



# EMSP | RIMS

## Winter Conference 2012

Prague | 24<sup>th</sup> and 25<sup>th</sup> November



*European network for best practice and research*



europaean multiple sclerosis platform aisbl

next page



What you should know about EMSP:

Multiple sclerosis (MS) is a complex, chronic, disabling disease, disrupting the transmission of signals in the brain. The average age of diagnosis is 20-40, a period when individuals are highly engaged in establishing their careers, raising their families and enjoying lifestyles. MS affects twice as many women as men. There are currently approximately 600,000 people diagnosed with MS in Europe each year. So far, no cure has been found.

EMSP is the umbrella organisation for 38 MS societies from 34 European countries. EMSP represents their interests at the European level and works to achieve its goals of high quality equitable treatment and support for people with MS.

What you should know about RIMS:

Rehabilitation in Multiple Sclerosis (RIMS), aims to link health care professionals in European MS centres and other settings, as well as researchers, in order to encourage professionals interested in MS to exchange their knowledge of clinical, scientific, social, economic and educational matters about the disease and to establish individual and scientific contacts between people with an interest in MS.

Individual membership for those who have a special interest in MS is also welcomed. RIMS has established a number of Special Interest Groups (SIGs). These groups aim to promote research and improve the care of people with MS and their caregivers.

Please visit RIMS' website: **www.euRIMS.org** for more information.

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## 24<sup>th</sup> November 2012 Program

**Social media in MS**  
Moderator: Silja Chouquet, Switzerland

12.00	<b>Registration</b>
12.30	<b>Light lunch</b>
13.00	<b>Welcome and introduction on EMSP</b> John Golding, President EMSP
13.05	<b>Social media in MS: Why it is important</b> <ul style="list-style-type: none"><li>- Social media: A cutting edge approach Silja Chouquet, CEO whydot GmbH,Riehen, Switzerland</li><li>- You and social media: presentation of survey results Silja Chouquet, CEO whydot GmbH, Riehen, Switzerland</li><li>- “Social media experiment”: a game to illustrate the power of connecting like-minded people Silja Chouquet, CEO whydot GmbH, Riehen, Switzerland</li><li>- Q&amp;A</li></ul>
13.50	<b>How to make it happen: successful use of social media and other IT solutions - Panel</b> <ul style="list-style-type: none"><li>- How AISM successfully used social media Isabella Baroni, Web Editor, MS Society of Italy, Genua, Italy</li><li>- Awareness campaigns: how social media can help Dr. Matt Jameson Evans, Chairman, HealthUnlocked, London, UK</li><li>- Organising life with MS with specialised apps Dorothea Pitschnau-Michel, Secretary General, German National MS Society (DMSG) and Past President EMSP, Hanover, Germany Adam Michel, Chief Executive, AMSEL, DMSG Chapter in Baden-Württemberg, Stuttgart, Germany</li><li>- X-Box supported rehabilitation for PwMS Pedro Carrascal, CEO MS Society of Spain (FELEM), Executive Board member EMSP Julio Álvarez Guzmán, Business Unit Manager, Wirtualware Health, Bilbao, Spain</li></ul>
15.00	<b>Coffee break</b>
15.45	<b>Social media/IT workshops:</b> <ul style="list-style-type: none"><li>- Creating a social media community Isabella Baroni, Web Editor, MS Society of Italy, Genua, Italy Silja Chouquet, CEO whydot GmbH,Riehen, Switzerland</li><li>- Awareness campaigns via social media Dr. Matt Jameson Evans, Chairman, HealthUnlocked, London, UK</li><li>- Organising life with MS with specialised apps Dorothea Pitschnau-Michel, Secretary General, German National MS Society (DMSG) and Past President EMSP, Hanover, Germany Adam Michel, Chief Executive, AMSEL, DMSG Chapter in Baden-Württemberg, Stuttgart, Germany</li></ul>
16.45	<b>Listening to you, the audience</b> <ul style="list-style-type: none"><li>- Report back from Workshop sessions</li><li>- Open floor discussion with audience Silja Chouquet, CEO whydot GmbH,Riehen, Switzerland Isabella Baroni, Web Editor, MS Society of Italy, Genua, Italy</li></ul>
17.00	<b>Closing remarks</b>
17.15	<b>End of the first conference day</b>
20:00	<b>Gala dinner</b>

