



**ANNUAL
REPORT
2021**



Message from the President

We look back at 2021 with unfulfilled hope.

We were hopeful we would work again without face masks, without protection materials, without the necessity to stay at an antisocial distance (the so-called “1.5 meters social distance”) and be able to have a natural conversation with the people we work with... in 2021 we were still not allowed to.

We were hopeful the world would open again after vaccinations and we were able to travel abroad freely and meet each other face-to-face again instead of via a computer screen... in 2021 we were still not able to.

We were hopeful to celebrate RIMS’ 30th anniversary with real foods and drinks... in 2021 we were not permitted to.

We look back at 2021 with proud.

Proud of bringing the RIMS community together and sharing expertise and knowledge in our second digital annual conference and being able to connect and raise our glasses to the 30th anniversary, albeit in our own countries and centers sharing memories of RIMS’ history.

Proud of all the health care professionals showing resilience to continuously changing situations at work and giving the best of themselves to support people in living with MS.

Proud of all the people with MS living with anxiety and uncertainty and not (always) being able to receive the care and rehabilitation they need.

Proud of all the researchers finding alternative ways to develop and disseminate knowledge related to MS rehabilitation.

Proud of all Special Interest Group (SIG) chairs and co-chairs for organizing the online SIG meetings and leading or being involved in several projects related to MS rehabilitation.

Proud of all Executive Board members, the RIMS secretariat and association management for their active contributions to and support for RIMS, even though we only met online in the past 2 years.

Proud of all RIMS members and RIMS partners for their loyalty to and continuous support for RIMS.

We look forward to the future with inspiration.

Inspired by the added value to be prepared for (the progression of) a disease, as a brain healthy lifestyle promoted by rehabilitation will increase resources of all, including people with MS.

Inspired by prediction models to make decisions on the (rehabilitation) management of MS.

Inspired by all remote rehabilitation interventions and monitoring possibilities, increasing the potential of rehabilitation for all people with and affected by MS.

Inspired by the experiences of the previous digital meetings to organize hybrid meetings in the future to reach a large audience of MS professionals and stakeholders across the globe.

Let's take all hope, proud and inspiration and make 2022 a wonderful year together!



Daphne Kos
RIMS President



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About RIMS

OUR MISSION

We are a specialized network of professionals, researchers and stakeholders promoting high-quality evidence-based rehabilitation to optimize functioning and quality of life of people with and affected by MS.

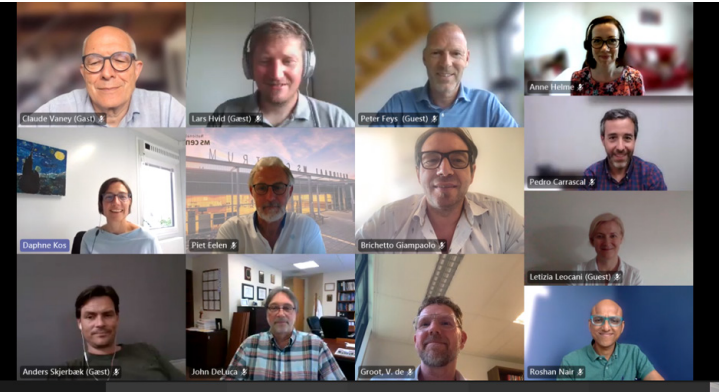
OUR AIMS

- Connecting – building bridges (between research & clinical practice, between professionals, between rehabilitation and other (health care) services, relevant organizations, industry partners)
- Facilitating translation of clinical questions to scientific evidence and implementation of research findings to clinical practice
- Supporting MS rehabilitation knowledge development and dissemination
- Promoting rehabilitation in MS

In 2021 RIMS celebrated its 30th anniversary. A video was created with contributions of several stakeholders of RIMS, like the founders, past presidents, SIG chairs, RIMS grant winners and several partners of RIMS.

ADVISORY BOARD

RIMS' Advisory Board was reinstalled in 2021. We met digitally with the Advisory Board on July 13th 2021 to discuss the mission, vision and plans of RIMS.



VIRTUAL MEETING BETWEEN THE ADVISORY AND EXECUTIVE BOARD OF RIMS, FROM LEFT TO RIGHT:

Claude Vaney, Lars Hvid, Peter Feys, Anne Helme, Daphne Kos, Piet Eelen, Giampaolo Brichetto, Pedro Carrascal, Letizia Leocani, Anders Skjerbaek, John Deluca, Vincent de Groot, Roshan Nair

RIMS Members in 2021

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 24 Center Memberships, 14 Individual Members and 6 Student Memberships.





