



REHABILITATION IN
MULTIPLE SCLEROSIS

RIMS-REHABILITATION IN MS
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ANNUAL REPORT 2015

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REHABILITATION IN
MULTIPLE SCLEROSIS



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Message from the President



Once again, what a great year 2015 was for rehabilitation!

In April, an outstanding Annual Conference took place in Milan, Italy with the Italian MS Society as host in collaboration with Besta Institute, San Raffaele and the Don Gnocchi Foundation. Videos of main lectures are available on our website, including that of RIMS 2015 honorary speaker M. Battaglia and PMSA co-chair G. Comi. The success was translated to our SIG group meetings, organised by their respective chairs together with the corresponding local organisers in Germany and Belgium. RIMS is very proud of the multidisciplinary approach during the SIG meetings and conferences. Besides, fellowships allowed international mobility for therapists

Rehabilitation was also highlighted during RIMS' involvement in events such as the Pan European MS multi-stakeholder colloquium, the European Charcot conference, as well as events held at the European Parliament. Milestones were also new collaborations. In June, there was the establishment of a memory of understanding was signed between RIMS and EMSP, the European MS Platform, with an engagement to collaborate intensively, amongst others highlighting rehabilitation in the MS PRO program. Furthermore, RIMS has chosen Multiple Sclerosis Journal as its official journal while it keeps endorsing the International Journal of MS Care.

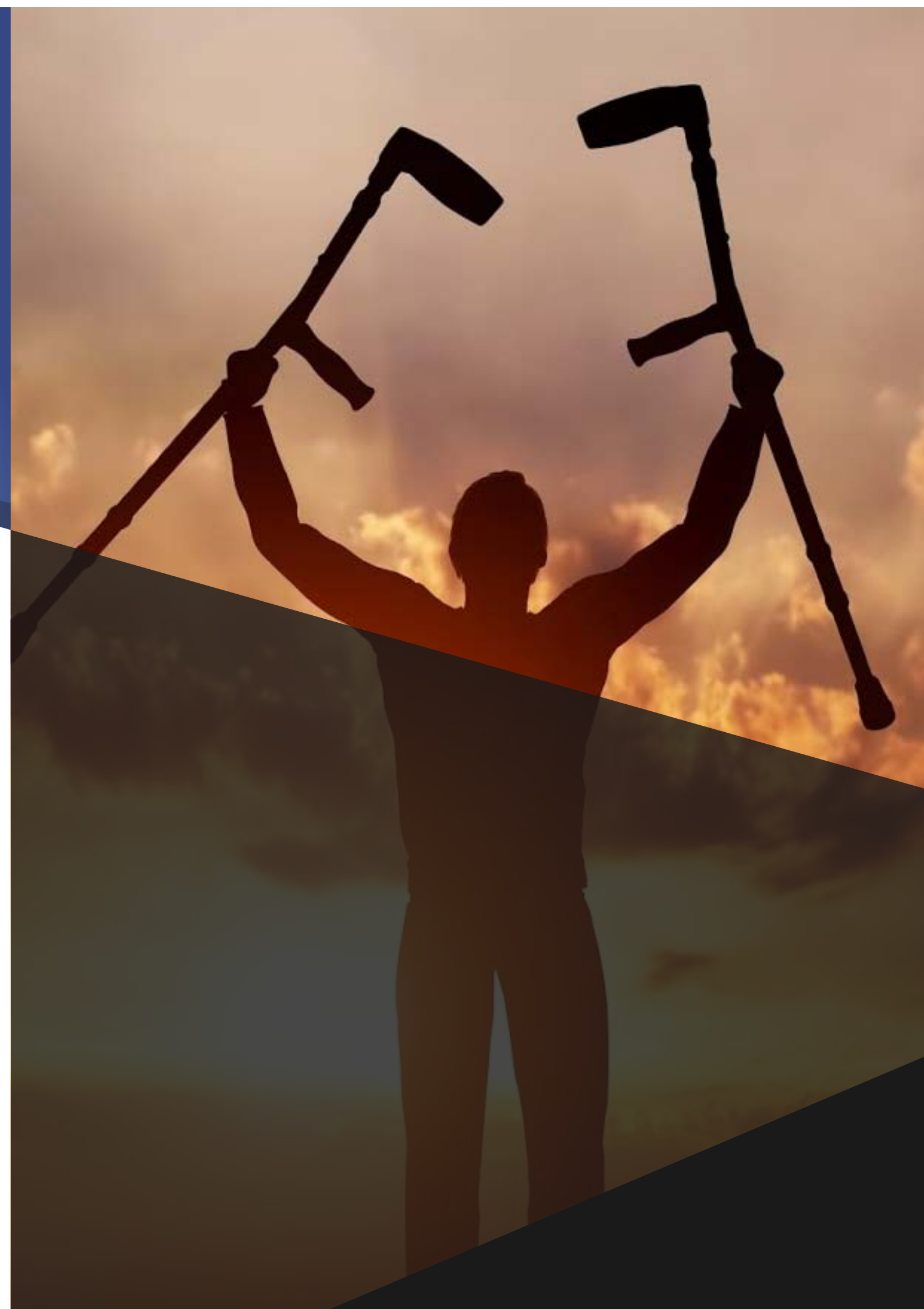
We acknowledge also support of our industry partners, as it enables us to lead a number of

clinical research projects within international networks. This year, we have a great variety of projects on topics such as multi-center collaboration on outcomes for mobility and arm function, cognitive-motor interference, fatigue management by App development (Pulse), adherence to rehabilitation interventions (ADAMS) and the 'living documentation system', that aims to provide easy tools to retrieve evidence-based information. Besides, the RIMS Grant 2015 was awarded to a network of speech therapists, led by CEMCAT, Spain.

