RIMS | REHABILITATION IN MULTIPLE SCLEROSIS

ANNUAL REPORT 2020

Message from the President

2020 ... a challenging year!

In the previous annual report (2019), we were looking forward to 2020 as "a challenging year". Although we were unaware of the COVID-19 pandemic we were encountering at that time... we were right... 2020 turned out to be a very challenging year!

Challenge #1:
Ensure continuity of rehabilitation practice and research

Due to restrictions to prevent further spread of the virus, many rehabilitation and research facilities temporarily closed down, provided services remotely or had to reorganize to guarantee safety and avoid risk of COVID-19 contamination. Probably every single rehabilitation practitioner and researcher was challenged to adjust the services to the circumstances and to ensure continuity of rehabilitation practice and research.

RIMS contributed to the development of the "Global COVID-19 advice for people with MS" of MS International Federation (MSIF), stimulating people with MS to continue rehabilitation activities as much as possible.

Challenge #2:
Use of technology in practice

To ensure the continuity of rehabilitation practice, the use of technology in rehabilitation accelerated tremendously: telephone/video-consultations, online training possibilities, smartphone applications, wearables .... and many more technology-supported practices were introduced or increasingly applied. Many rehab professionals expanded their expertise with new skills to realize these practices and to support people with MS in using technology.

It is interesting to look ahead wondering whether this trend will continue. RIMS distributed a survey within the RIMS and ECTRIMS network in which 2 to 13% of the responders indicated to continue using specific e-health technology in future.

To further contribute to the optimization of using technology in MS rehabilitation, RIMS is partner in several technology-related initiatives and projects (Patient Reported Outcome Measures (PROMS), MS Data Alliance, MS Patient Squad; Digital Solutions).

Challenge #3
Stay connected

Although RIMS was not able to keep its promise to welcoming you in Belgium in person in 2020, we were able to organize our annual conference in digital format in December 2020. It was a very successful meeting with many inspiring lectures by experts in the field of the theme "Collaborate and Engage in Personalized Rehabilitation". During the live discussion panels, the presenters had very active and inspiring interactions with the audience by means of the chat and polls. To facilitate networking, we created breakout rooms during the breaks and smaller meeting sessions for the Special Interest Groups (SIG's). Apart from the conference, two of our SIG's organized an in-between meeting in October as well.

We all learned a lot, not only about how to collaborate and engage in personalized MS rehabilitation, but also how to stay connected with each other during digital meetings and beyond. We will certainly use this experience for the organisation of our next annual conference(s), SIG meetings and other educational and networking events.

Challenge #4
Promote high-quality MS Rehabilitation

RIMS continued its work to promote high-quality MS rehabilitation by taking the lead or being part of several initiatives: Applying Evidence with Confidence in MS Rehabilitation (APPECO), MS Nurse PRO and Atlas of MS.

RIMS contributed to the conferences of the World Federation of NeuroRehabilitation (WFNR) and the European MS Platform (EMSP).

The special issue on "Rehabilitation in MS" of the International Journal of MS Care (produced by the network of RIMS) and the "Clinical Practice Guideline on Palliative Care of People with Severe MS" (initiated by European Academy of Neurology, RIMS and the European Association for Palliative Care) were published in 2020. Publication of report finding of the project "Rethinking MS in Europe" (European Brain Council) was submitted in 2020.

Looking ahead to 2021

2021 ... again a very exciting year ... along with the newly constituted Executive Board of RIMS I look forward to further expand high-quality MS rehabilitation in Europe and beyond and face (new) challenges!

2021 ... again a very special year ... RIMS will celebrate its 30th anniversary!
When the situation does not allow to celebrate this all together in person, we will reach out to you otherwise and keep the drinks for 2022, promised!

Gratefulness

I would like to thank all EB members who left the board, SIG chairs and co-chairs and the Seauton team for their commitments to create a unique organisation in MS rehabilitation.

And last, but certainly not least: thank you to all members and partners for your loyalty and commitment to RIMS! I look forward to meeting you all again in 2021!

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 practictioners 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 CMSC (the Consortium of Multiple Sclerosis Centers), 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), IJMSC (International Journal of MS Care) and WFNR (World Federation for NeuroRehabilitation).

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

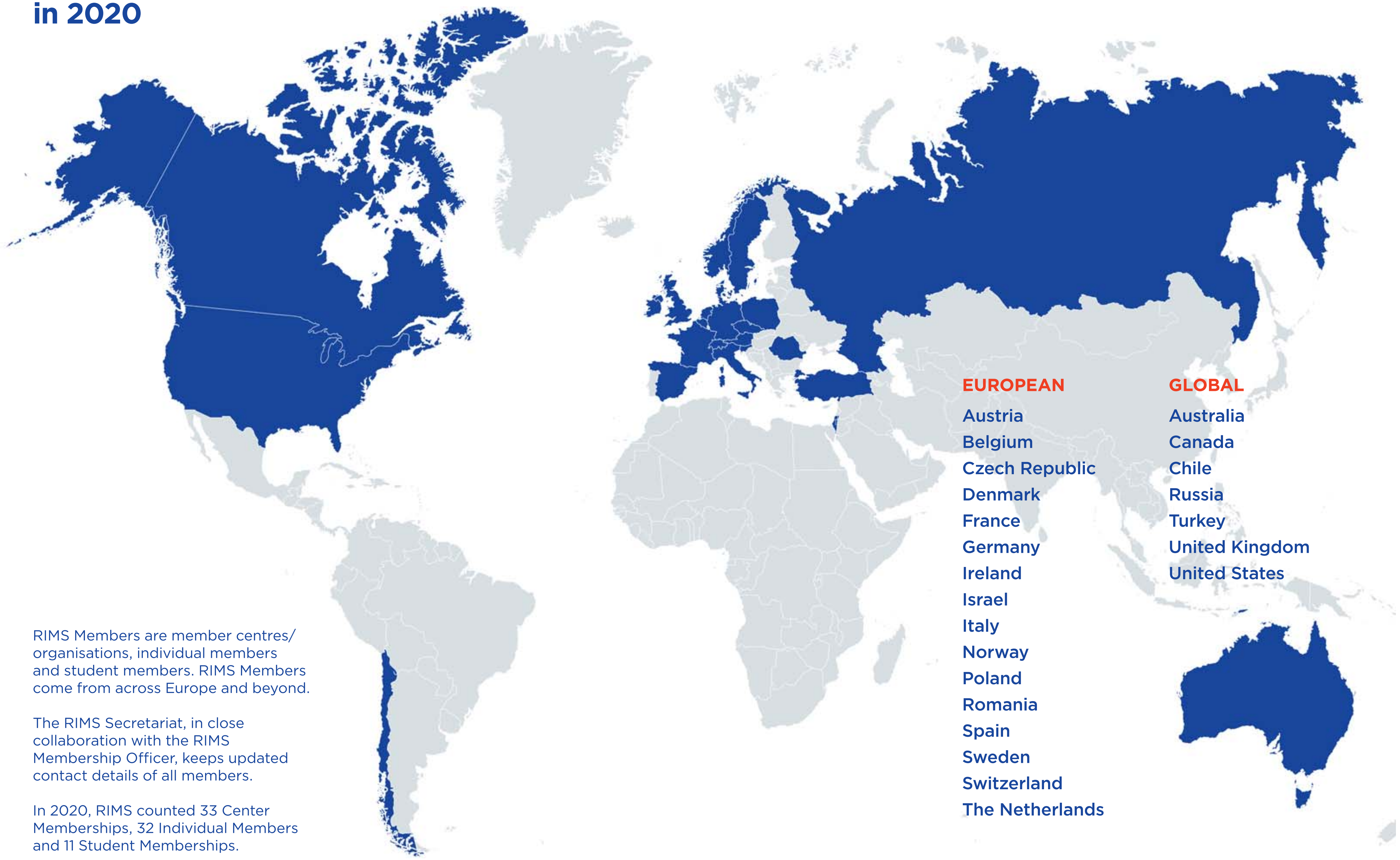
- Raise the profile of MS rehabilitation with the best researchers and practitioners.
- Improve the understanding of rehabilitation and its relevance at every stage of MS.
- Stimulate research and its translation to practice.
- Educate rehabilitation practitioners.

