



**ANNUAL  
REPORT  
2019**



## Message from the President

### 2019... MS rehabilitation on top!

#### MS rehabilitation on top of... the political agenda

Globally, there is a growing acknowledgement of the role of rehabilitation. At the WHO Rehabilitation 2030 meeting in July 2019, RIMS and other relevant organisations agreed on concrete actions to foster the implementation of rehabilitation in all countries.

Within Europe, RIMS collaborated in the Rethinking MS project and supported the launch in November 2019 to optimize how MS care is organized and provided to ensure timely diagnosis and personalised treatment, interdisciplinary and coordinated care and adaptable support in daily life – all very relevant to Rehabilitation in MS.

#### MS rehabilitation on top of... the research agenda

The evidence and acknowledgement of rehabilitation in all stages of MS is growing. A special issue of MS Rehabilitation was published in the Multiple Sclerosis Journal with many RIMS members sharing their expertise and highlighting the need for MS rehabilitation.

RIMS held the annual conference in September 2019 in Stockholm (Sweden), in a joint-meeting with ECTRIMS. Several RIMS sessions

focussed on the need for and evidence of a multidisciplinary, personalized approach in MS rehabilitation across the MS spectrum.

An additional conference at smaller scale was organized in June 2019 in Ljubljana (Slovenia) to share expertise about "Crossing the Interface to Explore New Possibilities", among rehabilitation practitioners and to ensure the continuity of the collaborative network.

#### MS rehabilitation on top of... network opportunities

RIMS stimulates networking and provided opportunities for rehabilitation practitioners to interact, learn and work with other centres. Special Interest Groups organized meetings, both during and in-between conferences, four members used the fellowship programme to get inspired in other centres and many members applied for the RIMS grant to collaborate in a joint research project.

Besides providing opportunities for its members, RIMS is partnering with relevant stakeholders, creating synergies to promote MS rehabilitation.

#### MS rehabilitation on top of... education

RIMS organized the second workshop in the go-local tour, in December 2019 in Milan (I), including keynote lectures and practical sessions. The workshop was well-attended by a variety of professionals and highly appreciated.

#### MS rehabilitation on top of... 2019.

On top of all efforts and events RIMS provided in 2019, we look forward to a challenging 2020. Not only will this be special year as we will warmly welcome you in Belgium for the annual conference, it will also be challenging to keep up the good standards in organizing networking opportunities and educational events. We do want to stay on top to enhance activity and participation for all people with MS whenever and wherever they need it!

I would like to thank all EB members, SIG chairs and co-chairs and the Seauton team for their commitments to create a unique organisation in MS rehabilitation. A special thanks goes to Vincent de Groot, past-president, who has steered the framework RIMS is now working in. And of course, thank you to all members for your loyalty and commitment to RIMS!



**Daphne Kos**  
RIMS President

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# About RIMS

RIMS is an international, non-profit organisation to develop, train and advocate evidence-based rehabilitation in the field of Multiple Sclerosis. RIMS is a multidisciplinary network of MS Rehabilitation Centres and individual health care practitioners and has become the point of reference with regards to MS rehabilitation in Europe and beyond.

RIMS was created in 1991, in Milan, Italy. Today, we closely cooperate with internationally renowned key players in the MS field such as ECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis), EMSP (European Multiple Sclerosis Platform), MSIF (Multiple Sclerosis International Federation), MSJ (the Multiple Sclerosis Journal) and IJMSc (International Journal of MS Care).

Membership gives you access to the resources of the network, encourages study visits, enables exchange of best practice and other skill improving activities. Therefore, we encourage all MS Centres, MS patient organisations and individual healthcare professionals and researchers to join the network.

## OUR MISSION

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

## OUR VISION

To advocate evidence-based rehabilitation to enable people to have access to rehabilitation when they need it.

## OUR AIMS

- Raise the profile of of MS rehabilitation with the best researchers and practitioners.
- Improve the understanding of rehabilitation and its relevance at every stage of MS.
- Stimulate research and its translation to practice.
- Educate rehabilitation practitioners.

# Our Members in 2019

RIMS Members are member centres/ organisations, individual members and student members. RIMS Members come from across Europe and beyond.

The RIMS Secretariat, in close collaboration with the RIMS Membership Officer, keeps updated contact details of all members.

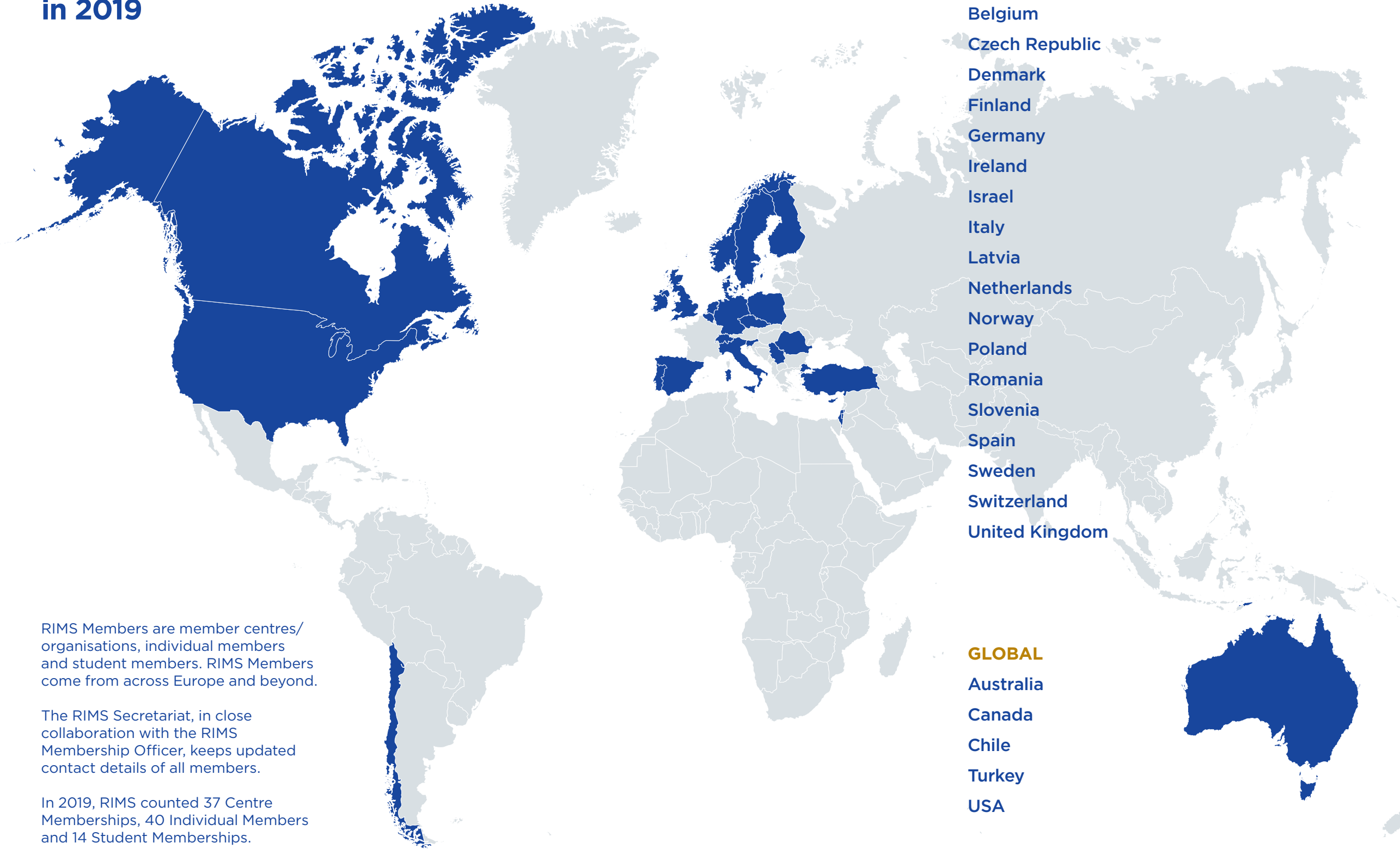
In 2019, RIMS counted 37 Centre Memberships, 40 Individual Members and 14 Student Memberships.

