

HUE-MAN

Kick-Off-meeting
Kiel 2006; May 1- May 2, 2006



<http://www.biochem.uni-kiel.de/hue-man/>



Kick-off meeting HUE-MAN

Dear partners of the HUE-MAN consortium,

as discussed before I am happy to invite you to the 1st official meeting of the HUE-MAN consortium which will take place from May 1st, 2006 to May 2nd 2006 in Kiel, Germany. Please find below the programm of our meeting and additional informations which you may find useful to get along in Kiel.

I am looking forward to meeting you all in Kiel.

Please do not hesitate to contact me in case of futher questions!

Best wishes

Paul

(1) List of participants and numbers of night accommodation is booked:

| Name | University/Place | night 1 | night 2 |
|------------------------|------------------|---------------|-----------------|
| | | accommodation | accommodation |
| | | 1.5.06-3.5.06 | 2.5.06 - 3.5.06 |
| Paul Saftig | Kiel | not needed | not needed |
| Judith Blanz | Kiel | not needed | not needed |
| Annette Schön | Kiel | not needed | not needed |
| Dag Malm | Tromsø | + | - |
| Oivind Nilssen | Tromsø | + | - |
| Hilde Monica Stensland | Tromsø | + | + |
| Ed Wraith | Manchester | + | + |
| Jobst Landgrebe | Göttingen | + | |
| Chieh Hsu | Göttingen | + | |
| Michael Beck | Mainz | + | |
| Jens Fogh | Copenhagen | + | |
| Lillian Rejkaer | Copenhagen | + | |
| Claes Andersson | Copenhagen | + | |
| Rudi d` Hooge | Leuven | + | + |
| Jiri Zeman | Prague | + | + |
| Jean-Claude Michalski | Lille | + | |
| Ulrich Matzner (guest) | Bonn | + | |

(2) Planned Schedule of the meeting:

Monday May 1st 2006 (Bank holiday in Germany)

Arrival in Kiel in the afternoon, the meeting will take place at the Hotel Maritim Kiel
(http://www.tagungshotel.com/hotel_1054814591.htm)

5pm: (conference room):

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

**(Dag Malm, Oivind Nilssen, Ed Wraith, Michael Beck, Lillan Rejikkaer, Jiri Zeman,
Paul Saftig)**

Topics and goals of this meeting:

Agreement on clinical assessment protocoll, Management and Coordination of the natural
history study, preliminary selection of patients attending the natural history study,
Communication, Ethical Issues and Approvals

Deliverables (Reminder):

- approval by the Ethics Committees (Delivery April 2007)
- Preliminary medical report of 19 pateints (Delivery date October 2007)
- Preliminary medical report of 38 pateints (Delivery date April 2009)
- Statistical report with medical comments (Delivery date April 2009)

8pm: Dinner at the hotel

9.30 pm: (conference room; all participants)

Invited speaker: Dr. Ulrich Matzner

Enzyme Replacement Therapies for lysosomal storage diseases

Tuesday May 2nd 2006

Breakfast until 8:30

From **8.30**: Official Kick-off Meeting for all participants

8.30-9:00 Brief welcome by Paul Saftig (*The mission of HUE-MAN*) and very brief round table introduction of all participants

9:00-9:30 Organisation of HUE-MAN consortium (Annette Schön, Paul Saftig Kiel)

9:30-10:20: *Partners Introduction: Please introduce your expertise, your institution and your contribution to HUE-MAN (if possible use transparencies to allow a quick run through):*

9:30-9:35: 5min. introduction of partner and partner's organization: Paul Saftig (#1)

9:35-9:40: 5min. introduction of partner and partner's organization: Jens Fogh, Lillan Rejkjaer (#2a,2b)

9:40-9:45: 5min. introduction of partner and partner's organization: Rudi D'Hooger (#3)

9:45-9:50: 5min. introduction of partner and partner's organization: Jobst Landgrebe (#4)

