

2nd Announcement

Third HUE-MAN Meeting



Sixth Framework Programme
2002 - 2006

September 27th, 2007

Perugia, Italy*

**This HUE-MAN meeting will take place immediately before the official ESGLD (European Study Group of Lysosomal Storage Diseases: <http://www.esgld.org/>) Meeting which will be from September 27th (6pm) until September 30th, 2007.*

Venue:

Hotel Brufani

<http://www.brufanipalace.com>

The meeting will take place at Thursday September, 27th, 2007 from 9am until approx. 4pm.

Arrival: Wednesday, September 26th, 2007

Departure: Depending if ESGLD conference attendance* is planned

Registration to the ESGLD conference until May 15th under : <http://www.esgld.org>

Please note: membership to the ESGLD is required!!

Hotel:

Hotel Brufani (<http://www.brufanipalace.com>)

The accommodation will cost 100 €/night including buffet breakfast (single room). Double room will cost 140 € including buffet breakfast. We will get a meeting room in the hotel for the HUE-MAN consortium during the 27/9/07.



Participant list (16/4/07) for the HUE-MAN meeting:

From Kiel: Paul Saftig, Judith Blanz

From Tromsø: Dag Malm, Hilde Monica Stensland, Oivind Nilssen, Oyvind Edvardsen

From Leuven: Rudi D'Hooge, Stijn Stroobants

From Manchester: Ed Wraith

From Göttingen: Torben Lübcke, Markus Damme

From Mainz: Michael Beck

From Copenhagen/Stockholm: Jens Fogh, Helena Reuterwall, Christian Friis, Claes Andresson,
Klaus Juel Olsen

From Prague: Jiri Zeman, Befekadu Debela

From France: Willy Morelle (to be confirmed)

Planned schedule of the meeting:

Wednesday September 26th 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 September 27th:

Breakfast until 8:00

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

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

WP1 and WP2 Judith Blanz & Paul Saftig: Enzyme replacement therapy in the mouse model;

Biochemical, histological and immunological analysis of alpha mannosidase knockout mice

WP9 *Helena Reuterwall & Claes Andersson*: Enzyme production of human LAMAN

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

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

WP7 *Willy Morell*: Development of the oligosaccharide analyses, Oligosaccharide analysis of urine and serum samples

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

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

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