Our Members in 2020

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 2020, RIMS counted 33 Center Memberships, 32 Individual Members and 11 Student Memberships.



EUROPEAN

- Austria
- Belgium
- Czech Republic
- Denmark
- France
- Germany
- Ireland
- Israel
- Italy
- Norway
- Poland
- Romania
- Spain
- Sweden
- Switzerland
- The Netherlands

GLOBAL

- Australia
- Canada
- Chile
- Russia
- Turkey
- United Kingdom
- United States

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.

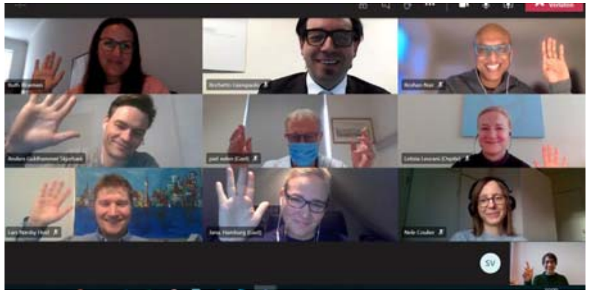
THE EXECUTIVE BOARD OF RIMS, FROM LEFT TO RIGHT:
Piet Eelen (BE), Anders Skjerbaek (DK), Jenny Freeman (UK), Christian Dettmers (DE), Vincent de Groot (NL), Daphne Kos (BE), Giampaolo Brichetto (IT), Jaume Sastre Garriga (ES)

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

2020-2023

At the end of 2020, the election of our 4 new Board Members took place. They have been approved by the RIMS Members during the General Assembly, which took place on Friday, December 4 during our Annual RIMS Conference.

We would like to thank Vincent de Groot, Jaume Sastra-Garriga, Christian Dettmers and Jenny Freeman for all their work and efforts they have made as a RIMS Board Member over the past years.



VIRTUAL MEETING WITH THE NEW RIMS BOARD, FROM LEFT TO RIGHT:
Ruth Bloemen (Secretariat), Giampaolo Brichetto (IT), Roshan das Nair (UK), Anders Skjerbaek (DK), Piet Eelen (BE), Letizia Leocani (IT), Lars Hvid (DK), Jana Pöttgen (DE), Nele Coulier (Secretariat), Daphne Kos (BE)

Name	Background	Country
Daphne Kos President (since June 2019)	Occupational Therapist	Leuven & Antwerp Belgium
Giampaolo Brichetto Vice-President & Secretary	Rehabilitation Physician	Genova Italy
Anders Skjerbaek Treasurer	Physiotherapist	Ry & Haslev Denmark
Roshan das Nair Membership Officer	Psychologist	Nottingham United Kingdom
Piet Eelen SIG Officer	Nurse Specialist	Melsbroek Belgium
Jana Pöttgen Fellowship Officer	Psychologist	Hamburg Germany
Letizia Leocani RiGra Officer	Neurologist	Milan Italy
Lars Hvid Communication Officer	Exercise Physiologist	Aarhus Denmark

Special Interest Groups (SIG)

Special Interest Groups (SIG's) aim to promote research, stimulate evidence-based rehabilitation and to support people with MS and their caregivers in living with MS. 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 often part of the meeting.

Bladder, Bowel & Sexuality

Chair
Doreen McClurg, United Kingdom
Doreen.McClurg@gcu.ac.uk

Co-chair
Sara Rinaldi, Italy
sara.rinaldi@aism.it

Communication & Swallowing

Chair
Leonie Ruhaak, the Netherlands
l.ruhaak@amsterdamumc.nl

Co-chair
Francesca DeBiagi, Italy
Francesca.debiagi@ospedalesancamillo.net

Mobility

Chair
Carme Santoyo, Spain
csantoyo@cem-cat.org

Co-chair
Lousin Moumdjian, Belgium
lousin.moumdjian@uhasselt.be

Occupation

Chair
Inger Grethe Loyning, Norway
ingergrethe.loyning@mssenteret.no

Co-chair
Sofie Ferdinand, Belgium
sofie.ferdinand@mscenter.be

Patient Autonomy

Chair
Anne Christin Rahn, Germany
anne.christin.rahn@uni-oldenburg.de

Co-chair
Andrea Giordano, Italy
andrea.giordano@istituto-besta.it

Psychology & Neuropsychology

Chair
Jana Pöttgen, Germany
j.poettgen@uke.de

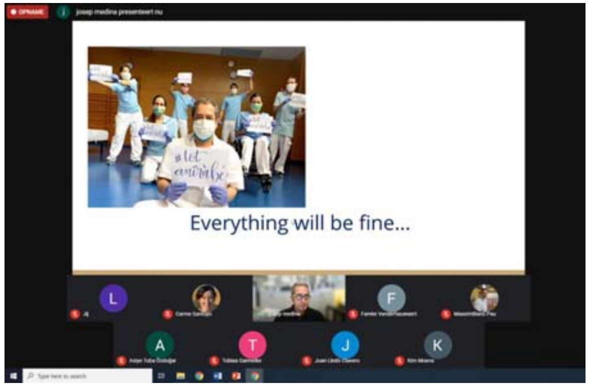
Co-chair
Anita Rose, United Kingdom
draerose@btinternet.com

Special Interest Groups
Meeting Schedule 2020

Due to the COVID-19 pandemic, most of the SIG in-between meetings were postponed to a later moment. However all SIG Groups organised an online meeting during the RIMS Conference on December 5, 2020.

