

**H. Bastian**

IQWIG, Köln

**P. Flachenecker**

Rehaklinik Quellenhof, Bad Wildbad, Germany

**R. Crockett**

Kings College, London

**G. Fulcher**

MS Australia, Sydney

**W. Gaissmaier**

Harding Center for Risk literacy MPI, Berlin, Germany

**C. Goss**

Department of Medicine and Public Health, Section of Psychiatry and Clinical Psychology, University of Verona, Italy

**J. Kasper**

Institute of Medical Sociology, Hamburg, Germany

**S. Köpke**

Dep. Of Health Sciences, Hamburg

**V. Matthews**

MS Trust, GB

**I. Mühlhauser**

Dep. Of Health Sciences, Hamburg, Germany

**A. Solari**

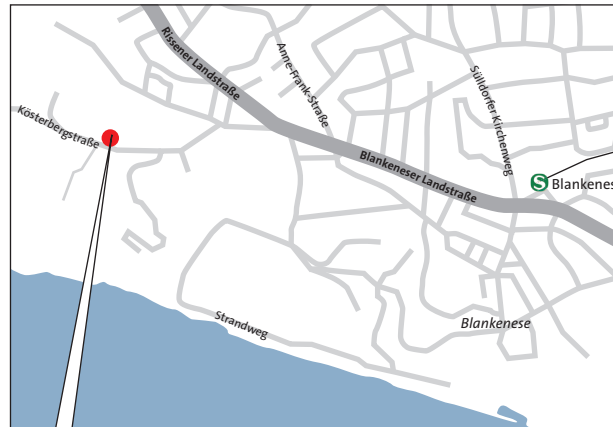
Istituto Besta, Milan, Italy

**A. Van Nunen**

National MS Center, Melsbroek, Belgium

Universitätsklinikum Hamburg-Eppendorf  
 Klinik und Poliklinik für Neurologie  
 Institut für Neuroimmunologie und  
 Klinische MS-Forschung (inims)  
 Prof. C. Heesen  
 Martinistrasse 52, 20246 Hamburg  
 Tel.: 0049-40-7410-54076  
 Fax: 0049-40-7410-56973  
 Internet: <http://www.inims.de>

Location of the meeting:



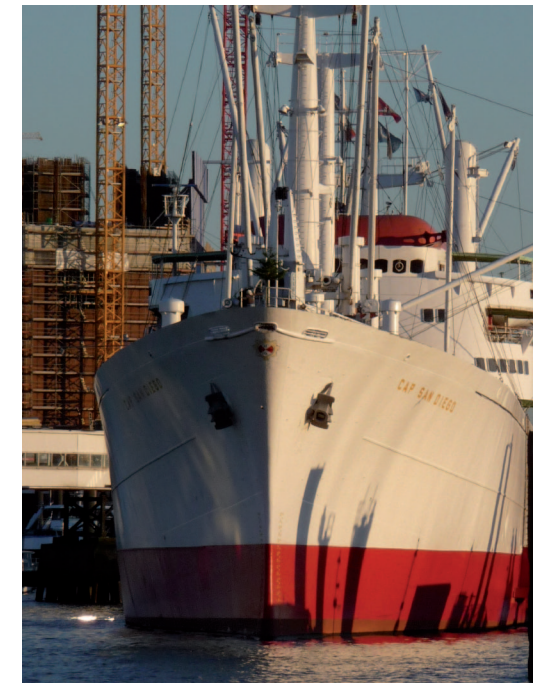
Elsa-Brändström-Haus, Kösterbergstr. 62, Hamburg



Universitätsklinikum  
Hamburg-Eppendorf

Institut für Neuroimmunologie und  
Klinische MS-Forschung (inims)

1<sup>st</sup> International Conference on  
Patient education in MS and  
RIMS special interest group  
meeting Patient information



