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Organisation operates and beliefs and assumptions made by management. As these expectations, estimates, forecasts and projections are subject to a number of risks, uncertainties and assumptions, actual results may differ materially from those projected. The Organisation, therefore, wishes to caution readers not to place undue reliance on forward-looking statements. Furthermore, the Organisation undertakes no obligation to update any forward-looking statements as a result of new information, future events or other developments.

## Message from the president



Dear RIMS supporter,

**2016 has been an interesting year for RIMS.** Within our international and multi-disciplinary network we have enjoyed many educational and networking activities: in our special interest groups, annual conferences and with external partners. The annual conference was organized jointly with ECTRIMS in London, with multiple RIMS sessions being well attended while our delegates were offered the full program. Special interest groups were successful in organizing meetings in 6 different countries. There was a change in chair in the SIG 'Speech & Swallowing': Leonie Ruhaak (NL) took over as chair from Margaux De Groote (BE). We thank Margaux for her dedication in previous years. Finally, high-level education was provided to neurologists and therapists by Excemed in collaboration with RIMS during a preceptorship on Rehabilitation taking place in Klinik Valens, Switzerland under leadership of dr. Jurg Kesselring.

A number of RIMS supported fellows got a professional experience abroad and the RIMS Grant enabled collaboration between seven MS Centres from five different countries. Projects have been further elaborated contributing to raising the standards of MS rehabilitation practice and research. In this annual report, you can read the

progress made in the projects on adherence in MS (ADAMS), cognitive-motor interference during mobility tasks, PULSE and APECCO, the living documentation system.

RIMS is steadily developing its website with more and more e-educational materials. Also in 2016, experts have provided new podcasts on a variety of subjects.

RIMS also engages as international partner in the MS community. We are pleased to inform you that ECTRIMS has decided to support a joint RIMS-EMSP application to develop a module on rehabilitation within the electronic MS PRO educational program. This will assist in educating MS specialist nurses on the multi-disciplinary and evidence-base of rehabilitation. RIMS is also providing advice on a project on employment that is led by EMSP. Rehabilitation research is having increased visibility, with MSJ now being the official journal of our organization.

Lastly, the executive board has decided to be professionally supported in the management of its association and in conference organization. Seauton has been selected to assist RIMS in elaborating its activities and providing long-term guidance to the association. We thank Lousin Moumdjian and Christoph Thalheim for efforts made in previous years till now.

We do also look forward to 2017 which is promising for MS rehabilitation. The educational and networking events will continue with amongst others the flagship annual conference in Barcelona (May) in collaboration with CEMCAT and regional Spanish partners. During the conference, there will be also workshops and focused project meetings by international partners as IMSCOG and MSIF. Rehabilitation is also in the spotlights with our partners of EMSP, during their annual conference in Athens (May), and of ECTRIMS which is organizing a summer school on symptomatic treatment and rehabilitation in Santiago di Compostella (June). Special interest groups will organize in-between meetings in autumn 2017. As well, our projects will deliver results presented to our community. At last, RIMS will take up its role as international partner in rehabilitation practice and research.

**Prof Peter Feys**  
President



## 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.

**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.**

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. 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.

### 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

### 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 in 2016

RIMS' Members are member centres/ organisations, individual members and student members. RIMS' 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 nonconsecutive) years.

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

## EUROPEAN

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

## GLOBAL

- Turkey
- USA

# The Executive Board 2014-2017

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



STANDING FROM LEFT TO RIGHT  
U. Dalgas (DK), P. Feys (B), C. Heesen (G), J. Sastre Garriga (ES), V. de Groot (NL)  
SITTING FROM LEFT TO RIGHT  
J. Freeman (UK), D. Kos (B), A. Solari (I), P. Hämäläinen (Fi)

Name	Background	Country
<b>Peter Feys</b> President	Rehabilitation Sciences and Physiotherapy	Hasselt Belgium
<b>Ulrik Dalgas</b> Secretary	Sport Scientist	Aarhus Denmark
<b>Daphne Kos</b> Membership Officer	Occupational Therapist	Leuven & Antwerp Belgium
<b>Vincent de Groot</b> Treasurer	Rehabilitation Physician	Amsterdam Netherlands
<b>Päivi Hämäläinen</b> SIG Officer	Neuropsychologist Head of rehabilitation center	Masku Finland
<b>Christoph Heesen</b> Board Member	Neurologist	Hamburg Germany
<b>Alessandra Solari</b> RiGra Officer	Neurologist	Milan Italy
<b>Jenny Freeman</b> Board Member	Physiotherapist	Plymouth United Kingdom
<b>Jaume Sastre Garrigo</b> Social Media Officer	Neurologist	Barcelona Spain

# Special Interest Groups (SIG)

Special Interest Groups (SIGs) aim to promote research, stimulate evidence-based rehabilitation and improve the management of persons with MS and their caregivers. Traditionally, an annual conference and intensive ‘in-between’ meetings of 1,5 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 commonly also organised.

<b>Mobility</b>	<b>Chair</b> A. Romberg, Finland anders.romberg@neuroliitto.fi  <b>Co-chair</b> P. Van Asch, Belgium paulvanasch@yahoo.com
<b>Bladder, Bowel &amp; Sexual Disorder</b>	<b>Chair</b> L. Lopes, Italy laura.lopes666@gmail.com  <b>Co-chair</b> P. Eelen, Belgium piet.eelen@ms-centrum.be
<b>Psychology &amp; Neuropsychology</b>	<b>Chair</b> J. Pöttgen, Germany j.poettgen@uke.uni-hamburg.de  <b>Co-chair</b> A. Rose, UK draerose@btinternet.com
<b>Communication &amp; Swallowing</b>	<b>Chair</b> Leonie Ruhaak, Netherlands lruhaak@nieuwunicon.nl  <b>Co-chair</b> Francesca DeBiagi, Italy Francesca.debiagi@ospedalesancamillo.net
<b>Occupation</b>	<b>Chair</b> J. Jansa, Slovenia jelka.jansa@kclj.si  <b>Co-chair</b> Sofie Ferdinand, Belgium sofie.ferdinand@mscenter.be
<b>Patient Autonomy</b>	<b>Chair</b> C. Heesen, Germany heesen@uke.de  <b>Co-chair</b> A. Solari, Italy solari@istituto-besta.it