On our website, you'll find a new page on E-education with documentation of presentations from annual conferences, podcasts on rehabilitation topics from experts in our network and information on outcome measures that were used in previous multi-center joint data collection studies on mobility. We acknowledge industry and ECTRIMS for their support for this program.

We ensure the development of RIMS with efforts from our executive board, SIG chairs and members; we aspire to provide the best practice and research in the coming years. With this note, I leave you to view our activities in the past year in detail, and I look forward to meeting you on one of our next meetings.


Peter Feys





Organisation Profile

Rehabilitation in Multiple Sclerosis (RIMS), the network of MS Centres in Europe was created in 1991 in Milan, Italy to enhance collaboration by the foremost MS Centres in Europe. Today, we embrace researchers and clinics in our European network for best practice and research.

OUR MISSION

We aim to enhance activity, participation and autonomy of people with MS by developing and advocating evidence-based rehabilitation.

OUR VISION

All people with MS throughout Europe have access to evidence-based rehabilitation when they need it.

RIMS is a fruitful network for all professionals working in the field of MS. Therefore we encourage all MS Centres, MS patient organisations and individual healthcare professionals and researchers to join the network.

These are some of the benefits of joining RIMS, together with a supportive network to exchange best practice, innovation and above all friendship and shared purposes to improve the lives of those who are living with MS. RIMS is an active network for MS professionals, researchers and centres. Membership gives you access to the resources of the network, encourages study-visits, enables exchange of best practice and other skill improving activities.

OUR AIMS

- Raise the profile of rehabilitation in MS and attract the best researchers and practitioners.
- Improve the understanding of rehabilitation and its relevance at every stage of MS.
- Manage the generation of new evidence on rehabilitation in MS by facilitating interaction between researchers and practitioners.
- Stimulate the implementation of new and existing evidence-based rehabilitation.
- Educate and train practitioners to integrate evidence into clinical practice

Our Members

RIMS members comprising of member centres/organisations, individual members, and student members come from across Europe, as well as international countries. According to the by-laws, a member is no longer considered to be a member following failure of payment of the membership fee for two (consecutive or non-consecutive) years.

The RIMS Member Coordinator keeps an updated contact details of all members.

2015

EUROPEAN

- Belgium
- Czech Republic
- Cyprus
- Denmark
- Germany
- UK
- Ireland
- Norway
- Poland
- Romania
- Serbia
- Switzerland
- Sweden
- Finland
- Italy
- Netherlands
- Slovakia
- Spain
- Greece
- Portugal

INTERNATIONAL

- Turkey
- USA
- Ghana

The Executive Board 2014-2017

RIMS is managed by an Executive Board, which — according to the by-laws — is composed of eight elected officers, including the President, Secretary and the Treasurer.



The executive board of RIMS, from left to right: U. Dalgas (DK), P. Feys (B), C. Heesen (G), J. Sastre Garriga (ES), V. de Groot (NL), J. Freeman (UK), D. Kos (B), A. Solari (I), and P. Hämäläinen (Fi)

NAME	BACKGROUND	COUNTRY
Peter Feys <i>President</i>	Rehabilitation Sciences and Physiotherapy (PhD)	Hasselt (Belgium)
Ulrik Dalgas <i>Secretary</i>	Sport Scientist (PhD)	Aarhus (Denmark)
Daphne Kos <i>Membership Officer</i>	OT (PhD)	Leuven & Antwerp (Belgium)
Vincent de Groot <i>Treasurer</i>	Rehabilitation Physician (PhD)	Amsterdam (Netherlands)
Päivi Hämäläinen <i>SIG Officer</i>	NeuroPsychologist (PhD); Head of rehabilitation center	Masku (Finland)
Christoph Heesen <i>Board Member</i>	Neurologist (PhD)	Hamburg (Germany)
Alessandra Solari <i>RiGra Officer</i>	Neurologist (PhD)	Milan (Italy)
Jenny Freeman <i>Board Member</i>	PT (PhD)	Plymouth (UK)
Jaume Sastre Garrigo <i>Social Media Officer</i>	Neurologist (MD)	Barcelona (Spain)

Special Interest Groups (SIG)



Photo taken during the Rims Executive Board + Special Interest Group Chair & Co-chair Meeting held on 9 Oct 2015 in Barcelona, Spain.

The Executive Board has established a number of Special Interest Groups (SIG). These groups aim to promote research and improve the management of persons with MS and their caregivers. Traditionally, a annual conference and intensive “in-between” meetings of 1½ to 2 days take place between conferences. During “in-between” SIG meetings at one of the member centres across Europe, there are scientific and clinical presentations on a chosen topic as well as free presentations. A clinical or practical session (e.g. patient cases, demonstration of technology; visit to a centre) is sometimes also organised.

SIG	CHAIRS AND CO-CHAIRS
Mobility	Chair: Anders Romberg, PhD, PT (Finland) anders.romberg@neuroliitto.fi Co-chair: Paul Van Asch, PT (Belgium) paulvanasch@yahoo.com
Occupation	Chair: Jelka Jansa, OT (Slovenia) jelka.jansa@kclj.si Co-chair: Sofie Ferdinand, OT (Belgium) sofie.ferdinand@mscenter.be
Psychology & Neuropsychology	Chair: Jana Pöttgen, Neuropsychologist (Germany) j.pottgen@uke.uni-hamburg.de Co-chair: Anita Rose, Neuropsychologist (UK) draerose@btinternet.com
Bladder, Bowel & Sexual Problems	Chair: Laura Lopes, MD (Italy) laura.lopes@aism.it Co-chair: Piet Eelen, Chief nurse (Belgium) piet.eelen@ms-centrum.be
Communication & Swallowing problems	Chair: Margaux De Groote, ST (Belgium) margaux.de.groote@klina.be Co-chair: Francesca DePiagi, ST francesca.debiagi@ospedalesancamillo.net
Patient Autonomy	Chair: Christoph Heesen, PhD, MD (Germany) heesen@uke.de Co-chair: Alessandra Solari, MD (Italy) solari@istituto-besta.it



SIG Reports

Psychology & Neuropsychology + Autonomy & Patient Education



The combined SIG In-between meeting was held last 27-29 November 2015 in Hamburg, Germany. The meeting was participated by 23 neurologists, psychologists, neuropsychologists, health scientists, a clinical trial manager, and a researcher, from Germany, Great Britain, the Netherlands, Belgium, Denmark, Italy, and Turkey.

