by the evaluating committees, as examplarily demonstrated in the upheld appeal against the negative funding recommendation by the National Institute for Health and Care Excellence in England.[5] While I fully support the conclusions outlined in Perehudoffs commentary, I firmly believe that the role and interests of HTA bodies in funding decisions should not be underestimated and deserve the proper level of attention to achieve progress towards more transparent medicines pricing practices.

## Contributors

JBA as the sole author of this Letter contributed to all aspects of the text.

## Declaration of interests

The author has no competing interests to declare.

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*E-mail address:* jasmin.barman@porphyria.network