## EUROPEAN

- Belgium
- Czech Republic
- Denmark
- Finland
- Germany
- Ireland
- Israel
- Italy
- Latvia
- Netherlands
- Norway
- Poland
- Romania
- Slovenia
- Spain
- Sweden
- Switzerland
- United Kingdom

## GLOBAL

- Australia
- Canada
- Chile
- Turkey
- USA





# The Executive Board 2017-2020

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:  
Piet Eelen (BE), Anders Skjerbaek (DK), Jenny Freeman (UK),  
Christian Dettmers (DE), Vincent de Groot (NL), Daphne Kos (BE),  
Giampaolo Brichetto (IT), Jaume Sastre Garriga (ES)

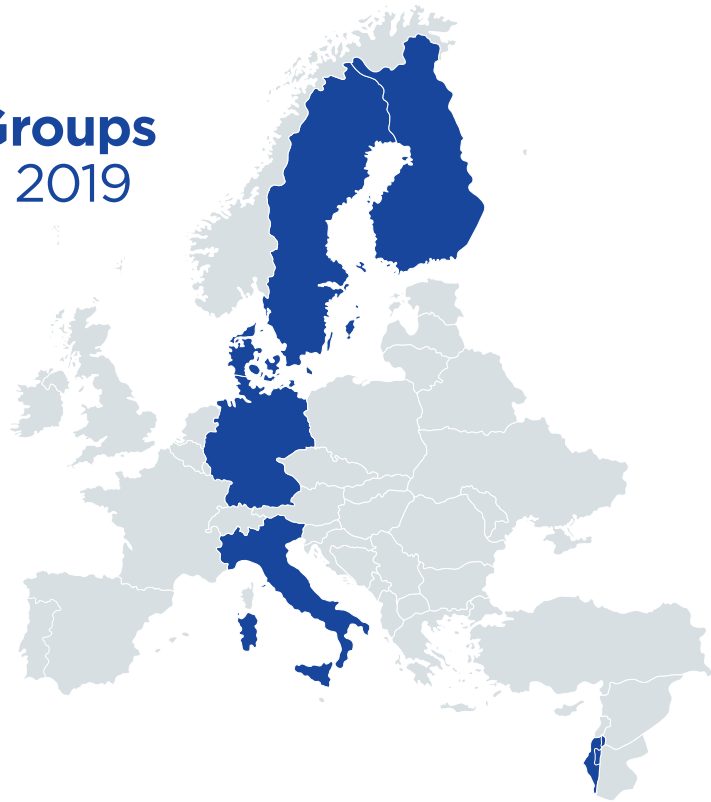
Name	Background	Country
<b>Vincent de Groot</b> Past President (until June 2019)	Rehabilitation Physician	Amsterdam The Netherlands
<b>Daphne Kos</b> President (since June 2019)	Occupational Therapist	Leuven & Antwerp Belgium
<b>Jaume Sastre Garriga</b> Treasurer	Neurologist	Barcelona Spain
<b>Giampaolo Brichetto</b> Vice-President (since June 2019) & RiGra Officer	Rehabilitation Physician	Genova Italy
<b>Christian Dettmers</b> Membership Officer	Neurologist	Konstanz Germany
<b>Piet Eelen</b> SIG Officer	Nurse Specialist	Melsbroek Belgium
<b>Jenny Freeman</b> Secretary & Fellowship Officer	Physiotherapist	Plymouth United Kingdom
<b>Anders Skjerbaek</b> Education Officer	Physiotherapist	Ry & Haslev Denmark

# Special Interest Groups (SIG)

Special Interest Groups (SIG's) aim to promote research, stimulate evidence-based rehabilitation and improve the management of persons with MS and their caregivers. Traditionally, an intensive 'in-between' meeting of 1,5 to 2 days takes 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> Carme Santoyo, Spain csantoyo@cem-cat.org
	<b>Co-chair</b> Lousin Moumdjian, Belgium lousin.moumdjian@uhasselt.be
<b>Bladder, Bowel &amp; Sexuality</b>	<b>Chair</b> Doreen McClurg, United Kingdom Doreen.McClurg@gcu.ac.uk
	<b>Co-chair</b> Sara Rinaldi, Italy sara.rinaldi@aism.it
<b>Psychology &amp; Neuropsychology</b>	<b>Chair</b> Jana Pöttgen, Germany j.pottgen@uke.uni-hamburg.de
	<b>Co-chair</b> Anita Rose, United Kingdom draerose@btinternet.com
<b>Communication &amp; Swallowing</b>	<b>Chair</b> Leonie Ruhaak, Netherlands lruhaak@nieuwunicum.nl
	<b>Co-chair</b> Francesca DeBiagi, Italy Francesca.debiagi@ospedalesancamillo.net
<b>Occupation</b>	<b>Chair</b> Inger Grethe Loyning, Norway ingergrethe.loyning@mssenteret.no
	<b>Co-chair</b> Sofie Ferdinand, Belgium sofie.ferdinand@mscenter.be
<b>Patient Autonomy</b>	<b>Chair</b> Anne Christin Rahn, Germany anne.christin.rahn@uni-oldenburg.de
	<b>Co-chair</b> Andrea Giordano, Italy andrea.giordano@istituto-besta.it

# Special Interest Groups Meeting Schedule 2019



**SIG Psychology & Neuropsychology together with SIG Patient Autonomy**  
November 28-29, 2019  
Hamburg  
Germany



**SIG Mobility**  
October 28-29, 2019  
Tel Aviv  
Israel



**SIG Bladder, Bowel & Sexuality**  
December 12, 2019  
Milan  
Italy



**SIG Occupation**  
November 8-9, 2019  
Genoa  
Italy



**SIG Patient Autonomy**  
September 11, 2019  
Stockholm  
Sweden



**SIG Communication & Swallowing**  
January 16-17, 2020  
Turku & Masku  
Finland



# SIG Report Psychology & Neuropsychology



In-between meeting for SIG Psychology & Neuropsychology together with SIG Patient Autonomy November 28-29, 2019 Hamburg, Germany



## About us

The SIG Psychology and Neuropsychology started as a Clinical Care Committee of Psychology and Neuropsychology in 1997 during the RIMS meeting in Bad Winzheim. The first chairman of the group was Rudi Vermote and co-chair Dawn Langdon. Since 2001 the group was lead by Päivi Hämäläinen and Agnete Jonsson (chair and co-chair, respectively). Liina Vahter has been chair since 2010 helped out by co-chair Anita Rose since 2011. Liina was leading the group until 2015 and Anita was her Co-Chair. From 2015 the Chair is Jana Pöttgen with again Anita as Co-Chair.

The idea of the group is to gain and maintain contemporary scientific knowledge about psychological and neuropsychological issues in MS and to share practical experience about everyday clinical work in different European countries within the RIMS network. The main role of our SIG is to provide evidence-based information regarding psychological and neuropsychological impairment in MS and its rehabilitation opportunities for RIMS members and other persons who are interested in this field. Our international collaboration is the best platform for team work.

The meetings have both lectures and case presentations with open discussion. To integrate current scientific knowledge into daily work is one of the main issues. Own international scientific projects are increasingly coming into focus.