SIG Mobility
October 16, 2020
Online Meeting

SIG Communication & Swallowing
October 19, 2020
Online Meeting



Everything will be fine...

SIG Report
Mobility

In-between meeting for
SIG Mobility
Online meeting

↘ 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.

↘ In-Between Meeting

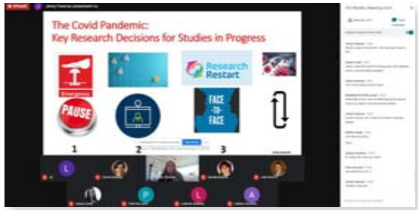
Where?
Online meeting

When?
October 16, 2020

Topic?
Overcoming Challenges and Creating Opportunities in MS rehabilitation

Participants
Carme Santoyo (SIG Chair) (ES), Lousin Moumdjian (SIG Co-chair) (BE), Massimiliano Pau (IT), Michela Deidda (IT), Klaus Pfeifer (DE), Famke Vanderhauwaert (BE), Kamila Řasová (CZ), Peter Feys (BE), Nickeline Schmidt Larsen (DK), Alexander Tallner (DE), Bernardita Soler (CL), Jenny Freeman (UK) , Alon Kalron (IL), Renee Veldkamp (BE), Cristina Bungardean (RO), Fanny Van Geel (BE), Noemí Martínez Lerín (ES), Rachma Scheffer - van Woerden (NL), Alexander Tallner (DE), Karin Weidenholm, Catherine Graham, Francesca Estrada (CH), Veronica G Garcia Marti (ES), Johanna Jonsdottir (IT), Blathin Casey (IR), Ludovico Pedullà (IT), Griet Gysemberg (BE), Edwin Roger Meza Murillo (ES), Ulrik Dalgas (DK), Tobias Gæmelke (DK), Feray Güngör (TR), Tori Smedal (NO), Elaine Coulter (UK), Cecilie Thrue (DK), Lisa Tedesco Triccas (BE), Lubomír Rodina (CZ), Monika Rode, Mohamed Belghith (TN), Una Nedeljkovic (RS), Iratxe Elorriaga Mínguez (ES), Izaskun Yeregui Prieto (ES), Erika Otxoa Rekagorri (ES), Klaus Gusowski (DE), Zuhal Abasıyanık (TR), Leen Boonen (BE), Rakel Berriozabalgoitia (ES), Begoña Cantero (ES), Lide Etxeberria (ES), Sofía Valdenebro (ES), Lander Álvarez, Mailaen Villaluenga (ES), Nelva Vallarino-Bernal (CR) , Asiye Tuba Ozdogar (TR), Kardelen Akar (TR), Kim Moens (BE), Marie Verellen (BE), Hildegard Van den Broek (BE), Marie-Louise Jørgensen (DK), Angela Davies Smith (UK), Georgia Andreopoulou (UK), Susan Coote (IE), Mary Davis (IE), Sofie Martin (UK), Dualta Griffin (IR), Tania Burge (UK), Siv Ohlin (SE), Karin Riemann-Lorenz (DE), Olivia Powell (UK), Ingrid Galán (ES), Yonca Zenginler Yazgan (TR)

SIG Report
Mobility



↘ Summary of the meeting

The outbreak of the coronavirus and the uncertainty about the development of the pandemic during the 2020 made us change our original plans for our 23rd SIG mobility in-between meeting, which was to take place in Bilbao. Therefore, the date was maintained but the meeting was organized in virtual format.

This change allowed for exploring new ways of functioning, facilitating the attendance of old and new colleagues as there weren't any travel or accommodation expenses. With this vision, but also focusing on maintaining the high-quality standards of our educational and networking yearly event we prepared a one-day meeting entitled “Overcoming Challenges and Creating Opportunities in MS rehabilitation”.

The program enclosed 3 keynotes and 12 oral presentations about experiences or case studies with digital therapy during COVID times both in clinical practice, education, or research, but also specific topics and results with fellow SIG mobility members. The virtual format provided us the opportunity to learn, interact and share clinical and research experiences in a really effective way.

The virtual SIG Mobility meeting was performed by Google Meet and followed for around 75 attendees from 18 different countries, mostly from Europe but also from Chile, Canada, Costa Rica and Australia. The SIG chair and co-chair prepared a technical guideline for lecturers and attendees, to facilitate the development and communication during the meeting. There were no remarkable technical problems and the meeting was recorded and shared with the participants after the consent of all the lecturers.

SIG Report
Mobility

↘ Summary of the meeting

Last 5th of December, during the RIMS Annual Conference, the SIG Mobility organized a Virtual Workshop with the title “*Understanding and guiding patient’s mobility throughout the disease progression*”. For more than two hours, 6 interdisciplinary specialists of neurorehabilitation in MS offered us a comprehensive and enriching overview about how to accompany patients during the evolution of the disease.

Dr. Giampaolo Brichetto offered a wide vision on patient and clinician reported outcomes to identify and predict MS progression. Mr. Bert Laermans offered a very visual and practical update on orthotic devices to facilitate gait in MS. Prof Eva Swinnen talked about her research with interesting finds on patients and health professionals' opinion about lower limb orthoses. A joint talk between Gael Spruyt (psychologist) and Johan Van Nieuwenhoven (physical therapist) focused on how to get an appropriate walking aid taking into account the impact and acceptance of mobility devices. Finally, we enjoy the very interesting testimony of David Seffer, who has MS and explained his experience since the diagnosis, along the disease progression and also during the Covid19 times.

More than 80 attendees from over 20 countries joined the session that was developed by Zoom with no remarkable technical difficulties, with a high satisfaction and participation from the audience.

↘ Future Plans & Meetings

↘ Next in-between meeting:
Bilbao Autumn 2021, depending on the pandemic situation

↘ SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Topic?
Understanding and guiding patient’s mobility throughout the disease progression

SIG Report
Communication & Swallowing

↘ 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.

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.

SIG Report
Communication & Swallowing

Summary of the meeting

The aim of the meeting was to share news about ongoing projects of the SIG as well as to begin new collaborations for future research activity.

Leonie started the meeting with a summary on ongoing SIG projects:
↘ DYMUS project (RIMS Grant 2015): A still ongoing project of the translation and validation of DYMUS into Spanish and Dutch. All data have been collected. Current status unclear.
↘ Systematic review (RIMS Grant 2016): A systematic review on dysarthria in MS. Unfortunately, a very similar review was published in the end of 2018, so a rethinking of the project should be done.
↘ Collaboration on a narrative review on swallowing and communication problems in MS. A revision of the paper has been resubmitted. We are awaiting approval.

