

Neuropsychology SIG In-Between Meeting: April 9th – 10th 2010 – Tallinn

Programme

Friday 9th April

Venue: MS Centre, West-Tallinn Central Hospital, Paldiski rd 68, Tallinn, Estonia

12.30 meeting in the hotel lobby for transportation to the West-Tallinn Central Hospital

13.00 welcome coffee and some snacks in West-Tallinn Central Hospital,

13.15 – 13.30 opening and short tour around MS centre.

13.30 – 14.00 welcome and overview of the last year in neuropsychological rehabilitation of MS – review of the articles. Paivi Hamalainen, Masku Neurological Rehabilitation Centre, Finland

14.30 – 15.00 overview of the last year in neuropsychology of MS – review of the articles. Liina Vahter, Estonian MS Centre, West-Tallinn Central Hospital, Estonia

15.00 – 15.30 overview of the last year in psychology of MS– review of the articles.

15.30 – 16.00 coffee 16.00 – 16.30 case of the young boy with aggressive MS. Liina Vahter

16.30 – 17.00 “Cognitive problems and what to do about it” - course in Denmark for PwMS and their relatives. Bente Osterberg, Danish MS Society

17.00 – 17.30 A New Guide to Cognition in MS and the website – Anita Rose, Walton Centre, Liverpool, UK

17.30 – 18.00 planning the next RIMS meeting and next in-between meeting. All participants

20.00 Dinner

Saturday 10th April 2010

Venue: hotel Uniquestay Mihkli, Endla 23, Tallinn

8.00 – 9.30 cognitive manual – updates, reviewing, editing.

9.30 – 10.00 coffee

10.00 – 13.00 cognitive manual – updates, reviewing, editing. Coffee and breaks when needed.

13.00 – 14.00 lunch

14.00 – 15.00 conclusions and further plans about the cognitive manual. Closing of the meeting. Paivi Hamalainen, Liina Vahter

15.00 departures

Minutes from the Meeting

Friday April 9th 2010

Research Update of Group

1. Paivi talked about the effectiveness of neuropsychological rehabilitation in MS talking about the systematic review she has completed and submitted to Cochrane. Also talked about a project in her centre due to start for next two years looking at the effectiveness of out-patients rehabilitation programme for severely handicapped patients but will also compare with less handicapped patients.
2. Liina conducted a review of Neuropsychology literature of MS 2009-2010.
3. Case presentation by Liina – update of a case presented 2006. Boy with aggressive MS.
4. Bente – talked about meetings carried out across Denmark MS Society arranged by looking at cognitive problems in MS. 85-100 people attended these meetings. 3 hr meetings 3pm – 8pm. Sessions and outcomes were as follows:
 - a. 1st presentation neurologist talking about MS.
 - b. Talk about cognitive problems – what they are etc.
 - c. How to help yourself with cognitive problems – how to use telephone, use calendars etc.
 - d. Psychological impact of having cognitive problems – existential crisis, reaction from spouses, shared a case about woman who did not know cognitive problems existed in MS and thought her husband was being awkward.
 - e. Last half hour was panel discussion and questions. Many questions were to the Dr about treatments etc.
 - f. Overall great participant satisfaction.
 - g. Overall highlighted significant need for this to be discussed in MS population.
 - h. Going forward looking to run more meetings looking at more of the invisible symptoms inc. Neuropsychiatric problems, fatigue etc.
5. Anita showed the cognitive booklet just published and discussed the attached website.
6. Paivi shared results of her study on effects of heat on cognitive performance in PwMS.
7. Paivi shared results of study looking at single dose rivastigmine.

Discussion about next RIMS meeting & next in-between meeting

1. RIMS joint with ECTRIMS this year 13th – 16th October Göteborg Convention Centre, Sweden. Could have a meeting if people are attending. The meeting would look at the cognitive booklet etc.
2. RIMS – Turku 13th – 14th May 2011.
 - a. The question posed from RIMS Executive Board is whether SIGS would like to organise a pre-workshop or do they wish to meet for Core SIG on Thursday 12th May. Decision made by those meeting in Tallinn was that we would meet on the Thursday for approx. 5hrs (suggestion would be noon – 5pm so that people can fly in the morning) as a Core Group rather than organise a pre-workshop. This will allow for us to complete the cognitive manual.
 - b. EB also wish for SIG workshops to be run on Friday 13th for 1-1.5 hr as a parallel session. But they do not wish them to be termed SIG workshops but instead would

like them to have “proper titles” with the appropriate SIG organising/running the session. Will need 90mins if we talk about psychological and neuropsychological topics. Plan to look at Neuropsychological Interventions for PwMS inc. sharing the cognitive manual work and Psychological Interventions for PwMS who suffer from fatigue (maybe inviting a lady from Holland who has just completed PhD in this topic).

- c. In-between meeting in October/November 2011. Venue needs to be arranged.

Saturday April 10th 2010

1. Cognitive Manual:

The cognitive manual was broken down into sections worked on in couples during the complete meeting:

1. Paivi and Bente: Neuropsychological Rehabilitation
2. Anita and Michelle Cognition in MS and Neuropsychological assessment
3. Liina and Wim: Strategies in managing cognition

We came back to discuss the three separate sections and discussed missed information, style of writing and other issues.

It was agreed that each couple would continue to work on editing their own section and submit to Paivi by end of May 2010 at which time she will create the final working document.

The final working document will then be sent at the beginning of June 2010 to the entire core SIG as a read only document with a comments sheet that people can comment on the document. This will need to be completed by end of August 2010. This will then be sent to the couples responsible for their section and they will collate comments and edit accordingly – suggestions for changes will be discussed in October 2010 at the ECTRIMS/RIMS conference and agreed. The completed document will be finished by end 2010 and will be presented at RIMS conference in Turku in May 2011.

Cognitive Manual Timeline:

1. End May 2010: Sections to be sent Paivi
2. Beginning June 2010: Liina to disseminate final working document to Core SIG for comments
3. End of August 2010: all comments received by Liina and sent to person/couple responsible for each section.
4. October 2010, Sweden: Comments discussed and agreed.
5. End December 2010: Manual completed
6. May 2011, Turku: Manual presented.

2. Changes to SIG

Paivi has said she wishes to step down from Chair of this group and Agnete has said she wishes to step down from Co-Chair. They have both worked tirelessly for the group for many years and those at this meeting were sad and offer best wishes.

Liina was proposed as the new chair. This post will commence in October 2010 at the ECTRIMS/RIMS meeting.

Anita was proposed as the new co-chair. This post will commence in May 2011 at the Turku RIMS meeting.

If anyone objects to these proposals or wishes to propose other candidates please e-mail Paivi within 4 weeks – by 10th May 2010.

3. Next in-between meeting:

Suggested Topics:

Self-esteem & self worth - Wim to co-ordinate

MS in family – genetic/hereditary link? – Liina to co-ordinate

Update of the literature of psychology/neuropsychology in MS (2010 – the time of meeting) – Coordinator to be decided

Paivi will update on the neuropsychological rehabilitation study - Paivi

MS & Sex – Anita to co-ordinate

Pain

Paediatric MS – an update