The action plan for the coming years is to finish the CompACT validation project, to publish the results in a scientific journal and to generate new projects we are interested in and we can work on in an international context. New interested psychologists and neuropsychologists are welcome and everybody who is interested in being involved in our research projects is invited to take part. Please send an e-mail to: j.poettgen@uked.de

## In-Between Meeting

**Where?**  
Hamburg, Germany

**When?**  
November 28-29, 2019

**Topic?**  
Lifestyle Interventions to Empower People with MS

**Participants**  
Jana Pöttgen (SIG Chair) (DE), Anne Rahn (SIG Chair) (DE), Andrea Giordano (SIG Co-chair) (IT), Valeria Grosu (RO), Thomas Lehnert (DE), Elena Frick (DE), Lisa Wenzel (DE), Anja Holz (DE), Wim van de Vis (NL), Lasse Skovgaard (DK), Nicole Krause (DE), Anna Barabasch (DE), Sofie Bergien (DK), Karin Riemann-Lorenz (DE), Emma Nicholas (UK), Alessandra Solari (IT), Michael Nissen (DK), Marie Lynning (DK), Christina Bungardean (RO), Astrid Kanoe (DK), Rebecca Morrison (DE), Julia Peper (DE), Susan Seddiq-Zai (DE), Christoph Heesen (DE), Jannie Engelbrecht (DK), Richard Nicholas (UK)



# SIG Report

## Psychology & Neuropsychology + Patient Autonomy

### Summary of the meeting

In total, 26 people from six European countries participated in the shared SIG psychology and patient autonomy in-between meeting in Hamburg, Germany. One of the participants was a patient representative.

One of the main aims of the meeting was to exchange shared research interests and to develop “synergy effects” between the participating centres. The program included presentations with theoretical background and practical research approaches/projects including the experiences to implement the projects into clinical work. We experienced a strong overlap of research interests and started to discuss and develop possible shared work. Because of the specific interest and knowledge of the centres in online research (including both cross-sectional data collection and online treatment with eHealth programs), new and further collaborative projects seem to be possible and not too difficult to establish.

The in between meeting gave many opportunities to discuss practice, exchange ideas, be inspired and make new friends and colleagues in the RIMS network. The network dinner at Thursday night was a perfect platform to discuss personal research interests in a friendly interaction.



### Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

SIG Psychology and Neuropsychology in-between meeting (date and time to be defined)

A more interactive exchange is planned to bring both research activities in Psychology and Lifestyle together. The Hamburg Group and the Danish Group will exchange knowledge and experiences on Lifestyle Management projects, the chances and difficulties of self-monitoring with online tools and the development of online tools to increase MS-specific food health literacy. The possibilities of collaboration on those topics will be explored in the first months of 2020.

Further, the Danish group showed also interest to participate in the planned multinational survey on the motherhood choice topic and to participate on research activities in the field of severe MS.

A joined and a separate meeting (SIG Psychology/Neuropsychology and SIG Patient Autonomy) during the RIMS Annual Conference in Belgium in June 2020 are planned. Another in-between meeting held in autumn 2020 at a RIMS member center (e.g. Kobenhavn) is planned.

# SIG Report

## Mobility



In-between meeting for  
SIG Mobility  
October 28-29, 2019  
Tel Aviv, Israel



### About us

The **SIG Mobility** consists predominantly of physiotherapists complemented by medical/rehabilitation doctors, researchers and adapted exercise specialists. It focuses its activities not solely on mobility issues in MS, but also on – for example – physical rehabilitation methodologic approaches, exercise training or technological rehabilitation innovations. The group has established its role as an active RIMS actor e.g. in terms of a number of successfully implemented European multi-center studies/projects.

### Participants

Carme Santoyo (SIG Chair) (ES), Lousin Moumdjian (SIG Co-chair) (BE), Griet Gysemberg (BE), Denise Anastasi (IT), Ludovico Pedulla (IT), Klara Novotna (CZ), Margit Mueller (IT), Claudio Solaro (IT), Rebecca Hamilton (UK), Rita Bertoni (IT), Thomas Bowman (IT), Elisa Gervasoni (IT), Johanna Jonsdottir (IT), Fabiola Mestanza Mattos (IT), Marianne Bome (DK), Camilla Hamre Clausen (NO), Anne Britt Rundhovde Skaar (NO), Tori Smedal (NO), Nickeline Schmidt Larsen (DK), Zuhal

### In-Between Meeting

**Where?**  
Tel Aviv, Israel

**When?**  
October 28-29, 2019

**Topic?**  
Brain, Cognition and Movement in MS: Challenges for Rehabilitation

Abasiyanik (TR), Asiye Tuba Ozdogar (TR), Massimiliano Pau (IT), Giuseppina Pilloni (IT), Kim-Charline Broscheid (DE), Antoine Vanbeylen (BE), Verónica García-Martí (IT), Bernadita Soler (CL), Fanny Van geel (BE), Renee Veldkamp (BE), Klaus Gusowski (DE), Famke Vanderhauwaert (BE), Malgorzata Piotrowska (PL), Renata Rautszko (PL), Stefano Addeo (IT), Rachma van Woerden (NL), Peter Feys (BE), Paul van Asch (BE), Andrea Tacchino (IT), Gilles Allali (CH)



## SIG Report Mobility

### Summary of the meeting

The SIG Mobility group gathered on the 28th and 29th October 2019 at the Sackler Faculty of Medicine and the MS Center at Sheba Medical Center in Tel Aviv, Israel. This was the 22nd in-between SIG mobility meeting, entitled: 'Brain, cognition and movement in MS: challenges for rehabilitation'. This meeting was attended by 67 delegates from 14 different countries (28 from Israel).

The meeting opened on Sunday evening with a welcome reception at the Kfar Maccabiah Hotel in which the most of the delegates were hosted. The evening included an interesting lecture about rehabilitation in child and juvenile MS and a cocktail dinner. This was followed by two days of engaging and manifold program consisting of 3 keynote and 28 free-paper presentations covering work related to: feasibility and effectiveness of virtual reality treatment, clinical motor interference during dual tasks, patients' perspective of walking with exoskeletons, biological variability during walking training with metronoms and music; results from different types of intervention such as art, dance, nordic walking, auditory cueing or spinal mobilization; clinical and instrumented assessment of physical activity, upper limb and balance; and promoting sports and physical activity in the community. In addition, the program included a dedicated brainstorming session for future collaborations or projects within the SIG Mobility group that will be continued in future meetings. In addition, a tour and 4 practical workshops were offered during our visit to the Sheba Medical Center, in which the delegates had the chance to learn and to experience advanced virtual reality systems for MS rehabilitation, gamification of physical rehabilitation or new tools for motor learning such as "Beatube" "Re-step" or "Bobo" systems.

The meeting was extremely well organized in every single detail thanks to the hard working of Dr. Alon Kalron and his team from the Sackler Faculty of Medicine and the Sheba Rehabilitation and MS Center. Additionally, a guided walking tour around old Jaffa (the old city in Tel Aviv) organized, and was followed by a Gala dinner with traditional dishes and

delicacies. The energy during the dinner was outstanding, as the social event consisted of an interactive music band that encouraged all the delegates to play unique musical instruments from around the world and dance until the late hours of the evening.

Both the scientific and social content of the meeting received very positive feedback of the event, as participants gave high regards to the excellent meeting organization, the many diverse topics covered, the hands on workshops and the networking strength of the SIG meeting between clinicians and researchers, in all stages of their careers. In addition, delegates were very pleased with the brainstorming session, and we look forward to the future multi-center work that would most certainly follow.



In-between meeting for SIG Mobility  
October 28-29, 2019, Tel Aviv, Israel

### Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

SIG Mobility in-between meeting in Bilbao (Spain), hosted by Pedro Carrascal and team.  
Date: October 16-17, 2020  
Place: Adembi (Fundación Esclerosis Múltiple Bizkaia)  
Topic: TBC

## SIG Report Bladder, Bowel & Sexuality



In-between meeting for  
SIG Bladder, Bowel & Sexuality  
December 12, 2019, Milan, Italy



### About us

The **SIG Bladder, Bowel and Sexuality** is an interdisciplinary group of health care professionals that includes nurses, rehabilitation doctors, physiotherapists, neurologists with a special interest in this topic. In the last years also gastroenterologists, psychologists and urologists were involved.