The other part of the meeting was dedicated to a new collaboration project: the translation and validation of APACS test. Leena Maria Heikkola made an introduction about pragmatics and MS. She defined pragmatics and she cited few studies on the matter. She highlighted that pragmatics issues in MS are often underestimated and she concluded that there is a lack of tools that assess this construct.

Giorgio Arcara then presented the test APACS (Assessment of Pragmatics Abilities and Cognitive Substrates; Arcara and Bambini, 2016). APACS assess pragmatics abilities and it is easily administrable with no specific training needed. APACS has already been translated in multiple languages by projects all over the world. The group discussed the possibility of beginning a new collaboration intended to translate the test in Finnish, Flamish, Dutch (and maybe Spanish) and adapt the English version to Australian patients. For that collaboration a RIMS grant will be asked, with Leena Maria Heikkola as first applicant and Giorgio Arcara as the coordinator of the project. A shared document was created in order to write the project and in order to fulfill the grant application.

Future Plans & Meetings

↘ On the next meeting scheduled on the 4th of November the members interested in the APACS project will better discuss participation in the project and how to divide the budget that will be asked. A few more meetings on APACS will be planned.

↘ Next in-between meeting:
depending on the COVID-19 situation

In-Between Meeting

Where?
Online Meeting

When?
October 19, 2020

Topic?
Online Update

Participants
Leonie Ruhaak (SIG Chair) (NL), Francesca De Biagi (co-chair) (IT), Giorgio Arcara (IT), Leena Maria Heikkola (FI), Antonella Nota (BE), Hans Bogaardt (AU), Sara El-Wahsh (AU), Alice Giachero (IT)

SIG Report
Communication & Swallowing

Summary of the meeting

COVID-19

We have discussed how our work settings changed during COVID-19. A few of us started to do paper work and literature research during the first lock down. Some others had to support nurses with feeding inpatients. Soon after these first weeks plans were made to treat patients outside of the institutions; through telerehabilitation or home visits. The problem with telerehabilitation is that not in every country this way of treatment can be reimbursed. The experience of Louise with home visits is very positive, because you can see the patients in their home environment: "I can really make a difference." After a while everyone was able to see inpatients again, but less and with strict time schedules to limit the risk. It asks a lot of flexibility from us.

APACS

Leena Maria explained our plans for translation and validation of APACS. As the deadline of the RIMS Grant application has been postponed to next year, we have more time to work on it. In the winter of 2021 we will have another online meeting.

INVENTORY OF KNOWLEDGE GAPS

In our two-yearly discussions some topics tend to come back. We decided to do an inventory on knowledge gaps in the field of communication and swallowing in MS. We have started to elaborate on problems we face in diagnosing and treating dysphagia. Leonie will make a Google doc in which everyone can contribute. The link will be sent by email to the members of the SIG. During the next in-between meeting we will work further on this document, but we encourage everyone to make adjustments in the meantime.

Future Plans & Meetings

↘ Francesca De Biagi has recently resigned from being co-chair as she has changed jobs. During our meeting we have agreed on **Leena Maria Heikkola** being ad interim co-chair. During the next conference there will be an official election for chairs and co-chairs.

SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Participants
Leonie Ruhaak (SIG Chair) (NL), Mireia Alvedert Serra (ES), Leena Maria Heikkola (FI), Louise Hovald Nørgaard (DK), Hélène Mathy (BE), Sofie Noë (BE)

SIG Report
Bladder, Bowel & Sexuality

↘ 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.

↘ Summary of the meeting

Three presentations were given.

One was by Hawra Dandan and PhD student who outlined her protocol around the use of transcutaneous tibial nerve stimulation and PwMS and bladder problems.

The second was another PhD student, Christine Addington from Glasgow Caledonian University who outlined her work regarding the impact of pelvic floor dysfunction in PwMS which includes a survey and interviews.

The third presenter was Doreen McClurg who presented on the results of the MOWOOT trial. Mowoot is a device that is used for undertaking abdominal massage for people with constipation. The results appeared to be promising. The remainder of the session was a discussion on the impact of COVID on services as well as the future of the SIG.

Doreen McClurg is stepping down as chair due to work pressures and Sara Rinaldi is taking over. Several people present expressed an interest with helping to organise the SIG and it was suggested more frequent virtual meetings might be a way to encourage contact and group dynamics.

The SIG chairs would like to thank the RIMS secretariat and the members of the SIG group for their support and wish them the best for the future.

↘ Future Plans & Meetings

- Sara Rinaldi is now the chair of the Bladder Bowel and Sexual dysfunction SIG.

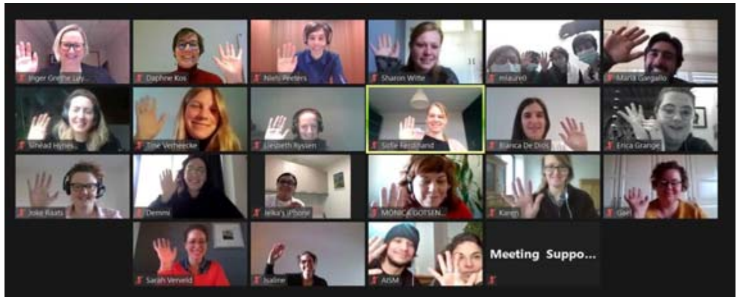
↘ SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Participants
Doreen McClurg (Chair) (UK), Sara Rinaldi (SIG Co-Chair) (IT), Antonis Kontaxakis (GR), Christine Addington (IE), Hawra Dandan (IE), Ursula Leibrecht (DE), Janneke Martens (NL), Caroline Vermeulen (BE), Lisa De Jaeger (BE), Maria Eugenia Lacasa Andrade (ES), Gloria Yaya Tur (ES), Koen Giesberts (BE), Kristel Cogghe (BE), Mie Dekeyser (BE), Kathleen Romasanta (BE), Tommy Vanwinnendael (BE), Piet Eelen (BE)

SIG Report
Occupation



Online meeting for SIG Occupation

↘ About us

The SIG Occupation is an interdisciplinary network of health care professionals with an interest in enhancing activitity 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.

↘ SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Participants
Inger Grethe Løyning (NO) (SIG Chair), Sofie Ferdinand (BE) (SIG Co-chair), Jelka Jansa (SI), Isaline Eijssen (NL), Liesbeth Ryssen (BE), Lene Moeller (DK), Tine Verheecke (BE), Heidi Van Casteren (BE), Meta Milo (BE), Leen Laureys (BE), Nicky Vandebroucke (BE), Ann Van Loock (BE), Marleen Van Den Eynde (BE), Demmi Janssen (BE), Mònica Gotsens Anguera (ES), Marià Gargallo Noval (ES), Erica Grange (IT), Judy Cornish (UK), Sinéad Hynes (IE), Niels Peeters (BE), Valeria Bergamaschi (IT), Maria Chekmeneva (RU), Daphne Kos (BE), Samantha Turner (UK), Sharon Witte (NL), Sarah Verveld (NL), Joke Raats (BE)

SIG Report
Occupation

Summary of the meeting

SIG Occupation started 2020 with planning of an in-between meeting hosted at Masku Neurological rehabilitation center. Unfortunately, the COVID-19 pandemic stopped us from arranging the event.