## Special Interest Groups Meeting Schedules 2016

### SIG Occupation

April 21st – 23rd, 2016  
Overpelt  
Belgium



### SIG Mobility

June 9th – 11th, 2016  
Valens  
Switzerland



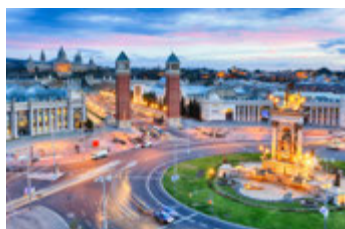
### SIG Psychology & Neuro-psychology

October, 2016  
London  
United Kingdom



### SIG Patient Autonomy

September 14th, 2016  
Barcelona  
Spain



### SIG Communication & Swallowing

November 17th – 18th, 2016  
Zandvoort  
Netherlands



### SIG Occupation

September 16th, 2016  
London  
United Kingdom



## SIG Report Bladder, Bowel & Sexual Problems



**Laura Lopes**  
Chair



**Roberta Motta**  
Secretary



**Piet Eelen**  
(co-Chair)

### ▾ About us.

The role of the Special Interest Group is to ensure the implication of evidence-based care for persons with multiple sclerosis in the field of sexual, urological and bowel problems. Scientific and clinical research in this field must be encouraged. For this purpose international collaboration and exchange of information will be organised.

In 2005 the Clinical Care Committee on SUBDIMS (committee preceding the SIG) published guidelines concerning conservative bladder management in advanced multiple sclerosis. (hyperlink: <https://doi.org/10.1191/1352458505ms1237oa>)

The action plan for the coming years will be to remain as active as possible in an European context, with all rehabilitation healthcare professionals with a special interest in bladder, bowel and/or sexual disorders in MS.

Another plan is to raise some more funds for the SIG to facilitate international exchange. Therefore, applications for international grants will be proposed.

### ▾ Members

The participating members on the SIG meetings are very diversified and variable. Several nurses and doctors participated at the SIG meetings during the last years.

Here is the list of SIG-member who participated in the last activities: Laura Lopes, Piet Eelen, Roberta Motta, Leen Bossaerts, Astrid Slettenaar, Monique Booy, Inga Zopp, Anita Pirecnik Noc, Karen Oksnevad, Marita Flo, Agnete Gade, Ozlem Taskapilioglu, Giovanna Konrad, Guido Francavilla and Sara Rinaldi.

### ▾ Meetings

In 2016 the SIG Bladder and Bowel had a meeting during the ECTRIMS/RIMS conference in London. In this meeting we reviewed the final version of our systematic review on bowel management in Multiple sclerosis. In 2016 we did not organize an in-between meeting.

### ▾ Publications

In the coming months Recommendations on bowel management in Multiple sclerosis by the SIG Bladder & Bowel will be published.

In the near future we want to organize a joint-in-between meeting with the SIG-psychology & neuropsychology on medical and psychological aspects of sexual problems in MS to finalize in a publication on Recommendations on sexual management in Multiple Sclerosis.



## SIG Report Occupation



In-between meeting  
for SIG Occupation  
April 21st – 23rd, 2016  
Overpelt, Belgium

### What is SIG Occupation?

SIG Occupation is one of the several professional interest's group, functioning within RIMS. It emerged from RIMS initiative back in year 1995 and an occupational therapist from Melsbroek, Belgium Mrs. Marijke Duportail. This SIG have since grown in membership and quality of the work. SIG Occupation welcome occupational therapist with an interest in multiple sclerosis and also other professionals who are interested into occupational therapy in MS.

### Meeting Schedule for 2016

In 2016 we hold two meetings; the annual in-between meeting and the short meeting meeting as a part of the ECTRIMS/RIMS congress 2016.

Annual in-between SIG Occupation meeting was in Overpelt, Belgium during April 21–23. This meeting was postponed from November 2015 due to national safety concerns. Local organizing team from the “Revalidation and MS Center, Overpelt”, was led by Veronique Truyens. The topic of this meeting was “Outcome measures in Occupational therapy”.

We have 25 participants from six countries, namely: Belgium, Denmark, Netherlands, Norway, Romania and Slovenia. Majority of our participants were occupational therapist, but also physiotherapists, a clinical epidemiologist, MD and a psychologist.

The second meeting was during ECTRIMS/RIMS congress in September 2016 in London. We had 15 participants from 6 countries.

The report below is based on the two SIG Occupation meetings held in 2016 (in London and Overpelt).

### Outcome measures used within Occupational therapy

Nowadays occupational therapist are encouraged to use top-down reasoning and client-centered practice by focusing first on the performance of the meaningful daily occupations and continue with the assessment on the relevant level of impairment(s). Several assessment tools and outcome measures were discussed as well as the way they are used with PwMS.

Understanding statistical properties of the scale is recommended.

## SIG Report Occupation



In-between meeting  
for SIG Occupation  
September 16th, 2016  
London, United Kingdom

FROM LEFT TO RIGHT  
Heidi Marie Visby Jacobsen,  
Sofie Schouteden, Lore Kerkhofs,  
Daphne Kos, Stefan Ilsebroux,  
Sofie Ferdinand, Lene Kallmayer,  
Marijke Duportail, Jelka Jansa,  
Isaline Eyssen.

### OT Recommendations for clinical practice

Brainstorming session about Recommendations for OT clinical practice for PwMS with an analysis of the previous work.

Meetings are well accepted and attendees valued the possibility to network, exchange best practices, have feedback and learn from others.

### Projects

Sofie Ferdinand has received RIMS grant 2016 for LBI project (Life Balance Inventory), (Matuska & Christensen, 2008). SIG's members also collaborate in APPECO and Pulse+.

