

Porphyryns and Porphyrias - International Patient Day

September 13th, 2015, Düsseldorf, Germany

Topic: New therapies in cutaneous and acute porphyrias

Venue: Düsseldorf, City Hostel ([Link](#))

Preliminary program and invited speakers

- 8.30 – 8.40 Welcome from the organizing committee
8.40 – 8.50 Welcome address by the chairman of the conference: Priv.-Doz. Dr. med. Jorge Frank, GER
8.50 – 9.40 Introduction of various patient organisations

Session 1: Cutaneous Porphyrias

- 9.40 – 10.40 Introduction to the cutaneous porphyrias: Dr. Janneke Langendonk, NL

Coffee Break (15 min)

- 10.55 – 11.55 Market Authorisation of Scenesse: Prof. Elisabeth Minder, CH
11.55 – 12:10 Patient view: EPP Patient from NL

Lunch (60 min)

- 13.10 – 14.10 Prospects for a splice modulating therapy for EPP: Prof. Daniel Schümperli, CH

Session 2: Acute Porphyrias

- 14.10 – 15.10 Introduction to the acute porphyrias: Prof. Christer Andersson, SWE
15.10 – 16.10 New siRNA based therapy for acute porphyrias: Prof. Robert Desnick, USA

Coffee Break (15 min)

- 16.25 – 16.40 Patient view: Desiree Lyon, President of the American Porphyria Foundation, USA

16.40 – 18.00 Closing of the Patient Day and informal exchange between patients & experts

Organizing Committee:



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