

2nd Announcement

Second HUE-MAN Meeting



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January 11th- January 13th, 2007

Brussels, Belgium

Venue:

The meeting place is the German contact office and Coordination Center for Science (Kowi):

<http://www.kowi.de/services/homebase/default.htm>

Koordinierungsstelle EG der Wissenschaftsorganisationen (KoWi)
Rue du Trône 98
B- 1050 Bruxelles

The meeting will take place at Friday January, 12th, 2007 from 9am until approx. 5pm.

Arrival: Thursday January, 11th, 2007

Departure: Saturday January, 13th, 2007 (or Friday, January 11th, 2007 after the meeting)

Hotel:

For most of you one or two nights were booked in:

**Hotel Stanhope Brussels
Rue du Commerce 9 – Square de Meeûs 4
1000 Brussels – Belgium
[t] +32 (0)2/506 91 11
[f] +32 (0)2/512 17 08**

**"Stanhope" Hotel, high standard, very nice, to the KoWi (our meeting site)
about 10 min footpath, to the Grand Place about 15 min footpath**

<http://www.stanhope.be/>><http://www.stanhope.be/>

Brussels:

For better orientation use this link to brussels city map:

<http://www.hot-maps.de/europe/belgium/brussels/homede.html>.

Planned schedule of the meeting:

Thursday January 11th evening:

Depending on the arrival time. We have reserved a conference room in the hotel. Please inform me about your arrival time.

Meeting of all partners associated with the Natural History Study of human Alpha Mannosidosis

(Dag Malm, Oivind Nilssen, Ed Wraith, Michael Beck, Jiri Zeman, Jens Fogh, Christian Friis, Paul Saftig)

Topics and goals of this meeting:

- an update on the ethical application process
- patient recruitment plans
- presentation of the final CRF
- discussion of the practical management of the study.

Friday January 12th:

Breakfast until 8:00

From **8.30 am**: Second HUE-MAN Meeting for all participants

8.30-8:50 Brief welcome by Paul Saftig (*The mission and Deliverables of HUE-MAN*) and very brief round table introduction of all participants including the new people working for the consortium

8:50-9:10 **From preclinical research to medical approval: insights from a company's view** (Jens Fogh)

9:10-10:00 **WP1 and WP2 Judith Blanz & Paul Saftig**: Enzyme replacement therapy in the mouse model; Biochemical, histological and immunological analysis of alpha mannosidase knockout mice

10:00-10:15: **WP9 Helena Reuterwall & Claes Andersson**: Enzyme production of human LAMAN

10:15-10:35: **WP 3 and WP4 Rudi D'Hooge**: Behavioural abnormalities in mouse alpha mannosidosis; Effect on CNS pathology and behaviour after treatment of human LAMAN

10:35- 10:55: WP5 *Torben Lübcke & Markus Damme*: Epigenetic influence of ERT in the mouse model; Comparison of the transcriptome in wildtype and alpha mannosidase knockout mice

10:55-11:15 WP7 *Jean Claude Michalski*: Development of the oligosaccharide analyses, Oligosaccharide analysis of urine and serum samples

11:15- 11:35: WP8 *Oivind Nilssen*: Mutation database, genetic epidemiology of human alpha-mannosidosis

11:35- 12:15: WP6, WP10: Natural History study in patients with alpha mannosidosis; Documentation and result management of the natural history study (Summary of the Discussion Panel from Thursday)- *Christian Friis*, clinical partners

12:15-13:15 Lunch/Snacks/photo session

13:15- 13:20 *Annette Schön (Kiel)* Administration of HUE-MAN

13:20-13:40 *Catherine Behrens (Brussels)* Insights into EU FP6 and FP7 instruments

13:40- 14:00 Coffee Break

14:00-15:00: Invited Speaker: Prof. Dr. Arnold Reuser, University Rotterdam
Enzyme Replacement Therapy in Pompe Disease

15:15-15:30: WP11 *Paul Saftig*: Coordination and management

15:30-16:30: Final discussion panel
Organization of the meeting in July 2007
Upcoming issues

about 17:00 end of the meeting

Departure