### In-Between Meeting

**Where?**  
Milan, Italy

**When?**  
December 12, 2019

**Topic?**  
Discuss of Different Work in our Centers and Future Work with possible Wellsptech

### Participants

Sara Rinaldi (SIG Co-chair) (IT), Piet Eelen (BE), Anna Adinolfi (IT), Laura Isolabella (IT), Federica Salmeri (IT), Marco Dellacava (IT), Elisabetta Pedrazzoli (IT), Francesca Coaro (IT), Giorgia Cancilleri (IT), Patrizia Segnani (IT), Giovanni Del Popolo (IT), Elena Corbella (IT), Fabiola Bolla (IT), Fabio Giuseppe Massucco (IT), Virginia Tipa (IT), Roberta Motta (IT)

# SIG Report

## Bladder, Bowel & Sexuality

### Summary of the meeting

The day before the RIMS Workshop in Milan, we met in Fondazione Don Gnocchi for our SIG in-between meeting. It was very interesting because we had time to compare our work about valuation and treatment (different Italian centers, Belgium...) and spoke about Navina study, that prof. G. Del Popolo explained (*The efficacy of Navina Smart in neurogenic bowel dysfunction*).

More participants made questions about this study. P. Segnani introduced the possibility for our SIG to collaborate with Wellspect for future studies (*Secure the independence with Navina Smart / Wellspect Investigator Initiated Studies program*).

Piet Eelen described the RIMS organization and SIG work. The people were very interested about the possibility to compare our work in this SIG group, and future possibility about studies.

### Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

During the meeting we will be discussing our proposed projects for next year which will include another SIG in-between meeting and developing patient information tools and/or a bladder education programme.

# SIG Report

## Occupation



In-between meeting for SIG Occupation  
November 8-9, 2019  
Genoa, Italy



### About us

The **SIG Occupation** is an interdisciplinary network of health care professionals with an interest in enhancing activity and participation for persons with MS. We welcome colleagues who are clinicians, researchers and educators. Our overall goal is to unite evidence-based and practice-based knowledge and skills and to explore the ways in which gaps in knowledge can be presented in order to enable, enhance and empower participation in persons with MS.

We have two meetings per year:

- A short, 3-hours meeting, attached to the Annual RIMS conference.
- An annual in-between meeting that takes two days and is organised with partial financial support from RIMS. The in-between meeting takes place in the member organisation that is willing to host it and is organised around a specific theme. It also includes future plans. Sometimes, in-between meetings are organised in collaboration with the other SIG's. Topics discussed with other SIG's in the past were: "wheelchairs in daily life", "cognition", "employment" and "upper limb" issues in PwMS.

### In-Between Meeting

**Where?**  
AISM, Genoa, Italy

**When?**  
November 8-9, 2019

**Topic?**  
Transforming Knowledge on Technology into Relevance for Clinical Practice

**Participants**  
Inger Grethe Løyning (NO) (SIG Chair), Sofie Ferdinand (BE) (SIG Co-chair), Cristian Campagnaro (IT), Valeria Bergamaschi (IT), Isaline Eijssen (NL), Heidi Marie Visby Jacobsen (DK), Heidi van Casteren (BE), Niels Peeters (BE), Jessica Podda (IT), Giampaolo Brichetto (IT), Andrea Tacchino (IT), Ambra Bisio (IT), Margherita Monti Bragadin (IT), Agnese Galletto (IT), Sinéad Hynes (IR), Zorana Sicherl (SL), Victoria Leavitt (US)



# SIG Report Occupation

## Summary of the meeting

We were happy to gather participants from 8 different countries in Europe and the US for this year's in-between meeting. The theme of our meeting was a follow-up of the theme for this year's annual RIMS conference in Ljubljana "Crossing the interface to explore new possibilities" with emphasis on technical opportunities. How can we integrate the knowledge of technology and make it relevant for our clinical rehab work.

The program included both theoretical lectures, practical try-outs of the equipment and a practical workshop in kinesiotope. We were inspired by how architects, designers, clinicians and patients can co-design new technical aids. We learnt about how telehealth can improve quality of life in persons with MS and technical solutions for motor evaluation. There were presentations on different types of digital or computerized rehab tools. The two-day meeting gave good opportunities to discuss practice, exchange ideas, be inspired and make new friends and colleagues in the RIMS network.

In addition, we were well taken care of by the local organizers who gave us delicious genuine Genovese culinary experiences and toured us through the AISM rehabilitation center with their technical lab and therapy facilities.

## Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

SIG Occupation in-between meeting  
Date: Autumn 2020  
Place & Topic: TBC



# SIG Report Patient Autonomy



In-between meeting for SIG Patient Autonomy  
September 11, 2019  
Stockholm, Sweden



## About us

### OVERALL GOALS

The Patient Autonomy SIG (formerly known as 'Patient Education') is committed to understand the decisional needs of people with MS and health providers along the disease trajectory, and to support shared decision-making (SDM) in MS. Strategies to enhance patient self-management and coping are also at the core of our group.

### OUR AIMS

- Design and evaluate evidence-based patient decision aids and behavioural interventions
- Develop and evaluate SDM and communication training programmes for health professionals
- Design and validate patient-reported outcome measures of knowledge and care satisfaction

## In-Between Meeting

Where?  
Stockholm, Sweden

When?  
September 11, 2019

Topic?  
Discussion of potential SIG Projects to work on

Participants  
Anne Rahn (SIG Chair) (DE),  
Andrea Giordano (SIG Co-chair) (IT), Piet Eelen (BE),  
Chris Heesen (DE), Alessandra Solari (IT), Miguel Angel Robles Sanchez (ES), Vicky Leavitt (US), Marie D'hooghe (BE), Ingrid Galán (ES),  
Rianne Wisgerhof (NL), Doreen McClurg (UK),  
Klara Novotna (CZ), Heleen Beckerman (NL), Inger Loyning (NO), Yvonne Hetteema (NL),  
Rebecca Morrison (UK), Insa Schiffmann (DE), Ingo Kleiner (DE), Eli Silber (UK)



## SIG Report Patient Autonomy

### Summary of the meeting

Around 20 MS health professionals and researchers (e.g. neurologists, psychologists, nurses, health scientists) as well as a patient consumer from 8 countries participated in the 2019 SIG interim meeting during the ECTRIMS conference in Stockholm. The meeting was also joined by people from other SIG groups.

We used this meeting to introduce and discuss 3 project ideas (advance care planning in people with severe MS, information needs of people with PPMS and motherhood choice in MS), devised in the last meetings and with the help of few collaborations. Concerning the motherhood choice project, several people expressed interest to be involved in a multi-national survey. We plan to realize the international survey without additional funding.

Further, the projects addressing patient autonomy in PPMS and severe MS were discussed. As the PPMS project would be probably easier to realize within the SIG with limited financial resources, there was also a lot of interest in the advance care planning project.

Therefore, our intention is to submit applications on steps of both projects to the RIMS RiGra grant programme (deadline: December 1, 2019).

Please find more details on the SIG-in between meeting together with SIG Psychology and Neuropsychology on page 14.

### Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

SIG Patient Autonomy in-between meeting will be decided in Leuven.

The next steps are to e-mail the SIG and all people, who visited the SIG meeting in Stockholm to build groups to proceed the work on the motherhood choice project and the applications on the other projects

## SIG Report Communication & Swallowing



In-between meeting for  
SIG Communication & Swallowing  
January 16-17, 2020  
Turku & Masku, Finland



### About us

The **SIG Communication and Swallowing** consists of a small group of speech and language therapists, occupational therapists and linguists coming from different countries in Europe, who are working with persons with Multiple Sclerosis (MS).

