



Red Blood Cell Disorders Committee


<http://www.bhs.be>

REPORT MEETING MAY 12, 2016

7:00 PM

Partners - guests present:

Olivier Ketelslegers, Veerle Labarque, Alina Ferster, Béatrice Gulbis, Ann Van Damme, Marie-Françoise Dresse, Anna Vanderfaeillie, Luci Pecheux, Lisa Balepa, Leonardo Gucciardo, Marie HOYOUX, Alice Bruwier, Laurence Dedeken, Bénédicte Brichard.

- Telemedicine: a tool for rare red blood cell disorders – Béatrice GULBIS
 - See annex telemedicine
 - Developed with a grant from the European Commissions, a telemedicine platform for diagnosis of rare RBC disorders is now open at
- Pregnancy in AS women: Lisa BALEPA and L. GUCCIARDO
 - See annex Pregnancy
 - A survey has been proposed; participation will be asked as well as input on its content.
- Revival of the Belgian SCD registry? Béatrice GULBIS et Alina FERSTER
 - Annex registry
 - Please look carefully at the items proposed and feel free to give your input.
 - The objective is now
 - i. To propose a simplified data base which allow catching patients with any adverse event, treatment, etc. Those selected patients might constitute the “material” for more details studies.
 - To propose an annual update for each patient
 - To go back to the local ethical committee for approval of that update.
- Update of the ASH meeting: Alina Ferster and Laurence Dedeken
 - Annex ASH
- Sickle cell day, June 19 – All partners
 - Propose a poster based on the rare disease plan
 - A POCT is available to screen for Hb S see
- <https://www.youtube.com/watch?v=rHLYL5tCCqI>
- The logo for BioMedomics, Inc. features a stylized molecular structure with blue, red, and white spheres and bonds, positioned above the text 'BioMedomics, Inc.' in a bold, black font.
- <http://www.biomedomics.com>