Thursday: Welcome in the Bistro Jimmy Elsass with Alessandra, Ambra, Andrea, Chris, Jana, Anita, David, Richard, Michelle, Mieke, Ozlem

Friday: Welcome and short introduction (Chris)

Presentations

- R. Moss-Morris:** Chances and limits of cognitive-behavioral treatment in depressed and fatigued MS?
A. Rose: Patient autonomy in MS patients with neuropsychiatric impairment
A. Solari/A. Giovannetti: Patient autonomy in severely affected MS patients – how to achieve?
D. Wilkie: Managing decisional conflict in MS – a question of evidence or psychology?

Discussions

Exchange and discussion in 4 work groups following the following questions:

- *Is patient empowerment a focus of rehabilitation at your center? What are the approaches applied?*
- *How do you assess neuropsychiatric factors in MS? Do you tailor interventions based on findings? How?*
- *How to assess the effects of empowering interventions?*
- *Which empowerment concepts would you aim to implement?*

Presentation of group discussion results

Main topics were: a) encounter with the diagnosis, b) the role of pharma industry, c) independent information about MS and its associated contents, d) balancing autonomy and education.

Guided visit at the Rehabilitation-Centrum Hamburg



SIG Reports

Mobility



The 2015 annual in-between meeting, entitled “Improving functioning in persons with MS – practical aspects and theoretical reflections”, took place on the 23rd and 24th October in the Quellenhof Neurological Rehabilitation Centre in Bad Wildbad, Germany. The local hosts for the meeting were chief physical therapist Klaus Gusowski and professor Peter Flachenecker.

Altogether 44 participants attended. Thirteen countries were represented: Belgium, Czech Republic, Denmark, Finland, Germany, Italy, Norway, Portugal, Serbia, Slovenia, Spain, United Kingdom and USA. The attendants consisted mainly of physical therapists (n=36). Other professions represented were sport therapists (n=3) and medical doctors (n=5). The participant number was somewhat lower than expected – at least partly due to an exceptionally high number of withdrawals and cancellations. The reasons for these were miscellaneous. Apparently, travelling connections may, however, have had an influence.

The programme consisted of oral and poster presentations as well as practically-oriented workshops. Among presentations, the talk given by prof. John de Luca (USA) on MS-related fatigue can be regarded as the highlight of the entire meeting. Other presentation topics receiving, deserved, interest were e.g. a local example on the combination of physiotherapy and active nursing and a Belgium review addressing music-based interventions within neurological populations. Parallel with the formal sessions useful time for informal communication and socialization was generously reserved. The first meeting day was completed by a memorable dinner with a “surprise cruise programme” remaining surely in everybody’s minds.

Meeting feedback was inquired by a small questionnaire. Completed forms were received from 21 participants. Using a 5-point scale from “absolutely not satisfied” to “fully satisfied” the

average quantitative ratings (6 questions) ranged between 3.7 (overall programme of the meeting) and 4.2 (accommodation and venue). In addition, participants were inquired their perceptions of the meeting by open questions. Responses revealed a wide variety of positive/encouraging remarks. E.g. the atmosphere was experienced as “very friendly” and there seemed to be “a good mix of practical and theoretical sessions”. Some – constructive – criticism was also received. Several respondents paid their attention on “too long breaks”. Moreover, a common reported shortcoming seemed to be the shortness of many – particularly poster – presentations.

Taken together, there are many reasons to maintain a strong optimism in the concept that the SIG Mobility continues to offer a platform for young researchers and clinical practitioners willing and aiming for collegial sharing of their work. After almost 20 years of existence this group has greatly developed and received a highly appreciated status in its active members. Nonetheless, the meeting in Bad Wildbad gave a few “lessons-to-be-learned” while progressing with determined steps towards the future and coming meetings.

Anders Romberg, *Chairman SIG Mobility*
Paul van Asch, *Co-chair SIG Mobility*

Local organisers:
Dr. Peter Flachenecker, and Klaus Gusowski



SIG Reports

Swallowing & Communication

Date: 26th – 27th of November

Participants Day 1: Francesca Di Biagi, Irene Battel, Leonie Ruhaak, Myrthe Hogebrink, Dorien Mennes, Anouk Nissen, Sara Reusens, Margaux De Groote

Participants Day 2: Francesca Di Biagi, Irene Battel, Leonie Ruhaak, Myrthe Bruggeman, Margaux De Groote



Topics

Group therapy for PwMS

– Margaux De Groote

During the presentation an interesting discussion evolved where the participants shared experiences and knowledge about group therapy. We noticed cultural differences and discussed different programs for group therapy. The project of our SIG is temporarily on hold because we have other priorities (see SIG future goals).

Dysphagia and MS

– Irene Battel

Irene did a very interesting presentation about her research on biofeedback for dysphagia for persons with MS. In addition we shared knowledge about neuromuscular electro-stimulation for dysphagia, which is used in the Netherlands and Italy.

