



## **Red Blood Cell Disorders Committee**

<http://www.bhs.be>

### **REPORT MEETING MAY 8, 2014**

7:30 PM

Partners present:

Samantha Benghiat, Laurence Dedeken, Veerle Labarque, Alina Ferster, , André Delannoy,, Jonathan Brauner, Béatrice Gulbis, Ann Van Damme, Philip Maes, Phu Quoc Lé, Marie-Françoise Dresse, Sophie Dupont, Marie-Agnès Azerad, Anna Vanderfaeillie.

- **Results of the neonatal screening (extension) for haemoglobinopathies in Belgium – O. Ketelslegers – B. Gulbis**

The results have been presented to the INAMI/RIZIV group.

#### **CENTRES INVOLVED**

- F. EYSKENS - DEPARTEMENT WELZIJN, ECONOMIE & PLATTELANDSBELEID – PCMA VZW – 2610 WILRIJK
- V. BOURS - CENTRE DE DEPISTAGE NEONATAL DE LIEGE CENTRE HOSPITALIER UNIVERSITAIRE DE LIEGE - CAMPUS DU SART TILMAN – TOUR 2 – ET+6B35 - 4000 LIEGE
- O. KETELSLEGERS – SERVICE DE BIOLOGIE CLINIQUE - CHR CITADELLE - BD DU 12E DE LIGNE, 1 - 4000 LIEGE
- B. GULBIS – C.U.B. HOPITAL ERASME – CENTRE DE DEPISTAGE NEONATAL DES HEMOGLOBINOPATHIES – POLE DES LABORATOIRES – ROUTE DE LENNIK 808 – 1070 BRUXELLES

Number of newborns tested during 6 months (July-December 2013) : 39.599 ; around 1/2350 newborns were affected by sickle cell disease while around 1/80 were heterozygous for HbS. Those newborns were distributed in all maternity wards involved.

With those numbers and distribution of cases in the maternity wards, it has been suggested to extend the neonatal screening for SCD. It has also been suggested to consider the overall care for that chronic and multiorganic disease. A proposal will be given within several weeks.

- **Sickle cell day June 19 – A. del Giudice**

The Red Cross - Rhines site has been contacted. A leaflet on rare blood groups (SCD) and the necessity to be a blood donor is available. It could be used either in June 14 (red cross annual day) and June 19 (SCD annual day). We are waiting for the answer from a manager in the Red Cross Institution.

RTL TV has been contacted in view to realise a TV spot. The delay might be a little too short...



Nevertheless, it has been proposed to review the poster previously used. At least it could be posted on our different websites and on the walls of our Institutions around June 19.

Follow-up: B. Gulbis contacted M. Lambermont (Director Red Cross – Rhines). The leaflets are indeed available; its electronic format should be also available and sent to B. Gulbis.

M. Lambermont has asked to inform the Red Cross communication department if any decision about a TV spot is made.

- Randomized study comparing N-acetylcysteine to placebo in sickle cell patients – André Delannoy – Marie-Agnès Azerad  
A few months ago, we considered joining a Dutch study comparing N-acetylcysteine to placebo in sickle cell patients. The Dutch investigators have welcome our participation and the coordinating investigator (Joep Sins) presented the study to one of the coordinators of the study in Belgium (Marie-Agnès Azerad) and parte, A. Delannoy) just before the meeting of the whole group. Practical aspects were discussed.  
To be conducted, as previously discussed, a financial support is needed. A second message will be send to the President, R. Schots, of the BHS.  
The follow-up is a positive answer from R. Schots and more precisely: “...to help you within a reasonable delay I need an approximate budget and timelines, as well as how you would like this to be organized in practice. »
- Follow-up “Foundation for Sickle Cell Disease Research (FSCDR)”- 8<sup>th</sup> Annual Meeting April 11, 2014 – Alice Ferster  
See Annex 1.
- Recommendations to be posted on the BHS website and other websites:
  - i. Follow-up of pregnancy; Waiting for the last remarks; than to be posted on the BHS website but also those of the Belgian gynaecologists and obstetricians.
  - ii. New recommendations on anaesthesia; finalized waiting for an answer from the secretary of the Belgian society of anaesthesiologists.
- **Others**  
Job description of a nurse in charge of patients with SCD is ready (A. del Giudice). The clinicians involved in those pathologies should read it and give their feedback, and than we will be translated in English.  
See Annex 2.