



Red Blood Cell Disorders Committee

<http://www.bhs.be>

MEETING SEPTEMBER 26, 2013

Partners present:

Samantha Benghiat, Laurence Dedeken, Cristina Epalza, Veerle Labarque, Alina Ferster, Olivier Ketelslegers, André Delannoy, Marie-Agnes Azerad, Angela Del Giudice, Jonathan Brauner, Béatrice Gulbis

General comment (A. Delannoy) – Level of evidence should be indicated for each aspect of the recommendations proposed.

General agreement: there is a lack of randomised studies in the field of haemoglobinopathies, recommendation are often those of experts. If an aspect is well identified, it is the opportunity to propose new studies.

Topics discussed:

1. Recommendations to be reviewed: follow-up of pregnancy.
[Questions were debated and recommendations will be finalized](#) - Lisa Ballepa - Samantha Benghiat
2. New recommendations on anaesthesia:
[Agreement of the partners on the final proposal – The document will be finalized, posted on the BHS website and sent to the vice-president of the “BELGIUM - Society for Anesthesia and Resuscitation of Belgium”](#)
luc.barvais@erasme.ulb.ac.be
3. Neonatal screening for haemoglobinopathies in Belgium:
[INAMI-RIZIV has signed an agreement in view to get the incidence of sickle cell disorders in Belgium. Tests are running. Data will be probably available in January 2014. Due to legal constraints, data will not be available for the whole territory](#) – Olivier Ketelslegers and Béatrice Gulbis
4. Reference centres (laboratory and clinical) for sickle cell disease: survey to be organized –
[A questionnaire will be proposed and sent through the BHS in view to know where facilities for diagnosis and follow-up of the patients are available i.e. transcranial Doppler echography, ...](#) Olivier Ketelslegers and Béatrice Gulbis
5. Meeting on sickle cell disease – March 13, 2014 – Alina Ferster
[The programme is now finalized.](#)
6. BHS training course on red blood cell disorders November 9: call for speakers
Béatrice Gulbis
7. Progress made at the BHS level to gain support for a “non oncologic hematology” reference nurse - Marie-Agnès Azerad.
[Provision of a nurse, which benefit? A study protocol to prove that benefit will be proposed.](#)
8. [The creation of a referent committee nurses for sickle cell patients was debated. Until now, this function is not recognized within any Institution and](#)



at the federal level. Many Goals, among which is the national representation of this function in the BHS and standardization of practices. A referent nurse occupies a vital place in the follow up of these patients. That group would work closely with red cells committee. Identification of such referent nurses who already have that role in the different Belgian centres will be made.

Angela Del Giudice

9. Information on meetings (TIF, Réseau français...) and new projects (ENERCA).