EUROPEAN

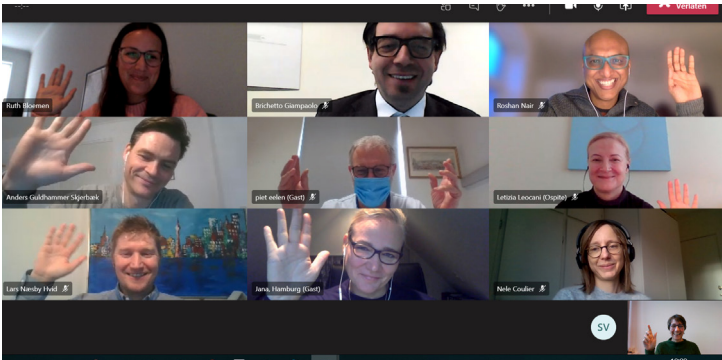
- Belgium
- Czech Republic
- Denmark
- Finland
- Germany
- Ireland
- Italy
- Norway
- Romania
- Spain
- Sweden
- The Netherlands

GLOBAL

- Australia
- Turkey
- United Kingdom

The Executive Board 2020-2023

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.



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	Occupational Therapist	Leuven & Melsbroek 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

Sara Rinaldi, Italy
sara.rinaldi@aism.it

Co-chair

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

Communication & Swallowing

Chair

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

Co-chair

Leena Maria Heikkola, Finland
leena.maria.heikkola@abo.fi

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.pottgen@uke.de

Co-chair

Anita Rose, United Kingdom
draerose@btinternet.com

Special Interest Groups

Meeting Schedule 2021

Our SIG's have all met online to meet and share thoughts.

SIG Mobility

October 1, 2021
Online Meeting

November 27, 2021
Online Meeting during
RIMS Conference 2021

SIG Patient Autonomy

November 27, 2021
Online Meeting during
RIMS Conference 2021

SIG Communication & Swallowing

April 23, 2021
Online Meeting

July 1, 2021
Online Meeting

November 27, 2021
Online Meeting during
RIMS Conference 2021

SIG Occupation

September 24, 2021
Online Meeting

SIG Bladder, Bowel & Sexuality

November 27, 2021
Online Meeting during
RIMS Conference 2021

SIG Psychology & Neuropsychology

October 1, 2021
Online Meeting

November 27, 2021
Online Meeting during
RIMS Conference 2021

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, sport scientists 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
joint together with
the Patient Autonomy Group

When?

October 1, 2021

Topic?

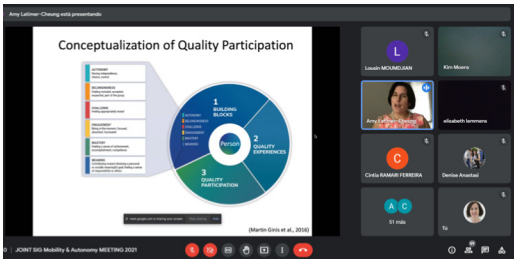
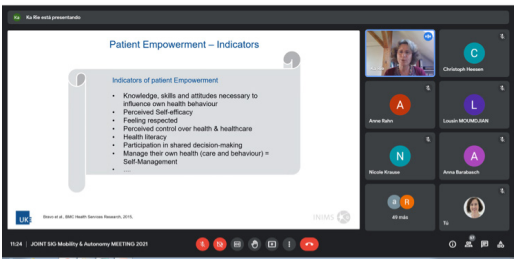
Empowerment:
Driving mobility forward!

Participants

87 participants from
16 countries

SIG Report

Mobility



Summary of the meeting

We had 88 registrations on the jointly hosted 2021 SIG Mobility-Patient Autonomy in-between meeting held online on October 1st, 2021, and around 60 MS health professionals and researchers (e.g. neurologists, physiotherapists, psychologists, nurses, health scientists) were connected and participated during the whole working day.

We used this meeting to discuss patient empowerment as a driver for mobility. We had two keynotes on this topic: “Empowerment: Is patient autonomy a key to sustained physical activity in MS?” by Karin Riemann-Lorenz from Germany, and “Two sides of the same coin: Promoting quality and quantity of physical activity participation among adults with a mobility impairment” by Amy Latimer-Cheung from Canada. Both were followed by an enriching discussion on motivational interviewing and the question on how to reach the target population.

Furthermore, we had two slots with 8 short presentations in total from the group members. These slots gained a lot of interest, and the presentations were followed by short discussions.

During the first slot, Andrea Tacchino, from Italy presented “Tele-assessment in MS. Results from a survey on health practitioners”. Erica Grange from Italy presented “Correlation between Manual Ability Measure-36 and three upper limb objective measures in people with

MS”. Rita Bertoni from Italy presented “Development of the Heat Sensitivity Impact Questionnaire (HSI-Q): an ongoing validation study”, and Lousin Moumdjian from Belgium presented “A case study of a person with progressive MS with cerebellar ataxia synchronizing finger-taps and foot-steps to music and metronomes at different frequencies”.