## 25<sup>th</sup> November 2012 Program

**Use of digital media for care and rehabilitation in MS**  
Moderator: Prof. Peter Feys, Belgium

09.00	<b>Welcome and information on RIMS</b> Peter Feys, Professor of Rehabilitation and Physiotherapy, PHL/University of Hasselt, RIMS President, Belgium
09.10	<b>RIMS multi-centre collaboration on walking aassessment</b> Peter Feys, Professor of Rehabilitation and Physiotherapy, PHL/University of Hasselt, Belgium
09.25	<b>Sportive challenges in MS and promotion using social media</b> Paul van Asch, Physiotherapist, Fit Up Team, Kontich, Belgium
10.00	<b>Coffee break</b>
10.30	<b>Internet-based physical activity promotions</b> Alexander Tallner, PhD, Sports Scientist, Institute of Sports Science, University of Erlangen, Germany
11.15	<b>Internet-based educational program for nursing (MS-NEED)</b> Vicki Matthews, MS Specialist Nurse Advisor to the MS Trust, Herts, RIMS Executive Board Member, UK
12.00	<b>Lunch</b>
13.15	<b>Recommendations for rehabilitation in people with MS</b> Thomas Henze, Neurologist, Passauer Wolf Neurological Rehabilitation Centre Nittenau, Nittenau, RIMS Executive Board Member, Germany
13.45	<b>Online survey on the content of physical rehabilitation</b> Kamila Rasova, PhD, Physiotherapist, Department of Rehabilitation, 3rd Medical Faculty, Charles University, Prague, Czech Republic
14.30	<b>Shared decision making in MS by using digital media</b> Alessandra Solari, Neurologist, Unit of Neuroepidemiology, Foundation IRCCS Neurological Institute C. Besta, Milan, RIMS Executive Board Member, Italy
15. 15	<b>Closing remarks</b> Thomas Henze, Neurologist, Passauer Wolf Neurological Rehabilitation Centre Nittenau, Nittenau, Germany
15.30	<b>End of the second conference day</b>







## Introduction

*John C. Golding, EMSP President*



## Introduction

*Prof. Peter Feys, RIMS President*



PROF. PETER FEYS

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John Golding was elected EMSP President in 2010.

He has been educated in Spain, England, Ireland and Norway. He holds academic and professional qualifications in Business Administration, Marketing and modern languages.

He has had MS symptoms since 1982 and was diagnosed in 1987.

John is now retired from professional life, but holds a number of non-executive directorships and appointments as board chairman of two companies and as board member of several other organisations. John has, since his retirement, also worked as Business Consultant for several companies.

John is an active member of (MSIF) and is member of the newly formed group “People with MS Advisory Committee” (PMSAC) who will advise the MSIF Board of Trustees on any issues related to the needs and aspirations of people with and affected by MS.

John was Vice President of EMSP between 2006-2010. John was Vice President of The Norwegian MS Society for a period of six year.

Prof. Peter Feys was elected RIMS President in 2011.

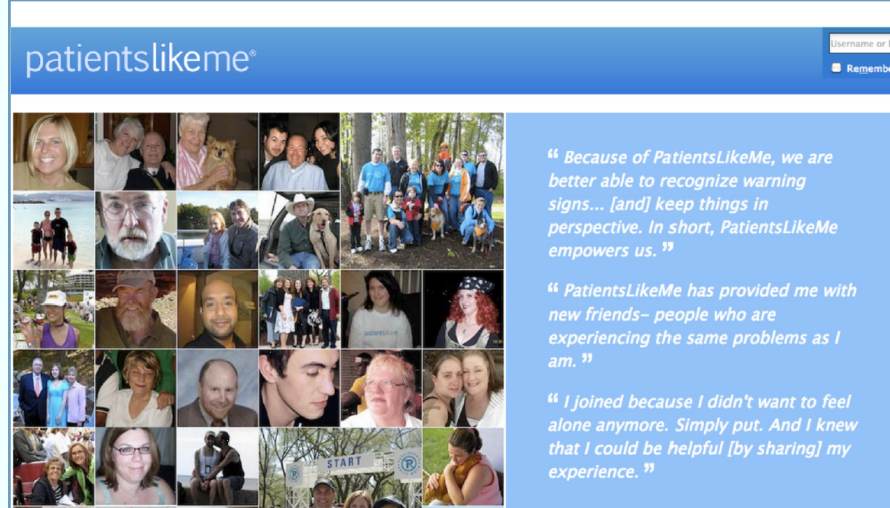
He has extensive clinical, educational, and scientific experience in the treatment of patients with neurological deficits in general, and with multiple sclerosis (MS) in particular.

