

EUROPEAN HAE REGISTER BOARD MEETING

October 15-18, 2006

Palazzo Feltrinelli

*Foresteria dell'Università degli Studi di Milano
25084 Gargnano (BS) – Via Castello, 3*



ORGANIZING COMMITTEE

The board of the European HAE Register which includes two representatives of patients' associations and the participants in the European concerted action NOVEL METHODS FOR PREDICTING PREVENTING AND TREATING ATTACKS IN PATIENTS WITH HEREDITARY ANGIOEDEMA - PREHAEAT -

MARCO CICARDI

KONRAD BORK

L. BOUILLET

ANETTE BYGUM

CHRISTOPH BUCHER

JANNE BJORKANDER

HENRIETTE FARKAS

HILARY LONGHURST

MARGARITA LÓPEZ-TRASCASA

ERIK WAAGE NIELSEN

MICHEL RAGUET

SARA SMITH

MARIEKE VAN HAM

SCIENTIFIC SECRETARIAT

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PROGRAM

October 15, 2006

16:00 Bus Milan-Gargnano

20:00 Dinner

October 16, 2006

9:00 - 10:30

The Register at present (Chairman K Bork)

9:00-9:15 Overview (M.Cicardi)

9:15-10:00 Pooled data from the Register (L.Zingale)

10:00-10:30 Discussion

10:30-11:00

Coffee break

11:00-13:00

Converting from European to International HAE Register? (Chairman T. Caballero)

11.00-11.15 Technical issues (J.Jakenfelds)

11.15-11.30 Specific national problems (B.Zuraw)

11.30-11.45 The role of patients' associations (A. Castaldo)

11.45-13.00 Discussion

13:00-15:00 Lunch

15:00-17:00

PREHAEAT projects an update (Chairman R. Perricone)

15:00-15.20 Hormonal problems in HAE (L.Bouillet)

15:20-15:40 Consensus on gynecological problems (T.Caballero/C.De Carolis)

15:40-16:00 H. Pylori and attacks (G. Füst)

16:00-16:30 Discussion

16:30-17:00 Coffee break

17:00-18:00

Register board members meeting

20:00 Dinner

October 17, 2006

8:30-10:00

PREHAEAT projects an update (Chairman H Farkas)

8:30-8:50 HAE mutation register present and future (M. Lopez-Trascasa, C. Drouet)

8:50-9:10 Risk-benefit of HAE treatments (K.Bork)

9:10-9:30 Standardization of C1-INH functional measurements (I.Wagenaar-Bos)

9:30-10:00 Discussion

10:00-10:30

Coffee break

10:30-13:00

New projects (Chairman H. Longhurst)

10:30-10:50 Home treatment program with pdC1-Inh (C. Sauer Mikkelsen)

10:50-11:10 Detection of mosaicism in HAE (R.Perricone)

11:10-11:30 HAE severity. Collection and evaluation of patients diaries (A. Menendez)

11:30-12:00 HAE severity scale and quality of life in HAE (T.Caballero–H.Longhurst)

12:00-12:20 The psychological profile of HAE patients (F. Di Bella)

12:20-13:00 Discussion

13:00-15:00 Lunch

15:00-17:00

The future of the Register (Chairman M. Cicardi)

Combining the interests of different parties: patients, scientists, physicians, pharmaindustries, health authorities

Proposal for new collaborative research projects

Fund rising and sponsoring scientific research in HAE

Discussion with all participants

17:00-17:30

Coffee break

20:00

Dinner

October 18, 2006

8:30 Bus Gargnano-Milan

SPONSORS:

DYAX/GENZYME

JERINI

PHARMING

ZLB BEHRING