During the second slot, Ludovico Pedullà, from Italy presented “Co-creation of a telerehabilitation intervention for people with MS: a shared-decision approach to increase engagement and empowerment”. Kamila Rasova, from the Czech Republic presented “White matter integrity changes following physical therapy in MS – persistent effect.” Thomas Bowman from Italy presented “What is the impact of Robotic rehabilitation on Balance and Gait outcomes in people with MS? A Systematic Review of Randomized Control Trials”. And finally, Cintia Ramari from Belgium presented “Implications of lower extremity muscle power and force for walking fatigability in MS”.

The last session of the meeting included two reports from patient representatives focusing on autonomy to gain mobility and adaptation of lifestyles, as well as a presentation by Stephanie Woschek (German Multiple Sclerosis Society, regional association Hesse) on physical activity support programmes. These reports were very much appreciated by the audience and led to a lot of questions. It was emphasized that an individual and patient-centered

SIG Report

Mobility

approach is key and that COVID 19 has shown that with online programmes, people could be reached having not taken part before, but on the other hand, not all people taking courses locally would participate online.

After more than 6 hours of a very fruitful and discussion-rich shared SIG meeting, the session closed at 17.15h.

Feedback:

We distributed a questionnaire to gain feedback from the participants on the meeting and received 25 responses. Overall, the participants were satisfied with the organization and the programme of meeting as with the quality of the presentations. However, some participants were also looking forward to meeting in person and some wished more time for discussions as well as more interactions.

➤ SIG Mobility Workshop during the RIMS Conference: 27th November 2021

Results from the International Survey of the impact of COVID-19 on physiotherapy rehabilitation, from patient's perspective and therapist's perspective was disseminated during the SIG-mobility workshop during the RIMS conference. Eleven countries participated in this survey, these were: Belgium, Spain, Italy, Ireland, UK, Norway, Israel, Turkey, Australia, Serbia, and Czech Republic. On average 3.500 persons with multiple sclerosis and 250 therapists responded to the survey. The session was dedicated to disseminating results of the patient and therapist surveys, followed by questions and discussion on how to shape MS rehabilitation moving forward.

Lousin Moumdjian, coordinator of the project, presented the "International Survey of the Impact of Covid-19 on physiotherapy rehabilitation" introducing the project from the initial idea, phases of development, organization of working groups and manuscripts writing. The working group on the patient's survey presented the preliminary results: Lousin Moumdjian showed the results on the research question "Did physical activity change during

Covid pandemic?"; Marietta van der Linden showed the first results around the research question "Factors influencing change in physical activity behavior"; Andrea Tacchino showed the initial results of the research question "Are we meeting the guidelines?" referred to the recent physical activity recommendations published by Kalb et al.

Carme Santoyo presented the results of the rapist's survey working group, based on the initial data analysis made by Turham Kahraman, focusing on the "Changes on the content and delivery of physiotherapy services during the Covid pandemic" and "Changes in the organizational framework of physiotherapy services and technology use during the Covid pandemic". After interesting and interactive discussions chaired by Alon Kalron, the group could draw the next steps for the project and publication strategy.

More than 80 attendees from over 20 countries joined the session with high satisfaction and participation from the audience.

➤ Future Plans & Meetings

➤ Next in-between meeting:

Looking forward to a face to face, or at least hybrid edition, depending on the COVID-19 situation.

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 19 MS health professionals and researchers (e.g. neurologists, psychologists, nurses, health scientists) participated in the 2021 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, Ri-Gra project) and motherhood choice in MS). Afterwards, we exchanged on the advance care planning in people with progressive MS project (ConCure-SM Phase 2 project) being conducted by the Italian group. Then, we discussed the results of a Cochrane review on patient education on fatigue in people with MS (co-authored by the Italian and the German groups), and discussed also on the development of a patient guideline with patient representatives being conducted in Germany.

➤ Future Plans & Meetings

- We would like to discuss projects of other participants at the next meeting and focus on the latter project presented related to the development of the patient guideline.
- The next meeting will be held in late Spring 2022, possibly

➤ SIG Meeting

Where?

Online Meeting

When?

November 27, 2021

Topic?

Update on current projects

Participants

15 participants from all over Europe

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

Everyone has updated on their current situation. Leonie has tried to write down the important aspects:

Louise: struggling with applying corona measures like social distancing within center. Focus of work is on Covid-19.

Marta: has started with writing draft of DYMUS RIMS Grant project for publication. Is organizing MS choir online. Also online rehabilitation treatment of dysphagia, free video's. If you want more information on the videos, you can email to mrenom@cem-cat.org.

Martha: is doing a maternity replacement at National MS center Melsbroek.

Sofie: explains lower capacity at the center. There are more stroke patients at the moment, which requires flexibility of the employees. Looking into alternatives for IPV.

Ingrid & Kelly: are now also giving rehabilitation treatment to Covid-19 patients. Are developing a care path for MS patients together with Melsbroek which requires selecting the same testing and screening methods.