He holds a MSc in Motor Rehabilitation and Physiotherapy with a specialisation in neurological rehabilitation (1994), as well as a PhD in Rehabilitation Sciences (2004), both from the University of Leuven (B). Peter is currently associate professor at the PHL/University of Hasselt (Belgium), and is affiliated to the REVAL research institute.

His research interests include, amongst others, movement disorders, motor imagery, clinical utility of outcome measures, physical treatment, rehabilitation technology and community behaviour. Peter’s research has been published widely in international neurological and rehabilitation journals.

Peter has been a member of RIMS since 1998, when he joined the National MS Centre in Melsbroek (B). He has been chair of the SIG Mobility since 2007, and secretary of RIMS between 2008 and 2011.





## Social media in MS: Why it is important

*Silja Choquet*



## How AISM successfully used social media

*Isabella Baroni*



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Silja Chouquet is the owner and CEO of Whydot GmbH, an agency specialising in social media analysis, consulting, coaching and training. Her fields of expertise are the creation of patient-focused social media communications and marketing campaigns.

Prior to starting her own business, Silja built a solid track record as a consultant and line manager in the health care industry with over ten years of experience. She worked for major pharmaceutical companies, where she held senior positions in sales, strategic planning, market research and business intelligence. Silja started her career as a senior consultant at Mercer Management (now Oliver Wyman). She holds a BS in International Business and Marketing from Georgetown University in Washington DC and an MBA from INSEAD.


Isabella Baroni works as web communication manager for AISM (Italian Multiple Sclerosis Society), the national charity in Italy devoted to MS, and is an active member of Multiple Sclerosis International Federation and of European MS Platform.

Isabella joined the Communications team of AISM in 2006. She is responsible for managing the corporate website and social media and she oversees the online communication staff and the online initiatives and projects of AISM.

She is passionate about understanding online social interaction and helping AISM create positive change through the power of digital media. Her interests include, among others, social networks as tools for users to support social causes and non-profit issues.

Isabella has a bachelor degree in Art History from the University "La Sapienza" in Rome, and she has worked in the internet industry since 2000 providing a vast array of services for online initiatives.

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## Awareness campaigns: How social media can help

*Dr. Matt Jameson Evans*



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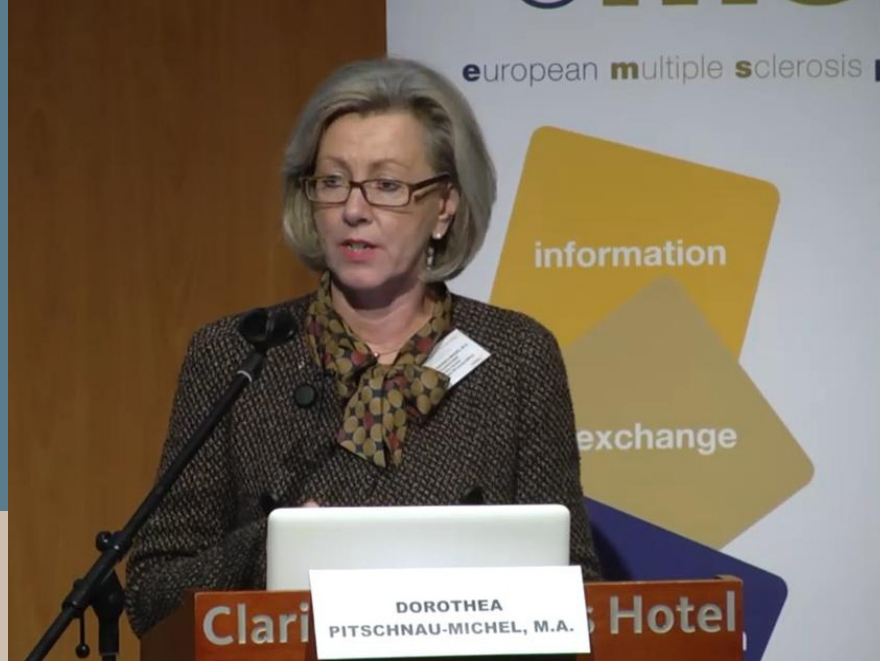


Dr. Matt Jameson Evans is a UK doctor and co-founder of HealthUnlocked.com. His background is in orthopaedic surgery and medical politics. He trained in Guys, Kings + St Thomas' Hospital, and the Royal National Orthopaedic Hospital, London (1995-2008). In 2006 he founded the online Doctors Organisation 'Remedy UK' and quickly generated a following of 15,000 UK doctors, lobbying on medical issues in the Houses of Parliament and throughout the UK mainstream media.