### Meetings in 2017

Date: May 4, 2017

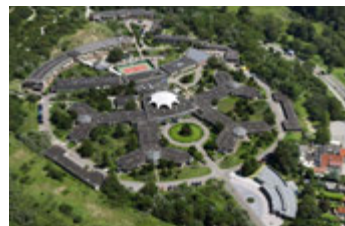
Topic: Shaping the future of MS through Occupational therapy  
Annual in-between meeting: October 12.-14. 2017 at the MS center Hakadal, Hakadal, Norway

Jelka Janša  
SIG OT Chair

Sofie Ferdinand  
SIG OT Co-chair

## SIG Report

### Communication & Swallowing



FROM LEFT TO RIGHT  
Francesca De Biagi, Fleur Robbers,  
Hélène Mathy, Leonie Ruhaak, Caroline  
Bruggeman, Fredrik Sand, Myrthe  
Hogebrink, Hilda Baeken, Ingrid The-  
unkens, Selma Giling.

#### SIG Meeting Communication & Swallowing

November 17th – 18th, 2016  
Nieuw Unicum  
Zandvoort, Netherlands

#### Local organizers

Leonie Ruhaak (NL)  
Myrthe Hogebrink (NL)  
Caroline Bruggeman (NL)

#### Background

The SIG Communication and Swallowing in-between meeting took place in Zandvoort on 17th-18th November 2016. The meeting was participated by 17 speech and language therapists. The topic of the reunion was cognitive communication disorders in MS and developing possible new research.

#### Day one - November 17th 2016

Background on cognition and communication disorders in MS by two presentations:

1. Cognition in MS (Larissa Meijer, neuropsychologist)
2. A screening for cognitive communication problems (Bregje Willems, SLP)

Guided visit at Nieuw Unicum

Discussion on communication disorders in MS:

1. Research in diagnostics of language problems in MS (Caroline Bruggeman, SLT)
2. Case studies (Fleur Robbers, SLP)
3. Workshop and discussion of diagnostics and treatment (Myrthe Hogebrink, SLT)

#### Day two - November 18th 2016

Update on current activities and making future plans:

1. Current RIMS Grant project: validation of DYMUS questionnaire (Leonie Ruhaak, SLP)
2. Cognitive communication problems in MS: designing a research question (Leonie Ruhaak, SLP)
3. SIG Communication & Swallowing Future plans and goals (Francesca Di Biagi, SLP)

At the end of the meeting, the chair and co-chair of the SIG were (re-)elected with the following result:

**Chair:** SLT Leonie Ruhaak  
(New Unicum, Zandvoort, Netherlands)

**Co-chair:** SLT Francesca De Biagi  
(Hospital San Camillo, Venice, Italy)

## SIG Report

### Communication & Swallowing



SIG Meeting Communication  
& Swallowing  
November 17th – 18th, 2016  
Zandvoort, Netherlands



## SIG Report Mobility



FROM LEFT TO RIGHT  
Laura Martina, Thomas Bowman,  
Denise Anastasi, Rita Bertoni,  
Jonsdottir Johanna, Elisa Gervasoni,  
Marcin Uszynski, Davide Cattaneo

### In-between meeting for SIG Mobility June 9th – 11th, 2016 Valens, Switzerland

The 2016 in-between meeting, entitled “Recommendations for physical rehabilitation in MS – what and why?” was held on 9th to 11th June in Kliniken Valens, Switzerland. The meeting was attended by 51 persons – mainly PTs – from 13 countries (Belgium, Czech Republic, Denmark, Finland, Germany, Ireland, Italy, Netherlands, Norway, Romania, Sweden, Switzerland and United Kingdom).

**June 9th:** Pre-satellite Symposia on FES (in collaboration with Bioness).

**June 10th:** The day started with a keynote talk (V. von Wyl, CH). Thereafter a number of oral presentations under the following themes were given: “Behavioural changes and goal setting”, “Cardio-autonomic responses”, “Alternative training methods”. Moreover, the day included therapeutic demonstrations (e.g., robotics, spasm management) and a klinik tour.

**June 11th:** A keynote talk (J. Kesselring) was followed by free presentations under themes “High intensity training” and “Specific assessments”. Meeting was ended in chairman’s information.

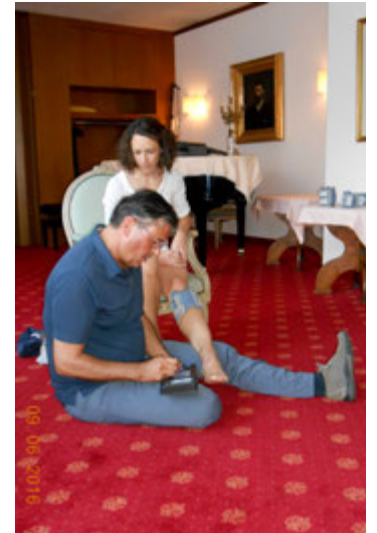
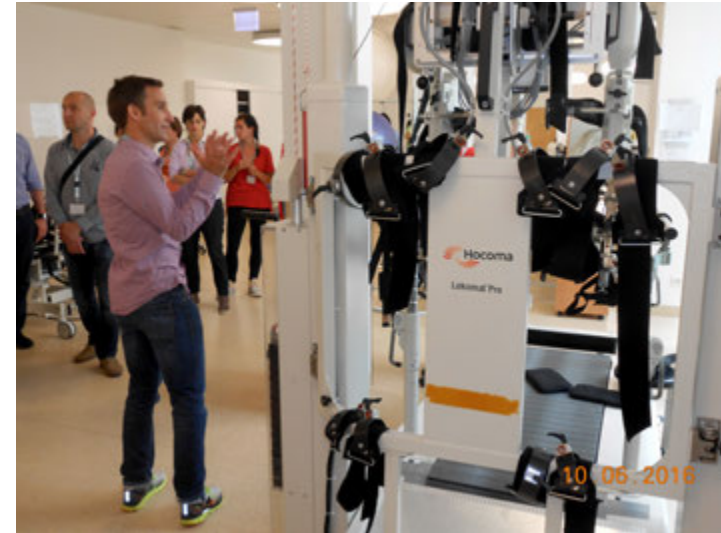
Feedback (27 respondents): On a 5-point scale from “absolutely not satisfied” to “fully satisfied” the average ratings (6 questions) varied between 3.3 (social events) and 4.4 (accommodation & venue). Quotes from the open questions revealed a variety of opinions; “friendly atmosphere”, “appreciated the possibility of networking”, “more practical demos/workshops”, etc.