Leena Maria: will start in January as a senior Lecturer in Speech Pathology. Now studying Speech Pathology and working on APACS translation and validation.

Leonie: is currently not working with MS patients nor research, but happy to organize SIG meetings. Will continue being SIG chair until next election at the conference, so that position will be open. If you want more information about being co-chair, you can contact Leonie.

In-Between Meeting

Where?

Online Meeting

When?

April 23, 2021

Participants

9 participants from the Netherlands, Finland, Denmark, Spain and Belgium

Future Plans & Meetings

➤ We agreed on organizing a check-in meeting every three months. The main focus is to see and hear how everyone is doing. During these meetings we can determine to plan another meeting on a certain topic as well.

SIG Report

Communication & Swallowing

Summary of the meeting

Everyone has introduced themselves and has updated on their current situation. Due to summer holidays we were with a very small group.

What's new?

Leena Maria has written on an article that will be published in Aphasiology. Two of her Master's students will start with data collection on APACS translation in Finnish.

Anouk introduced her new colleague Sanne van Cleuvenbergen. Sanne will be focusing on the MS patients in their clinic. They have had many Covid-19 patients and they have worked as nurses instead for a while.

Martha kept on working at National MS Center Melsbroek after the pregnancy replacement.

Leonie has a new job starting in September. This means that she might not be present at the next meetings.

SIG Meeting

Where?

Online Meeting

When?

July 1, 2021

Participants

5 participants from the Netherlands, Finland and Belgium

Future Plans & Meetings

➤ In September we have planned to have a SIG meeting of 3 hours. We are looking for an organizer or at least input of speakers/topics. The meeting will be on a Friday. The date will be set by using a doodle.

➤ At the RIMS conference of 26–27 November we will have SIG meeting of 3 hours as well. The RIMS board told us we can invite 2 speakers to our meeting. Let us know if you have any topics/speakers you want to learn about/from.

SIG Report

Communication & Swallowing

Summary of the meeting

SWALLOWING ASSESSMENT

We had to invited speakers, Dr. Nicole Pizzorni and Prof. Antonio Schindler, to present their research on mealtime assessment of swallowing. First, Prof. Schindler presented theoretical and practical reasons for the importance of mealtime assessment of swallowing. Dr. Pizzorni then presented the MAS (Mealtime Assessment Scale) developed by her team to assess swallowing during mealtime. At the end, there was a general discussion on the need for mealtime assessment of swallowing.

APACS

Leena Maria explained our plans for translation and validation of APACS. The SIG will submit a grant application to continue working on the adaptation and validation of APACS into Finnish and Australian English.

Inventory of knowledge gaps

In 2021, the SIG co-operated to publish a review article "Update on recent developments in communication and swallowing in multiple sclerosis" in *International Journal of MS Care* focusing on recent developments in communication and swallowing in MS. This was done in response to knowledge gaps in the field of communication and swallowing in MS. The SIG continuously surveys the research in the field in order to find possible knowledge gaps.

Inventory of knowledge gaps

In spring 2021, Francesca De Biagi resigned from being co-chair as she has changed jobs. Also Leonie Ruhaak, who has been the chair of the SIG for 3 years, resigned at the end of the year due to a change in her working situation. Leena Maria Heikkola was chosen as the ad interim co-chair in spring 2021, and she was elected the new chair in the November meeting. Dr. Hans Bogaardt was elected the new co-chair.

SIG Meeting

Where?

Online Meeting during
RIMS Conference 2021

When?

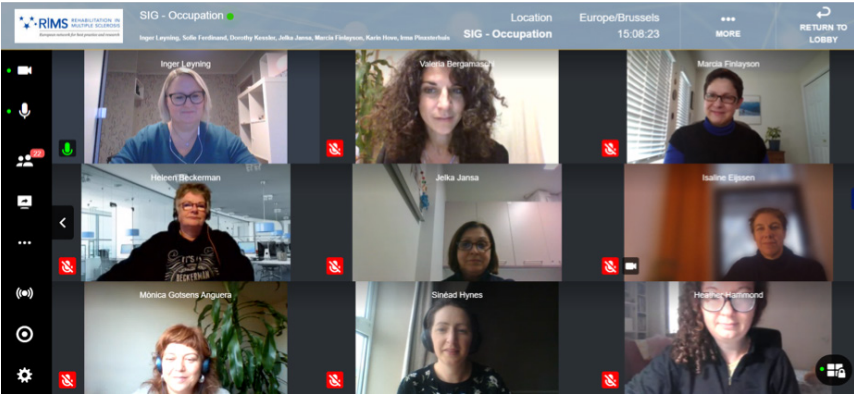
November 27, 2021

Participants

10 participants from all over
Europe

SIG Report

Occupation



In-between meeting for
SIG Occupation
Online meeting

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.

SIG Meeting

Where?

Online Meeting

When?

