

SIG Mobility

More than 30 participants attended the SIG Mobility session during this year's annual meeting in Barcelona. After a case presentation by our host showing the pertinent use of aids, speakers from different centres presented novel treatment methods to enhance mobility and function.

Peter Feys from Belgium showed how ice in various situations is a valuable tool. Angela Davies Smith, physiotherapist from United Bristol Healthcare Trust, UK spoke on her study on the use of functional electrical stimulation to improve gait. Mrs. Annaleena Viramo-

Koskela from Masku reviewed the use of vibration therapy and last but not least our colleague from the Guttman centre in Barcelona, Josep Medina, introduced us to different training methods using treadmill walking.

We are planning to hold the next SIG mobility meeting in Genoa, Italy on 17th February 2007. If you are interested please join us. Contact person is Claude Vaney: Vaney.Claude@bernerklinik.ch

Claude Vaney, Chair

MEETING CALENDAR

For information about these and other professional conferences see www.docguide.com

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 will be hosted by the Rehabilitation Centre Melsbroek in Belgium in May 2008.

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

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 want more information about RIMS or how to become a member you are welcome to contact Brita Loevendahl who is the "New 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. The amount is not cumulative and expires if not utilised within the RIMS financial year.

For more information visit our website: www.rims.be

NETWORK is published for RIMS at the Swiss Multiple Sclerosis Society, Zurich, Switzerland
July 2006

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Network



Reports from the 11th RIMS Annual Conference in Barcelona May 10-12, 2006

New ideas – new people!

313 professionals participated in the joint meeting of Institute Guttman's XVIII Technical Workshop and the 11th RIMS Annual Conference in Barcelona May 10-12, 2006.

The 11th RIMS Annual Conference was a great success with a record number of participants and 49 scientific poster presentations. The traditional awards for Best Poster Presentation and the Best Platform Presentation were nominated. As two posters received equal ratings the Executive Board decided to award the prize to two posters: "The Role of Nutrition in MS Fatigue. A Survey of 118 Three-Day Food Records" by Hanna-Maria Viholainen and Päivi Hämäläinen (Finland) and "Neurogenic Dysphagia in MS. Nursing Role" by M. Teresa Marques Ten, Laura Terrafeta Turigas, Angeles Barahona Arroyo (Spain). The award for the Best Platform Presentation went to "Physical and Cognitive performance can be predicted in Recently Diagnosed MS" by Dr Vincent de Groot (Netherlands).

During the conference the SIG Chairs and Executive Board held a meeting. All SIGs chairs gave a short report of their in between meetings. It became clear during the discussion that a more regular contact between Executive Board and SIG Chairs and Co Chairs was desired and that information on Executive Board decisions will be regularly communicated. The Chair of SIG on Communication and Swallowing, Guy Ganty had previously informed the Executive Board that he was no longer able to be active in this SIG. In addition the long time Chair of SIG on Occupation, Marijke Duportail also decided to resign her post. The new Chairs for both these groups were nominated, the Chair for Communication and Swallowing Disorders will be Dr Rosa Terre (E) and Antonella Nota (B) and Marta Renom (E), and both speech therapists will function as Co Chairs. Daphne Kos (B), speech therapist was elected as the new Chair of SIG on Occupation started with Dr Stephan Ilsbrouckx (B) as Co Chair.

Many thanks to Guy and Marijke for their hard work throughout the years.

By the end of 2005 several centres had failed to pay their annual fees, neither had they reported their wish to resign. As a result in spring and early summer 2006 the Executive Board has been trying to contact these centres with an inquiry into their situation. On the other hand, an especial pleasure for me, several new members joined our organisation during the Annual Conference. I therefore have no doubt that the following years will show a growth in members, increasing activities in SIGs and a vivid multi-professional involvement in all RIMS activities.

I wish to thank all members for this past year. Your contribution has been of crucial importance for us all.

The next RIMS Annual Conference will be a joint ECTRIMS/RIMS conference in Prague, 10-13, October 2007. Hoping to see you there!

Eija Luoto
RIMS President

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 Integration and Participation

This meeting of the SIG "Integration & Participation" took place within the framework of the annual RIMS conference 2006. The workshop was open to all participants with an interest in goal setting in this particular area. We chose to continue the discussion begun at our last meeting. We sought the golden mean by presenting, as an introduction to this meeting, a summary of the conclusions of our last meeting. One of our most crucial conclusions pointed out that there is an absolute need for a common language on the field of participation. The problem of setting clear and achievable rehabilitation goals in this domain is very familiar to all field workers.

An attempt to deal with this problem is the use of the RAP in multidisciplinary team work with PwMS. The background and principles of the RAP (Rehabilitation Activity Profile) were explained. This consists of a team communication instrument to describe problems, disabilities and handicaps in the different fields of human functioning, and acts as a starting point to formulate concrete rehabilitation goals. This tool, originally conceptualised by the team of Professor Lankhorst (V.U. Amsterdam, The Netherlands), was introduced in the National MS Centrum Melsbroek in 1998. The purpose was to promote team communication and to design more efficient team meetings in which transparency is created with concrete goals and action plans for the rehabilitation process.

The RAP consists of 3 different steps. Firstly, team members literally write down the problem experienced by the PwMS as it is described in their own words. In step 2, the clinical observations of the therapist are added. Finally, concrete goals in the domains of motor skills, personal care, communication, occupation and relationships are set. This was illustrated in the presentation of several recognizable examples. In the RAP-model, levels of autonomy are always specified in the goals, using an active and simple language and always from the PwMS's point of view. The RAP demands that the time for the achievement is specified and that the goals are measurable.

