



Red Blood Cell Disorders Committee

<http://www.bhs.be>

REPORT MEETING NOVEMBER 12, 2015

7:00 PM

Put on the agenda:

Proposals of new SCD studies

- **Evaluation of risks related to sedation in children undergoing IRM/ARM? (A. FERSTER HUDERF)**
 - Retrospective analysis at Huderf
 - Possible to join to perform final multicentric analysis
 - If interested: Please contact alina.ferster@huderf.be

- **Is transition from pediatrics to adult care at risk in our practice? (A.Ferster HUDERF)**
 - Retrospective analysis at Huderf and CHU-Brugmann in patients followed at least during 3 years before and after transition to adult care
 - Possible to join to perform final multicentric analysis
 - If interested: Please contact alina.ferster@huderf.be

- **6 minutes' walk test in children and young adults with SCD and new haemolytic parameters: can we predict vascular damage ? (L.Dedeken)**
 - Cross-sectional study
 - Possible to join
 - If interested: Please contact laurence.dedeken@huderf.be

- Belgian registry and neonatal screening – Phu-Quoc LE
- French thalassaemia registry; follow-up – Béatrice GULBIS
 - i. Only few centres have reported the number of patients; before deciding to implement a Belgian registry (see French registry), we would like to approach the number of patients regularly followed in Belgium.
- Telemedicine project - ENERCA – Béatrice GULBIS
 - i. The project is ongoing. As soon as the platform will be open, Belgian experts will be asked to participate.
- Belgian plan for rare diseases: update for laboratories? - Béatrice GULBIS (Annex 3)
- Reference nurse in non-oncological haematology – Translation of the document reporting the job description is ongoing. A group has been constituted within the BHS and should meet.
- A questionnaire on the use of hydroxyurea is proposed (when do you start, at which dose) and will be discussed in May .



- Information: 6th European meeting Rare anaemias Amsterdam November 21-22; ESH/ENERCA training course Lisbon January 2016; Sickle cell meeting February 18, 2016 - [Béatrice GULBIS \(Annex 3\)](#)

NEXT MEETING: May 12, 2016.