

Committee annual report

Committee chair

Name of committee : Red Blood Cells Disorders		
Chair : Gulbis Béatrice	Since : 2006	Date of last « election » : 2012

Committee members : name (E-mail)

Active members: Marie-agnes.AZERAD@chu-brugmann.be alina.ferster@huderf.be Phuquoc.LE@huderf.be a.delannoy@skynet.be anna_vanderfaellie@stpierre-bru.be Beatrice.Gulbis@erasme.ulb.ac.be Cristina_EPALZA@stpierre-bru.be marie.francoise.dresse@chrcitadelle.be olivier.ketelslegers@chrcitadelle.be pierre.philippet@chc.be veerle.labarque@uz.kuleuven.be dngay@hotmail.com	Axelle.Gilles@ulb.ac.be alain.kentos@hotmail.com Christophe.CHANTRAIN@CHC.BE samantha.benghiat@gmail.com Timothy.Devos@uzleuven.be Jonathan.Brauner@erasme.ulb.ac.be Laurence.DEDEKEN@huderf.be
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Activities in year 2012

Date	Activity
9-02-2012	Committee meeting
7-06-2012	Committee meeting
18-10-2012	Committee meeting
	Main activities <ul style="list-style-type: none"> • Annual meeting: <i>Sickle cell disorders and other red blood cell disorders</i> Meeting in Brussels – 1-03-2012 – CHU Saint-Pierre • Development of the Belgian database for sickle cell disorders. • Final results of the ENERCA survey: “European survey: facilities for patients with rare and very rare anaemias” and more specifically the Belgian results. A summary was sent to the participants. • Review of the ongoing trials on red blood cells disorders • New clinical trial : development of a biobank of adult SCD patients’ samples • Belgian recommendations: review of ENERCA documents adapted to the Belgian healthcare practice and new documents (see minutes of committee meeting 18-10-2012) • Collaboration for the creation of a “Emergency and healthcare card” for patients with beta-thalassaemia major or intermedia. • Compilation of information available on haemoglobinopathies. • Proposal for transition from paediatric to adult care • To propose de creation of a nurse working group on haemoglobinopathies within the BHS nurse committee

! Please provide minutes of all this year’s committee meetings !

Publications in year 2012**Plan (policy, activities with approximate dates...) for next year****Policy:**

- **Belgian registry of patients with SCD:** follow-up; how to sustain the registry (we need to hire a data manager and raise funds); decision to open the database in view to use it as a day to day clinical database.
- **Recommendations to be reviewed:** sickle cell disorders: follow-up of pregnancy
- **New recommendation:** anaesthesia for patients with SCD or heterozygous for HbS
- **Clinical trial:** implementation and development of the biobank of adult SCD patients' samples

One meeting is already scheduled: 25-04-2013.

Comments / requests for the BHS board