MEETING May 31, 2018

7:00 PM

Hof ter Müsschen *https://www.hoftermusschen.be/*

Participants

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Minutes

1. Clinical trials: update Annex 1 + the discussion conducted to the objective that if feasible centres should not compete. One centre should concentrate the patients involved in the trial (i.e. last NAC study).
   Parallel studies are allowed if not interventional.
   A study is presented: "Proton pump inhibition for secondary hemochromatosis in hereditary anaemia, a phase III placebo controlled randomized cross-over clinical trial" UMC Utrecht is presented (Annex 2).
   The study on alloimmunization ongoing in Belgium (LHUB-ULB/HUDERF) is actually too difficult in its organization to, become multicentre.

2. Neonatal screening for SCD: update (Annex 3)
3. Difficult cases: Annex 1 +
   A girl (born in 2012 and coming from Syria) presented anaemia (erythroblastopenia) at the age of 2.5 months The family went through Turquey, than Egypt and finally Belgium. She had several RBC transfusions and was occasionally under chelation. Diagnosis was Blackfan Diamond anaemia but she doesn't respond to steroids. She has a splenomegaly, iron overload (liver 20 mg /g; no cardiac overload) has been demonstrated.
   Biological parameters:
   Hb 7.8 g
   Main actual treatments:
   RBC transfusions 2 U each 3 to 4 weeks
   Iron chelation
   Vit D
   The questions are:
   Erythroblastopenia related to Blackfan Diamond anaemia?
   Thrombocytopenia and leucopenia: related to splenomegaly?
   Splenomegaly > splenectomy depending on the final diagnosis?

4. SCD day, June 19: program and patient associations (Annex 1)
   The meeting proposed is totally devoted to patients After discussion it seems that it is too late to contact the patients. It has been proposed to keep it in mind for next year The agenda of the day will be discussed at the next BHS meeting