September 24, 2021

SIG Report

Occupation

Summary of the meeting

SIG Occupation had a digital in-between meeting Sept 24th this year. Sinéad Hynes and her colleagues at the National University of Ireland Galway put together a very nice program with varied presentations. Daphne Kos had a key presentation with update on rehabilitation approaches for fatigue in MS and later we had an interactive session discussing CBT approaches vs fatigue management programmes based on energy conservation. From Ireland we learnt about getting involved in MS research – from the patient perspective and occupational therapist perspective. Other presentations were: Cognitive assessment virtual vs in-person; Needs and Experiences of families living with paediatric MS; and Occupational Therapy in Russia.

We experienced a larger number of participants at our in-between meeting than usual and we are very happy about that. Making the event easily accessible digitally creates possibilities to reach out to an audience who would not be able to travel to an in-person meeting. The COVID pandemic has made us take a huge step into the digital world and we see there are some positive outcomes of that. November 27th we had a 3-hour meeting during the annual RIMS digital conference. Topics were: The use of the Activity Calculator for fatigue management, Development of an Fatigue diary app, and Occupational Performance Coaching. We are grateful for the contributions from the presenters. We hope the participants have found our meetings inspiring and educational. We are thankful for all the positive feedback from participants. We look forward to seeing everyone in person in 2022.

Future Plans & Meetings

SIG Occupation In-between meeting is planned to be a face-to-face meeting hosted at Masku Neurological rehabilitation center, Finland in the beginning of September. We will explore the possibility to have a hybrid format for persons who want to participate virtually. Our SIG group has also been asked to arrange two of the RIMS webinars planned for 2022. We have suggested different topics for the RIMS Executive Board and the confirmed topics will be announced later this year.

There will be a short meeting during the joint ECTRIMS/RIMS congress 26th – 28th October 2022

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.

➤ SIG Meeting

Where?

Online Meeting during
RIMS Conference 2021

When?

November 27, 2021

➤ Summary of the meeting

The SIG Bladder, Bowel and Sexuality was happy to finally meet again after a difficult year of the pandemic and saying goodbye to our chair Doreen McClurg. Piet Eelen (former SIG chair) started our meeting with an introduction of our SIG Bladder, Bowel and Sexuality about the past, present and future. And then there was the exiting news of a new chair and co-chair: Corinne Oosterlinck and Sara Rinaldi. Followed by an official election.

We shared the following studies with the SIG members:

➤ Study Genova: 'Lower Urinary Tract Dysfunction in Patients with Multiple Sclerosis: a post-void residual analysis of 501 cases on July 10, 2020' (Sara Rinaldi)

➤ Study Melsbroek: 'Percutaneous tibial nerve stimulation for the treatment of bowel incontinence symptoms in people with multiple sclerosis versus sham' (Piet Eelen)

We ended our meeting by sharing some thoughts about the future, questions from the audience and details about our next meeting.

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. At the RIMS congress in December 2021 the new chair Sarah Thomas from UK was elected. Again, Anita Rose from UK is the 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 neuro-psychological impairment in MS and its rehabilitation opportunities for RIMS members and other persons who are interested in this field. But also shared research projects were conducted in the past and are planned in the future. Our international collaboration is the best platform for team work.

The meetings have both lectures and case presentations with open discussion. To enhance the evidence based knowledge many scientific work and results are distributed. To integrate current scientific knowledge into daily work is one of the main issues. Own international scientific projects are increasingly coming into focus. Recent collaborative works were a review regarding sexual dysfunctions in MS and the relation to psychological and neuropsychological aspects in MS. Another review focused on psychological interventions to treat sexual dysfunctions in MS. Both projects result in scientific publications (see DOI: 10.7224/1537-2073.2020-012; DOI: 10.1371/journal.pone.0193381).

The current project – the CompACT validation – was finished 2020 and the first paper regarding the development process is published (DOI: 10.3390/ijerph19063150).

Next step is to publish the psychometric results in a scientific journal. Now the focus is again 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: saraht@bournemouth.ac.uk

▾ SIG In-Between Meeting

Where?

Online Meeting

When?

October 1, 2021

Topic?

A mindful exercise

Organisational aspects/next in-between meeting/SIG chair election

Presentation of the Finland database of clinical outcomes (MyMS PRO register) by Paivi

Exchange about COVID-19 and its relation to our clinical work

Clinical cases of interest

Perspectives

SIG Report

Psychology & Neuropsychology

Summary of the meeting

In total, 25 SIG Members participated in the meeting. Welcome and general introduction from Anita. Unfortunately, due to illness Jana was unable to attend as current Chair. Everyone sends Jana their best wishes.

Election of Sarah Thomas as next SIG Chair following Jana stepping to take up position as executive board member of RIMS. Anita to continue as co-chair.

Anita took us on a wonderful woodland walk in a mindfulness exercise.

Sarah Thomas gave a presentation describing the development and usability testing of an app comprising the homework tasks of the FACETS fatigue management programme.

