

RETHINKINGMS

IN TIMES OF COVID-19



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The COVID-19 pandemic has posed numerous challenges for healthcare systems — which have seen care of essential services interrupted, chronic illnesses deprioritised in the face of this emergency and a worrying increase of mental health issues. This was also particularly vivid for people living with multiple sclerosis (MS), their families, carers and health care professionals, causing significant disruption of care and impact on their daily lives. Existing uncertainty around MS as a neurodegenerative chronic condition has been tremendously accentuated by the additional uncertainty brought on by the COVID-19 emergency.

The MS community has witnessed the pandemic unfold from an uncomfortable distance, not directly involved but progressively affected. While recent research shows that there is no clear evidence patients living with MS are at a higher risk of COVID-19 infection compared to the general population, the heavy long-term consequences due to care disruption and mental health impact on the MS community should not be underestimated.

In 2018, the RETHINKING MS project was launched with the aim to provide insight on unmet needs and challenges. We wanted to emphasise the need to rethink the care provided for MS so that every person living with MS in Europe has their needs met for timely diagnosis, personalised treatment, interdisciplinary and coordinated care and adaptable support in daily life. These recommendations were particularly pertinent in the context of unique health crisis. With this new chapter, "RETHINKING MS in times of COVID-19", EBC sheds light on the challenges faced by people living with MS and highlight good practices that emerged in the midst of pandemic disruptions.

We look forward to the "RETHINKING MS in times of COVID-19" to act as a catalyst in health policy discussions and planning, contributing to provide solutions to reshape health and social systems as capable of addressing the staggering burden of chronic disease and greater care needs. The COVID-19 pandemic has demonstrated to us that current care models need to be restructured and optimised. We are now facing the great opportunity for Europe to apply the lessons learned and to address the silent pandemic of noncommunicable disorders, which MS undoubtedly belongs to.

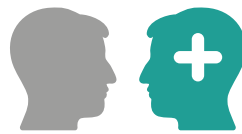
Professor Monica Di Luca,
President, European Brain Council



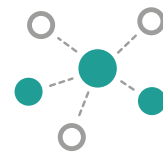

CALL TO ACTION

With this report, we challenge the status quo and refresh the European policy debate on the way MS care is organised, recognise the consequences of the burdens during the COVID-19 pandemic and encourage multi-stakeholder-driven policy. Accordingly, we call on policymakers and decision-makers across Europe to continue to develop and implement national strategies for MS that enable:

**Timely diagnosis
and personalised
treatment**



**Interdisciplinary
and coordinated
care**



**Adaptable
support
in daily life**



The following organisations endorse the “RETHINKING MS in times of COVID-19” paper, including the call to action and policy recommendations that emerged from the project, to help improve the quality of life and care for people living with MS in Europe.



INTRODUCTION



“Multiple Sclerosis gives you the opportunity to see your life differently because it alters your perception of how you think about yourself, how you think of others and how you think of your quality of life.”

Moira Tzitzika, Psychologist, Panteion University of Social and Political Studies, Greece

Multiple sclerosis (MS) is a progressive disease of the central nervous system where an immune response destroys brain, optic nerve and spinal cord tissue^{1,2}, leading to irreversible motor disability and cognitive impairment over time³. Typically, diagnosis occurs between the ages of 20 and 40⁴, greatly impacting a person’s career, income and family life.^{5,6} Affecting over 1.1 million people across Europe⁷, MS brings with it considerable costs to health and social welfare systems, as well as the wider economy in terms of decreased productivity from both people with MS and their carers.^{8,9,10,11,12} The unpredictable and invisible nature of some symptoms makes it particularly challenging to diagnose and manage. Furthermore, the personal and societal impact of MS grows significantly as the condition progresses and disability worsens.^{13,14,15}

There is currently no cure for MS and management focuses on timely diagnosis, disease-modifying therapies (DMTs), symptomatic therapies, rehabilitation and social care.^{16,17} Personalising and optimising each of these components can help people adapt to life with MS.¹⁸ However, suitable pharmacological therapies are not available to treat all symptoms, very often interrelated, and healthcare professionals may not be adequately equipped to fully support people outside of clinical settings, placing added importance on rehabilitation and social care to support daily living.^{19,20,21}

Due to its complexity and variability of symptoms, MS is generally difficult to treat and handle. Include a health emergency such as the COVID-19 pandemic, which has significantly impacted every sphere of society, and the repercussions have been particularly severe for people living with chronic conditions such as MS. We have witnessed the concerning shift in triage guidelines regarding treatment prioritisation in an emergency, which saw treatment for people living with chronic conditions deprioritised.

How did people living with MS manage to continue receiving care despite this decreased prioritisation of their treatment plans? What were the challenges people with MS experienced during the coronavirus pandemic and what lessons can be learned from them?