Basics of methodology

– Joke Raats

Joke gave an intensive and very useful presentation about qualitative and quantitative research, how to search articles on the internet efficiently and how to look at the methodology of an article in a critical way. Afterwards we practiced our knowledge.

Grant Project: DYMUS questionnaire

– Marta Renom

Marta presented the methodology of the DYMUS project through SKYPE. There was a discussion about the importance to mention cognition of the participants and about who has to be blinded in the project. It was a very useful presentation.

Telerehabilitation

– Marta Renom

Marta spoke about their telerehabilitation project for dysphagia. Because of financial reasons, they decided to put the videos with exercises for free on the internet (keyword: trhlab.net on <http://www.youtube.com>).

SIG Reports

Occupation

Occupational therapists (OTs) with interest in multiple sclerosis have the possibility to join the SIG OT. SIG OT is one of several professional interest's group, functioning within RIMS. It emerged from RIMS initiative and leading OT from Melsbroek, Mrs. Marijke Duportail, back in 1995 and have since grown in membership and quality of the work.

In the year 2015, two meetings were scheduled:

- The first one took place during Annual RIMS conference in Milan on April 11, 2015. Daphne Kos (immediate past Chair of our group) and Tarja Huila (immediate past Co-chair) stepped down and Sofie Ferdinand (new co-chair) and Jelka Jansa (new chair) has taken over their roles.
- The second one was scheduled for Overpelt in November 27-28, 2015. It was expected to hold 35 participants (please, refer to attached participants list, preliminary programme and proposed budgeting). Unfortunately and due to the unexpected terrorist threat to Brussels airport, several participants decided not to travel. Therefore, after discussion with RIMS board, it was decided at the very last minute to postpone the event for April 21-23, 2016. RIMS board was kind enough to reimburse cancellation cost for accommodation in the total amount of 2700 € and 4 airfare cancellation fees (Burganden, Jensen, Kam, Jansa). All receipts are with RIMS treasurer.

Registration for SIG OT 2016 is now in process, using RIMS on-line facilities.

Research Facilities

SIG OT members have completed the multicentre AMPS study and in year 2015 the manuscript of the study has been submitted for publication. Publication has not yet been successful, but core AMPS group keeps working on it.

For November 2015 meeting, we planned to talk about the new RIGRA application. Since we were not able to meet in person in Overpelt, the core group for a new OT study about the multicentre validation of Life Balance Inventory became really active by using Skype and email and managed to submit this proposal on time in early 2016. Thanks to the core group (Daphne Kos, Marijke Duportail, Helen Beckerman, Isaline Eyssen and Sofie Ferdinand who submitted proposal).

Participation at RIMS EB-SIG meeting in Barcelona, 9.10.2015

Sofie Ferdinand and Jelka Jansa were kindly invited to participate at the EB meeting.

Jelka Jansa, SIG OT chair
Sofie Ferdinand, SIG OT Co-chair

RIMS 20th Annual Conference

Milan, Italy on the 9-11th of April, 2015

We would like to acknowledge the international presence (19 European member countries and 4 non-European member countries) of conference attendees and presenters marking the great networking collaborations for MS rehabilitation that RIMS is pleased to bring together during our yearly conferences.

We further thank the platform presenters for their work and talks, as well as the authors who have exhibited their posters.

The conference concluded with the honorary talk of Mario A. Battaglia from Italy, where after, colleagues were congratulated and presented with platform presentation and poster winning awards.

The conference was organised by AIMS, FIMS and Besta Institute, in collaboration with San Raffaele Hospital and Don Gnocchi Foundation.

THIS YEAR'S THEME:

Translational Research and Patient-Centered Outcomes



Organizing committee and workshop contributors (Left to right): D Cattaneo, GP Brichetto, P Zaratin, A Solari, MA Battaglia, M Messmer Uccelli, P Feys, G Comi



Honorary lecturer, Professor Mario A. Battaglia

BEST POSTER PRESENTATIONS

FIRST PLACE

Changes in thalamic resting-state functional connectivity induced by a home-based cognitive rehabilitation program in patients with multiple sclerosis
Laura De Gilgio (Italy)

SECOND PLACE

No Uhthoff phenomenon due to ambient temperature in a large natural cohort of multiple sclerosis patients
Jan-Patrick Stellmann (Denmark)

THIRD PLACE

Oropharyngeal and oesophageal dysphagia in MS: pathophysiology, severity and risk factors
Astero Constantinou (Ireland)

BEST ORAL PRESENTATIONS

FIRST PLACE

Structural brain plasticity changes following an action observation therapy training of the dominant right upper limb in healthy subjects and patients with multiple sclerosis
Silvia Fumagalli, et al (Italy)

SECOND PLACE

Health is a matter of change: Health locus of control among persons with multiple sclerosis
Turhan Kahraman et al (Turkey)

THIRD PLACE

49 progressive resistance training improves muscle strength and function but does not affect circulating cytokines for PwMS treated with interferon-beta
Tue Kjøhede et al (Denmark)

Projects

Applications for 2016

The submission form is available on <http://eurims.org/Programs/rims-grant-program-rigra.html>

The program aims to facilitate collaboration between RIMS members from different centers and countries in the domain of MS rehabilitation.

Application form should be completed and sent by email to the RIMS Grant Officer by January 31st 2016, midnight CET (she is also available for clarification at solari@istituto-besta.it). Only electronic submissions are accepted and applications involving a minimum of three RIMS members from different institutions of three different countries will be considered.

The results will be announced by the end of May, early June 2016.