The aim of our group is to exchange experiences on assessment and treatment in communication and swallowing. Moreover we would like to foster research in MS by developing projects together (for example: Translation and Validation of the DYMUS questionnaire). It's always exciting to network and exchange knowledge. During the year we keep in touch by e-mail and Skype meetings using our best English. Once a year we organize a 2 days meeting which is supported by RIMS and takes place each year in a different location.

### BACKGROUND FOR THE ESTABLISHMENT OF THE COMMITTEE

A questionnaire sent to European hospitals and rehabilitation centres for PwMS (reported during the MARCH Congress in Paris - 1996) was a good opportunity to develop links between Speech Therapists and create an international group on Communication & Swallowing Disorders in MS. The lectures were published in "Communication and Swallowing Disorders" edited by M. Charlier and P. Ketelaer, 1996. The group on Communication and Swallowing Disorders was born within the MARCH programme in 1996 and contributed to the publication of "A problem-Oriented Approach to Multiple Sclerosis", Ketelaer P, Prosiegel M, Battaglia M & Messmer Uccelli M (Edts) Acco, Leuven/Amersfoort, 1997. Because of an important need for specific assessment and rehabilitation techniques, all members of the group decided to extend the activities after the MARCH programme.

### In-Between Meeting

#### Where?

Turku & Masku, Finland

#### When?

January 16-17, 2020

#### Topic?

Let's communicate!

#### Participants

Leonie Ruhaak (SIG Chair) (NL), Sarah Vanlievendael (BE), Leena Maria Heikkola, Piia Siivonen, Eeva-Liisa Warinowski, Ella Bäcklund, Anni-Liina Foudila, Louna Juntunen, Salla Mäkelä, Sannii Nurmi, Terhi Paasch, Riitta Saari, Lotta Seppänen

## SIG Report

### Communication & Swallowing

#### GOALS

Because of the very small representation of Speech Therapists specialised in MS, the primary goals of our CCC are recruiting colleagues in Europe, improvement and sharing of knowledge and experience about the treatment of respiratory diseases, voice and speech disorders, neurolinguistic and cognitive communication problems, swallowing disorders, development of a common and specific evaluation of the communication and swallowing disorders, information and implication of other disciplines in the different rehabilitation processes of communication and swallowing disorders.

#### Summary of the meeting

Many thanks to our local organizer Leena Maria Heikkola. She enabled a two-day meeting for our SIG in Finland with the topic "Let's communicate!". Four speech therapists, one linguist (and speech therapist to be) and seven speech therapy students attended the meeting.

#### Activities:

On the first day we visited the Masku Neurological Rehabilitation Center. Director Päivi Hämäläinen warmly welcomed us and she kicked off with a general introduction on the history and the current state of the center. Furthermore, Päivi presented about neuropsychological aspects and cognitive rehabilitation in MS. Then, Piia and Eeva-Liisa shared their years of experience in working with MS patients. They showed us how the focus of their work has currently shifted to stroke patients instead of MS patients due to financial restrictions. Interesting fact: the kitchen of the center has three salad consistencies, namely normal, chopped and pureed. After lunch, physiotherapist Anders Romberg accompanied us for a guided tour through the center. Leonie ended the day with an update on the SIG and she presented two studies which she recently has conducted: the diagnostic accuracy of DYMUS and an explorative study on the optimal parameters of NMES in the treatment of dysphagia in MS.

The next day we met at the Åbo Akademi University. Through an internet connection with Australia and Italy we discussed the current practice and developments in language and communication in MS. Sarah El-whash presented her PROMs and cross-sectional studies on language and communication. Giorgio Arcara and Francesca De Biagi showed their work on pragmatics testing. We brain stormed about writing a grant proposal on the translation and validation of pragmatics testing. Host Leena Maria showed us Turku without snow. The meeting was closed by two presentations about naming in Dutch and Finnish patients with MS.

#### Future Plans & Meetings

3-hour workshop within the Annual RIMS Conference in the MS centre in Melsbroek on June 4, 2020.

SIG Communication & Swallowing in-between meeting in autumn 2020, with Venice (IT) as preliminary meeting venue with Francesca De Biagi and Giorgio Arcara serving as host

## Joint RIMS-ECTRIMS Conference

The RIMS-ECTRIMS Conference, held in Stockholm from September 11-13, was a great success. Besides organising teaching courses, educational and scientific sessions, and scoring oral and poster presentations, we also scheduled a Board Meeting and a Stakeholders Meeting. All to put Rehabilitation in MS on top of the discussions!

#### RIMS booth

This year all of our board members and SIG (co-)chairs welcomed you at our RIMS booth. A lot of interested people had a look and tried their best at the challenging Nine-hole-peg-test. Congrats to Aliona Jakubasz, winner of the RIMS lottery!

#### RIMS prize winners

**Best Poster Award**  
Stefanos Enricos Prouskas (NL)

**Best Oral Presentation**  
Daria Trojan (CA)





## Annual RIMS Conference

The Annual RIMS Conference 'Crossing the Interface to Explore New Possibilities' was held in Ljubljana, Slovenia from June 20-22, 2019.

The conference welcomed 252 delegates from 25, mostly European countries, 13 speakers, 38 platform presentations and 29 poster express presentations. The meeting and programme were developed in close collaboration with the MS Centre Ljubljana.

RIMS is proud that attendees appreciated the presentations of the diverse and dynamic group of faculty, and that valuable contacts have been established during the networking moments.

### RIMS prize winners

#### Best Poster Award

**Wanja Wolff** (DE)

**Ine Nieste** (BE)

**Heleen Beckerman** (NL)

#### Best Oral Presentation

**Lousin Moumdjian** (BE)

**Karin Riemann-Lorenz** (DE)

**Martin Langeskov-Christensen** (DK)



### SIG meetings

The following SIGs held a meeting during the conference on June 20th, 2019 from 16:00 – 19:00.

#### SIG Patient Autonomy

➤ **Topic:** Update of ongoing projects and presentation of project ideas

➤ **Guest speakers:** Christoph Heesen, Sascha, Carolin, Claudia Marck, Richard Nicholas, David Wilkie.

➤ **Conclusion:** After this fruitful meeting, the group decided to work on two project ideas to be submitted to the RIMS RIGRA Annual Call.

#### SIG Communication & Swallowing

➤ **Topic:** Current knowledge and practice

➤ **Conclusion:** Studies on communication and swallowing in MS are scarce. When we treat MS patients we need to use our practical knowledge integrated with evidence of interventions in other diseases.

#### SIG Mobility

➤ **Topic:** Enhancing Social Participation through Sporting and Physical Activities"

➤ **Guest speakers:** Paul Van Asch, Andrej Martic, Roshan das Nahir, Elaine Coulter, Johanna Jonsdottir, Lousin Moumdjian, Carme Santoyo

➤ **Conclusion:** The session included an opening lecture, a case report, a panel discussion and a practical session to share, show and discuss on how to empower people with MS to enhance their social participation through sport, leisure and physical activity. The combination of this interactive and practical session was really valued by the audience.

## Annual RIMS Conference

### SIG Psychology & Neuropsychology

➤ **Topic:** The meaning of illness

➤ **Guest speakers:** Jannie Engelbrecht, Kenneth Pakenham, John Deluca, Roshan DasNair

➤ **Conclusion:** Jannie presented her professional and personal experiences as well as psychological knowledge. The conclusion was that regarding disease processing people are shaped by their upbringing. How they learned to deal with an illness as a child can be seen in their awakening. This can mean both, that a disease is only seen as a burden and patients feel helpless and/or victimized, or that illness is accepted as a challenge the person has to deal with. Our job is to enhance the capacity of patients to accept their fate and to live their life. The ACT in practice presented by Kenneth took up the topic and gave a further insight into the application of the therapeutic approach of ACT.