Next in-between meeting: November 17th – 18th, 2017, Revalidatie & MS Centrum, Overpelt (BE)

**Anders Romberg**  
Chair SIG Mobility

**Paul van Asch**  
Co- Chair SIG Mobility

## SIG Report Mobility





## SIG Report

### Patient Autonomy



The AutoMS project  
(i.e. the origins of the SIG Autonomy)

**SIG Meeting**  
**Patient Autonomy**  
September 14th, 2016  
London, United Kingdom

The SIG autonomy met on Wednesday, 14 September 2016 during the ECTRIMS conference. Final data of the AUTOMS project, i.e. results of the European survey (currently submitted) were discussed.

Based on the feedback from 7 European countries (N=986) the risk knowledge questionnaire for relapsing remitting MS (RIKNO 2.0) showed a mean of 41% correct answers. Overall risk knowledge was low and differed between participating countries. These data indicate a substantial need for better informed patients.

As already consented during the interim meeting in Hamburg 2015 further development of educational modules around the questionnaire items was agreed upon. Recent results from the Hamburg group of web-based trials on communicating absolute risk reduction and confidence interval knowledge for MS treatment trials was presented and discussed.

The ongoing Italian project Managing the transition in Secondary Progressive MS (ManTra) was presented, as well the invitation to join in. A scoping review has recently been finished; personal interviews with MS patients, and focus groups of experts and caregivers will take place in 2017.

In addition, the German-Italian initiative on an education tool for motherhood choice (WeMOMS – web based motherhood choice decision aid) was presented, currently submitted to the US NMSS. Further countries interested in participating are welcomed, as for the web-based MRI education tool “Understanding Imaging in MS - UMIMS”.

## SIG Report

### Patient Autonomy



The first SIG Autonomy and  
Psychology joint meeting  
(Hamburg, 26-28 November 2015)

The SIG (formerly “Patient Education”) has been renamed to “Autonomy”, to emphasize the active role of people with MS. In addition, as shared decision making includes not only information exchange but relation-building and partnership, it was confirmed a close partnership and cooperation with the SIG Psychology. In general there was a consensus that collaborative projects will enhance and facilitate both SIGs. ManTra and WeMOMS are current projects with the highest potential for such interaction, as new, jointly conceived projects.

If you are interested, please come and join in!

## SIG Report Psychology & Neuropsychology



FROM LEFT TO RIGHT  
Jana Pöttgen, Jannie Engelbrecht,  
Anita Rose, Roshan dasNair,  
Alessandra Solari, Paivi Hamalainen,  
Michelle Pirard

**SIG Meeting Psychology  
& Neuropsychology**  
October 2016  
London, United Kingdom

### Participants

Leen Knevels, Roshan dasNair,  
Jannie Engelbrecht, Michelle  
Pirard, Päivi Hämäläinen,  
Alessandra Solari, Jannie  
Engelbrecht, Anita Rose,  
Jana Pöttgen

**Michelle Pirard presented the status quo of our sexuality  
review project and explicated the next steps:**

We conducted a scoping review in the field of psychological aspects of sexual dysfunction in MS.

- We conducted a database search (Cinahl, Medline, PsycINFO) with 479 results in PsycINFO, 848 results in Medline and 415 results in Cinahl.
- The list of articles was reviewed and 115 articles were selected and reviewed in more detail.

The output will be:

- An elaborate section based on our findings will describe the presence of sexual problems in MS related to psychological and neuropsychological aspects.
- A focus on rehabilitation of sexual problems based on our findings.

**Anita Rose gave an update for rehabilitation knowledge  
in neuropsychology.**

Neurorehabilitation = process of assisting individuals to maximise their independence and to improve their ability to be able to function in all aspects of life following a neurological injury or illness.

No curative pharmacological treatment for cognitive MS symptoms exist. No studies to date that consider rehabilitation in a holistic way.

## SIG Report Psychology & Neuropsychology

When evaluating the effects of rehabilitation intervention, the aim should be to use appropriate outcome measures which reflect, in addition to the severity of the cognitive symptom, its effects on everyday activities and how the individual copes with the cognitive deficit.

Greater collaboration between clinicians and researchers is needed so the divide of imaging and “day to day” intervention is reduced.

Multicentre/national research thus providing consistency in outcome and intervention?

**SIG Sexuality review  
group meeting**  
November 2016  
Hamburg, Germany

### Participants

Wim van de Vis, Michelle  
Pirard, Jannie Engelbrecht,  
Jana Pöttgen

We updated the database selection and checked again for additional studies/papers and extracted the data of the additional studies. Next step is the paper submission.

We also discussed next projects:

- international validation of a MS Sexuality Questionnaire
- international study to find relations between sexuality and cognition (BICAMS) and perceived impairments (interview)
- write the manual to treat sex. dysfunction
- select recommendations to treat SD in relation to psychological problems
- the main factor we have to care about - more clinical aspects

### Future plans for our SIG

- Develop Sexuality Manual for therapists (based on knowledge gained from review) – possibly in collaboration with the Bladder and Bowel SIG
- Joint (multinational) validation of a sexuality questionnaire for MS
- Possible new project – narrative approach to illness perception in MS
- Next SIG meeting (as part of RIMS) in Barcelona (May 2017)
- Next SIG in-between November 2017
- In addition we discussed a holistic approach for goal assessment in rehabilitation.