Elsa-Brändström Haus  
Hamburg, 22. – 23. 1. 2010

Dear colleagues,

Evidence-based patient education and information as well as shared-decision making are increasingly recognized as tools to increase empowerment and self-management strategies in chronic diseases. Although concepts have been available for decades, and were transferred to several diseases, in MS this approach is in its infancy. Recently, a working group on patient education and shared-decision making has been established within the European Consortium "Rehabilitation in MS" (RIMS) with input from the RIMS-"Participation" group. This first international conference on patient education in MS addresses MS experts from any health profession from care and research work. It follows 2 aims:

1. To give an up-to-date overview about information, education and empowerment concepts in MS and
2. To bring together researchers and clinicians for project development

We are looking forward to fruitful discussions and hope to see you in January 2010!

C. Heesen  
A. Solari

PS: Please indicate your participation via the enclosed fax-form or email to be sent to:

Institute of Neuroimmunology and  
Clinical MS Research, MS Day Clinic

G. Rattey, secretary

Martinistr.52

20246 Hamburg

Fax: 0049-40-7410-56973

Email: multiplesklerose@uke.de

## Program

Friday, 22.1.

- 9:00-9:30 **Opening:** R. Martin, Chair inims  
M. Härter, Chair Dep. Psychol. UKE  
T. Henze, Executive Board RIMS
- Patient education and information 2010**
- 9:30-10:00 **What can we learn from education programmes in other chronic diseases?** (I. Mühlhauser)
- 10:00-10:30 **Patient education and empowerment – what support is needed?** (H. Bastian)
- 10:30-11:00 **From innumeracy to insight – how to communicate risks** (W. Gaissmaier)
- 11:00-11:30 Coffee break
- 11:30-12:00 **Assessment of patient-physician relationship** (C. Goss)
- 12:00-12:20 **How to measure and judge on health choices** (R. Crockett)
- Patient education focussing MS – overview**
- 12:20-12:40 **Patient education concepts within the MS trust – UK** (V. Matthews)
- 12:40-13:00 **Patient education programs in German MS Rehab centers – current status** (P. Flachenecker)
- 13:00-13:20 **Educational concepts in the National MS Center Melsbroek - Belgium** (A. Van Nunen)
- 13:20-14:00 Lunch

## RIMS SIG Patient Information Meeting-1

- Designing a trial: methodological issues**
- 14:00-14:30 **Theoretical frameworks** (J. Kasper)
- 14:30-15:00 **Defining the Intervention** (A. Solari)
- 15:00-15:30 **Study design and outcomes** (S. Köpke)
- 15:30-16:00 Coffee break
- 16:00 -17:00 **Patient education modules**  
(10min. short presentations)  
D. Pöhlau, Asbach; S. Köpke, Hamburg; M. Lang, Ulm;  
B. Saestedt, Hannover; J. Drulovic, Serbia; S. Arnade,  
Berlin; G. Pearce, Sydney; U. Zettl, Rostock
- 17:00-17:30 **Round table: Implementation into routine care – who does and who pays?**
- 19:00 Dinner

## Program

Saturday, 23.1.

- 7:00-9:00 Breakfast

## RIMS SIG Patient Information Meeting-2

- 9:00-10:00 **Trials on Patient information in MS – the past and presence**  
**The motherhood choice** (G. Fulcher)  
**EBSIMS, ISDIMS, PEPADIP and PEPIMS** (C. Heesen)  
**SIMS** (A. Giordano)
- 9:30-10:00 **New outcome measures**  
**Risk knowledge**  
**Health care involvement and empowerment**
- 10:00-10:30 Coffee break
- 10:30-11:30 **Outline AUTOMS**  
**European collaborative study on AUTOmy preferences, risk knowledge and decision making in RRMS**
- 11:30-12:30 **Project discussion**
- 12:30-13:00 **Perspectives:**  
**Collaborative work within RIMS and other organisations**
- 13:00 Lunch and farewell