Jessica Podda gave a presentation about analysis of a large dataset to identify predominant cognitive phenotypes in MS. Jessica described how typically after completing a comprehensive cognitive battery people with MS are often labelled as ‘impaired’ or not impaired’ using arbitrary criteria (eg. related to performance cut offs below normative values etc.). A taxonomy that recognizes predominant cognitive phenotypes could increase knowledge about cognitive impairment, could be used in prehabilitation, could be used to predict transition to more severe phenotypes and could lead to tailored interventions. DOI:<https://doi.org/10.1016/j.msard.2021.102919>

Their analysis of data (including the MoCA, the SDMT and the HADS as well as demographic and clinical information) from 872 people (pwMS consecutively enrolled in the ongoing PROMOPRO-MS initiative, a large, multi-centre prospective study in which people complete measures every 4 months) with MS identified 4 cognitive phenotypes:

- Memory difficulties only
- Minor memory and language deficits with mood disorders
- Moderate memory, language and attention impairments
- Severe memory, language, attention, information processing and executive functioning difficulties.

Jessica noted that the four cognitive phenotypes could be conceptualized as being on a continuum. There are future plans for longitudinal work using the same rich dataset.

We had a stimulating and enthusiastic exchange and discussion regarding the presentations and other updates. The SIG group members were excited about the cognitive phenotyping work.

We had discussions about various aspects of the research that Jessica presented. The large sample size and population-based sample were particularly impressive. There were some concerns about the insensitivity of the MoCA and Jessica concurred that other cognitive tests should be included in future work (such as those capturing deficits in planning or inhibitory control).

SIG Annual Meeting

Where?

Online Meeting

When?

November 27, 2021

Topic?

SIG chair / co-chair election

A mindful exercise

Presentation of the development and usability testing of an app comprising the homework tasks of the FACETS fatigue management programme presentation about analysis of a large dataset to identify predominant cognitive phenotypes in MS

Exchange and discussion

Perspectives/next in-between meeting

Members of the group felt that having cognitive phenotypes could enable more detailed and efficient communication (having a common language) amongst the MDT and also with patients (potentially giving patients a richer and more nuanced understanding).

Anita mentioned that it would be interesting to see if the results found in the Italian sample would be replicated in other countries and cultures.

Jessica mentioned plans to digitize cognitive assessments (such as the BICAMS) - starting off with focus groups to share experiences of researchers and patients. Anita suggested possible scope for some international collaboration in this area. It was suggested it would be very helpful to include the entire test including the delayed recall component of the California Verbal Learning Test. Jessica was asked how the digitized tests would be delivered and whether they would be fully remote. Jessica explained the plans were to use speech recognition and that the voice of the therapist would be replaced by a recording and the patient would say aloud all the words they can remember. The tester would still need to be present.

We also discussed the challenges of trying to objectify early cognitive alterations in patients who are professionally active and are experiencing changes that are not showing up on standard testing batteries. Cognitive fatigability was suggested as a possible means to objectify this subtle decline as currently it is often a case of looking at subtests to try to see what might have changed for the person. We discussed the idea of presenting some case studies and Anita suggested this could be a great topic for the next in-between meeting.

We discussed cognitive interventions and fatigue Sarah noted that in the FACETS programme participants are signposted to resources such as the MS Trust Staying SMART website. <https://mstrust.org.uk/resources/staying-smart>. Anita suggested the possible use of digital boosters and tailored patient interfaces through apps.

Susan reflected on experiences from recruiting to driving simulator research. While some patients are really curious and keen to take part others are defensive and concerned. Anita reflected that it can be really challenging when people feel they are safe to do things when it is very clear that they are not.

📌 Future Plans & Meetings

We discussed a possible in-between meeting next year - presenting case studies of early cognitive decline and getting an update from Jessica on the digitization of cognitive assessments project. We will email the group for their thoughts.

Annual RIMS Conference

The Annual RIMS Conference 'Transforming Rehabilitation in MS through Collective Learning: Maximising Stakeholder Engagement', took place digitally from November 26-27, 2021.

The main themes of the conference were Neuro-biological Effect of Rehabilitation, Digital Health and Impact of COVID-19 on MS Care. We virtually welcomed 240 attendees of 25 international countries, 12 speakers and 9 chairs.

Participants were able to visit our digital poster area where they could see the 9 recorded platform presentations and the 61 submitted poster abstracts. You can find the recording on the RIMS website www.eurims.org.

RIMS prize winners

Best Poster Award
Samuel Sanchez (ES)
Klara Novotna (CZ)
Michela Ponzio (IT)

Best Oral Presentation
Morten Riemenschneider (DK)
Ludovico Pedulla (IT)
Insa Schiffmann (DE)

SIG meetings

The SIG meetings were held during the digital conference on Saturday, November 27. You can read all about it on page 12-25.

