

President's message (May 2009)

Dear Members

It is my pleasure to inform that we got altogether 247 registered participants for the 14th Annual Conference of RIMS in the sunny and warm city of Genoa 23-25, April 2009. So, although it seemed at some point that we could get less participants than we had hoped for, the result at the end was really good and regarding the time of global economic difficulties, we have all the reasons to be satisfied.

RIMS General Assembly was organised on Friday, April 24th, 2009. Because we did not meet the quorum, all members will receive a member letter with the minutes of General Assembly and they are able to give their approval or objections regarding the decisions done at the General Assembly.

All SIGs organised their scientific workshops. The number of participants in these parallel organised sessions was high, which naturally pleases us very much. Also, an idea of establishing a new SIG on the topic "Patient information" was presented and on this new topic, there also was one workshop. We shall here news about this in the very near future. You can find more information about SIGs on our [www](#) pages.

The traditional RIMS Awards for Best Poster and Best Oral Presentation with 500 Euros were nominated.



The Best RIMS Poster Award: F. Fink (G). "Efficacy of an executive function intervention program: a placebo-controlled trial. (photo)

The Best RIMS Oral Presentation Award: A. Solari (I). "Effectiveness of an information aid for newly diagnosed PwMS"

A special CMSC award (invitation to CMSC conference) was given to J. Paltamaa (F) for her oral presentation: "Responsive of physical functioning measures in PwMS who are ambulatory"

Once more I take the opportunity to thank our local organiser, Dr Claudio Solaro and Italian MS Society as well as Genoa Neurological Department for their fruitful collaboration.

Building up RIMS conference with such an expertise was a pleasure and I am sure as the participants found the program interesting and stimulating.

Eija Luoto, RIMS President

Reports of the SIG Meetings at the 14th Annual RIMS Conference in Genoa, 24th April 2009

SIG Mobility

The SIG Mobility meeting was initially overwhelming, with more people attending (approximately 50) than there were chairs present in the room. As a consequence, the meeting may have been less interacting than anticipated

The activities and current projects of the SIG Mobility group were first presented in an overview by Peter Feys. Afterwards, more details were provided:

1. Paul Van Asch (B) provided feedback on the workshop “MS & Sport” that had been organised in Hasselt prior to the Annual Conference with 27 attendees. A general framework of physical exercises as well as cases had been presented. It is clear that interest in this topic is rising in multiple European countries.
2. Peter Feys (B) introduced the multi-centre study on walking that was initiated in previous in-between workshops in Haslev (2008) and Hasselt (2009). Before the conference, 18 centres have agreed to participate and were in the process of asking permission of their local ethical committees as well as translating the MFIS and MSWS-12 into their language following a validation procedure. Domien Gijbels (B) presented in detail the outlines of the measurements included in the protocol and announced some minor changes that were agreed on in the workgroup (see also A. Romberg, V. De Groot, B. Gebara and C. Vaney). All centres will now receive the instruction manual and database, so that the study can be executed in the coming months.
3. Kamila Rasova (CR) presented the initiatives for studying the content of physical rehabilitation in Europe (see also workgroup with Thomas Henze, G). This subject will also serve as main topic for the next SIG in-between meeting 2010 that will take place in Prague, May 14-16th (tentative dates).

For more information about the SIG Mobility workgroup, please consult www.rims.be.

Chair : Peter Feys

Co-Chair: Paul Van Asch

SIG Psychology and Neuropsychology

Approximately 20 psychologists, neuropsychologists and other professionals participated in the session dedicated to the Special Interest Group on Psychology and Neuropsychology. After welcoming the participants, **Liina Vahter** presented an overview of the studies on the efficacy of neuropsychological rehabilitation in multiple sclerosis. In summary, there are only few studies in this field, the study populations have been relatively small and not all of these are randomized, controlled trials. Moreover, the rehabilitation methods as well as the outcome measures have varied considerably, making it difficult to draw conclusions on the efficacy of cognitive rehabilitation in MS. However,

retraining of specific cognitive functions, such as learning and attention may have positive effects on cognitive performance. Moreover, multimodal rehabilitation programs including information, counseling, compensatory strategies and neuropsychotherapy may enhance mood state and coping with cognitive impairments. More research is required in the field to be able to conclude what kind of neuropsychological rehabilitation should be offered.

Michael Nissen then presented the process of planning a study to evaluate the psychological interventions offered for newly diagnosed patients in the Danish MS Society. The study consists of both qualitative and quantitative data collection and analyses and the design is based on the collaboration of clinicians and researchers. After the presentation, the study design was discussed. The participants also discussed the difficulty in evaluating and demonstrating the effects of psychological interventions on the patients. Combining qualitative and quantitative data was considered an appropriate way to evaluate the effects of psychological interventions. The use of Goal Attainment Scale (GAS) as a possible method to set goals and evaluate the effects of interventions was also discussed.