In 2008 he co-founded HealthUnlocked with business partner Jorge Armanet. HealthUnlocked is a health technology company that partners with patient organisations, healthcare providers and industry. It uses online tools to support patients as well as health care providers and generates real world data regarding the effectiveness of clinical services and treatments.







## Organising life with MS with specialised apps

*Dorothea Pitschnau-Michel, M.A.*



## Organising life with MS with specialised apps

*Adam Michel*



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Dorothea Pitschnau-Michel has a Magister Artium (MA) in sociology, psychology and economics. She has worked for more than 25 years within the German MS society, the last 20 years as Secretary General of the German National MS Society (DMSG, Bundesverband e.V.). Located in Hanover, DMSG Bundesverband has 16 regional chapters, 895 self help groups, 4,230 volunteers, 245 full-time employees, 45,231 members and approx. 130,000 MS affected persons.

She is also Managing Director of the MS Forschungs- und Projektentwicklungs- gGmbH (MS Research and Project Development Society) which is dealing with the implementation of research projects e.g. "Deutsches MS-Register". Furthermore she has a Deputy presidency within the Deutsche Multiple Sklerose Stiftung (German MS Foundation) which promotes research work, granting of support to individuals and to the regional chapters of DMSG.

Dorothea is also very active internationally. She has been a Board Member of the EMSP since 1998. She was elected in 2006 to EMSP President, acting since 2010 as Past President of the EMSP. Since 2003 she has been member of the Nominating Committee of the MSIF (Multiple Sclerosis International Federation) and since 2005 an MSIF Board Member.

Adam Michel has been Chief Executive of AMSEL, chapter of DMSG in Baden-Württemberg, Germany since 1980. The chapter has 8,700 members, 60 self help groups, 500 volunteers and 30 full- and half-time employees.

Additionally Adam Michel is active in several organisations acting as: Vice President of AMSEL Sponsors' Association, Vice President of the AMSEL Foundation, Fundraising-committee member of MSIF (Multiple Sclerosis International Federation), Chair of the DMSG CEO's committee. He represents the chapter in two neurological clinics (one acute-clinic with 100 beds and one rehabilitation-clinic with 138 beds) where the Amsel Foundation has a part-ownership.







## X-Box supported rehabilitation for PwMS

*Pedro Carrascal*




## X-Box supported rehabilitation for PwMS

*Julio Álvarez Guzmán*



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Pedro Carrascal is the CEO of three organisations: FELEM (the Spanish MS Federation); the Biscay MS Society and the MS Basque Foundation. He graduated with a Bachelor degree in Law from the University of Deusto in 1996, a Diploma in Foreign Trade from the Chamber of Commerce of Bilbao in 1997 and a Masters in Business Administration (MBA) from the University of Basque Country in 2004.

Since 2007 Pedro has been a member at large of the MSIF Board (the first Spanish person in the history of MSIF) and has participated with the role of "Champion of Development" in the MSIF strategic plan. FELEM has also become the first MSIF "supporting organisation" in April 2010.

In 2012 Pedro was coopted to the Executive Committee of EMSP.

Julio Alvarez is the head of the eHealth Business Unit in VirtualWare Group based in Bilbao, Spain.

Julio is a marketing specialist with over 10 years of experience in the pharmaceutical industry. He was product manager and marketing manager in biotech companies such as Biogen Idec and Bayer Schering Pharma, promoting multiple sclerosis drugs.





PROF. PETER FEYS



RIMS multi-centre collaboration on walking assessment

Prof. Peter Feys, RIMS President



Sportive challenges in MS and promotion using social media

Paul van Asch



PAUL VAN ASCH

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Prof. Peter Feys was elected RIMS President in 2011.