# RIMS 21<sup>st</sup> Annual Conference

The 21<sup>st</sup> Annual RIMS Conference took place in collaboration with ECTRIMS at the ECTRIMS conference in London, September 14th – 16th, 2016.

The joint conference enabled RIMS to emphasise the importance of rehabilitation, to strengthen relations with its stakeholders and to recognise the effort of all its Members.

## RIMS prize winners

**Best oral presentation**  
**Winner: P. Laffaldano et al.**  
 (Bari, IT) under supervision of Maria Trojano.

Superior and middle frontal gyrus activity during N-Back correlates with the effect of computer-assisted cognitive rehabilitation.

**Best poster presentation**  
**Winner: M. Heine et al.**  
 (VU Amsterdam, NL) under supervision of Vincent de Groot.

Does aerobic training alleviate fatigue and improve societal participation in patients with multiple sclerosis? The TREFAMS-A multicentre randomised trial.

## General Assembly

Was held on September 15th, from 17:00 - 18:30, in the South Galary Room 27.

## SIG meetings

The following SIG's held a meeting during the conference on September 16th, from 17:00 - 18:30.

**SIG autonomy**  
 Capital Lounge Room 3

**SIG Occupation**  
 South Galary Room 27

**SIG Bladder, Bower & Sexuality**  
 London Suite 1

**SIG Mobility**  
 South Galary Room 29

**SIG Psychology & Neuropsychology**  
 South Galary Room 28

## Stakeholder Meeting

Was held on September 15th, from 15:30 - 17:00, in the South Galary Room 27.

## RIMS teaching course & scientific sessions

**Teaching course 14: Patient empowerment and coping**  
 September 14th, 2016

**Chairs:**  
 A. Solari (Milan, IT)  
 C. Heesen (Hamburg, DE)

**RIMS parallel session 1**  
**Multi-Disciplinary Rehabilitation**  
 September 15th, 2016

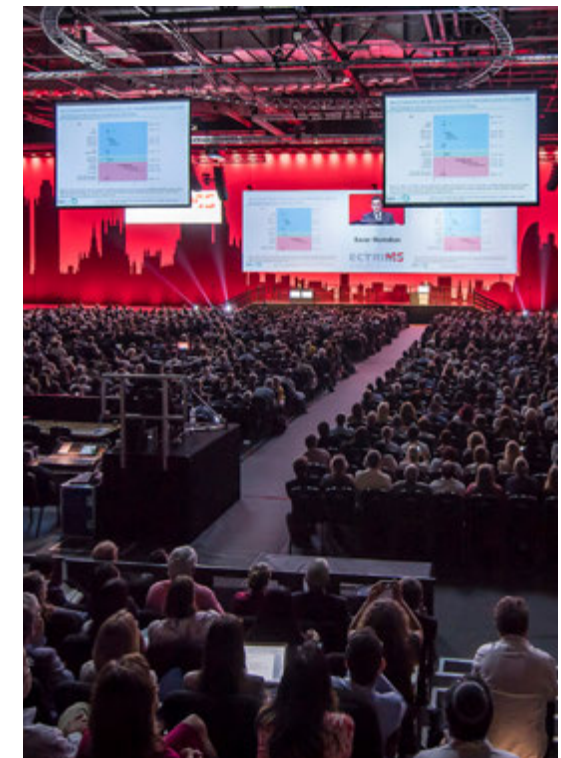
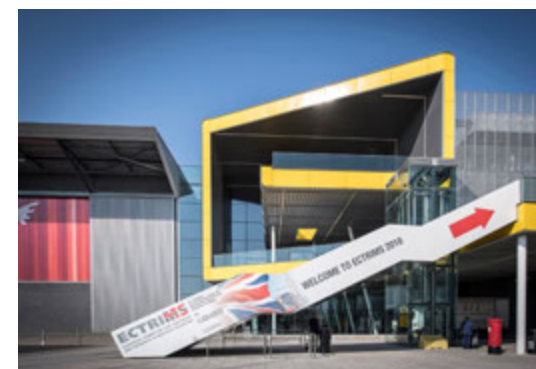
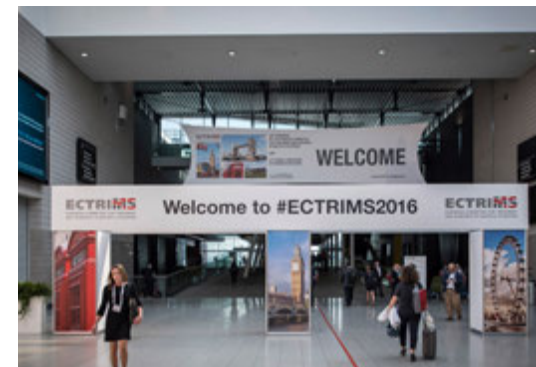
**Chairs:**  
 A.J. Thompson (London, UK)  
 U. Dalgas (Aarhus, Denmark)

**RIMS parallel session 2**  
**Symptomatic management**  
 September 15th, 2016

**Chairs:**  
 P. Hamalainen (Masku, FI)  
 D. Kos (Leuven, BE)

**RIMS parallel session 3**  
**Neurobiology & rehabilitation**  
 September 16th, 2016

**Chairs:**  
 G. Comi (Milan, IT)  
 K. Sastre-Garriga (Barcelona, ES)





## RIMS Grant Programme

### RiGra2017: New Criteria for Applications

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

#### Mandatory criteria

- The applicant must be a RIMS member (at the individual or center level) at the time of submission
- Only electronic submissions are accepted

#### Additional (non mandatory) criteria

- The applicant is an early career researcher, or a young (<36 year old) clinician
- Multicenter and international collaborative projects, particularly between RIMS members/centres.

#### Grant amount

In the 2017 call, one project will be granted € 15.000.

#### Deadlines

Submission Deadline:  
1st October 2017, 23h45  
Application details can be found on the RIMS website.