Our group has therefore only had one meeting this year, during the annual RIMS conference digitally on December 5th. We were happy to have a large number of participants to our digital meeting. The program was a combination of invited research presentations and interactivity discussing and sharing our clinical practice during the pandemic. Thank you for all contributors. This year, as previous years, we had participants joining our group for the first time. We are happy to increase our network and hope for possibilities to meet in person in 2021. We will plan for an in-between meeting late fall of 2021 and we will of course have a meeting during the annual RIMS conference.

Future Plans & Meetings

- Future plans: short meeting during the Annual RIMS Conference and 1 $^{1/2}$ day in-between meeting late fall 2021
- Next in-between meeting: venue to be confirmed

SIG Report
Patient Autonomy

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

Summary of the meeting

Around 14 MS health professionals and researchers (e.g. neurologists, psychologists, nurses, health scientists) participated in the 2020 SIG interim meeting during the RIMS virtual conference.

We used this meeting to update on and discuss 2 current SIG projects (information needs of people with PPMS (NIPS, RiGra project) and motherhood choice in MS). Afterwards, we exchanged on the advance care planning in people with severe MS project of the Italian group.

We shortly exchanged on grant opportunities and planned to have a virtual conference in spring 2021 and hopefully another meeting towards the end of 2021.

Future Plans & Meetings

- We would like to discuss projects of other participants at the next meeting and focus also on lifestyle.
- The next meeting will take place virtually in February or March 2021.

SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Topic?
Update on current projects

Participants
Anne Rahn (SIG Chair) (DE), Andrea Giordano (SIG Co-chair) (IT), Markus Wiemann, Rieke Schnackenberg, Chris Heesen, Alessandra Solari, Anne Christin Rahn, Andrea Giordano, Maaike Ouwerkerk, Julia Peper, Marie D'hooge, Heleen Beckerman, Klara Novotna, Gisela Carrés González, An Van Nunen

SIG Report
Psychology and Neuropsychology

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@uke.de

SIG Meeting

Where?
Online Meeting

When?
December 5, 2020

Topic?
Mindfulness, Covid-19 and future plans

Participants
Jana Pöttgen (SIG Chair) (DE), Anita Rose (SIG co-chair) (UK), Marte Forland (NO), Ana Ožura Brečko (SI), Julia Segal (UK), Gaetano Perrotta (BE), Jolien Steyaert (BE), Ana Maria Canzonieri (ES), Mieke D'hooghe (BE), Michelle Pirard (BE), Blanca De Dios Perez (UK), Sara Navarro Gómez (ES), Mònica Nieves Collado (ES), Lourdes Assens Tauste (ES), Sarah Thomas (UK), Karen Turpin (CA) , Kris Van Der Wegen (NL), Melloney Schenk (NL), Jan Holmberg (FI), Ambra Mara Giovannetti (IT), Tinne De Strooper (BE), Menno Schoonheim (NL)

SIG Report
Psychology & Neuropsychology

Summary of the meeting

In total, 18 SIG Members participated in the meeting. The chairs as well as the participants enjoyed the virtual contact and the personal exchange. The agenda of the meeting was as follow:
Welcome and general information; Exchange and talk about COVID-19 and its relation to our clinical work; Case studies; Update and first results of the Comp-ACT Project (Ambra); Organisational aspects/next in-between meeting; Conclusion and perspectives

First, the SIG meeting started with a mindful exercise, operated by Ambra Mara Giovannetti (IT). Ambra picked up the group and transferred them to a wonderful journey into self-reflection and personal selfcare.

After the exercise the participants discussed their personal / professional experiences at the moment with the Covid-19 pandemic. Most of the participants experienced a big impact and burden of COVID-19 aspects in our clinical work. The group discussed the influences and possible ways to coping with the burden.

Julia presented a case (positive thinking and dysfunctional reflection and behaviour of the objective current situation in clinical sense).

The update and first results of the Comp-ACT Project has been postponed to the next meeting.

Future Plans & Meetings

- Jana Pöttgen has been selected as an Executive Board Member, therefore, she would like to overhand the position of SIG chair. The election will take place during the next in-between meeting. If you are interested in signing up for this position, please send an e-mail to: j.poettgen@uke.de
- Online in-between meeting is planned for spring 2021

Annual RIMS Conference

The Annual RIMS Conference 'Collaborate and Engage in Personalised Rehabilitation', originally planned to take place in Leuven, was held digitally from December 4-5, 2020.

Due to the COVID-19 pandemic, we were forced to organise a digital conference. However, the RIMS Organising Committee maintained to keep the unique RIMS atmosphere during our interactive programme. The main themes of the conference were Organisation of Future-proof Rehabilitation, Creating Synergies to Optimize Practice & Research and Translating Knowledge into Practice.

We virtually welcomed 250 attendees of 29 international countries, 13 speakers and 8 chairs. Participants were able to visit our digital poster area where they could see the 24 recorded platform presentations and the 99 submitted poster abstracts.

Our RIMS President, presenting live in the digital studio.

RIMS prize winners

Best Poster Award

Verónica Gemma García Marti (ES)
Lasse Skovgaard (DK)
Rachel Dennett (UK)

Best Oral Presentation

Sarah El Wahsh (AU)
Evelyne Wiskerke (CH)
Kyra Theunissen (NL)

SIG meetings

The SIG meetings were held during the digital conference on Saturday, December 5 from 10:45 – 13:00. You can read the reports in the chapter 'SIG Report'.

General Assembly

The General Assembly was held at the beginning of the digital conference on December 4 from 9:00 – 9:30. The RIMS members of 2020 voted for the new elected Board Members and approved the financial report of 2020.

RIMS teaching courses and PhD Session

The programme was shortened to accommodate the digital character of the Conference, therefore the Teaching Courses, PhD session and Nurse Training Programme have been postponed to next year.

SAVE THE DATE

RIMS Annual Conference

THEME to be confirmed

November 25-27, 2021

INFO: www.eurims.org

RIMS
REHABILITATION IN
MULTIPLE SCLEROSIS

European network for
best practice and research

RIMS Grant Programme

RiGra 2022: 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

- The applicant 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 2021 call, one project will be granted financial support.