General Assembly

The General Assembly was held at the beginning of the digital conference on November 26. The RIMS members of 2021 approved the financial report of 2021.



38th Congress of the European Committee
for Treatment and Research in Multiple Sclerosis



27th Annual RIMS Conference



ECTRIMS 2022

SAVE THE DATE

26-28 October 2022
Amsterdam / NL

www.ectrims-congress.eu

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

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 2022, 23h45
Application details can be found on the RIMS website at Career advancement: www.eurims.org

Announcement winner

2020: February 2021
2021: February 2022
2022: February 2023

RIMS Grant Application 2019 Winner

Anne Christin Rahn

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

RiGra project NIPS: Needs of people with primary progressive multiple sclerosis.

SUMMARY

For people with primary progressive multiple sclerosis (pwPPMS) very limited immunotherapeutic and evaluated management options do exist. This mirrors a substantial psychological and physical burden for 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. Based on the available evidence, an interview guide will be developed. A qualitative interview study with pwPPMS and health professionals (HPs) will be performed in 6 participating European countries. Based on data synthesis, a survey with HPs will be developed and conducted in the participating countries. This could serve as a basis for a larger survey study to verify the hypothesis on unmet needs and patient information gaps in PPMS and to set up an intervention development agenda. The NIPS project started in 2020. So far, we have performed the scoping review, gained ethical approvals from the participating countries, and developed the interview guide for pwPPMS and HPs. At the moment, the interviews are being conducted in the participating countries and will be analysed until June 2022.

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

Consultant neurologist, Department of neurology, Kings College Hospital, London, UK

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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

The Patient Reported Outcomes Initiative for MS (PROMS)

RIMS' lead:
Giampaolo Brichetto

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

The impact of COVID-19 pandemic on physical activity and use of technology in people with multiple sclerosis and on physical therapy practices and beliefs: an international RIMS-SIG Mobility study

The Special Interest Group for Mobility (SIG Mobility) of the RIMS network, launched an international survey study to investigate whether and how physical activity and physical therapy may have changed during the COVID-19 pandemic in people with MS (PwMS).

A multi-centre international online survey study was conducted within 11 participating countries. Each country launched the survey using online platforms for a total duration of 6 weeks from May to July 2021. The survey ascertained physical activity performance and its intensity, the nature of the activities conducted and the use of technology to support home-based physical activity pre- and during the pandemic. A separate survey was used for the perspective of physical therapists and people with MS.

Data are analyzed and discussed during the SIG Mobility meeting and several dedicated project meetings. The results will be disseminated to the professional community and to the community of people with MS.

Project MultipleMS

RIMS' lead:
Letizia Leocani

RIMS has participated to the meeting in partnership with Multiple-MS, where the effort to collect big data was emphasized and acknowledged, together with the commitment to explore the most efficient method to make these valuable information available beyond the timeline of the project.

www.multiplems.eu

Project Floodlight MS (Roche)

RIMS' lead:
Daphne Kos

RIMS is part of the Roche's "MS Digital Solutions Patient Squad", focusing on developing digital health tools and solutions with and for people living with MS, like Floodlight MS. The group including people with MS and a RIMS representative met 3 times in 2021 to provide feedback and input for the development and implementation of digital tools.

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



International
Journal of **MS**CARE

IJMSC is a peer-reviewed international bi-monthly publication focusing on multiple sclerosis and related autoimmune disorders of the central nervous system. The primary goal of IJMSC is to publish original articles covering various clinical aspects of MS, particularly those relevant to the multidisciplinary management of the disease and its consequences. Topics include neurologic, nursing, rehabilitative, psychological, and psychosocial care and quality-of-life issues of people with MS and reflect the diversity of the journal's readership. 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 47 MS organisations with links to many others.

For more information, please visit
www.msif.org

**MULTIPLE
SCLEROSIS
JOURNAL**

MSJ

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



World Federation for NeuroRehabilitation

The World Federation for Neurorehabilitation (WFNR) is a not-for-profit global, multidisciplinary organisation with a mission to raise awareness of neurorehabilitation, provide training and education, encourage research and collaboration and provide a forum for all professionals interested in neurorehabilitation across the world. The WFNR has over 5000 members worldwide, 37 Special interest Groups and is affiliated to 41 National Societies. WNR is currently celebrating its 25th anniversary.



Partnership Work

EMSP

MS Nurse PRO 2021

MS Nurse Professional (MS Nurse PRO) is a freely accessible accredited e-learning programme on multiple sclerosis for nurses and other health care professionals (HCP) caring for people living with MS.

The programme is developed by the EMSP (European Multiple Sclerosis Platform) in partnership with RIMS, IOMSN (International Organization of MS Nurses) and ECTRIMS.

The actual programme still consists of 6 modules, that equate approximately 35 hours learning time.