### RIMS Grant Application 2015 Winner

#### The life balance of European people with MS: A clinimetric study

Life balance is a concept concerning all human beings. A balanced person is able to spread time (and energy) optimally across the different life domains (work, leisure, self-care and rest). A satisfying pattern of daily activity is healthy, meaningful and sustainable (Matuska & Christiansen, 2009).

Especially in people with multiple sclerosis (MS) the ability to self-steer an optimal balance in daily activity may be compromised (Matuska & Erickson, 2008). Occupational therapists have an important role to assess, raise awareness about and optimize life balance.

The European life balance project team aims at evaluating test-retest reliability, cross-cultural and construct validity of the translated versions of the Life Balance Inventory (LBI) in people with MS within different European cultures.

To reach this research aim, a team of clinicians and researchers collaborated to translate and independently back-translate the LBI in six languages (Danish, French, Spanish, Slovenian, Dutch and Flemish).

Inconsistencies have been discussed with the developer of the original (American) scale. The translated versions will be evaluated in a sample of at least 30 people with MS in all countries/languages areas. LBI will be registered twice with an interval of maximum one week to evaluate test-retest reliability.

A user friendly and uniform digital assessment battery is created in all versions to improve quality in data collection.

To evaluate construct validity, relations of the LBI with quality of life fatigue, depression and self-efficacy will be evaluated.

This case study can inspire rehabilitation professionals to initiate international research collaboration. The results of the validation study contribute to the usefulness of the Life Balance Inventory in several European countries and languages areas for clinical practice and international research focussing on life balance.

## Project E-Educational Material



#### PODCASTS



#### CONFERENCES



#### OUTCOME MEASURES

### Education Project: RIMS Lead : Jenny Freeman

The provision of educational resources remains a priority for RIMS members, who comprise of a wide range of clinicians and clinical academic researchers 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. Our ongoing aim is to utilise a multi-faceted approach to providing educational resources. Developments over the past year have included following:

#### The provision of up-to-date evidence based educational materials on the RIMS website

The past year has seen an increase in the 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). See <http://eurims.org/Resources/resources.html>.

- The podcasts address different domains of rehabilitation disciplines, with new additions to the site including an overview of therapeutic drug management, the management of balance and falls, and physical activity.
- The webcasts from 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 multicenter data collection with the engagement of MS centers from across Europe and the US.

It is our intention to continue to steadily increase the range of podcasts provided by specialists working within a broad range of areas relevant to the rehabilitation of people with MS. Plenary sessions from the RIMS conferences in Barcelona 2017 will be videotaped to enable RIMS members to reflect on and consolidate the knowledge gained from expert speakers from across a range of specialities.

## Project PULSE +

**PULSE +**  
Lead: Daphne Kos

The PULSE+ project started in 2014 and aimed at developing a mobile application and website to manage activities in daily living of people with MS. In the app, people would be encouraged to register their energy and satisfaction level throughout the day and after performing activities.

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

The past year RIMS was involved in providing feedback on the demo version of PULSE, which was created with the input of people with MS, rehabilitation professionals and researchers. Unfortunately, PULSE will not be launched as APP but might be integrated in web-based platforms of TEVA.



PULSE expert meeting  
Melsbroek, Belgium

## Project AD@MS-PA

**'Adherence@MS-Physical Activity'**  
Lead: Chris Heesen

Systematic reviews support the beneficial effects of physical activity (PA) and exercise on various outcomes among people with MS (pwMS). However, most PA interventions have been short-term and long-term adherence has not been assessed. As pwMS are known to be less physically active than the general population, ADAMS-PA was initiated to assess the barriers and facilitators of long-term adherence to PA in pwMS.

The findings of three behavior change models associated with PA behavior change (HAPA by Schwarzer et al., Physical Activity Maintenance Model by Nigg et al. and MOVVO Model by Fuchs et al.) were focused and a review of the MS-specific literature was performed to guide further steps.

Based on the review 12 interviews with MS exercise experts from various disciplines and five European countries, mostly RIMS members, to identify constructs possibly relevant for long-term PA in MS. We used the Theoretical Domains Framework to structure the variety of constructs, identify valid scales and to develop a comprehensive survey questionnaire. The interviewees frequently mentioned disease specific factors (e.g. fatigue, impairment, walking limitations), confirmed most of the HAPA constructs and additionally four major themes emerged: 1. Exercise History, 2. Experienced consequences when being physically active after MS diagnosis, 3. Motivation and 4. Environmental factors from the social and physical environment. Details will be presented at the RIMS conference in Barcelona.

Drawing on these results a comprehensive survey questionnaire was developed with S. Coote, Limerick and R. Motl, Alabama, which covers disease specific and personal factors as well as factors of the social and physical environment.

Currently the web-based questionnaire is being applied in Germany. First results will be available by end of April 2017. Analyses will be done with path analysis comparing barriers and facilitators among pwMS in different stages of change.

An additional European and US survey is planned in late 2017 to assess variations among MS populations possibly related to cultural differences or the country-specific health care system.

The work is done by Karin Riemann-Lorenz as a PhD project (k.riemann-lorenz@uke.de).

## Project APPECO

**'Applying Evidence  
with Confidence in  
MS Rehabilitation'**

**A living documentation  
system translating evidence  
to clinical practice**

**Leads: Martin Heine,  
Heleen Beckerman,  
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 goals of this application are to make rehabilitation evidence real-time accessible, to support health professionals in evidence-based decision making, and provide the tools to implement the best-evidence into the clinical practice. This intuitive web-based application 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 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.



## Project APPECO

### PROGRESS

This project had its kick-off during ECTRIMS in Barcelona 2015. During ECTRIMS 2016 in London we were already able to show-case a demo version of the platform. In conjunction with the feedback received during this exciting conference as well as the continuing support of an international advisory board of renowned experts within the MS rehabilitation field, we were able to improve the demo-version and refine all the intricate processes underlying the APPECO platform.