Deadlines

Submission Deadline: 1st December 2021, 23h45
Application details can be found on the RIMS website at Career advancement: www.eurims.org

Announcement winner

2020: February 2021
2021: February 2022

RIMS Grant Application 2019 Winner

Anne Christin Rahn

Abteilung "Internationale Versorgungsforschung", Department für Versorgungsforschung, Fakultät VI Medizin und Gesundheitswissenschaften, Carl von Ossietzky Universität Oldenburg

"Needs of people with primary progressive multiple sclerosis – a cross-cultural mixed-methods study."

SUMMARY

Primary progressive multiple sclerosis (PPMS) accounts for around 15% of people with MS and is diagnosed often when relevant persisting disability is already present. Only very limited immunotherapeutic and evaluated management options do exist. This mirrors a substantial psychological and physical burden for people with PPMS (pwPPMS). Within the NIPS (Needs of people with primary progressive multiple sclerosis) project, a scoping review on the needs and knowledge of pwPPMS will be performed assuming that very little research is available in this patient group. Based on the evidence, an interview guide will be developed. A qualitative interview study with pwPPMS and health professionals will be performed in 7 participating European countries. Based on data synthesis, a survey with health professionals will be developed and conducted. This could serve as a basis for a larger survey study to verify hypothesis on unmet needs and patient information gaps in PPMS and to set-up an intervention development agenda.

PROJECT PARTNERS

Dr. Andrea Giordano (co-applicant)
Unit of Neuroepidemiology, Fondazione IRCCS Istituto Neurologico C. Besta, Milan

Dr. Alessandra Solari
Head, Unit of Neuroepidemiology, Scientific Directorate, Fondazione IRCCS Istituto Neurologico Carlo Besta (FINCB), Milan

Dr. Sinéad Hynes, BSc, PhD, PgCert (co-applicant)
School of Health Sciences | Áras Moyola, NUI Galway

Dr Eli Silber
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Prof. Dr. phil. Sascha Köpke
Full Professor for Clinical Nursing Science, University of Cologne, Faculty of Medicine and University Hospital Cologne, Institute of Nursing Science

Prof. Dr. Christoph Heesen
Institute for Neuroimmunology and Multiple Sclerosis, Universitätsklinikum Hamburg-Eppendorf (UKE)

Patient representatives:
Dutch Nationaal MS Fonds: Yvonne Hettema & Rianne Wisgerhof-van Dijk

Project APPECO

‘Applying Evidence with Confidence in MS Rehabilitation’

Lead: Martin Heine, Heleen Beckerman, Vincent de Groot

APPECO
Evidence | Implementation | Confidence

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. 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 and upgrade an online platform for the identification, inclusion, data-extraction, analysis and reporting of randomized clinical trials on MS rehabilitation for fatigue and cognitive impairments. In total, more than 140 clinical trials were 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.

The APPECO website consists of 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 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 56 outcome domains (e.g. fatigue, depression, pain) 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 2020

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 was able to expand APPECO with the evidence on interventions related to mobility, balance, depression and pain, and to update the evidence regarding the treatment of fatigue and cognitive complaints. So far, this resulted in the data extraction and analysis of nearly 650 MS rehabilitation studies, of which 24.6% relates to cognition, 24.3% to fatigue, 23.2% to mobility, 17.0% to depression, 5.9% to balance and 5% to pain. APPECO also contains information on more than 40 other patient-reported outcomes.

FUTURE POINTS OF ACTION

The project team expects to continuously update the topics in the system and add new topics. Furthermore, interactive content and e-learning materials will become available 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.

With the financial support of multiple sponsors other MS symptoms as focus areas can 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.

Publication from this project: Heine M., Beckerman H., Hämäläinen P., de Groot V. Evidence-Based Rehabilitation for Multiple Sclerosis Made Easy: The Online Applying Evidence with Confidence (APPECO) Platform. Int J MS Care. 2020 Nov-Dec; 22(6):263-269.

Project
EAN Guidelines on Paliative Care in MS

Lead:
Alessandra Solari,
Jaume Sastre-Garriga

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 followed the Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology [1].

Ten *clinical questions* were formulated, involving health professionals and over 950 MS patients and caregivers from the participating countries via an online web survey and focus group meetings [2]. They 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 were formulated for the clinical questions where evidence was lacking: advance care planning, discussion with health professionals of the patient's wish to hasten death, and interventions for health professionals.

This Guideline has been simultaneously published (open access) in the European Journal of Neurology (EAN official journal) [3], and in the Journal of Palliative Medicine (EAPC official journal) [4]. A commentary was also published in the Multiple Sclerosis Journal [5], and news have been posted on the EAN Pages (https://www.eanpages.org/2020/07/13/new-ean-guideline-on-palliative-care-of-people-with-severe-progressive-multiple-sclerosis) and on the EAPC blog (https://eapcnet.wordpress.com/2020/06/29/new-guideline-on-palliative-care-for-people-with-severe-multiple-sclerosis). Such publications and initiatives make the dissemination phase easier within the scientific community. However, we acknowledge that for the implementation phase behavioral and organizational changes are surely needed.

Besides providing evidence-based guidance to health care professionals involved in the care of people with severe, progressive MS, this Guideline emphasizes the need for further research on the integration of palliative care and MS care, 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 care professionals caring for this patient population.

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5. Solari A, Oliver D; EAN Guideline Task Force. Palliative care in multiple sclerosis: European guideline. Mult Scler 2020; 26(9):1009-1011.

Project
Rethinking MS in Europe

RIMS' lead:
Jenny Freeman

Between Nov 2018 – 2020, RIMS was a member of the expert advisory group for an important European Brain Council and Health Policy Partnership initiative. The purpose was to create a policy narrative on neurodegenerative disorders across Europe, focusing upon provision of care for people with MS. Overall, the intention was that this would create greater visibility to the unmet needs of people with MS. This work culminated in a pan-European policy report, which included country specific profiles for Denmark, Italy, Spain and Romania alongside templates for policy development in each of the four countries. The recommendations included a call to action policymakers and decision makers across Europe to develop and implement national strategies for MS in three key areas: (1) Timely diagnosis and personalised treatment; (2) Interdisciplinary and co-ordinated care; and (3) Adaptable Support in daily life.

The launch of this MS policy document was held in November 2019 at the European Parliament in Brussels, hosted by the Members of European Parliament Interest Group Meeting on Brain, Mind and Pain. A session entitled "Disparity in MS Care and Support across Europe" was held, wherein short individual presentations were given, and where a strong emphasis was placed on rehabilitation. The president of RIMS, Daphne Kos was an invited audience member alongside representatives from other key organisations such as the MS International Federation, European MS Platform, European Foundation of Neurological Associations and the European Charcot Foundation.

To complement the policy documents, in December 2020 the expert advisory group submitted an article to promote wider dissemination of the report findings; "Rethinking MS in Europe: Prioritizing integrated services for people with multiple sclerosis".