He has extensive clinical, educational, and scientific experience in the treatment of patients with neurological deficits in general, and with multiple sclerosis (MS) in particular.

He holds a MSc in Motor Rehabilitation and Physiotherapy with a specialisation in neurological rehabilitation (1994), as well as a PhD in Rehabilitation Sciences (2004), both from the University of Leuven (B). Peter is currently associate professor at the PHL/University of Hasselt (Belgium), and is affiliated to the REVAL research institute.

His research interests include, amongst others, movement disorders, motor imagery, clinical utility of outcome measures, physical treatment, rehabilitation technology and community behaviour. Peter’s research has been published widely in international neurological and rehabilitation journals.

Peter has been a member of RIMS since 1998, when he joined the National MS Centre in Melsbroek (B). He has been chair of the SIG Mobility since 2007, and secretary of RIMS between 2008 and 2011.

Paul Van Asch is a physiotherapist specialising in neurology and sport.

Paul has been head of the physiotherapy department at the National Multiple Sclerosis Centrum, Melsbroek, Belgium (1986 and 2006).

In 2006 he founded his own company and is now manager of Fit Up bvba at the Fitness- and Physiotherapy Centre, Kontich, Belgium.

Between 2001 and 2007 he was RIMS Secretary, the network of European MS Centres. Since 2007 he has been Co-Chair of the Special Interest Group (SIG) on Mobility within RIMS.

On the international level, Paul also has acted as Editorial Board member of MSIF’s (Multiple Sclerosis International Federation) publication “MS in Focus” (2004-2008).

In 2010 Paul was elected as President of “Move to Sport vzw”, a Belgian organisation to promote sport for PwMS and education for professionals.

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ALEXANDER TALLNER, PhD

## Internet-based physical activity promotions

*Alexander Tallner, PhD*



*Vicki Matthews, MSc*

## Internet-based educational program for nursing (MS-NEED)



VICKI MATTHEWS, MSc

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Alexander Tallner graduated in sports science in 2005 and has been working at the Institute of Sports Science and Sports of the University of Erlangen-Nuremberg since 2007. His main scientific focus lies in the field of multiple sclerosis and exercise.

In 2012, he finished his PhD exploring the relationship between physical functioning and physical activity in people with multiple sclerosis. Further research interests include physical activity assessment and promotion, behavioural exercise therapy and internet-delivered physical activity interventions. Alexander has been a member of RIMS and participant of SIG Mobility meetings since 2011.

Vicki Matthews, an MS Specialist nurse, is currently chairing the syllabus committee for the MS Professional Nurse Programme. Vicki belongs to the International Organisation of MS Nursing, the UK MS Specialist Nursing Association and is a committee member of RIMS and the Royal College of Nursing Neuroscience Forum. She has a Masters Degree in rehabilitation counselling and has worked as a nurse specialist and counsellor in both general neurology and MS. Her special interest is the emotional experience of MS.

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## Recommendations for rehabilitation in people with MS

*Prof. Thomas Henze*

## Online survey on the content of physical rehabilitation

*Kamila Rasova, PhD*

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Prof. Thomas Henze has been working in the field of clinical neurology since 1980. He completed his neurological training at the Neurologic University Hospital of Goettingen/Germany. In 1992 he moved to Kliniken Schmieder at Allensbach/Lake of Constance, a large neurological rehabilitation hospital, and, in 2002, was appointed as head of Reha-Zentrum Nittenau/Bavaria. Since the 80s he has been engaged in the treatment of MS patients. Since 2001 he has been a member of the Medical Advisory Board of the German MS Society (DMSG).

In 2004 he acted as leading author of the German consensus guidelines on symptomatic MS treatment which were also published in 2007 within the Code of Good Practice by EMSP. In 2012 Prof. Henze acted as leading author of the 2nd edition of "Recommendations on Rehabilitation Services for Persons with MS in Europe" published by EMSP. He has also been reviewer for numerous national and international MS journals as well as scientific societies.

He has been a member of the Executive Board of RIMS since May 2008.

Kamila Rasova gained her PhD in physiotherapy (2001) and in neuroscience (2004) at the Charles University in Prague. Since 2007, she has worked as an assistant professor at the Third Medical Faculty, Charles University in Prague where she is in charge of courses for pre-graduate and post-graduate students of physiotherapy and general medicine, presentations on conferences and workshops and thesis tutorials for pre-graduate and graduate students. Moreover, she works as a physiotherapist and Research Affiliate at the Department of Rehabilitation, Third Medical Faculty, Charles University in Prague. Her main field of research is the rehabilitation of people affected by neurological diseases, especially people with MS.