Päivi Hämäläinen informed the group about the past and ongoing activities of the SIG on psychology and neuropsychology. She told them about the preparation of cognitive manual, a project the group is working with. The next in-between meeting is planned to be held in the Netherlands, organized by Wim van de Vis, from the 30th and 31st of October, 2009. The meeting is dedicated to the preparation of the cognitive manual. Those participants interested in the activities of the SIG were asked to contact the e-mail key person or either of the chairs of the group.

Päivi Hämäläinen

SIG Occupation

Theme: ADL – a functional approach in the Occupational Therapy

Overview of presentations

- Usefulness and relevance of the official ICF Core Sets for MS in assessing and treating ADL performance (presentation of Andrea Weise, OT (Valens, CH))
Jelka Jansa, OT (Ljubljana, SI)
- Results of survey 'Role of OT in personal ADL of people with MS'
Daphne Kos, *Chair SIG Occupation*, OT (Artesis University College Antwerp, B)
- Pressure problems and Occupational Therapy Intervention
Tarja Huilla, OT (Masku, FI)
- Mindmap about advisory role of OT: state of the art + discussion
Stephan Ilsbrouckx, *Co-chair SIG Occupation*, MD (Melsbroek, B)

Participants

Name	Institution	Profession	Country
Kos Daphne (Chair)	Artesis University College Antwerp	OT	Belgium
Ilsbrouckx Stephan (Co-chair)	National MS Centre Melsbroek	MD	Belgium
Jakobson Jytte (Webmaster)	Sclerosecenter Haslev	OT	Denmark
Huilla Tarja	Masku Neurological Rehabilitation Centre	OT	Finland
Vanderbeeten Pascal	National MS Centre – Melsbroek	OT	Belgium
Jansa Jelka	University Medical Center Ljubljana	OT	Slovenia
Zajc Dejana	Institute for rehabilitation Ljubljana	OT	Slovenia
Kallmeyer Lene	Sclerosecenter Ry	OT	Denmark
van Gemert Leonie	Blixembosch	OT	Netherlands
Gotsens Monica	Hospital de Dia_Fem Lleida	OT	Spain
Meneanetti Luca Alesio	AISM Rehab Centre Vicenza	OT	Italy
Gioia Marcassa	IRCCS San Camillo	OT	Italy
Verza Riccardo	AISM Rehab Centre Padova	OT	Italy
Borsi Enrica	Direziona Medica Ospedamera	Nurse	Italy
Galetto Agnese		OT	Italy
Lamers Ilse	Provinciale Hogeschool Limburg Hasselt	PT	Belgium
Nicolosi Laura	AUSL Parma	MD	Italy
Raspa Raffaello	Villa Adria San Stefano (rehab centre)		Italy
Pantamaa Jaana	University of Syvaskyla	PT	Finland

Recommendations about advisory role of OT

Stephan Ilsbrouckx has presented the overview created by the OT colleagues in Melsbroek about the process of advice of assistive devices and housing. We discussed the overview and reached consensus about a European version. Stephan will modify the document based on the comments/additions/suggestions made during this meeting and send it to all members for a final check. After approval of all core members of the SIG, the document will be published on the RIMS website. The aim of this overview is to inform OT's (including students) about all aspects of advising assistive devices and housing in people with MS.

Next meeting

The next in-between meeting will take place in Finland on November 20-21 2009. It will be a triple joint meeting with SIG Integration & Participation and SIG Communication & Swallowing. Theme of this meeting will be "Participation of persons with MS by empowering communication". The aim is not only to focus on communication disorders and assistive devices, but also to address the communication between patient and care givers.

Due to time limit, we did not have the possibility to prepare the next meeting. Everyone who wants to present their experiences/research concerning the theme of the meeting, is invited to send it to Daphne Kos (daphne.kos@artesis.be). Daphne Kos will contact the chairs of the other SIG's to prepare the meeting.

Daphne Kos

SIG Communication and Swallowing

Introduction

The chair of this SIG is Rosa Terré, who could not attend the RIMS in Genoa this year. Co-chair are until now Antonella Nota and Marta Renom. Web responsible is Antonella Nota. In the last assembly it was suggested to keep only one co-chair. It is still to decide how it will be reorganized.