RIMS Grant Application 2015 Winner



2015: DYMUS QUESTIONNAIRE FOR DYSPHAGIA translation/validation in Dutch & Spanish

Lead: Xavier Montalban (ES) in collaboration with Belgium and Chile

Eight centers participated in the project from four different countries: Belgium, Holand, Spain and Chile. The centers are:

- **Cemcat (Vall d'Hebron); coordinating center (Barcelona):** Xavier Montalban, *Neurologist, Director of Cemcat, applicant*; Ingrid Galán, *Physician*; Marta Renom, *Speech and Language (SL) Therapist*; Xavier Sibera, *Physician*
- **Institut Guttmann. Hospital de Neurorehabilitació. Badalona (Barcelona):** Rosa Terré, *Physical Medicine and Rehabilitation*
- **Asociación de Esclerosis Múltiple de Bizkaia (ADEMBI). Bilbao (Bizkaia):** Lorena Gonzalo / Itziar García, *SL Therapists*
- **Hospital de Dia Miquel Martí i Pol. Fundació Esclerosi Múltiple (FEM). Lleida:** Mireia Aldevert, *SL Therapist*
- **Hospital slide Mas Sabater. Fundació Esclerosi Múltiple (FEM). Reus (Tarragona):** Anna Villanueva, *SL Therapist*
- **Unidad Esclerosis Múltiple. Hospital Clínico Pontificia. Universidad Católica de Chile:** Patricia Feliu, *SL Therapist*
- **The Rehabilitation Centre Mick. Brasschaat. Belgium:** Margaux De Groote, *SL Therapist*
- **New Unicum. Zandvoort. Holand:** Leonie Ruhaak, Caroline Bruggeman and Myrthe Hogebrink, *SL Therapists*

Education Project: RIMS

Lead : Jenny Freeman



Podcasts



Conferences



Outcome measures

Over the past year RIMS has been developing educational resources for the broad spectrum of health professionals working within the area of MS rehabilitation. This educational programme is in line with a key strategic aim of RIMS to educate and train practitioners, from a variety of disciplines, to integrate evidence into clinical practice.

The intention is to utilise a multi-faceted approach to providing educational resources, which includes the development of the following:

- **Participation in existing education programmes: adding a module on rehabilitation in the MS PRO electronic learning tool for nurses, leading to certification.** RIMS and EMSP have invested in a 'memory of understanding' that was signed by both presidents in June 2015. This memory of understanding identifies projects of collaboration. The creation of a separate module on rehabilitation, to be added in the e-program and to be translated in at least 7 different languages, has been accepted as the main focus of collaboration in the coming year. ECTRIMS has been invited to support and collaborate in this program. Key contributors have been identified to assist in the development of this module of evidence based rehabilitation throughout 2016.

- **The provision of up-to-date evidence based educational materials on the RIMS website.** Over the past year the RIMS web-site has been steadily populated with a growing number of e-education resources, which include: podcasts, conference presentations (video and ppt formats) as well as a collection of clinical outcome measures (tests and patient-reported outcome measures). For more information, see www.eurims.org/Resources/resources.html.

- *The podcasts address different domains of rehabilitation disciplines, such as the management of fatigue, cognition, upper limb function, and physical activity*

- *The conference presentations reflect the multi-disciplinary content of scientific programs from RIMS conferences, EMSP-RIMS joint program, and ADAMS ('adherence in MS') thematic meetings.*

- *The webpage on outcome measures provides information on clinical tests and patient reported measures in the domain of mobility, arm function and health-related quality of life. This content has been provided by the projects on joint multi-center data collection with the engagement of MS centers from across Europe and the US. A particular focus has been on providing translations of PRO's that were generated for these studies. In future, it will be investigated whether RIMS can support SIG groups (special interest groups) to complete information for their respective domains.*

We are pleased that the webpage on e-resources has already had over 2000 hits. It is anticipated that there will be a snowball effect in terms of future usage.

During 2016 it is our intention to continue to monitor use of these e-educational resources and to further develop the existing resources. For example 10 respected clinical researchers within the field have been asked to provide podcasts in a range of areas including the management of: depression, bladder and bowel, intimacy and sexuality, therapeutic drug management, vocational rehabilitation, tremor and ataxia and balance rehabilitation. Plenary sessions from the RIMS / ECTRIMS conferences in 2016 will be videotaped. It is also our intention to canvas the views of RIMS members to ensure that we meet their needs. In doing so it is possible that we will extend our educational programme to include formats other than e-based materials.

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

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PULSE+

Lead : Daphne Kos

The PULSE project aims at developing a mobile application and website to manage activities in daily living of people with MS. In the app, people will be encouraged to register their energy and satisfaction level throughout the day and after performing activities.

The project is initiated and funded by Teva Pharmaceuticals Europe and technical development is performed by Digitas LBI. RIMS is involved in the project by sharing expertise to build the application and website and by collecting user's experiences.

The past year several RIMS expert meetings took place where people with MS, rehabilitation professionals and researchers provided feedback on the content and format of PULSE. In 2016 PULSE will be launched, in close collaboration with RIMS.

PULSE+

Spend your energy on the things that matter



Adherence to Behavioural Interventions In Multiple Sclerosis (AD@MS-2): Follow-up Meeting Report

Lead : Chris Heesen

Following the second ADAMS meeting in London in 2014 an initiative was started to collect patient narratives on handling their disease with a special focus on adherence in UK and Germany. However, applications to national funders were not granted. Hence it was decided to put remaining resources into a qualitative and quantitative survey work on adherence issues in relation to physical activity behaviour changes. This work will conduct interviews with major RIMS members working on interventions to enhance pwMS physical activity and in parallel conduct a web-based survey to compare attitudes, barriers and facilitators between countries in Europe lead by C. Heesen in Hamburg. In addition qualitative interviews were performed around adherence behaviors in first and secondline immune treatments. Based on this work currently a questionnaire to possibly classify and predict adherence behaviors in MS is under

development which should be as well available in different European countries. In addition recent interactions with pharmaceutical companies indicate an ongoing interest in narratives as patient support tools. Stage of these initiatives will be discussed at the SIG education group meeting during the ECTRIMS/RIMS meeting in London.

