

## **In-between meeting of RIMS SIG in psychology and neuropsychology**

**Ljubljana, Slovenia**

19.04.2013

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### **Participants:**

Anita Rose, UK

Aleš Pražnikar, SL

Francesca Bevilacqua, IT

Barbara Dolenc, SL

Elena Pinzan, IT

Jannie Engelbrecht, DK

Bente Osterberg, DK

Elisenda Anglada, Spain

Ana Ozura, SL

Michelle Pirard, BE

Saša Šega, SL

Liina Vahter, EE

### **DAY 1**

09.00 – 09.30 Welcome and introduction. prof. dr. Saša Šega, MD, head of MS center

Review of the MS Centre and management of PwMS in Slovenia.

9.30 – 10.00 Neurorehabilitation at University Medical Centre Ljubljana. mag. Aleš Pražnikar, MD, head of neurorehabilitation department

10. 00 – 10.30 Short tour around. All parts of neurology clinic were introduced to us. Different topics about system about treatment and rehabilitation of neurological patients in different countries was discussed.

10.30 – 10.45 coffee

10.45 – 12.00 Introduction of the group. Who we are, how to become a clinical psychologist/neuropsychologist in different countries, what do we do in everyday work. All members

12.00 – 13.00 lunch

13.00 – 14.30 Cognitive manual – finally finished? Anita Rose, Liina Vahter

Final corrections: done by the end of May

Liina to contact Päivi/RIMS executive board about publishing/making pdf of the booklet and putting it on the website, to check also where the old booklets have „disappeared” from the RIMS website.

Liina to send to Anita the list of core group members to insert to the booklet

National coordinators to be added for further contacts

All „section leaders” will send the references to Anita

Michelle will send Nicholas’s e-mail address to Liina to be added to the list

14.45 – 15.00 coffee

15.00 – 15.30 Neuropsychological assessment and individual treatments for in-patients in an Italian rehabilitation Center. Francesca Bevilacqua  
Discussion followed about pros and cons of different test batteries.

15.30 – 16.00 Danish project – children with MS and their parents. Bente Osterberg  
Discussion followed about treatment possibilities for children with MS in different countries.

16.00 – 16.30 Discussion

19.00 Dinner at the restaurant Druga Violina  
We had a dinner which included also a short lecture about how the work in the restaurant/workshop and other facilities has been organized – by mentally handicapped youth.

## **20.04.2013**

### **DAY 2**

9.00 – 10.00

Addition to the program – review from Michelle/Melsbroek – observational list for cognitive symptoms checklist to use for multidisciplinary team. Discussion followed.

Case about childhood MS – danish experience of a teenager girl. Bente Osterberg

Discussion - teamwork for the PwMS and employment issues in different countries.

10.00 – 10.30 coffee

10.30 – 12.30 review from the literature (Anita Rose and Ana Ožura)  
Cases – sexuality and MS – 1. Jannie, 2. Michelle

Discussion – starting with the new topic „Sexual problems and couple issues in MS for psychologists and neuropsychologists” (Jannie and Wim to be in charge)  
- possible plan for booklet?

- article different from booklet (review, International Journal of Rehabilitational Medicine)
- discussion

So many reviews, not too much to add

- systematic review from SIG group – Anita will sort out the methods
- research question – to specify what is missing from the previous reviews
- Ana will contact the editor of International Journal of Rehabilitational Medicine
- psychological impact, self-esteem etc problems, different sides
- questionnaire for PwMS – about sexual problems, in surveymonkey, in local MS Societies
- relationship issues
- cognition and sexual problems
- cultural differences? Religion?
- everyone will think 5-6 questions to ask PwMS – about problems,
- afterwards – to e-mail to the group – Ana and Anita will put them together, final questionnaire to be prepared for Copenhagen
- at the same time recommendations will be prepared – for psychological counselling
- working title – „Psychology and sex in MS”
- Michelle to contact Piet Eelen – how SIG in bladder and bowel topics feels about our plan, any recommendations they may have

12.30 – 13.30 lunch

13.30 – 15.00

Updating members list, next meeting – ECTRIMS in Copenhagen? We will meet after Friday's cognitive session at 12.15 as there is no information about SIG meetings during next RIMS meeting available and it would be very hard to plan activities with such a short notice.

Bente will get retired, new member will contact the group from Danish MS Society.

Next in-between meeting – where?

Ry, Denmark, 3.-4.10.2014

Enschede?

Venice?

Further ideas:

- Italian project about adl and cognitive problems, self awareness – who is over/underestimating their performance – maybe presentation in Ry?
- a meeting about rehabilitational strategies?
- questionnaire which should be used (Michelle in charge, there is a project in Melsbroek, multidisciplinary tool in use for everyone) – when it is ready to be published on RIMS website

To-do list from Barcelona:

Topics for meeting in Ljubljana:

- i. „Sexual problems and couple issues in MS for psychologists and neuropsychologists“ (Wim, Jannie and Bente to be in charge) – **started, in progress**
  1. possible plan for booklet
  2. article different from booklet (review, International Journal of Rehabilitational Medicine)
  3. review from the literature (Anita and Ana to be in charge)
  4. cases (Jannie, Wim, Bente, Michelle to be in charge)
  5. discussion (all members of the group)
  6. SIG in bladder and bowel to be contacted? (Liina)
  7. general session for RIMS conference to be prepared at the same topic (all members)
- ii. computer based rehabilitation programmes, cell-phone etc based rehab strategies, applications (for example „Tap to Talk“) etc – us to be more informed. Small video cameras in use all of the time of the day for training recognitional memory – **to be covered in next meeting**
- iii. research and further publication planning – **started, in progress**
- iv. preparation for the RIMS/ECTRIMS in Copenhagen – open and more general session prepared by our SIG? **Not too much information available, will meet after cognition session on Friday, if we have session for SIG, will cover ongoing projects? Difficult to plan in so short notice.**

Some additional topics to be covered in the future:

- v. early diagnosed and benign PwMS – psychological and neuropsychological problems
- vi. PwMS in advanced stages – psychological and neuropsychological problems
- vii. suicide and MS
- viii. palliative care and MS
- ix. to continue with cases and discussion („grand round“) – **cases were discussed in Ljubljana**
- x. adapting tests (Rey figure copying in Ipad etc)
- xi. how to test people who cannot write and see
- xii. how to test very young people – big change in „hardware“