The objective of this new chapter, “RETHINKING MS in times of COVID-19”, is to provide concrete and tangible testimonies from relevant stakeholders – clinicians, MS patients, patient advocates, pharma representatives – impacted by the disruption in care, which proved both an obstacle and an accelerator for the implementation of good practices. Qualitative research was undertaken through semi-structured interviews, which elicited empirical knowledge from the different interviewees. This method allowed us to gather valuable insight into the stakeholders’ personal experiences during the COVID-19 pandemic: the challenges they faced and the strategies they used to handle them.

We highlight how the lives of people living with MS and their families have been affected by COVID-19. In addition to providing a voice to those side-lined by the pandemic response, the gathered testimonies shed light on the need to rethink MS and MS care in terms of coordination, integration and prioritisation in order to ensure optimal care for people living with MS in Europe. Our aim is to contribute to continued awareness raising of MS at EU policy level as well as to feed into the current European policy debate on the direct and indirect consequences arising from the COVID-19 pandemic and encourage stakeholder engagement in EU health policy making.

FACTS AND FIGURES



MS is a chronic, progressive, potentially disabling disorder with a considerable social impact and economic consequences despite its relatively limited prevalence. It is a major cause of non-traumatic disability in young adults.²²



A total of 2.8 million people are estimated to live with MS worldwide (35.9 per 100,000 population).²³



An estimated 1.1 million people live with MS in Europe.²⁴



The mean age of diagnosis is 32 years.²⁵



Women are twice as likely to live with MS as men.²⁶



In Europe, the average cost of MS, including indirect and direct medical and non-medical costs, is estimated at 15.5 billion euro per annum.²⁷



Less than half of people living with MS are employed.²⁸

QUOTES



“We were forced to make rapid changes to MS service, putting most of our services online and giving people with multiple sclerosis much more responsibility in managing their own disease. I think that’s the missing link that we’ve had in healthcare: how to provide patients with the necessary skills to be the managers of their own disease.”

Gavin Giovannoni, Professor of Neurology, Barts and the London School of Medicine and Dentistry, UK



“COVID-19 was first driven by uncertainties influencing the daily lives of patients. However, within a very short time period – meaning, a couple of months within a year – this uncertainty created closer relationships with our patients. I think it’s a general human attitude that a crisis also allows to bring people together.”

Thomas Berger, President, Austrian Society of Neurology; Chair Scientific Committee, European Academy of Neurology



“We need to remember that we have to manage patients with a complex chronic disease, with complex treatments, in a complex era of health emergency. We cannot separate these two situations because people with MS, in a way, live two different emergencies.”

Maura Pugliatti, Full Professor of Neurology, University of Ferrara, Italy



“The COVID-19 crisis opened new opportunities for people with MS. The pandemic triggered an urge to consider and test the integration of technology, including telehealth and remote monitoring in all areas of neurological care and chronic diseases.”

Johan van Beek, Senior Director, Head of Personalised Health Solutions, Worldwide Medical, Biogen

MULTIPLE SCLEROSIS IN TIMES OF COVID-19

Timely diagnosis and personalised treatment



“COVID-19 allowed us to get to know our patients more closely, understanding their anxieties, their needs and their requests even better than as compared to a situation without the crisis.”

*Thomas Berger, President, Austrian Society of Neurology;
Chair Scientific Committee, European Academy of Neurology*

A timely diagnosis is essential in management of MS in order to enable a prompt initiation of disease-modifying therapies (DMTs) and symptomatic treatment, which, in return, can prevent potentially irreversible disability. Moreover, diagnosis is a crucial moment in the patient pathway, taking into consideration the emotional response to diagnosis and the post-traumatic stress disorder (PTSD) identified in a significant number of those newly diagnosed with the chronic, irreversible condition.²⁹ Pandemic aside, under “normal circumstances” there are often delays to diagnosis due to low MS awareness among the general public and healthcare professionals as well as inadequate access to diagnostic facilities and MS specialists.^{30 31 32 33 34 35} This was heavily aggravated and accentuated further by the COVID-19 outbreak; for example, non-urgent medical investigations were put on hold and many people were stranded on an uncompleted diagnosis pathway and exposed to untreated MS.³⁶

People with MS report that the pandemic has caused broad disruption to health and social care services, which has impacted on their own health and wellbeing. Due to the disruption provoked by this health emergency, MS patients have been given much more responsibility over their own care.³⁷ Many have been taught to observe their own symptoms and progress via self-monitoring/management applications and other online tools, which has empowered them and provided them with more confidence and knowledge,^{38 39} making consultations more efficient. Nevertheless, the increased use of digital tools and telemedicine has not been observed across all spectrums of patient profiles. We need to keep in mind a group of patients, especially the elderly and people of low socioeconomic status or poor health literacy, who are at risk of being left behind by the digitalisation and reconfiguration of healthcare systems.^{40 41}

This considered, COVID-19 has spurred an increased focus on existing inequalities towards vulnerable populations. Acknowledgement of these inequalities, prioritisation of regular monitoring and personalised approaches are needed to ensure optimal and timely care for all people with MS, regardless of their treatment regimen and of their personal situations.