Heesen C, Bruce, J., Gearing, R., Moss-Morris, R., Weinmann, J., Hamalainen, P., Motl, R., Dalgas, U., Kos, D., Visioli, F., Feys, P., Solari, A., Finlayson, M., Eliasson, L., Matthews, V., Bogossian, A., Liethmann, K., Koppke, S., Bissell, P. . **Adherence to behavioural interventions in multiple sclerosis: Follow-up meeting report (AD@MS-2).** Multiple Sclerosis Journal - Experimental, Translational



'Applying Evidence with Confidence in MS Rehabilitation'

A living documentation system translating evidence to clinical practice
Lead : Vincent De Groot

INTRODUCTION

With the current rate of growth of evidence in MS Rehabilitation, systematic reviews that are publishing available evidence, also those of the Cochrane Collaboration, typically lag behind the most currently published research findings due to the enormous amount and complexity of work regarding thorough quantitative analysis. Thus, when reviews, and clinical guidelines based on evidence, are published they are in fact already outdated to some extent while an update may not follow within the first 5 years or even not occur at all for a specific intervention. The most important goal of this application is to make rehabilitation evidence real-time accessible, and to support health professionals in decision making. The app provides a deeper, focused dive into the content of systematic reviews on which the treatment programs are based, within a structured and layered format. The content of the app will not be a simple summary of reviews; but additional content will be collected to assist implementation of effective rehabilitation treatment, for example video presentations and treatment protocols.

AIM

This project aims to develop, set-up, and implement a case example (template) of an internet-based Living Documentation System providing a fluid and up-to-date comprehensive database linking evidence to practice in MS Rehabilitation with an open-source dissemination strategy.

PROGRESS

This project formally started during the kick-off meeting during the ECTRIMS in Barcelona, 2015. An European content advisory board has been installed to provide solicited and unsolicited feedback to the project team. Within the first year, a case-example of a living based documentation system will be developed focusing on MS-related fatigue. In the second year, this case-example will be expanded with a second case-example focusing on cognition. A demo-version of the first case-example is expected to be ready during the ECTRIMS-RIMS meeting in London, September 2016.

PARTNERS

VU University Medical Center, Amsterdam, Netherlands; and **Masku Neurological Rehabilitation Center**, Masku, Finland

CONTRIBUTORS

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² Masku Neurological Rehabilitation Center, Masku, Finland

genzyme

Cognitive-motor interference in persons with MS: dual task assessment & training

Lead : Peter Feys, Päivi Hämäläinen, Ilse Baert

Dual tasking (DT) such as walking while talking on the phone or while reading off a shopping list is very frequently required in everyday life. However, simultaneous performance of motor (walking) and cognitive (talking, memory etc.) tasks can be difficult, and leading to a worse performance (dual task cost; DTC). This cognitive-motor interference is greater in elderly and patients with neurological conditions compared to healthy persons, impeding daily life functioning. Walking dysfunction and cognitive impairment are very prevalent in multiple sclerosis (MS) already in an early disease phase.

This research proposal firstly aims to investigate the magnitude of the DTC according to different types of cognitive distractors (information processing, memory, attention, etc.), its reliability as experimental outcome measure and its association with factors as severity of cognitive or motor dysfunction, fatigue and quality of life. Secondly, it is proposed to develop and test an innovative rehabilitation program where cognitive and motor functions are trained integrated during walking instead of separately. It is hypothesized

that effects on DT will be greatest after integrated training. Analyses will allow identifying which patient profiles respond best.

Leading and coordination of this multi-center study will be done at the University of Hasselt, REVAL under the supervision of Prof. Dr. P. Feys and Dr. I. Baert and at Masku Neurological Rehabilitation Centre, Finland under the supervision of Prof. Dr. P. Hämäläinen and Dr. A. Romberg.

Partners are: University of Hasselt, REVAL, Belgium, Masku Neurological Rehabilitation Centre, Finland FISM Scientific Research, AISM, Italy; Sheba medical Center, Telhashomer, Israel.

Additional Recruiting centers are: National Multiple Sclerosis Center Melsbroek, Belgium; Rehabilitation and Multiple Sclerosis centre Overpelt, Belgium; AZ Klina, campus De Mick, rehabilitation, Brasschaat, Belgium; MS society Flanders, Belgium

 **NOVARTIS**

Fellowship Exchange Programme

The call for the fellowship exchange programme is now open. Deadline for application is December 1st 2015, and June 1st 2016. In the current call, two fellows can be refunded up to € 1.000 each.

The fellowship is available to young European professionals, in order to facilitate their training in rehabilitation related to Multiple Sclerosis among RIMS member centres. The goal of the programme is to promote the multidisciplinary approach to rehabilitation in MS and to encourage the exchange of information and professional growth for those working in the field of MS.

You can find all information (criteria, procedure and documents to apply) on our website at <http://eurims.org/Programs/the-rims-fellowship-program.html>.

Please contact the RIMS administration desk (secretariat@eurims.org) when you have any questions regarding the fellowship programme.