The second part was a debate between Roshan and John regarding the rehabilitation of cognitive impairment in MS and its qualification as standard of care in MS rehabilitation. The open discussion with pro's and con's was inspiring for all participants.

At the end we discussed the plans for a next inbetween meeting and ideas for future tasks and projects.

### SIG Bladder, Bowel & Sexuality

➤ **Topic:** Learning from each other

➤ **Conclusion:** We held a 3-hour workshop within the RIMS Annual Conference in Ljubljana on June 20, 2019. During the meeting we had presentations by Doreen McClurg on Abdominal massage for constipation, transcutaneous tibial nerve stimulation for bladder dysfunction by Sara Rinaldi and a PhD student Hawri AIdandan, presented her review on the prevalence of bladder dysfunction in MS. We discussed our proposed projects for next year including an article on bladder dysfunction for a special edition of the MS Journal. We also discussed another SIG in-between meeting and developing patient information tools and/or a bladder education programme.

### SIG Occupation

➤ **Guest speakers:** Daphne Kos, An van Nunen, Sinéad Hynes, Katja Brancelj Galič, Marta Vidmar, Metka Moharič, Dejana Zajc

➤ **Conclusion:** Prof. Daphne Kos was invited to link the topics on technology from this year's annual RIMS conference to clinical relevance for rehabilitation practice. The presentation on sleep was interesting and educational in both a personal and professional matter. Sleep matters for activity and participation. Three presentations of newcomers in our group presenting their research or clinical practice was also very welcomed.

### General Assembly

Was held on June 21st, 2019 from 16:20-17:50, in the plenary room at the Ljubljana Exhibition and Convention Centre (Gospodarsko Razstavisce).

### RIMS teaching courses on June 20, 2019

#### Falls in MS

➤ **Course Coordinator:**

Uroš Rot, MD, PhD, Medical Centre Ljubljana

➤ **Aim:** To provide an overview of issues related to falls in MS

- Balance problems in the earliest stages of MS
- Exploring the underlying psychological factors relevant to issues about falling/near falling in PwMS. Balance issues explored in depth.
- How to prevent and how to manage falling

#### Upper Extremity & Modern Technology

➤ **Course Coordinators:**

Prof. Marko Munih, Faculty of Electrical Engineering, Ljubljana & Jelka Jansa, OT, MSc, University Medical Centre Ljubljana

➤ **Aim:** To provide an insight into the issues about rehabilitation of the upper limb by considering the use of modern technology

- Motor control upper limb (considering pathophysiology of upper limb control)
- Movement disorders in MS
- Role of trunk in the use of the upper limb
- Robot-based arm therapy (incl clinical hand assessment tools)



## 2<sup>nd</sup> RIMS Workshop

The 2<sup>nd</sup> RIMS Workshop, 'Rehabilitation in Progressive MS' was held in Milan, Italy on 13 December 2019.

This second edition of the RIMS 'Going Local' tour was organised by RIMS with the much appreciated support of the Don Carlo Gnocchi Foundation and the Italian MS Society Foundation. Together with our local hosts Giampaolo Brichetto (board member RIMS) and Davide Cattaneo, we were able to bring together **83 delegates from 13 countries**. This was for all delegates a great opportunity to interact with healthcare professionals, researchers and patient representatives sharing knowledge and experiences on topics related to rehabilitation in Multiple Sclerosis.



We started with a welcome by our hosts, Davide Cattaneo and Giampaolo Brichetto, our RIMS president, Daphne Kos and the invited speaker Marco Rovaris. The programme contained 5 key note lectures and several practical sessions.

### PROGRAMME

**KEY NOTE I: Symptoms and Issues in Progressive MS**  
**Vincent de Groot**

**KEY NOTE II: Palliative Care in MS**  
**Alessandra Solari**

#### PRACTICAL SESSION 1

Physical Outcome Measures in MS – Anders Skjerbaek  
Managing Time and Energy in Daily Life – Daphne Kos  
Dysphagia in MS – Francesca De Biagi  
Management Techniques Bladder and Bowel Problems – Sara Rinaldi and Piet Eelen

**KEY NOTE III: Treating progressive MS: the Disease Modifying Drugs Perspective**  
**Marco Rovaris**

**KEY NOTE IV: Rehabilitation in Progressive MS**  
**Jenny Freeman**

**KEY NOTE V: Implications of Exercise in Progressive MS**  
**Ulrik Dalgas**

#### PRACTICAL SESSION 2

Robotic and Wearable Devices – Davide Cattaneo, Giampaolo Brichetto and Margherita Monti Bragadin  
Neuropsychological Rehabilitation – Cognitive Training and other Techniques – Jessica Podda and Andrea Tacchino  
Priming Rehabilitation – Ludovico Pedullà and Marco Bove



## Fellowship Exchange Programme

The current call for the fellowship exchange programme is open with application deadline set on July 1st and December 1st 2020. 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: [www.eurims.org](http://www.eurims.org).

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

### 2019 beneficiaries of a RIMS Fellowship:



**Gogem Topcu (UK)**

**FROM**

University of Nottingham,  
United Kingdom

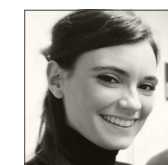
**TO**

Amsterdam University Medical  
Centre, The Netherlands

**PERIOD:**

14.10.2019 till 18.10.2019

Gogem: "I have enjoyed every second of my visit to the MS Centre Amsterdam – I have met wonderful people there, made excellent connections and learnt a lot. Huge thanks to the Amsterdam team for hosting and organising a brilliant programme for me, and to the RIMS for giving me this opportunity."



**Verónica García (ES)**

**FROM**

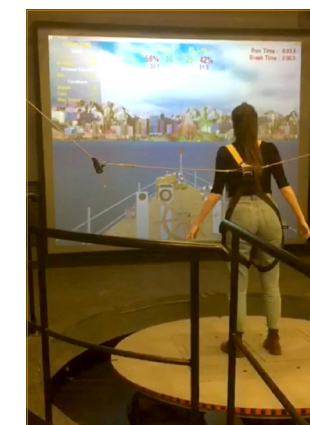
University of Valencia, Spain  
University of Cagliari, Italy

**TO**

Sheba Medical Center,  
Tel Aviv, Israel

**PERIOD:**

11.01.2020 till 16.01.2020



**Gloria Perini (IT)**

**FROM**

Don Carlo Gnocchi  
Foundation, Milan, Italy

**TO**

Sheba Medical Center,  
Tel Aviv, Israel

**PERIOD:**

14.03.2020 till 22.03.2020

# RIMS Grant Programme

## RiGra 2021: Criteria for Applications

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

### Mandatory criteria

- Applicants must be a RIMS member (at the individual or center level) at the time of submission.
- Only electronic submissions (via email), submitted within the deadline (December 1) are accepted.

### Non-mandatory criteria

- The applicant is an early career researcher or a young clinician (<36 year old).
- Multi-center and international collaborative projects, particularly between RIMS members/centres (at least two different countries).

### Judging criteria

- Projects feasibility with the amount granted
- Relevance for RIMS is well described
- Provide a detailed budget

### Grant amount

In the 2020 call, one project will be granted financial support.