Recent activities (2008-2009)

Developed Topics:

1. Booklet on Communication in MS: *Talking about communication in MS*

Information for patients, caregivers and professionals

Marta Renom (Spain)
Antonella Nota (Belgium)
Montse Martinell (Spain)
Eeva Gustafsson (Finland)
Eeva-Liisa Warinowski (Finland)
Rosa Terré (Spain)

2. Review on scales to assess communication in daily life

There are no specific scales for MS. Tools for aphasia or geriatric population were reviewed. Usefulness of the ICF Core Set for MS for this aim was introduced.

Marta Renom (Spain)
Montse Martinell (Spain)

3. Protocol of treatment of swallowing disorders

Techniques and exercises for the rehabilitation treatment in MS were presented
Rosa Terré (Spain)

4. Translation into spanish of the booklet: *Talking about communication in MS*

Ingrid Galán (Spain)
Marta Renom (Spain)

5. Validation of the ICF Core Set for MS among SLT

Pilot Phase

Coordination: Marta Renom
Participation: Rosa Terré, Antonella Nota, Montserrat Martinell, Mireia Aldevert, Sara Logos,
Marta Renom

Delphi study: Validation of the ICF Core Set for MS

ICF Research Branch, WHO FIC CC - Ludwig-Maximilian University, Germany
Coordination: Michaela Coenen, Andrea Wiedenman, Marta Renom

Participation: Rosa Terrm, Antonella Nota, Montserrat Martinell, Mireia Aldevert, Sara Logos, among others

6. Alternative and Augmentative communication (AAC)

Antonella Nota

7. Validation of the ICF Core Set for MS among SLT

Marta Renom

Future activities

Joint meeting with the SIGs Integration and Participation and Occupation about Alternative and Augmentative communication (AAC). Masku, Nov 2009

Finishing the validation of the ICF Core Set for MS among SLT

Marta Renom

SIG Participation: Patient information and shared-decision making

At the **RIMS CONFERENCE, 23-25 APRIL 2009** an initiative for a possible new SIG was started in the emerging field of care-oriented research. Included in this discussion were the chairs of the SIG participation. It was decided to have a close exchange and possibly visits to interim meetings of the other group until the RIMS conference in 2010.

Why is information relevant?

Knowing the risks and benefits of interventions, value of diagnostic tests and facts about prognosis gives the patient the opportunity to match these factors with his/her own values and increases the ability of shared decision making with physicians. Therefore, evidence-based patient information (EBPI) that, similarly to a drug treatment, is rigorously developed, regularly updated and tested for effectiveness should be a major area of clinical research.

Why focussing on participation?

Integration and participation is the major goal of all medical and rehabilitative efforts referring to the International Classification of Functioning, Disability and Health (ICF, WHO 2001). By addressing participation we emphasize that it is the ultimate target of health care, and improvement of impairment or surrogate markers are noteworthy provided that they are related to participation changes. Furthermore, most studies on chronically ill patient management have shown that not only participation in family, job and society but the active engagement of patients in their care is of major relevance to improve outcomes. Therefore, addressing participation means empowering patients to gain mastery over their lives (J. Rappaport 1982).

Why is education relevant?

Health might be more adequately conceptualized as the ability to adapt rather than complete physical, psychological and social well-being. Measures which increase adaptive behaviour are training and education. Therefore, we believe that education is a major topic in rehabilitation. Other behavioural-educational interventions might focus on psychological factors such as disease coping, training groups or mindfulness-based meditation, neuropsychological dimensions as meta-cognitive training or physical dimensions such as exercise training. These are areas of stimulating overlap with other SIGs. Nevertheless they are complex interventions content and effectiveness of which needs to be fully documented.

Education may lead to deeper processing of self-concept, more elaborated perceptions and weighting of symptoms and goals as well as judgement on the health care process. Furthermore, any health care intervention should improve quality of life. Therefore, patient-reported outcome measures are at the core of this approach.

Overall goals

- ✓ To establish EBPI as a first step in MS rehabilitation at the beginning of the disease
- ✓ To make EBPI devise and provision a central quality criterion in the management of people with MS (PwMS)
- ✓ To show that EBPI enhances active role realisations and possibly affects health behaviours and health status

Objectives

To review educational concepts, patient information and decision support tools of MS rehab centres in Europe

To assess unmet PwMS needs in the area of patient information in Europe by starting international collaborations

To systematically review, develop and test effectiveness of new MS information tools. Of primary relevance are diagnosis, prognosis, relapse management and immune therapy. Our final aim is that these tools are integrated in a comprehensive multi-cultural modular system of standardised and up-to-date educational instruments.

To assess, develop and validate in different cultures MS risk knowledge tools. Again, of primary relevance are diagnosis, prognosis, relapse management and immune therapy.

To review, develop and validate in different cultures MS specific patient-reported outcome measures to assess involvement in health care and empowerment.