Silvia Tome
Physiotherapist

From the center:
Fundacion Privada Madrid contra la Esclerosis Multiple

To: National MS center Melsbroek



Jakub Świderski
from Poland

From the center:
National MS Center Dabek, Poland

To: Fundacion Esclerosis Multiple de Madrid, Spain



Blaca Isabel Marin Leon
Physiotherapist

From the center:
Fundacion Privada Madrid contra la Esclerosis Multiple

To: Sclerosehospitaletne I Danmark

Partnership Work

ECTRIMS

EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

ECTRIMS is a professional organisation dedicated to the understanding and treatment of multiple sclerosis. A joint RIMS-ECTRIMS conference is organised every 3 years; the upcoming one is in September 2016 in London.

For more information, please visit
www.ectrims.eu



EMSP (European Multiple Sclerosis Platform) works according to a three-pillar approach to ensure that people with MS have a real voice in determining their own objectives and priorities: campaigning through advocacy and awareness-raising, collecting and sharing knowledge and expertise, encouraging research and data collection. RIMS collaborates with EMSP on the rehab module MS Pro project.

For more information, please visit
www.emsp.org

**MULTIPLE
SCLEROSIS
JOURNAL**

Multiple Sclerosis Journal (MSJ) is a peer-reviewed international journal that focuses on all aspects of multiple sclerosis, neuromyelitis optica and other related autoimmune diseases of the central nervous system. All abstracts from RIMS conferences are published in MSJ.

For more information, please visit
msj.sagepub.com

International **MS** CARE
Journal of **MS** CARE



IJMSC is a peer-reviewed international bi-monthly publication focusing on multiple sclerosis and related autoimmune disorders of the central nervous system. The primary goal of IJMSC is to publish original articles covering various clinical aspects of MS, particularly those relevant to the multidisciplinary management of the disease and its consequences.

Topics include neurologic, nursing, rehabilitative, psychological, and psychosocial care and quality-of-life issues of people with MS and reflect the diversity of the journal's readership. Categories of manuscripts considered include original research, clinically relevant reviews of the literature, case reports, consensus statements, controversies, book reviews, and letters to the editor.

For more information, please visit www.ijmsc.org

Our Sponsors

In 2015, RIMS has continued to benefit from the unconditional support coming from five companies being listed above. This funding enabled RIMS to further develop its network of rehabilitation experts through jointly executed cross border projects and research.

RIMS acknowledges the importance of this support and confirms its strict following of EFPIA's Code of Ethics.



"At Teva Pharmaceutical Industries, we improve people's health through our products, integrated R&D, generic medicines and global businesses."

www.tevapharm.com



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"At Biogen, we develop, market and manufacture therapies for people living with serious neurological, autoimmune and rare diseases. "

www.biogen.com



"We have pioneered the development and delivery of transformative therapies for patients affected by rare and debilitating diseases for over 30 years."

www.genzyme.com



"We are committed to finding solutions to improve the lives of the approximately 2.3 million people around the world living with MS, whether through our treatments, or in determining new ways to measure patient outcomes."

www.novartis.com



Financial Report

RIMS PROFIT & LOSS ACCOUNT 2015				
IN		OUT		
Membership fee	€ 13,130	Executive board	€ 69,591	
		Accountant	€ 366	
Industry funding	€ 382,745	Consultancy	€ 21,874	
		Office costs	€ 827	
Interest	€ 89	Website	€ 3,430	
		Podcasts	€ 1,500	
		Meetings and travel	€ 18,789	
		Administration	€ 20,000	
		Annual report	€ 2,806	
		Grants	€ 5,432	
		DYMUS	€ 1,110	
		Fellowship	€ 1,942	
		2014 RIMS grant	€ 2,380	
		Conference costs	€ 16,900	
		Awards	€ 1,510	
		Travel bursary	€ 2,259	
		Accreditation	€ 3,600	
		Conference recording	€ 5,429	
		Presents	€ 123	
		Abstracts MSJ	€ 3,980	
		Projects	€ 89,002	
		Cognitive Motor Interference	€ 10,000	
		Pulse	€ 9,228	
		Content of physical rehabilitation	€ 8,712	
		ADAMS-2	€ 61,063	
Total		Total		
Result 2015		€ 215,038		

RIMS BALANCE 2015				
Debit		Credit		
Fixed assets	€ -	Equity	€ 135,373	
Non-current assests	€ -	Current liabilities	€ 338,616	
Current assets	€ 473,989	SIGs	€ 10,398	
Bank account 31-12-15	€ 392,203	- 2015 Mobility	€ 6,000	
Savings account 31-12-15	€ 81,786	- 2015 Occupation	€ 3,500	
		- 2015 SIG Communication & swallowing	€ 898	
		Projects	€ 313,613	
		- Applying Evidence with Confidence	€ 140,938	
		- Cognitive Motor Interference	€ 110,675	
		- Pulse	€ 2,000	
		- ADAMS-2	€ 60,000	
		RIMS Fellowships	€ 715	
		- Swiderski	€ 715	
		RIMS grants	€ 13,890	
		- 2015 DYMUS	€ 13,890	
		Non-current liabilities	€ -	
Total		Total		
€ 473,989		€ 473,989		

“CHANGE YOUR THOUGHTS
AND YOU’LL CHANGE
YOUR WORLD.”

- NORMAN VINCENT PEALE

Why Join RIMS?



Individual members as well as all professionals from a member centre are able to get a RIMS Annual Conference registration fee at a special reduced member price.



A number of Special Interest Groups (SIG's) have been established. The groups meet at least once a year during RIMS annual conference. The SIG's also organise professional annual in-between workshops, which are supported financially by RIMS. For SIG in-between workshops, the member centres' professionals are offered one free hotel night and free meals for such occasions.



RIMS offers a Fellowship Exchange Programme to young European professionals, preferably non-doctors, to facilitate their training in MS rehabilitation at RIMS member centres. The aim of the programme is to promote the multidisciplinary approach to rehabilitation in MS and to encourage the exchange of information and professional growth for those working in the field of MS.