Understanding MS

What causes the disease and how the disease affect a persons' future life



Clinical Presentation

The different types of multiple sclerosis and their clinical features



Diagnosis & Assessment

The diagnostic criteria and associated tools



Care & Support

The relationship of the person with MS and the MS nurse



Treatment

The pharmacologic management of MS



Rehabilitation

From goal setting to the different types and methods of rehabilitation

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. Successful completion of the accompanying tests leads to a certificate or an accreditation depending from the country.

Also in 2021 we had an increase in registered users as well as in completers of MS Nurse Pro. In 2021 we had more then 650 new members from all over the world, more then 8000 users in total and 825 completers of the programme!

MS Nurse PRO is already launched in 15 countries in Europe and is available in 12 languages (English, French, German, Czech, Romanian, Italian, Spanish, Portuguese, Greek, Norwegian, Polish and Dutch). In 2021 MS Nurse Pro was translated in Hungarian, which will be launched soon.

The availability of MS Nurse Pro in different languages and the accreditation of the programme expresses its value in empowering nurses. Nurses from around Europe tell us that MS Nurse PRO improved their patient care and changed their clinical practice.

The development of the new Module-7 on 'Research in MS' and the complete makeover of Module-4 started in 2021. But MS Nurse Pro is more than just an e-learning module, it's a platform that can track

your own learning and contributions and you can share your expertise with colleagues, you can engage yourself in topical discussions related to MS care, find colleagues near you, submit questions in your own mother tongue to experts and share best practices! MS Nurse PRO continue also to offer organizational and financial support to partner MS Societies to co-organize national stakeholder meetings or promotional and educational events on MS nursing.

In 2021 MS Nurse PRO was integrated into the programme of the BCU (Birmingham City University) in the UK, on bachelor and master level, and is recognized with 6 to 8 credits on the European Credit Transfer System (ECTS). EMSP will offer 10 grants to cover fees for young HCP.

MS Nurse PRO took the step in 2021 to move from an e-learning programme only to a leading European platform on education and support for nurses and HCP's caring for people with MS. The Community Management Team of EMSP started in 2021 to establish the development of 'MS Nurse Ambassadors, to provide at European and at national level, online and offline educational content, sharing best practices, networking events and peer group support opportunities for nurses across Europe.

EMSP hope to bring national MS nurse organizations together as a European faculty for MS nursing and enable a stronger voice and greater lobbying presence for all its members.

Get in touch with MS Nurse Pro:

- The Platform
www.ms nursepro.org
- Support and community management
community@ms nursepro.org
- Syllabus committee
syllabus@ms nursepro.org
- Project Management and Promotion
ms nursepro@emsp.org
- Co-funding opportunities
debianka.mukherjee@emsp.org

Partnership Work

European MS Platform (EMSP)

Virtual Conference 2021

The EMSP Virtual Conference took place on June 9-11th 2021 and focused on the theme “MS Nursing and Care in a Changing World”. RIMS participated with a presentation “Dealing with fatigue”, as well as in the discussion panel on “Impact of COVID 19: challenges and best practices”.

Partnership Work

World Federation of Neurorehabilitation (WFNR)

RIMS is part of the WFNR Special Interest Group “Multiple Sclerosis and Demyelinating Disorders” and contributed to two conferences to spread the awareness of the disease, its management and multi-disciplinary rehabilitation care.

“Outcome measures in MS: how to monitor the effect of rehabilitation” at the IX Annual Conference of Indian Federation of Neurorehabilitation (IFNRCON) 10-11th April 2011.

“Transmural rehab teams in MS” at the 4th Asia Oceanian Congress on Neuro Rehabilitation (AOCNR 2021) 6-8th August 2021.

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 ‘clinicians, researchers and data custodians’ (06/07/2021). During this meeting, all stakeholders reflected upon 1) the key activities the MSDA should be focusing on to address the most urgent needs related to scaling-up real-world MS data and 2) the key values and governance principles the MSDA and its members should adhere to co-create a trustworthy, transparent and sustainable real-world MS data ecosystem.

The full report can be found here:

www.msdataalliance.com/wp-content/uploads/2021/10/MSDA-Stakeholder-Focus-Group-Report-.pdf

Partnership Work

MS International Federation

RIMS contributed to the update of the ‘Global COVID-19 advice for people with MS’

www.msif.org/wp-content/uploads/2021/06/June-2021-MSIF-Global-advice-on-COVID-19-for-people-with-MS-FINAL.pdf

RIMS is represented in the International Medical & Scientific Board (IMSB) of MSIF. The IMSB provides advice on the research and clinical activities of MSIF.

Our Sponsors

In 2021, 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 & Annual Conference Partners



"As pioneers in neuroscience, Biogen discovers, develops, and delivers worldwide innovative therapies for people living with serious neurological diseases as well as related therapeutic adjacencies."



"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."

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 preferred.

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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3020 Herent

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Notes



**CONNECT
WITH US**



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for best Practice and Research
in MS Rehabilitation



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