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POSTER PRESENTATION

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European Porphyria Network (EPNET) for information, epidemiological data, quality and equity of service

Jean-Charles Deybach¹, Samantha Parker^{2*}, Mike Badmiton³, Sverre Sandberg⁴

From 5th European Conference on Rare Diseases (ECRD 2010)
Krakow, Poland. 13-15 May 2010

Porphyrias are metabolic diseases that affect about 1 in 20,000 of the EU population. Most healthcare professionals rarely encounter these disorders and there is disparity between countries in the levels of support provided for patients and their carers.

EPNET is a DG Sanco funded project (1/4/2007-31/3/2010) with 15 participating countries that aims to establish a network of specialist porphyria centres, each working to agreed quality criteria. Work achieved:

1. Information on porphyria for patients in 10 languages, and for healthcare professionals in English, is available at <http://www.porphyria-europe.org> with easily downloadable pdf files.

2. Data on the safety of drugs in acute porphyria has been collected from participating countries (2901 drug reports on 616 drugs). Information is disseminated on <http://www.drugs-porphyria.org>

3. European Quality Assessment (EQA) schemes have been established for specialist laboratories (24 participants in 17 countries) and data on laboratory performance collected annually. Variations between centres are being addressed and diagnostic protocols developed.

4. The EPNET registry now contains data on 371 patients (320 new cases; 51 with long term complications) that is being used to calculate the incidence of each porphyria in participating countries and the prevalence of long term complications. The incidence of new cases of acute intermittent porphyria is around 0.15/million/year in most countries.

The initial purposes of the EPNET project have been achieved; we have established a rich data resource, a

network for improving quality of care and a European platform for expert exchange.

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