RIMS will support up to five fellowships annually, each with duration of one week, with a fellowship of €1000.



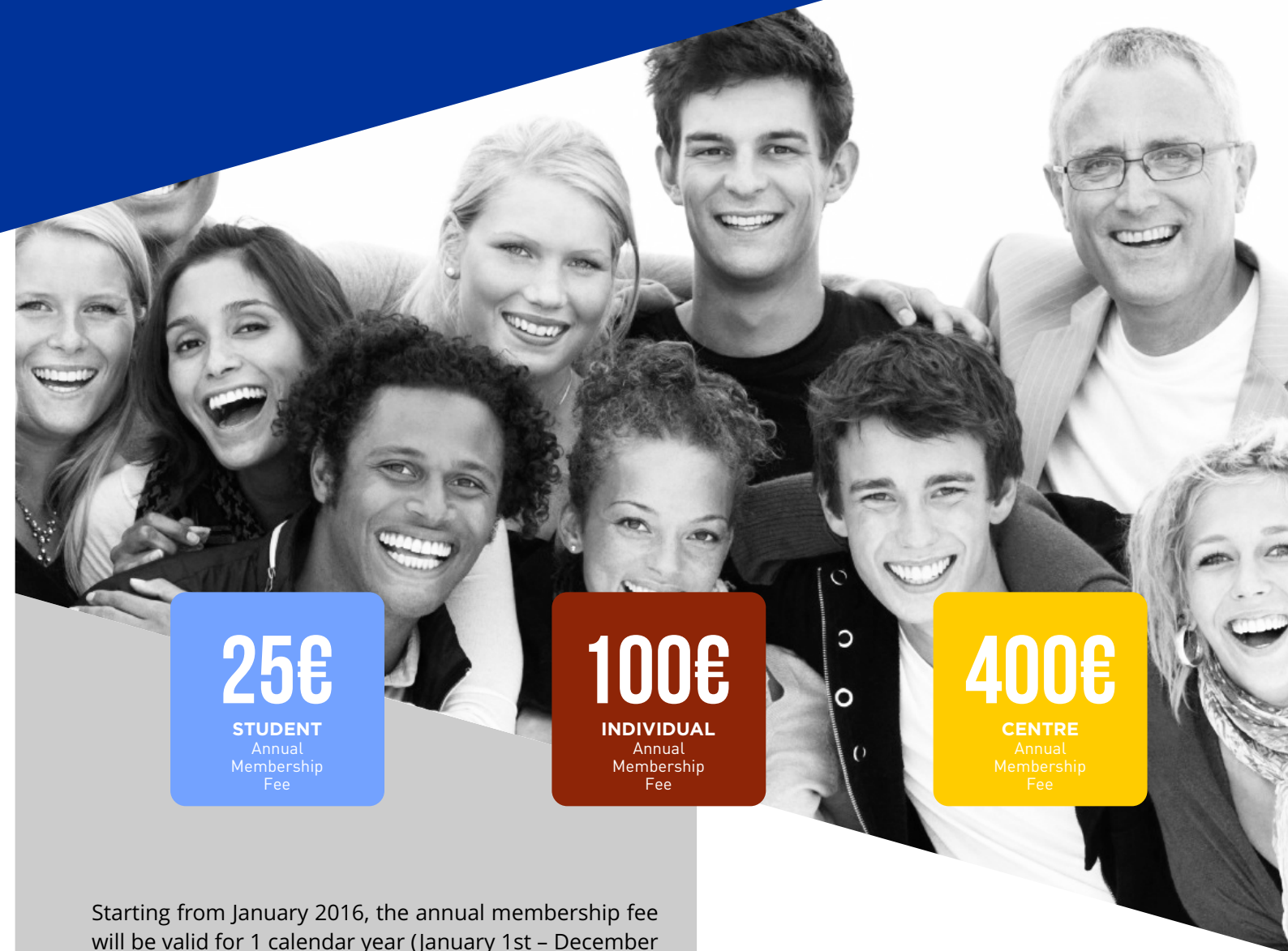
RIMS offer a special Grant Program to support multi-centre studies, a shared best practice network, or a SIG project. RIMS will support up to two grants annually, with a sum of max €5000 per one project.



The Grant is available for European professionals, in order to facilitate their projects related to MS. At least three members (individual or centres) from three different European countries have to be involved.



Some of the SIG's have published papers or pamphlets on important MS issues. These are distributed among RIMS members.



25€

STUDENT
Annual
Membership
Fee

100€

INDIVIDUAL
Annual
Membership
Fee

400€

CENTRE
Annual
Membership
Fee

Starting from January 2016, the annual membership fee will be valid for 1 calendar year (January 1st – December 31st). One can join RIMS at any time of the year, but the membership will expire at the end of that year.

An exception will be made for all current members whose membership will expire between September and December 2015; when they renew their membership for 2016, this will be valid until December 31st 2016. The amount of the annual fee will not be changed.

All current members will receive a notification about the expiration of their membership in December 2015, with an invitation to renew and pay their membership fee for 2016. Online payment is strongly encouraged; however offline payment is possible on request.

Students who would like to join RIMS will be requested to send a student identification document.

Note: If you ask for an invoice, please follow the registration process on the website, and select the offline payment in order to be registered in the system.

Be Part of RIMS

Pay Online

Visit us at our website at

 www.eurims.org/administration/how-to-join.html

Please contact secretariat@eurims.org for assistance or more information.

Pay via Bank

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BIC: GEBABEBB

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A STRONG POSITIVE MENTAL ATTITUDE
WILL CREATE MORE MIRACLES
THAN ANY WONDER DRUG.