A comprehensive overview of this project, and access to these documents can be found on **www.braincouncil.eu/rethinkingms** (accessed Jan2021).

Project
COVID-19 Questionnaire

Lead:
Giampaolo Brichetto

In July 2020, RIMS launched a survey "IMPACT OF COVID-19 EMERGENCY ON REHABILITATION SERVICES FOR MULTIPLE SCLEROSIS: a RIMS Global survey". The survey aims at outlining a view of the consequences and effects of emergency on the activity of MS healthcare professionals (and rehabilitation centers) in the field of rehabilitation globally.

The survey has been launched among members of RIMS network and also, through the ECTRIMS newsletter, to member of ECTRIMS Community.

We received answers from 200 delegates and/or representative of rehabilitation centers mainly from Europe. In particular, the results showed that the use of devices for rehabilitation (both motor and cognitive rehabilitation) is a key aspect in order to guarantee rehabilitation services also during a pandemic crisis. Results showed also that phone/videocall/streaming sessions were important during the pandemic to provide support to people with MS, in parallel the use of low-cost devices and already developed Apps (also commercial Apps) was crucial to provide tele-rehabilitation. Moreover, the survey showed that the framework for delivering online rehab services is extremely fragmented in Europe and there is a need for standardization.

Results of the survey will be published in a peer-reviewed journal in the next months.

Project
Floodlight (Roche)

RIMS is part of the Roche's "MS Patient Squad: Digital Solutions" to discuss development of the application "Floodlight MS", including the use by people with MS and health care professionals. The group met 6 times in 2020.

Project
The Patient Reported Outcomes Initiative for MS (PROMS)

RIMS' lead:
Giampaolo Brichetto
and Daphne Kos

The Patient Reported Outcomes Initiative for MS (PROMS) will bring together the global MS community, people with and affected by MS, healthcare workers and researchers, healthcare industry and many more, to enable science with and of patient input in research, clinical trials of new therapies, and the design of healthcare systems.

Patient Reported Outcomes (PROs) reflect the experiences that patients have in relation to their treatment or condition. This could include how they feel, their symptoms or what they are able to do.

The PROMS initiative aims to ensure an informed and quality participation of people with MS in the decision-making processes of research and healthcare regarding their treatments and performances. The initiative focuses on the symptoms and aspects of living with MS that matter most to patients. Efforts to enable the uptake of existing PRO into clinical practice and regulatory agencies decision-making processes will be greatly enhanced and informed by a commonly held strategic PRO research agenda and roadmap, shared by all relevant stakeholders. The PROMS initiative will take a global approach to tackling this challenge. It will advocate for a set of standardised PROs to be used in therapies development and health care and promote research to develop new PROs to meet the needs of all relevant stakeholders. The programme of work will be led and coordinated jointly by the European Charcot Foundation and the MS International Federation. It will build on the experience and expertise of the Italian MS Society, who will act as the lead agency on behalf of the global MSIF movement.

Strategic priorities of the PROMS agenda include:

RESEARCH, VALIDATION AND DEVELOPMENT

- Identify the most important functional domains for people with MS that will lead to the prioritisation of functional domains. This is particularly important to ensure the validity of the content.
- Fill critical gaps in the knowledge base that hinder progress towards the development of a clear roadmap for research needs and progress.
- Research, validate and develop relevant PROMs.

CLINICAL MANAGEMENT

- Identify current PROs and PROMs for use in clinical care and collected in regulatory and clinical records and advice.
- Satisfy the position of regulatory agencies on PROs and PROMs (e.g. MSOAC EMA document).
- Promote, coordinate, implement and support initiatives to validate and harmonize ODPs across cultures.

E-HEALTH

- Establish the current return on e-Health investments for all stakeholders involved.
- Enable patients, doctors and other stakeholders to benefit from the long-term benefits of e-Health.

HEALTHCARE

- Translate standardized data into a performance measure (PRO-PM) that captures the most important results to improve long-term well-being.
- Enable PRO-PMs in innovative reimbursement models, regulatory frameworks and their algorithms to support clinical decisions. PROMS.

RIMS is involved in the initiative overall in the SSC and in particular in WG on Research Validation and Development (Giampaolo) and in the E-Health Working Group (Daphne).

Our Partners

The Consortium of Multiple Sclerosis Centers (CMSC) is the largest North American multi-disciplinary membership organization dedicated to defining and advancing the standard of care of MS patients. Our mission is to promote high quality MS care through education, training, clinical research, networking, and targeted advocacy efforts.

ECTRIMS is a professional organisation dedicated to the understanding and treatment of Multiple Sclerosis. A joint RIMS-ECTRIMS conference is organised every 3 years.

For more information, please visit
www.ectrims.eu

The European Multiple Sclerosis Platform (EMSP) is a Pan-European umbrella organization with over 30 years of expertise. We work together with our members and our partners to ensure that the more than 1 million people living with MS in Europe, have a real voice in determining their own priorities. We rely on a growing network of 43 member organisations from 37 European countries.

The needs of the 1 million people with MS in Europe are the main focus of our advocacy and awareness-raising campaigns to influence European decision-makers and EU policy-makers. We gather data and provide knowledge and expertise to relevant stakeholders and encourage high quality research and the dissemination of excellent, evidence-based information on MS .

Our flagship projects aim to improve quality of life of people with Multiple Sclerosis, as well as to ensure that they receive high quality equitable treatment, care and can access employment.

Learn more about EMSP here:
www.emsp.org

Or here:
annualreport.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. Recently completed projects include the publication of a theme issue with content from RIMS members in 2020.

For more information, please visit
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

Multiple Sclerosis Journal (MSJ) is a peer-reviewed internatio-nal 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 confe-rences are published in MSJ, the official journal of RIMS.

For more information, please visit **journals.sagepub.com/home/msj**

The World Federation for NeuroRehabilitation (WFNR) is a not-for-profit global organisation and brings together national and regional societies active in the field of neurorehabilitation. It is a multidisciplinary organisation of professionals who work in neurological rehabilitation and in related fields. The WFNR promotes the development and the improvement of the quality of neurorehabilitation across the world. It stimulates the exchange of knowledge and scientific research between clinicians and others with an interest in the field. The WFNR collaborates with other clinical and scientific societies to enhance the impact of neurorehabilitation for the benefit of patients.