Now, approximately 2 years after the kick-off, we are proud to share with you a case-example of the internet-based Living Documentation System we named: APPECO (APPLYing Evidence with CONfidence). The APPECO platform hosts up-to-date information on the effectiveness of rehabilitation for patients with MS regarding the domains "fatigue" and "cognition". A framework has been developed that 1) automatically identifies newly published research on MS rehabilitation, 2) puts each new study through an automated reviewer process to determine eligibility, and extract relevant information from the publication, 3) request additional information from corresponding authors to assist implementation into clinical practice, 4) an online front-end for corresponding authors to add the additional information to the respective publication, and 5) an intuitive front-end for health care professionals to access up-to-date evidence for the effectiveness of rehabilitation for fatigue and cognition in patients with MS. In the next phase, we aim to create an independent pool of "reviewers" that will ensure that the APPECO platform remains up-to-date, and potentially expand to other domains of interest to health care professional working in MS rehabilitation. Interested?

**Go to [www.appeco.net](http://www.appeco.net) and witness the revolution of evidence-based medicine in first hand.**

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VU University Medical Center, Amsterdam, Netherlands  
Masku Neurological Rehabilitation Center, Masku, Finland

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<sup>1</sup> Department of Rehabilitation Medicine, VU University Medical Center, Amsterdam, The Netherlands

<sup>2</sup> Masku Neurological Rehabilitation Center, Masku, Finland



## Project CMI in persons with MS

**Cognitive-Motor Interference in persons with MS**  
Lead : University of Hasselt, REVAL, Belgium  
(P. Feys & I. Baert)

### Participants

Masku Neurological Rehabilitation Centre  
Finland

FISM Scientific Research, AISM, Italy

Sheba medical Center, Tel-hashomer, Israel

in collaboration with Flemish MS centers (National Multiple Sclerosis Center Melsbroek, Belgium; Rehabilitation and Multiple Sclerosis centre Overpelt, Belgium; AZ Klina, campus De Mick, rehabilitation, Brasschaat)

supported by the MS Society Flanders and the Centre Hospitalier Universitaire de Liège; Belgium

This is a development & research project on cognitive-motor dual task assessment and training with multiple partners. A technology-supported assessment and training methodology has been developed in 2016 within a multi-disciplinary team consisting of physical and occupational therapists, neuropsychologists and medical doctors in interaction with engineers of UHasselt (EDM/IMO) & PXL in Flanders. Currently, patients are being enrolled in clinical trials. Methodology and results will be shared within the RIMS network including special interest groups in the second half of 2017.

Dual tasking (DT), doing two things at once, such as walking while talking on the phone or while reading off a shopping list is very frequently required in everyday life. Cognitive-motor interference (CMI) occurs when the performance capacity of a motor or cognitive task decreases when both are performed simultaneously (dual task) compared to single task execution being the so-called dual task cost (DTC). This CMI is greater in elderly and patients with neurological conditions compared to healthy persons, impeding daily life functioning. Problematic cognitive-motor DT has been related to unemployment and fall risk. Walking dysfunction and cognitive impairment are very prevalent in persons with MS (pwMS), already starting in an early disease phase. Moreover, even in patients without clinically evident motor or cognitive impairment, this "invisible disability" may arise during multi-tasking performances. Therefore, this study focus on the measurement of CMI and effectiveness of integrated dual task versus singular motor task training. The goal of the study is to enhance current rehabilitation treatment content, in order to improve daily life mobility and related quality of life of pwMS.

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.

Dual task assessment and training include an interactive adaptive system with therapist interface. A tablet application with headset (see figure below) was developed together with engineers and experts in neuropsychology and has been refined based on pilot training. This user-friendly, affordable technical software system provide stimuli to perform cognitive tasks during walking and record the patients' answers on the tablet and via headset microphone. Moreover, training is provide in a tailor-made matter, including performance feedback which guide exercises progression.

## Fellowship Exchange Programme

The current call for the fellowship exchange programme is open with application deadline set on June 1st and December 1st 2017. In each call, two fellows can be refunded up to €1000 each.

The fellowship is available to young European professionals, preferably non-doctors, 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 document to apply) on the RIMS website.

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

### 2016 beneficiaries of a RIMS Fellowship:



#### Lupo Elisa (PT) & Lorenzon Angela (PT)

##### FROM

Fondazione Ospedale San Camillo, Lido di Venezia, Italy

##### TO

National MS Center Melsbroek, Belgium

PERIOD: 06-12 June 2016

Elisa: "The opportunity to meet each professional and to learn how they work in a multidisciplinary team was a real added value for me."

Angela: "The opportunity to compare and share different work experiences with MS patients strengthened my expertise."



#### Zenginler Yonca (PT)

##### FROM

Biruni University, Faculty of Health Science, Division of Physiotherapy and Rehabilitation, Istanbul, Turkey

##### TO

Centre Neurologique et de Réadaptation Fonctionnelle Fraiture, Belgium

PERIOD: 01-07 May 2017

#### Sevenants Mieke (OT)

##### FROM

National MS Center Melsbroek, Belgium

##### TO

Valens Clinics Rehabilitation Centre, Switzerland

PERIOD: January-March 2017

## Partnership Work



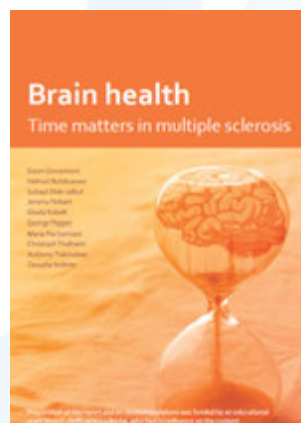
### RIMS Stakeholder Meeting

RIMS organised a "Stakeholder Meeting" at its joint ECTRIMS-RIMS Annual Conference in London, September 14th. The objective was to strengthen the relationships with its profit and non-profit stakeholders. RIMS presented its ambition to shape the future of MS rehabilitation and discussed ways to collaborate with all its stakeholders.



### Preceptorship on Rehabilitation

High-level education was provided to neurologists and therapists by Excemed in collaboration with RIMS during a preceptorship on Rehabilitation taking place in Klinik Valens, Switzerland under leadership of dr. Jurg Kesselring.