She has experience with MS rehabilitation research funded from national grants, and three grants from the European societies. She is author of 20 works in Journals with IF and five monograph peer reviewed books and several papers in clinical journals.

She is a member of the following professional organisations: Rehabilitation in Multiple Sclerosis, Network of European MS Centres, Czech Union of Physiotherapists, Czech Society of Rehabilitation and Physical Medicine, Czech Society of Neurology (UNIFY) and Union Roska, Czech Multiple Sclerosis Society. She founded the non profit organisation "Centre of Complex Neurorehabilitation Care for Patients with Multiple Sclerosis (CEROS)".

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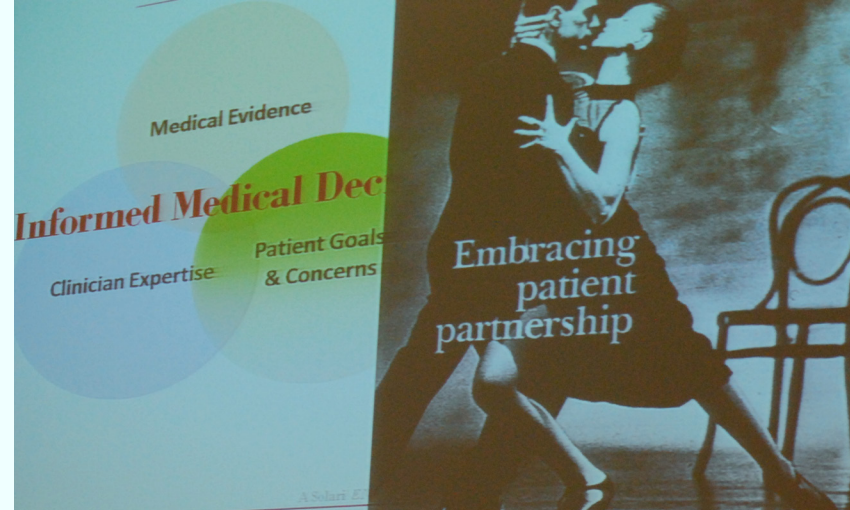
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## Shared decision making in MS by using digital media

*Dr. Alesandra Solari*



## Closing Remarks

*John C. Golding, EMSP President*



## Closing Remarks

*Prof. Thomas Henze, RIMS Executive Board Member*

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Alessandra Solari is a neurologist. Her main area of research is the validation of instruments and outcome measures (chiefly patient-reported outcome measures) for clinical, epidemiological, and quality of care studies in neurological diseases, particularly multiple sclerosis (MS). Her other main interest is the design of independent randomised controlled trials (RCTs) mainly on rare diseases and complex interventions.

Dr. Solari is currently investigating methods of conducting outcomes research in disease management and quality of care programs. As part of this field of research she is carrying out a prospective study on community-based cohort of MS patients, examining relationships between disease status, quality of life and health care utilisation. She has also devised a structured information aid for people with newly diagnosed MS.

Dr. Solari designed and implemented a patient self-assessed version of the Minimal Record of Disability for MS; she validated the Italian version of the 54-item MS Quality of Life (the most-used disease-specific health-related quality of life questionnaire); the Italian version of the Chicago Multiscale Depression Inventory; and the Italian version of the Control Preference Scale. Dr. Solari's team recently produced a short questionnaire on MS knowledge for patients and their significant others, the MS Knowledge Questionnaire, which was then validated in French for France by the Mapi Institute.

In a short review of the two conference days, John Golding and Prof. Thomas Henze highlighted the most important aspects of the conference and expressed their thanks and congratulations to all involved in the organising and running of the Prague Conference.

This great educational, networking and social event was made possible by the hard work of many people. Most importantly the dedication and contribution of the excellent presenters was recognised.

A great thank you goes from both organisations to the participants of the congress who actively contributed to the success of this event.

Last, but not least John Golding and Prof. Thomas Henze expressed thier appreciation to the congress manager, Anna-Maria Niculescu, who ensured that all possible details were considered.

Tick on Thomas Henze's image to join the closing remarks.





## Acknowledgements

Thank you for the generous support of our work



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