Partnership Work
EMSP

MS
Nurse
PRO
A European community
for MS professionals

Nurse PRO in 2020

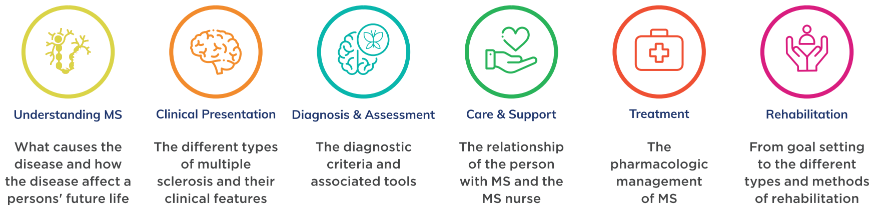
MS Nurse Professional (MS Nurse PRO) is a freely accessible accredited e-learning programme on multiple sclerosis for nurses and other health care professionals caring for people living with MS. The programme is developed by the European Multiple Sclerosis Platform in partnership with RIMS, IOMSN (International Organization of MS Nurses) and ECTRIMS.
The actual programme consists of 6 online modules (see Figure), with accompanying tests, that equate to approximately 30 to 35 hours learning time upon successful completion.

The foundation programme is accredited by seven international institutions, among them the Royal College of Nursing and the International Organization of MS Nurses and is endorsed by more than 25 national and international organizations.

Up until now MS Nurse PRO has been launched in 15 countries and is available in 12 languages (see map), as many European nurses do not speak fluent English, but we find it important having the opportunity to study in your own mother tongue. The availability in so many languages, together with the accreditation that has "currency" in many European countries, means that MS Nurse PRO has real value and is empowering for nurses throughout Europe.

The targeted audience of MS Nurse PRO are nurses who work with people with MS (PwMS) or nurses who like to work with PwMS, MS Nurse Specialist and other allied health care professionals. In fact nearly 1 in 10 of all registered users are other health care professionals. 91% of the registered MS Nurse PRO users are general nurses, MS Nurses or neurology nurses.

In 2020 MS Nurse PRO was introduced to and will be integrated into university programmes in the UK and Germany, enabling those who complete the course to gain credits towards a first level or postgraduate degree course. This recognition confirms the quality of course content.



Nurse PRO in 2021

MS Nurse PRO will move from being an e-learning programme with limited interaction with experts and peers, to being the lead platform for a European community of MS nurses that provides, at both a European and a national level, online and offline educational content, sharing of best practice, networking events and peer group support opportunities for nurses across Europe. It will bring national MS nurse organisations together as a European faculty for MS nursing and enable a stronger voice and greater lobbying presence for all its members.

MS Nurse PRO wants to be responsive to the changing landscape of MS care and to world events that impact on MS care, such as the COVID 19 pandemic. MS Nurse PRO is looking to collaborate with the national MS societies in countries MS Nurse Pro is not yet actively promoted, e.g. Russia. The main objective of the partnership is: to proof-read the translated learning materials in the national language and to introduce and actively promote MS Nurse PRO in the country. Finally, in 2021 MS Nurse PRO Module 7 on 'Research in MS' and Module 8 on 'Progression in MS' will hopefully be launched.

Feedback from course completers clearly demonstrates the positive impact MS Nurse PRO has on clinical practice and improved patient care and experience. 97% of nurses (who have undertaken the course) report the course as being relevant to their day-to-day practice and 62% report that it has positively changed their MS practice.

We like to encourage you to get in touch with MS Nurse Pro:
www.msnursepro.org

Partnership Work
EMSP Virtual Conference 2020

EMSP organized a Virtual Conference on 19-20 November 2020 about “Understanding Progressive Multiple Sclerosis”. Over 500 participants (e.g. people with MS, healthcare professionals and policymakers) took part in the event. RIMS participated with a presentation entitled “Current trends in rehabilitation for Progressive MS care across Europe”, as well as in the discussion panel on “Access to healthcare for persons with Progressive MS”.

Partnership Work
International Journal of MS Care

The International Journal of MS Care released in December 2020 a theme issue 'Rehabilitation in MS' featuring articles from RIMS Special Interest Groups, with Prof. Heesen as guest editor.
It concerned two special editorials - one by Prof. Heesen and Prof. de Groot and another by Prof. Feys - lead of the issue. The online versions of many of the theme issue articles are accessible on the website

https://meridian.allenpress.com/ijmsc

Partnership Work
MS Data Alliance

MSDA is a global multi-stakeholder collaboration working to accelerate research insights for innovative care and treatments in people with Multiple Sclerosis (MS). MSDA set up the “Global Data Sharing Initiative” in order to support people with MS, healthcare professionals and researchers during the pandemic. RIMS was engaged in the Stakeholder Focus Group Meeting (18/11/2020) concerning the topic: "Addressing Global Data Sharing Challenges - What did we learn from COVID-19?". During this meeting, all stakeholders reflected upon the major lessons learned during the global initiative referred to as “COVID-19 in MS: a Global data sharing initiative” (GDSI), followed by a brainstorm on how these lessons may be inserted in future plans.

https://msdataalliance.com/activities/stakeholder-focus-group-meeting-18-nov-2020

Partnership Work
MS International Federation

GENERAL RECOMMENDATIONS ON COVID-19
RIMS contributed to the development of the “Global COVID-19 advice for people with MS”

http://www.msif.org/wp-content/uploads/2021/01/Jan-2021-MSIF-Global-advice-on-COVID-19-for-people-with-MS-FINAL.pdf

ATLAS OF MS
RIMS is one of the stakeholders of Atlas of MS and was engaged in the stakeholders’ meeting (02/12/2020) to discuss dissemination of key messages from the clinical management module of the Atlas survey and advocacy work around access to diagnosis and treatments at a national level.

www.atlasofms.org/map/united-kingdom/epidemiology/number-of-people-with-ms

Partnership Work

World Federation for NeuroRehabilitation

During the WFNR World Congress of NeuroRehabilitation on October 7-11, 2020, RIMS organized a seminar “Advances in MS rehabilitation” with the following contributions: “Multidisciplinary and comprehensive approach in MS rehabilitation” (Daphne Kos, Leuven/Melsbroek, BE), “Biological effects of exercise therapy in multiple sclerosis” (Lars Naesby Hvid, Aarhus, DK), “Cognitive rehabilitation in multiple sclerosis” (Roshan das Nair, Nottingham, GB).

https://wfnr.co.uk/events/previous-world-congress

RIMS attended the inauguration meeting of the new Special Interest Group “Multiple Sclerosis and Demyelinating Disorders” during the conference.

Our Sponsors

In 2020, 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.

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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. RIMS members are offered free attendance to the SIG in-between meeting and the social dinner free of charge.

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

€25
(€30,25 incl VAT)
STUDENT
Annual Membership Fee

€100
(€121 incl VAT)
INDIVIDUAL
Annual Membership Fee

€400
(€484 incl VAT)
CENTRE
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 prefered.

Pay Online

Visit us at our website at **www.eurims.org/administration/how-to-join.html**

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

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Since 2016, SEAUTON BVBA (www.seauton-international.com) is the assigned association management company and conference organizer of RIMS.

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