Following this the participants engaged in exercises in goal setting especially on the levels of autonomy in the domains of occupation and relations. Concrete ideas on possible goals were discussed from the point of view of 'What is a realistic but sufficiently ambitious goal', 'What can we do as a team to provide choices for the PwMS', 'How to communicate goals with patients and their relatives?', 'How can you measure whether goals are achieved, especially on the non-physical participa-

tion level?', 'Who should assess this achievement? The team, the PwMS only, team + PwMS?'

The success of these exercises lead us to decide that we need to plan plenty of time at the next inbetween meeting to discuss the many aspects, including philosophical ethical issues evolving from case studies. Everyone involved in the SIG has a broad, personal experience in working with PwMS and their families. The need to find a common language is very recognizable and examples of specific situations are multiple, regardless of the professional or national background. The reality of peoples' concrete stories brings up so much interesting material to help us look at their authentic way of being and dealing with MS as a challenge to go on 'being someone'.

Although the SIG is still in a growing stage and the organization of an in-between meeting unclear, there is a possibility that the next in-between meeting will be in the NMSC in Melsbroek (B), perhaps in spring 2007 between the next two RIMS annual meetings.

Rina Verdoodt, Chair

SIG Occupation

The theme of the meeting during the RIMS congress in Barcelona was "The advisory role of the OT in the housing of persons with MS".

Marijke Duportail (OT, B) presented a summary report of our in-between meeting in Melsbroek in March this year. Mónica Ramos (E) explained the methodology of the advisory process. Tarja Huilla (F) presented the advisory process during the rehabilitation course. Daphne Kos (B) described the (lack of) evidence based practice concerning the advisory role of occupational therapists. Finally, Marijke Duportail (B) presented the draft version of the recommendations on the advisory role of the occupational therapist. We will further discuss these recommendations by email and try to have them published.

Kirsten Søndermark (D) invited us to Haslev (DK) for our next in-between meeting, which will take place in **May, 11-12 2007**. Theme of that meeting will be „Work and MS: the role of OT". If you are involved or interested in the assessment, advice, counselling or training of job performance of persons with MS, please join us! More practical information will follow later this year.

Marijke Duportail has resigned her position as chair and will be replaced by Daphne Kos (OT, B). Stephan Ilsbrouckx (MD, B) will be co-chair. Tarja Huilla (OT, F) is to become actively involved in the organisation of the SIG.

On behalf of all core members, I would like to thank Marijke for her hard work in starting up and organising the Occupation SIG, which has made great progress in the past 15 years.

Daphne Kos, Chair
Stephan Ilsbrouckx, Co-chair

SIG Communication and Swallowing

As Guy Ganty, SLP in Melsbroek MS Centre has resigned as chair of Special Interest Group on Communication and Swallowing, Antonella Nota, SLP in Melsbroek MS Centre, accepted the responsibility of SIG organisation for RIMS meeting in Barcelona.

Dr Rosa Terre discussed the swallowing disorders to be found in PwMS. She showed videofluoroscopy images to illustrate her presentation. The dietician Hanna-Maria Viholainen reported her role in nutritional problems with PwMS and how she manages to adapt recipes to maintain appetizing appearance. The speech and language pathologist Marta Renom reported the results of a questionnaire sent to all SLP from European centres on how they work. She received only three answers. These answers reveal that a common protocol of assessment and a common approach must be established to enable a better exchange of data and plan potential studies.

Finally, Antonella Nota summarized the Communication and Swallowing group evolution within RIMS and opened the discussion on future activities. The main goals are:

1) Increase the number of active participants in RIMS's SIG on Communication & Swallowing. For example, the ECTRIMS/RIMS conference from 10th-13th October 2007 and the 12th RIMS annual Conference may be a good opportunity and window to become better known to a larger professional group. CPLOL (European Speech & Language Pathologists Association) will hold a European Conference from 15th-17th September 2006. We intend contacting this group to reach a larger number of SLP and may propose a topic on linguistic disorders in neurodegenerative diseases such as MS for the next conference in 2009.

2) Investigate the interest for a multi-centre study on various aspects of communication

3) Develop a common protocol of assessment

4) Develop effectiveness measurements

5) To develop a booklet on different topics such as:
- Communication disorders in MS
- Cook booklet (adaptation of food from European recipes).

6) Organize joint meetings with other SIG groups on special topics.

Antonella Nota, Organiser

SIG Psychology and Neuropsychology

The session consisted of three presentations. Professor Helmut Hildebrandt from Germany talked on the effects of MS on cognition and cognitive treatment. Julia Segal from UK talked about her experience of the effects of cognitive impairments on relationships. Psychologist Liina Sema-Vahter from Estonia presented data on the Estonian survey of young people with MS.

The presentations were interesting and covered a broad spectrum of topics. During the meeting the chair of the SIG, Päivi Hämäläinen from Finland, presented the newly published booklets: Personality, Behaviour and Multiple Sclerosis and Emotional Reactions and MS. The booklets can be found at www.rims.be and they may be translated into other languages. The group was awarded a further 500€ funding as a sign of recognition for their hard work in preparing these booklets.

Plans for further meetings were discussed and it was agreed that the group should prepare the program two months before the meeting. Initial ideas for the program were:

- Each participant presents the contents of his/her work in the form of a case study to illustrate their way of working.
- Discussion about how we use booklets written by group members.
- Other possible topics were:
 - Cognitive fatigue
 - Complicated, challenging cases – how to cope?
 - Medications and cognition
 - Stress, copying and quality of life
 - Computerized training, awareness, frontal functions

Päivi Hämäläinen, Chair

SIG for Bladder, Bowel and Sexual Disorders

also met during the RIMS conference unfortunately at the time of going to press no report on their meeting is available.