

MEETING CALENDAR

For information about these and other professional conferences see
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11TH ANNUAL CONFERENCE OF RIMS BARCELONA 2006

The next annual meeting of RIMS will be held in collaboration with the world renowned Guttmann Centre in Barcelona, Spain from May 10th - 12th 2006. For more details see www.rims.be.

Joint Meeting of MSIF, European MS Platform and the UK MS Society

April 20th- 23rd, 2006
Manchester, England, UK
For information: info@mssociety.org.uk

20th Annual Conference of the Consortium of Multiple Sclerosis Centres (CMSC)

May 31st-June 4th 2006
Phoenix, Arizona, USA
For information: www.ms-care.org

The 12th Annual Conference of RIMS will be a joint conference with ECTRIMS

in 11th - 14th October 2007 in Prague, Czech Republic
RIMS focus will be on SIG Activities and workshops.

The 13th Annual Conference of RIMS will be hosted by
the National Multiple Sclerosis Centrum in Leuven, Belgium in May 2008.

RIMS Annual Membership Fees

Centre: 400 Euro
Individual: 130 Euro
Student: 25 Euro
Company: 750 Euro

Current members who have not yet paid their annual membership fee are kindly asked to do so:
International Bank Account Number:
(IBAN) DE98 7002 0270 0665 8212 18
SWIFT (BIC).HYVEDEMMXXX to:
RIMS - Rehabilitation in Multiple Sclerosis.
Bank: HypoVereinsbank AG München

Join RIMS as a member

RIMS is a fruitful network for all professionals working in the field of MS. Therefore we encourage all MS Centres, MS Societies and individual professionals to join the network. If you would like more information about RIMS or how to become a member you are welcome to contact Brita Loevendahl who is the Members Coordinator for the RIMS Executive Board. She can be reached at 0045 27 11 78 81 or mail: brita.loevendahl@mail.dk. She will endeavour to get back to you as quickly as possible.

SIG Funding Opportunity

RIMS Special Interest Groups (SIG) may apply to the Executive Board for a maximum of 2,500 Euro for the purpose of organising interim meetings. 1,000 Euro will be paid to the organisers before the meeting as soon as an official programme with the preliminary budget has been sent to the president. 1,500 Euro will be paid out after the meeting as soon as a short report of the meeting has been delivered for placing on the website and for publication in Network

The amount is not cumulative and expires if not utilised within the RIMS financial year.

For more information please contact: eija.luoto@ms-liitto.fi

NETWORK is published for RIMS at the Swiss Multiple Sclerosis Society, Zurich, Switzerland
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Network

RIMS
rehabilitation
in
multiple sclerosis
european
network of ms centres

RIMS Questionnaire 2005

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Following the last RIMS Meeting in Tallinn Estonia participants were asked to complete a short assessment questionnaire. We asked for input on several RIMS activities, namely on the annual meeting, the Special Interest Groups (SIG), the RIMS website and our newsletter, Network. We received 17 replies in all, 15 from MS centres and it was gratifying to see that most people were satisfied with the work of RIMS. As we expected and indeed hoped for there was some criticism and a number of good ideas. We will take these into account when planning further activities. We would like to thank all of those who participated in the questionnaire. If you have any further comments or suggestions please do not hesitate to contact us.

SIG Meetings

SIG Psychology and Neuropsychology / 2005

The group met twice during 2005. The first meeting was at the RIMS annual meeting in Tallinn, where the core group met on the May 22nd organised by Liina Sema. At that time, we decided to ask the Executive Board of the RIMS if they would be interested in publishing two booklets prepared by the group, Personality, Behaviour and MS and Emotional Reactions and MS. In Tallinn, the group continued work on the text of the booklet on emotional response.

The second meeting of our SIG was in Genoa, Italy from October 28th and 29th organised by Roberta Litta. By this time the group had received the decision of the Executive Board that RIMS is willing to publish the two booklets. They will be published in both paper and electronic versions on the website of RIMS. Naturally, our group was delighted with this decision.

In Genoa, the core group were shown around the Italian MS Society and Mario Alberto Battaglia presented a survey related to young people with MS. Other topics of the meeting were behavioural modifying drugs (case example - Wim Van de Vis), interferons and cognition (review - Liina Sema-Vahter) and the presentation of a book published by Bente Osterberg and her colleague "Being in the world with a chronic disease". Furthermore, during 2005 we have been up-dating the website information on our group. Further information about the activities of our group can be found at www.rims.be

Network is the official
newsletter of RIMS,
a non-profit organisation
of multiple sclerosis
centres in Europe,
bringing together all
health care professionals
involved in the care
of persons with MS.
<http://www.rims.be>

SIG Social Integration and Participation

The SIG Social Integration and Participation met on October 21st -22nd 2005 at the National Multiple Sclerosis Centrum Melsbroek, Belgium (B)

Participants from different Rehabilitation disciplines in Cyprus, Denmark, UK, the Netherlands and Belgium took part in this meeting with the title "Focus on Participation".

In an introduction An van Nunen led the audience through "Concepts of Autonomy and Participation", a philosophical and conceptual approach on what autonomy and participation could really mean to PwMS and in the concept of Rehabilitation.

Mieke Cardol, attached to the Institute for Health Services Research (NL) explained the development of the IPA (Impact on Participation and Autonomy) Questionnaire. This is a generic instrument, designed to give the Rehab team insight into the patients' self reported assessment of the impact of health conditions on their level of autonomy and participation. The IPA has been evaluated as an assessment tool for MS and other chronic diseases. It has been validated and translated into various languages and has been shown to be a good tool in compiling an inventory of needs as well as for long term outcome assessment.

