

Final Announcement

Fifth HUE-MAN Meeting



(Friday) October 31st, 2008- (Saturday) November 1st, 2008

Prague, Czech Republic

Venue:

The meeting place is the

IBIS Praha Wenceslas Square 4

Katerinska 36

12000 – PRAGUE

CZECH REPUBLIC

Tel : (+420)2/22865777

Fax : (+420)2/24941201

Meeting Room: *Smetana (6th floor)* reserved for Friday 31.10.08 (late afternoon) and 1.11.2008 (full day; conference package)

Local organization: Befekadu Asfaw (basfaw@nbox.cesnet.cz)

The official meeting will take place from Friday October 31st. 2008 (arrival day), until Saturday, November 1st 2008 until about 4 pm.

Arrival: Friday 31.10.2008

Departure: Saturday 1.11.2008 (after the meeting)

Hotel:

Accommodation is reserved for us at:

IBIS Praha Wenceslas Square 4

Katerinska 36

12000 – PRAGUE

CZECH REPUBLIC

Tel : (+420)2/22865777

Fax : (+420)2/24941201

Link:

http://www.ibishotel.com/ibis/fichehotel/gb/ibi/3195/fiche_hotel.shtml

The Ibis Praha Wenceslas Square hotel is located 5 min from the centre, close to the I. P. Pavlova (line C) metro station. 800 m from the largest convention centre in Prague, the hotel offers 181 airconditioned rooms and also features a restaurant, a terrace, a bar serving snacks 24 hours and private indoor parking. Guests may also use the sauna, swimming pool and fitness centre at the Novotel (an entrance charge applies). WiFi wireless internet access for guests on a business trip.



Room rate: 100 €/night + 9% VAT; Breakfast: 10 €/day; Payment: individually by guests

Prague:

For better orientation use this link to Prague:

<http://www.prague.cz/>

List of participants: (confirmed)

Kiel: Paul Saftig, Judith Blanz

Mainz: Michael Beck, Sandra Delgado Sanchez

Leuven: Rudi D'Hooge, Stijn Stroobants

Manchester: Ed Wraith, Sarah Phillippo, Simon Jones

Zymenex: Jens Fogh, Ulla Jorgensen, Christian Friis, Claes Andersson

Helena Reuterwall

Göttingen: Torben Lübke, Markus Damme

Tromsø: Dag Malm, Oivind Nilssen, Hilde Monica Riise

Prag: Jiri Zeman, Befekadu Asfaw Debela, Martin Magner, Olga Brantova

Lille: Jean Claude Michalski

Planned schedule of the meeting:

Friday October 31 afternoon:

Kiel: Paul Saftig,

Mainz: Michael Beck, Sandra Delgado Sanchez

Manchester: Ed Wraith, Sarah Phillippo, Simon Jones

Zymenex: Jens Fogh, Ulla Jorgensen, Christian Friis,

Tromsoe: Dag Malm, Oivind Nilssen, Hilde Monica Riise

Prag: Jiri Zeman, Befekadu Asfaw Debela, Martin Magner, Olga Brantova

4-6pm:

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

Topics and goals of this meeting:

- **Recent news from Zymenex**
- **Status on the patient recruitment**
- **Protocol and CRF issues**
- **Deviations and best practice**
- **Interim data from the study and discussion**
- **Financial issues**

Meeting for all HUE-MAN participants at 6.30 pm in the hotel reception area:

Departure for Dinner

(place still to be determined; costs for dinner to be paid individually)

Saturday November 1st:

Breakfast until 8:50

From **9 am**: Fifth HUE-MAN Meeting for all participants

9:00-9:15 Brief welcome by Paul Saftig (*The mission and Deliverables of HUE-MAN*) and very brief round table introduction of all participants; Update on Amendment request (extension of HUE-MAN)

9:15-10:00 WP1 and WP2 Judith Blanz & Paul Saftig: Enzyme replacement therapy in the mouse model; Biochemical, histological and immunological analysis of alpha mannosidase knockout mice

10:00-10:30: WP9 Helena Reuterwall & Claes Andersson: Enzyme production of human LAMAN

10:30- 11:00 Coffee Break

11:00-11:30: WP 3 and WP4 Stijn Stroobants & Rudi D'Hooge: Preclinical experiments and behavioural assessment in alpha-mannosidosis mice

11:30- 12:00: WP5 Torben Lübcke & Markus Damme: Epigenetic influence of ERT in the mouse model; Comparison of the transcriptome in wildtype and alpha mannosidase knockout mice

12:00-12:30 WP7 Jean Claude Michalski: Development of the oligosaccharide analyses, Oligosaccharide analysis of urine and serum samples

12:30- 13:30 Lunch

13:30- 14:00: WP8 Oivind Nilssen: Mutation database, genetic epidemiology of human alpha-mannosidosis

14:00- 14:30: 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

14:30-14:50 Coffee and photo session

From 14:15: What's after HUE-MAN : A new proposal within the FPVII EU network.

Coordination and management; Organization of the meeting in October/November 2008; Upcoming issue

about 16:00 end of the meeting; Departure or Fun in Prague