

## Committee annual report

(all cells can be expanded as needed)

### Committee chair

Name of committee : Red Blood Cell Disorders		
Chair : Béatrice Gulbis	Since : 2006	Date of last election : 09-02-2012

### Committee members : name (E-mail)

<p>Azerad Marie-Agnès (<a href="mailto:marie-agnes.azerad@chu-brugmann.be">marie-agnes.azerad@chu-brugmann.be</a>)          Bailly Benjamin (<a href="mailto:Benjamin.Bailly@erasme.ulb.ac.be">Benjamin.Bailly@erasme.ulb.ac.be</a>)          Benghiat Samantha          Brauner Jonathan          Cotton F. (<a href="mailto:fcotton@ulb.ac.be">fcotton@ulb.ac.be</a>)          Delannoy A. (<a href="mailto:a.delannoy@skynet.be">a.delannoy@skynet.be</a>)          Devos Timothy (<a href="mailto:timothy.devos@uzleuven.be">timothy.devos@uzleuven.be</a>)          Dierickx Daan (<a href="mailto:daan.dierickx@uz.kuleuven.ac.be">daan.dierickx@uz.kuleuven.ac.be</a>)  <a href="mailto:dngay@hotmail.com">dngay@hotmail.com</a>          Dresse Marie-Françoise (<a href="mailto:marie.francoise.dresse@chrcitadelle.be">marie.francoise.dresse@chrcitadelle.be</a>)          Epalza Cristina (<a href="mailto:cristina_epalza@stpierre-bru.be">cristina_epalza@stpierre-bru.be</a>)          Ferster Alina (<a href="mailto:alina.ferster@huderf.be">alina.ferster@huderf.be</a>)</p>	<p>Gilles Axelle (<a href="mailto:Axelle.Gilles@ulb.ac.be">Axelle.Gilles@ulb.ac.be</a>)          Gulbis Béatrice (<a href="mailto:bgulbis@ulb.ac.be">bgulbis@ulb.ac.be</a>)          Kentos Alain (<a href="mailto:akentos@ulb.ac.be">akentos@ulb.ac.be</a>)          Ketelslegers Olivier (<a href="mailto:olivier.ketelslegers@chrcitadelle.be">olivier.ketelslegers@chrcitadelle.be</a>)          Labarque Veerle (<a href="mailto:veerle.labarque@uz.kuleuven.be">veerle.labarque@uz.kuleuven.be</a>)          Le Phuquoc (<a href="mailto:phuquoc.le@huderf.be">phuquoc.le@huderf.be</a>)          N'Gay Didier          Philippet Pierre (<a href="mailto:Pierre.philippet@chc.be">Pierre.philippet@chc.be</a>)          Vanderfaeillie Anna (<a href="mailto:anna_vanderfaeillie@stpierre-bru.be">anna_vanderfaeillie@stpierre-bru.be</a>)          Vertongen Françoise (<a href="mailto:francoise.vertongen@stpierre-bru.be">francoise.vertongen@stpierre-bru.be</a>)          Wolff Fleur</p>
--	--

### Activities in year 2011

Date	Activity
24 & 25-02-2011	<i>Sickle cell disorders and other red blood cell disorders</i> Meeting in Brussels – see programme attached
All the year	Implementation of a national registry of patients with SCD: retrospective study: Continued introduction of patient data in the Belgian database.  Organisation of the ENERCA survey: "European survey: facilities for patients with rare and very rare anaemias" and distribution in Belgium

**! Please provide minutes of all this year's committee meetings !**

### Publications in year 2011

<p>1) de Montalembert M, Ferster A, Colombatti R, Rees DC, Gulbis B; European Network for Rare and Congenital Anaemias <i>ENERCA clinical recommendations for disease management and prevention of complications of sickle cell disease in children.</i> <b>Am J Hematol. 2011 Jan;86(1):72-5</b></p> <p>2) Gulbis B, Ferster A, Vertongen F <i>Hemoglobinopathies in Belgium</i> <b>Belgian Journal of Hematology -Edition: 2010 - Nr. 2 - 50-6.</b></p> <p>3) Phu-Quoc Lê, MD<sup>1</sup>, Alina Ferster, MD<sup>1</sup>, Françoise Vertongen, MD, PhD<sup>2*</sup>, Christiane Vermylen, MD, PhD<sup>3</sup>, Anna Vanderfaeillie, MD<sup>4*</sup>, Catherine Heijmans, MD<sup>1*</sup>, André Efira, MD<sup>5*</sup>, Ba-Cuong Nguyen<sup>6*</sup>, Malou Ngalula Mujinga, nurse<sup>1*</sup> and Beatrice Gulbis, MD, PhD <i>National Clinical Data Base for Sickle Cell Disease In Belgium</i> <b>52<sup>nd</sup> ASH annual meeting</b></p>
--

**Plan (policy, activities with approximate dates...) for next year**

- **Policy:**
  - **Belgian registry of patients with SCD:** presentation of the actual results; presentation of the new projects; 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.
  - **Discussion regarding the recommendations edited by the European group ENERCA**
    - Recommendations for prenatal screening, antenatal diagnosis and genetic counselling of haemoglobinopathies
    - Recommendations for first line management and standard follow-up of children affected with sickle cell disease
    - Recommendations for first line management and standard follow-up of adults affected with sickle cell disease
    - Recommendations for the Neonatal screening for SCD
  - **Update of the recommendations for diagnosis and management of hereditary spherocytosis**
- **Two meetings are already scheduled in February, 9 and June, 14.**

**Comments / requests for the BHS board**

--