The final speaker, Annelies De Boeck, illuminated her work in evaluating the use of the IPA in the context of the Melsbroek Rehabilitation Centre. She examined the reliability, validity and responsiveness of the IPA in 50 PwMS treated in the NMSC from April to June 2005.

With this theoretical background in mind, case presentations from the daily practice in the NMSC initiated the interactive part of the meeting leading to a variety of conclusions and take home messages.

- A progressive disease risks reducing autonomy and participation
- Rehabilitation activities should aim at improving autonomy and participation
- The Rehab team attempt to define the individual values PwMS in the field of participation, and to provide "choices" with which a PwMS can identify

- Environmental factors on different levels (micro- meso- macro) influence Rehab outcome
- There is an absolute need for a common vocabulary in discussing autonomy and participation
- There is an absolute need for a quality assessment tool for A&P. IPA might be a good choice. Further exploration of the value and suitability of existing assessment tools is needed

Finally, topics to be discussed in the SIG meeting during the next RIMS congress in May 2006 in Barcelona (E) were identified. The development of a common vocabulary in the field of autonomy and participation is basic to enable future discussions. In order to increase the attractiveness and accessibility of this topic for all interested participants, we will focus on "goal setting" in the field of participation. Theoretical insights in Rehab goal setting will form the basis of the discussion, together with case presentations.

SIG Mobility

Around 40 people attended the SIG Mobility Workshop meeting held at the Finnish MS Rehabilitation centre situated in breathtakingly beautiful countryside in Masku from March 9th to March 11th 2006. The meeting combined excellent lectures with a tour of the centre and included a demonstration of how outdoor mobility can be encouraged despite snow and bitterly cold temperatures using snow bikes and other equipment

The meeting concentrated on defining what "improvement" means for the PwMS in the context of MS Rehabilitation and highlighted the problems the differing expectations of the team and the client can cause. The main Guest speaker, Professor Mark Wiles from Cardiff, fulfilled a long held wish to visit Finland with a fascinating and thought provoking lecture on the difficulty of defining outcome measures in MS rehabilitation.

The combination of intellectual stimulation and Finnish hospitality made for a memorable meeting and provided much food for further thought.

SIG Occupation

A well attended meeting of the SIG Occupation took place on March 17th - 18th 2006 at the Nati-

onal Multiple Sclerosis Centrum, in Melsbroek (B). Theme was the advisory role of the occupational therapist in the housing of PwMS. The participants worked further on producing guidelines for good practice.

- Home assessment needs to be performed within the home environment
- Home visits are not possible in most OT settings, but the advisory process of housing is similar in the countries of the core members of the SIG (=experts)
- OTs in rehabilitation centres perform the assessment of the functional possibilities of the client in combination with the home (physical and social) environment
- If home assessment is not possible, OT in rehabilitation needs to refer the client to community OT
- OTs are responsible for the advice, guidance and follow up of the housing process
- If home assessment is not possible, the advice can be based on pictures, photographs and schemes of the house situation
- OTs are responsible for training on the use of assistive devices
- OT in rehabilitation centres can provide information concerning the client's situation to the community OT
- Housing includes assistive devices in and around the home, architectural structural modifications, wheelchair use in and around the home and the use of environmental control systems
- Process of advice will be of higher quality if it is performed by specialized OTs in various areas (housing, wheelchairs, environmental control)
- The assistive devices have to be tried out before purchasing
- The try-out can be performed in the rehab. centre, but preferably in the home situation. This is especially important for people with cognitive problems
- Throughout the advisory process, the OT has to take into account the level of coping of the client
- The OT has to consider the degree of acceptance of the disease and the limitations a client experiences
- The OT has to use psychological strategies to introduce assistive devices in the daily life of clients and the family

- Values of patients are important – client centred practice – holistic view"
- OT is the communicator and translator of the needs between company/architect and patient/client
- The advice needs to be followed up
- The follow up is preferably performed in the home situation
- If not possible in the home situation, the follow up can be performed by inventories, phone calls, emails, pictures of the performed home modifications
- There is a lack of evidence concerning the advisory role of OT in persons with multiple sclerosis
- There is a lack of the use of appropriate instruments to assess home environment
- The usefulness of Housing Enabler in persons with MS needs to be studied

SPECIAL INTEREST GROUPS

All SIGs are planning to meet in the course of the RIMS conference in Barcelona in May 2006. For more information on time and place please contact the group chairman or our website www.rims.be.

Mobility

Dr. C. Vaney (CH), Chairman
Dr. H. Albrecht (D), Co-chairman

Bladder, Bowel and Sexual Disorders

Prof. D. De Ridder (B), Chairman
Co chair to be elected in May 2006 in Barcelona

Psychology and Neuropsychology

Dr. P. Hämäläinen (FL), Chairman
Dr. A. Jonsson (DK), Co. chairman

Communication and Swallowing

Dr. G. Ganty (B) has resigned as Chairman. The new chair and co chair will be appointed in May 2006 in Barcelona

Social Integration and Participation

R. Verdoodt (B), Chairman
An van Nunen (B), Co-chairman

Occupation

M. Duportail (B), Chairman
D.Kos (B), Co-chairman

For more information please contact the SIG group coordinator: jlutz@multiplesklerose.ch