To initiate European comparative studies on MS risk knowledge and autonomy preferences and their matching to realized roles in medical decision making.

To initiate collaborative randomised controlled trials (RCTs) with other SIGs on educational interventions in MS.

To study factors relevant in MS decision making, especially in cooperation with the SIG neuropsychology.

To offer a methodological platform for other SIGs to study complex interventions (e.g., devise and validation, design, conduct and analysis of RCTs).

First steps

Systematic review on PwMS information tools and their effectiveness, and definition of urgently needed areas. A Cochrane Review has already been applied for.

Consensus approach on relevant MS risk knowledge in different disease stages.

Translation and exchange of existing instruments has been started, a review among health professionals and PwMS in different European centres is to be initiated.

Assessment of role preferences of PwMS in different cultural settings tailored to disease stage and decisions to be taken. A revision of the Control Preference Scale (CPS; Degner 1997) is under development. Administration of different versions of the CPS in collaborating centres is planned.

Translation and adaptation of existing EBPI tools into different languages/cultures. This could be soon initiated for the Evidence-Based Self-management In Multiple Sclerosis (EBSIMS), a structured educational program on relapse management in Multiple Sclerosis.

Development of new EBPI tools and study of effects of different formats (and combinations): booklet, face-to-face interview, group session, and internet-based. A follow-up meeting should discuss the area of utmost importance and initiate a systematic review of the evidence.

Next steps

An interim meeting in addition to the SIG meeting Participation in Jan 22-23th 2010 in Hamburg is planned. We aim at involving university and hospital MS centres from Europe as well as the MS Societies for this meeting.

Topics for the interim meeting:

- Systematic review on patient information tools;
- Risk knowledge consensus;
- Presentation of an EBPI example and discussion of adaptation and implementation in other countries;
- New tools - what is needed?
- Update on ongoing projects.

At a SIG meeting in Goteborg we aim to present the following:

- Preliminary results of the systematic review on patient information tools;
- Consensus strategy on risk knowledge questionnaire

We invite you to join us.

Please feel free to contact the below mentioned chairs:

C. Heesen, MD heesen@uke.de

A. Solari, MD solari@istituto-besta.it

SIG: Bowel, Bladder and Sexual Disorders

(SUBDIMS)

Approximately 35 persons from 10 different countries participated in the SUBDIMS workshop.

Agenda:

1. Presentation of collaborator multicentre study
2. Bowel management approach: centres experience
3. Presentation of a bowel management questionnaire
4. Discussion on topics and location of the next meetings

Report:

1. Presentation of collaborator multicentre study, by Laura Lopes, MD

We presented the draft protocol of the prospective, randomized controlled, multicentre study we want to set up in six European MS Centres called: 'A randomized controlled trial of transanal irrigation versus conservative bowel management in MS patients'.

In this study about 100 MS patients with neurogenic bowel dysfunction will be enrolled. They will be randomly assigned to a study group: half of them will be treated with transanal irrigation (Peristeen® from Coloplast®), 3 times a week, and the other half will be treated with conservative bowel management.

The trial period will be 10 weeks.

The training will be done by expert nurses.

2. Bowel management approach: centres experiences, by Piet Eelen, RN

A presentation of conservative bowel management strategies in Melsbroek, Belgium.

The presentation focused on:

- Nursing assessment
- A bowel management algorithm
- Bowel assessment by pellet investigation to determine the difference between a 'transit problem' and an 'evacuation problem'
- Presentation of a prospective study in 53 PwMS: 'The division of pellets in the colon in accordance to the EDSS'
- General tips and tricks for a good education of the colon

3. Presentation of a bowel management questionnaire, by Roberta Motta, RN

The aim of the questionnaire is to investigate the different approaches used to manage bowel disorders in MS in European MS Centres in order to develop guidelines for optimal bowel management.

A draft of the questionnaire was presented and discussed.

In the following weeks the definitive questionnaire will be send by mail to as many European MS Centres as possible.

Please can we ask you to participate as much as possible!

4. Discussion about the topics and the location of the next in-between meeting

1. **June/July 2009:** Coloplast, Denmark
 - present and discuss the protocol of the multicentre study
 - discuss the practical arrangements with the participating centres

2. **November/December 2009:** in-between meeting in Melsbroek, Belgium
 - finalise the study protocol and 'study kick-off'
 - review the definitive questionnaire
 - determine how to do a literature review on articles of bowel management

3. **13 – 15 October 2010:** RIMS conference Göteborg, Sweden
 - the first results of the questionnaire will be presented
 - the preliminary results of the study will be presented

Laura Lopes
Chair SUBDIMS

Piet Eelen
Co-chair SUBDIMS

Roberta Motta
Webmaster SUBDIMS