### Endorsements

RIMS endorsed the Brain Health Initiative, a policy initiative to stimulate debate about advocating a treatment approach in multiple sclerosis that aims to minimize disease activity and maximize lifelong 'brain health'.

EMSP (European Multiple Sclerosis Platform) works according to a threepillar 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 collaborated in 2016 with EMSP on the rehab module of the MS Pro Project and RIMS contributed to the Ready for Work Guidelines.

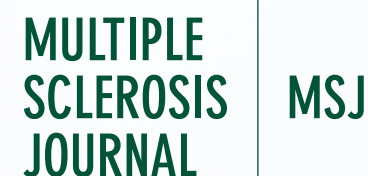
For more information, please visit [www.emsp.org](http://www.emsp.org)



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. MSJ is the official journal of RIMS.

For more information, please visit [msj.sagepub.com](http://msj.sagepub.com)



ECTRIMS is a professional organisation dedicated to the understanding and treatment of multiple sclerosis.

A joint RIMS-ECTRIMS conference is organised every 3 years. In 2017, ECTRIMS is organizing a summer school on symptomatic treatment and rehabilitation in collaboration with RIMS. It takes place on 13-15 June 2017, Santiago de Compostela/Spain.

For more information, please visit [www.ectrims.eu](http://www.ectrims.eu)



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](http://www.ijmsc.org)



International  
Journal of **MS**CARE



# Our Sponsors

In 2016, RIMS has continued to benefit from the unconditional support coming from the industry. 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.

“As part of our long-term commitment to the MS community, we are proud to support RIMS, and the important work they do in advancing comprehensive care for people living with MS.”

**SANOFI GENZYME** 

“Bioness is a great supporter of RIMS as we have seen how much the Bioness FES technology for Foot Drop and/or knee instability has helped persons with MS in walking much better, preventing fatigue and improving Quality of Life.”

 **Bioness**  
LiveOn™

“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.”


 **NOVARTIS**

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

 **Biogen.**



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

 **Neuroscience**

“We are internationally recognized as a biotechnology leader, with innovative and successful products along with a promising development pipeline.”



# Financial Report

## RIMS PROFIT & LOSS ACCOUNT 2016

IN		OUT		
Membership fee	€ 10.568	Executive board		€ 59.450
Industry funding	€ 146.190	Accountant	€ 831	
		Consultancy	€ 22.500	
		Office costs	€ 788	
		Website	€ 3.750	
		Meetings and travel	€ 14.131	
		Taks	€ 139	
		Annual report	€ 1.587	
		Association management	€ 14.294	
		Podcast	€ 500	
		Horizon2020 application	€ 930	
		<b>Special Interest Groups</b>		<b>€ 23.232</b>
		Mobility 2015	€ 6.110	
		Occupation 2015	€ 3.672	
		Communication and swallowing 2015	€ 898	
		Psychology	€ 5.000	
		Occupation 2016	€ 2.500	
		Mobility 2016	€ 4.274	
		ECTRIMS dinner	€ 777	
		<b>Grants</b>		<b>€ 9.915</b>
		DYMUS	€ 3.562	
		Fellowship	€ 2.647	
		Review Sexuality	€ 3.707	
		<b>Conferences</b>		<b>€ 1.302</b>
		Awards	€ 800	
		Booth and transport	€ 502	
		<b>Projects</b>		<b>€ 221.853</b>
		Cognitive Motor Interference	€ 100.675	
		Pulse	€ 1.928	
		Applying Evidence with Confidence	€ 118.743	
		Palliative care	€ 507	
<b>TOTAL</b>	<b>€ 156.758</b>	<b>TOTAL</b>	<b>€ 315.752</b>	

RESULT 2016 € 158.994

## RIMS BALANCE 2016

DEBIT		CREDIT	
Fixed assets	€ -	Equity	€ 91.201
Non-current assets	€ -	Current liabilities	€ 223.835
Current assets	€ 315.036	<b>SIGs</b>	<b>€ 1.300</b>
Bank account 31-12-16 BE32001504450802	€ 233.208	SIG Communication & swallowing	€ 1.300
Savings account 31-12-16 BE76047051101195	€ 81.827	<b>Projects</b>	<b>€ 212.207</b>
		- Applying Evidence with Confidence	€ 142.207
		- Cognitive Motor Interference	€ 10.000
		- ADAMS-2	€ 60.000
		<b>RIMS grants</b>	<b>€ 10.328</b>
		2015 DYMUS	€ 10.328
<b>TOTAL</b>	<b>€ 315.036</b>	<b>TOTAL</b>	<b>€ 315.036</b>

## Why join RIMS?



### Annual Conference at reduced registration fee.

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.



### Join a Special Interest Group.

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.



### Make use of the RIMS Grant.

RIMS offer a **Grant Program** to support multi-centre studies, a shared best practice network, or a SIG project. RIMS supports one grant annually, with a sum of max €15 000.



### Get access to privileged information.

Some of the SIG's have published papers or pamphlets on important MS issues. These are distributed among RIMS members. E-Education material (podcasts, webcasts from conference presentations and outcome measures) are available on the RIMS website and provide useful information for your research or clinical practice.



### Take advantage of the Fellowship Exchange Programme.

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.

## Be part of RIMS!



**25€**  
STUDENT  
Annual Membership Fee

**100€**  
INDIVIDUAL  
Annual Membership Fee

**400€**  
CENTRE  
Annual Membership Fee

The annual membership fee is 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.

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

**NOTE:** If you need an invoice for the payment of your membership, please follow the registration process on the website and select the offline payment method.

**IMPORTANT:** mention your membership id as a reference when paying offline.

The secretariat will send you the invoice once payment has been received.

## Pay Online

Visit us at our website at [www.eurims.org/administration/how-to-join.html](http://www.eurims.org/administration/how-to-join.html)

Please contact [secretariat@eurims.org](mailto:secretariat@eurims.org) for assistance or more information.

## Pay Offline (via Bank)

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BIC: GEBABEBB

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