9:50-9:55: 5min. introduction of partner and partner's organization: Ed Wraith (#5)

9:55-10:00: 5min. introduction of partner and partner's organization: Michael Beck (#6)

10:00-10:05: 5min. introduction of partner and partner's organization: Jiri Zeman (#7)

10:05-10:10: 5min. introduction of partner and partner's organization: Dag Malm (#8)

10:10-10:15: 5min. introduction of partner and partner's organization: Oivind Nilssen (#9)

10:15-10:20: 5min. introduction of partner and partner's organization: Jean Claude Michalski (#10)

10:20-10:35: coffee break

10:35-12:00: *Work packages and Deliverables: Please summarize briefly the state of the art and the planned projects focussing on the Deliverables mentioned in the HUE-MAN contract*

10:35- 10:50: **WP1 and WP2 Paul Saftig**: Enzyme replacement therapy in the mouse model; Biochemical, histological and immunological analysis of alpha mannosidase knockout mice

10:50-11:10: **WP 3 and WP4 Rudi D'Hooge**: Behavioural abnormalities in mouse alpha mannosidosis; Effect on CNS pathology and behaviour after treatment of human LAMAN

11:10- 11:20: **WP5 Jobst Landgrebe**: Epigenetic influence of ERT in the mouse model

11:20- 11:40: **WP6 Lillan Rejkjaer, Dag Malm**: Natural History study in patients with alpha mannosidosis (Summary of the Discussion Panel from May 1st 2006)

11:40- 11:50: **WP7 Jean Claude Michalski**: Development of the oligosaccharide analyses, Oligosaccharide analysis of urine and serum samples

11:50- 12:00: **WP8 Oivind Nilssen:** Mutation database, genetic epidemiology of human alpha-mannosidosis

12:00-12:10: **WP9 Claes Andersson:** Enzyme production of human LAMAN

12:10-12:15: **WP10 Lillian Rejkaer:** Documentation and result management of the natural history study

12:15-12:20: **WP11 Paul Saftig:** Coordination and management

12:20-13:30: Lunch and photo session

13:30-14:15: Dag Malm: Alpha Mannosidosis from a clinical point of view

14:15-14:45: Final discussion panel; Organization of the meeting in December 2006; Upcoming issues

about 15:00 end of the meeting

Departure

Hotel: Hotel Maritim in Kiel (http://www.tagungshotel.com/hotel_1054814591.htm)

Costs: - you will have to cover your travel costs and the accomodation (approx. 75 €/night). This money has to be reimbursed from your local organisation using your share of the HUE-MAN money*.

Costs for meals and conference facilities will be covered by us as the local organizer.

* 45 days after the signature of our contract by the EU-officials the University of Kiel is supposed to receive the first pre-financing payment of the requested budget. The money will then be distributed to all partners according to the agreed financial plan. Costs for travel and personal from the start of the EU project (1.4.2006) are usually prefinanced by the local organisation. Please contact your local EU-officer for further advice.

(6) Getting to Kiel/from Kiel:

by plane:

If you fly into **Hamburg-Fuhlsbüttel**, take the **Autokraft Airport Bus** ("Kielius") to Kiel Central Bus Station (ZOB). The bus leaves in front of the airport once every hour (<http://www.kielius.de/fahrplan.htm>). When you leave the airport, turn left until you reach the bus stop. The bus company offers a special taxi service. If you tell the driver upfront, he'll order a taxi for you to pick you up at the ZOB.

by car:

Via Hamburg: Take the motorway A7 for Kiel. On the B76 from Lübeck and the A 7 from the south. Exit at "Kiel-Mitte". In Kiel, follow the signs to the "Ostseekai". Drive north along the "Düsternbrooker Weg/Hindenburgufer", along the shore of the Kieler Fjord, past the ministries and the marina. Turn left at the sign "Hotel M" and then right into the hotel (marked "M").

by train:

Kiel Hauptbahnhof with ICE and IC connections. Approx. 10 minutes by taxi to the hotel.