### Deadlines

Submission Deadline:  
1st December 2020, 23h45  
Application details can be found on the RIMS website  
at Career advancement: [www.eurims.org](http://www.eurims.org)

### Announcement winner

2019: March 2020  
2020: February 2021

# Project APPECO

## ‘Applying Evidence with Confidence in MS Rehabilitation’

Lead: Martin Heine,  
Heleen Beckerman,  
Vincent de Groot

### AIM

The RIMS project ‘Applying Evidence with Confidence in MS Rehabilitation, or so-called APPECO project, is a living documentation system aiming to translate scientific evidence about MS rehabilitation treatments to clinical practice, and can be found at [www.appeco.net](http://www.appeco.net). The most important goal of this open access application is to make evidence in MS rehabilitation real-time accessible, and to support health professionals worldwide in treating patients with MS. It bridges the gap between systematic reviews and clinical practice, and offers a solution for MS therapists who do not have the ability to assess systematic reviews on their merits and could generalize the findings to their clinical practice.

### PROGRESS SINCE INCEPTION

In 2015-2018, we were able to develop an online platform for the identification, inclusion, data-extraction, analysis and reporting of randomized clinical trials on MS rehabilitation for fatigue and cognitive impairments. Thus far, more than 140 clinical trials have been added to APPECO, already providing insight into the effectiveness of a range of interventions on these important patient symptoms. The financial support of Sanofi Genzyme is highly appreciated.

The great amount of scientific literature continuously being published makes it difficult for any health professional to keep his/her knowledge up to date. A possible aid would be a “living documentation system”, to which relevant data from new publications is continuously added. This would make it possible for a broad medical user group to always have the latest evidence on various interventions available. The target users of APPECO are all physiotherapists, occupational therapists, psychologists, clinical neuropsychologists, social workers, speech therapists, MS nurses, rehabilitation physicians, neurologists, residents and students, further summarized as MS therapists, working with patients with MS in various community-based and institutional health care settings in- and outside Europe. Health care professionals can make a synthesis of the information on their turn, to inform persons with MS on evidence-based rehabilitation treatments.

In 2018, the APPECO website was upgraded to a user-friendly and professional web-environment. Per type of rehabilitation treatment APPECO displays the total number of studies, quality of evidence, and short and long-term effects of the treatment. In a simple and elegant way, for each intervention it is shown whether the intervention has a significant positive effect or not. Effect sizes and their 95% confidence intervals are graphically presented relative to the duration of the intervention. Three quality stars are assigned to each study in order

# Project APPECO

to help the user determine the best evidence through clinical and academic reasoning. Studies can be filtered by using these quality stars, for example by only viewing studies of sufficiently high quality or only studies with a specific domain as primary outcome. The 53 outcome domains (fatigue, cognition, and 51 others) are logically grouped according to the International Classification of Functioning, a common model in rehabilitation medicine. More importantly, for each study intervention, a structured summary according to the Template for Intervention Description and Replication (TiDIER checklist) is available, which can be saved/printed in pdf format for clinical use.

## POINTS OF ACTION IN 2019

To fully exploit the potential of what APPECO can offer to the MS clinical community, the platform had to be expanded beyond fatigue and cognition. With financial support from the Dutch MS Research Foundation and Roche, the project team has now been able to expand APPECO with the evidence on interventions related to mobility, depression and pain. This resulted in the data extraction of a further 100 MS rehabilitation studies and 500 additional outcomes derived from these studies.

## FUTURE POINTS OF ACTION

An urgent key step for the near future is approaching study authors of clinical trials on the APPECO website to consider uploading relevant “therapy tools” to facilitate implementation of evidence-based MS rehabilitation.

Furthermore, the project team expects in the short term the development of interactive content and e-learning materials that will guide the clinician using the platform, and to facilitate evidence-based clinical decision making (with confidence), and guide organisations of health care professionals in using the platform in guideline development and care pathways.

RIMS is a not-for-profit European Network for best practice and research in MS Rehabilitation for Rehabilitation in MS ([www.eurims.org](http://www.eurims.org)), that cannot carry out its work without the generous support of its sponsors. With the financial support of multiple sponsors other MS symptoms as focus areas will be added to APPECO. A complete and up-to-date living documentation system of randomized clinical trials on MS rehabilitation will help RIMS to building a research agenda to prioritize future research in the field of MS rehabilitation.

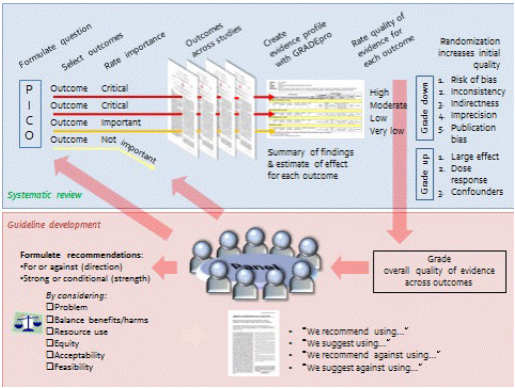
# Project EAN Guidelines on Palliative Care in MS

The Clinical Practice Guideline on Palliative Care of People with Severe MS was a joint initiative of the European Academy of Neurology (EAN), RIMS, the European Association for Palliative Care (EAPC), and has been endorsed by the ECTRIMS and by the MS International Federation (MSIF).

The guideline was devised by a **task force** of health professionals from three disciplines (neurology, palliative care, and rehabilitation), methodologists, and patient advocates from nine European countries (Bulgaria, Germany, Denmark, Israel, Italy, the Netherlands, Serbia, Spain, and the UK). The project was carried over from 2017 and 2019, following the Grading of Recommendations Assessment, Development and Evaluation (**GRADE**) methodology [1].

The task force formulated **10 clinical questions**, involving health professionals and over 950 MS patients and caregivers from the participating countries via an online web survey and focus group meetings [2]. The clinical questions encompassed general and specialist palliative care, advance care planning, discussing with health professionals the patient's wish to hasten death, symptom management, multidisciplinary rehabilitation, interventions for caregivers (two clinical questions), and interventions for health professionals (two clinical questions).

For six of these questions (general and specialist palliative care, symptom management, multidisciplinary rehabilitation, and interventions for caregivers) **34 evidence-based recommendations** were produced (one of which was a strong recommendation) and one good clinical practice point. Six additional good clinical practice points (overall, **seven good clinical practice points**) were formulated for the clinical questions where evidence was lacking: advance care planning, discussion



with health professionals the patient's wish to hasten death, and interventions for health professionals. Further research on the integration of palliative care and MS care is needed, including consideration of the various models of palliative care provision. Research is also needed on advance care planning, support and training programs for caregivers, and on training programs for health professionals caring for this patient population.

## References

1. Leone MA, Keindl M, Schapira AH, Deuschl G, Federico A. Practical recommendations for the process of proposing, planning and writing a neurological management guideline by EAN task forces. Eur J Neurol 2015; 22: 1505-1510. doi:10.1111/ene.12818.
2. Köpke S, Giordano A, Veronese S, et al. Patient and caregiver involvement in formulation of guideline questions: Findings from the EAN Guideline on Palliative Care of People with Severe Multiple Sclerosis. Eur J Neurol. 2019; 26(1):41-50.



## Project Rethinking MS (European Brain Council)

**On 6 November 2019, the European Brain Council (EBC) and The Health Policy Partnership (HPP) were able to present preliminary reports from the RETHINKING MS project during a meeting of the MEP Interest Group on Brain, Mind and Pain.**

Attendees were welcomed by **Joke Jaarsma, European Federation of Neurological Associations (EFNA)**, and **Deirdre Ryan, Pain Alliance Europe (PAE)** – the group's coordinating organisations. Two of the group's MEP co-chairs addressed the audience: **Tilly Metz MEP (Greens, Luxembourg)** and **Jaroslav Duda MEP (EPP, Poland)**. They both stressed their personal and professional interest in this topic – and referenced figures which highlight why these disease areas are such a cause for concern. MEP Duda reference a recent study which estimated neurological disorders to be the world's largest cause of disability in 2015 and the second largest cause of global death. He also spoke of how 179 million people in Europe live with a brain disorder, and an additional 150 million with chronic pain. MEP Metz acknowledged that member states retain large competencies in the area of health, but she stressed that EU action can provide much added value.

