



**Sunday, October 13th**  
**Get together afternoon**  
**patients & families**



European  
Reference  
Networks



Endo-ERN

**X-linked Rickets hypophosphatemia (XLH)**  
**Rachitisme hypophosphatémique vitamino-résistant**  
**héréditaire (RVRH)**

- 2.30 pm ▼  
Welcome and presentation of the families  
*Prof. C. Heinrichs – Mr Pol Harvengt – Mr Bernard Ramaekers and patients' families*
- 2.45 pm ▼  
What is RVRH-XLH ?  
*Prof. C. Heinrichs*  
Patient care: how to care for children? What are the new treatments?  
*Dr E. Boros*
- 3.30 pm ▼  
Presentation byt the Belgian XLH Alliance  
*Anna Koltunowska*  
Identification of objectives and priorities of relation patients/parents  
What are the relation's goals ? How to achieve them ?  
What are our pioriities within the next 12 months ?
- 4.15 pm ▼  
**Roundtable – Q&A**  
*Moderators : Pr C. Heinrichs – Mr Pol Harvengt – Mr Bernard Ramaekers*  
Coffee & refreshments  
Conclusion
- 5.00 pm ▼

**Queen Fabiola Children's**  
**University Hospital**

Avenue Crocq 15 – 1020 Brussels –  
Auditorium Henri Vis – Level -1

Free entrance  
Registration  
required before  
**10/10/2019**