EBC and HPP have been working together to create RETHINKING MS, a new project calling for change in how MS care and support is organised. The project began in 2018. EBC and HPP collaborated with experts from across Europe to build an interdisciplinary consensus around practical and sustainable policy responses to MS at the European level. Building on the findings from the 2017 Value of Treatment report, this pan-European policy narrative identifies key challenges in MS care and makes recommendations for how they can be addressed.

As different countries face specific challenges, it is important to consider the national context when advocating for policy change. For this reason, RETHINKING MS also takes an in-depth look at Denmark, Italy, Romania and Spain. The dedicated reports on each country, now available for Denmark, Italy and Spain, provide a more specific analysis of MS policy, care and support available for people with MS in each country.

Opening presentations on European disparities in access to neurological and pain treatment were from **Neil Betteridge, European Alliance for Patient Access (EAFPA)** and **Donna Walsh, EFNA**. Both explained how access issues are increasingly focused on appropriate services, as well as access to innovative but expensive therapies.

The country profiles were presented with the support of the speakers previewing the findings of the RETHINKING MS project. Pedro Carrascal (President, European Multiple Sclerosis Platform), Prof. Per Sorensen (Neurologist from Denmark) and Prof. Jenny Freeman (Rehabilitation Specialist from the UK) presented individual case studies in MS, highlighting the disparities in MS care and support across the EU and what possible policies could be put in place to help achieve equitable access to care.

Following these presentations on the MS case study, a moderated discussion was opened by EBC Executive Director, **Frederic Destrebecq**, with discussion with a wide group of key stakeholders: **Professor Mario Battaglia, President of the Italian Association of MS [AISM]**; **Valentina Polylas, Director of the European Regional and Local Health Authorities**; **Maira Tzitzika, MS Psychologist in Greece and expert for the RETHINKING MS project**; **Dr Brona Fullen, President Elect, European Pain Federation**; **Dr Stanimir Hasardzhiev, Secretary-General, Patient Access Partnership [PACT]**; and **Sylvain Giraud, Head of Unit, DG SANTE B1, Health Systems, at the European Commission**.

The full detailed event report is available on the Brain Mind Pain Interest Group website.

## Our Partners



ECTRIMS is a professional organisation dedicated to the understanding and treatment of Multiple Sclerosis. A joint RIMS-ECTRIMS conference is organised every 3 years. This year we had our joint conference in Stockholm from September 11-13, 2019.

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



Founded in 1989, EMSP is a team of experts in MS and advocates in health and social policies who represent 41 national MS patient organisations in 36 countries and over 770,000 people with MS in Europe. Their needs are the main focus of its advocacy and awareness-raising campaigns, to influence European decision-makers and EU policy-makers. We gather and provide knowledge and expertise to relevant stakeholders and encourage high quality research and the dissemination of excellent, evidence-based information on MS. EMSP's flagship projects aim to improve quality of life of people with Multiple Sclerosis, as well as access to ensure that they receive high quality equitable treatment, care and employment and that they have a real voice in determining their own objectives and priorities. RIMS collaborated in 2017 with EMSP on the rehabilitation module of the MS Nurse Pro e-learning online training system for MS Nurses and to the Ready for Work Guidelines, another important EMSP project focusing on the communication between healthcare professionals and patients, as well as promoting 'workability' (supporting people into employment) as the priority outcome of the clinical care.

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



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. Ongoing collaboration between RIMS and the IJMSC is facilitated by a memorandum of understanding. Current projects include the publication of a theme issue with content from RIMS members in 2020.

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



The MS International Federation is a unique global network of MS organisations, people affected by MS, volunteers and staff from around the world. Our movement is made up of 48 MS organisations with links to many others.

For more information, please visit [www.msif.org](http://www.msif.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, the official journal of RIMS.

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



## Partnership Work

### MS Nurse PRO (EMSP)

The European Multiple Sclerosis Platform (EMSP) in partnership with Rehabilitation in MS (RIMS), the International Organisation on MS Nurses (IOMSN) and the European Committee for Treatment of Multiple Sclerosis (ECTRIMS) launched the 6th module focussing on Rehabilitation of the MS Nurse PROfessional programme, the first accredited e-learning curriculum for nurses and allied health professionals specializing in the field of multiple sclerosis (MS).

In 2019, 7772 people registered for the programme, of who 2806 people completed the course. The annual increase of about 600 registrants and 350 completers indicate the ongoing success of the course.

The rehabilitation module was launched in Romania in 2019. The committee performs an ongoing monitoring of the need for updates and additions.

The programme is accredited for nurses, but freely available for all health care professionals.

For more information, please visit:

<http://www.msnursepro.org/index.aspx>



# Our Sponsors

In 2019, 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.

## MAIN PARTNERS



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



“It is a privilege for Roche to support RIMS in their mission to raise the profile of rehabilitation and thereby transform the lives of people living with MS.”



“Founded in 2011, MedDay is a pioneering biotechnology company addressing neurodegenerative disorders in areas of potential high unmet medical needs. MedDay explores brain metabolic pathways through its innovative and proprietary research platform, SPECMET, to support the discovery of additional assets. At MedDay, we are driven by patients’ needs, placing people living with neurodegenerative conditions and their families at the heart of everything we do.”

## ANNUAL CONFERENCE EXHIBITORS



## WORKSHOP EXHIBITORS





## Why become a Member of RIMS?



### Annual Conference and Workshop at reduced registration fee

Individual members as well as a maximum of six professionals from a member centre are able to get a RIMS Annual Conference and RIMS Workshop 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 Programme

RIMS offers a Grant Programme to support multi-centre studies, a shared best practice network, or a SIG project. RIMS financially supports one grant each year.



### Get access to E-Educational Material

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 rehabilitation professionals, 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.

## Membership Types & Fees



<b>€25</b> (€30,25 incl VAT) <b>STUDENT</b> Annual Membership Fee
<b>€100</b> (€121 incl VAT) <b>INDIVIDUAL</b> Annual Membership Fee
<b>€400</b> (€484 incl VAT) <b>CENTRE</b> Annual Membership Fee

The annual membership fee (incl VAT) 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.

**IMPORTANT:** Always mention your Membership ID and name or institution when paying via bank transfer.

All members need to create an online account on the RIMS website. Bank transfer payment of Membership fees is preferred.

### 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 transfer)

TO: Seauton BVBA  
 Vaartdijk 3/002  
 3018 Wijkmaal  
 BE0464 882 990

BANK: Bank J. Van Breda & CO NV  
 Mechelsesteenweg 147  
 3020 Herent

IBAN: BE89 6451 2078 9485  
 SWIFT (BIC): JVBABE22

# Contact Information



**DAPHNE KOS**  
(Current) President  
daphne.kos@kuleuven.be



**VINCENT DE GROOT**  
(Past) President  
v.degroot@vumc.nl



**JAUME SASTRE GARRIGA**  
Treasurer  
jsastre-garriga@cem-cat.org



**CHRISTIAN DETTMERS**  
Membership Officer  
c.dettmers@kliniken-schmieder.de



**PIET EELEN**  
SIG Officer  
piet.eelen@mscenter.be



**NELE COULIER**  
RIMS Secretariat  
secretariat@eurims.org



**RUTH BLOEMEN**  
RIMS Secretariat  
secretariat@eurims.org



**SOFIE VANDENBERGH**  
RIMS Secretariat  
secretariat@eurims.org



**PETER VAN DEN NIEUWENHOF**  
Webmaster  
secretariat@eurims.org

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KU Leuven  
Tervuursevest 101 box 1501  
3001 Heverlee  
Belgium

[secretariat@eurims.org](mailto:secretariat@eurims.org)  
[www.eurims.org](http://www.eurims.org)