Interdisciplinary and coordinated care



“Healthcare services should be person-centred, with management focused on patients’ needs, rather than organisationally driven.”

Jenny Freeman, Professor in Physiotherapy and Rehabilitation, Plymouth University, UK

Monitoring and management of a multifactorial and heterogeneous disease such as MS requires a neurologist to draw on expertise from a range of disciplines. This interdisciplinary approach – where care is provided by a diverse group of specialists in a collaborative manner – is essential for all people living with MS.^{42 43 44 45}

In the wake of the COVID-19 pandemic, face-to-face consultations were reserved only for urgent MS patients and the overwhelming majority of visits were done virtually, especially during the first months of the outbreak.^{46 47 48 49 50 51} Communication between health care professionals and the formation of multidisciplinary teams in MS care has been affected by the use of telemedicine tools. Many traditional methods of care delivery were forced to evolve and the need to innovate became urgent to avoid a complete breakdown of care. Such disruption, particularly in the case of chronic conditions such as MS, can lead to dramatic repercussions if the disease remains untreated.⁵²

This sudden digital shift has accelerated a wider trend within healthcare to build solutions that are more patient-centred, more flexible and more accessible.⁵³ On the other hand, the rapid and massive adoption of telemedicine questions the traditional doctor-patient relationship, the importance of personal contact in healthcare delivery and the benefits of direct human interactions. Telemedicine should not come at the cost of the safety of patients or the quality of care delivered. How can an optimal balance in times of a swift transitional period such as COVID-19 be ensured? How can telemedicine reach all patients as safely and equally as possible? What is the best approach to offering telemedicine alongside in-person care? A personalised approach to care⁵⁴ is one of the key points to ensure optimal use of telemedicine, if deemed valuable both for patients and health care professionals. Furthermore, clear and transparent standards encompassing the use of telemedicine as well as telemonitoring will need to be defined.⁵⁵ Diagnosis or symptoms-based criteria for triaging and scheduling patients for in-person and virtual visits should take into account patients’ needs with a particular attention to social determinants that can limit access to care.⁵⁶

Adaptable support in daily life



"From my perspective, the key message for people with MS is to be proactive in how they manage their condition. We can be supported by healthcare professionals, but it is our responsibility to learn about MS and know the options available to us. It is hugely important to live a healthy lifestyle, exercise regularly and improve our diet."

George Pepper, Co-founder and CEO, Shift.ms, UK

Social care can greatly improve quality of life for people with MS, depending greatly on prompt access to a broad range of health and care services⁵⁷ and provide essential support to carers and family members. Social workers and occupational therapists can also provide support to people with MS in their professional and daily lives. Due to the unpredictable nature of MS, this personalised rehabilitation and social support must be initiated and adapted promptly.⁵⁸

Government policies encouraging and promoting a healthy lifestyle as well as incentives embedded in healthcare systems play an important role from a public health perspective. While public policy can contribute to improvement of the general health of the population and decrease the risk of chronic non-communicable diseases (CNCDs), healthy lifestyle decisions remain undoubtably individual responsibility.⁵⁹ In this regard, brain health interventions addressing various lifestyle risk factors associated with MS can slow the onset and worsening of MS, reduce the impact of comorbidities, and are important for overall health and wellbeing.^{60 61 62}

The COVID-19 pandemic has further highlighted the importance of these lifestyle factors for MS outcomes, such as a regular physical activity, a healthy diet, safe sun exposure or vitamin D supplementation and not smoking. Supporting patients living with MS to adopt a healthy lifestyle on a long-term basis, especially in such challenging times, can lead to positive results and improvement of patients' conditions. There are many ways in which MS patients can be supported, for instance, through easy access to rehabilitation, behavioural techniques and strategies, personal mentoring and coaching, disability-friendly sport facilities and greater awareness of physical impairment associated with MS.⁶³

Informal carers -- people in or out of employment providing informal, substantial and usually unpaid personal care, assistance or support to a relative in a non-professional, unpaid capacity⁶⁴ — have been indispensable during the COVID-19 pandemic.⁶⁵ They have been crucial in the transition to remote-based care delivery, particularly for MS patients with cognitive impairment.⁶⁶ However, despite their invaluable contribution, there is often limited support available to help carers, with formal support for carers often available only in the later stages of MS.^{67 68} It is important to identify the main carer(s) for each individual early in the process and appropriately include them in the care pathway alongside close family members.⁶⁹ Care must be individualised to each person and their specific symptoms,⁷⁰ meaning regular monitoring is a crucial method of personalising care and treatment. Informal carers play a crucial role in the management of MS and need to be provided with sufficient support to reduce the burdens associated with disease care.

LESSONS LEARNED FROM THE COVID-19 PANDEMIC



"COVID-19 has given us an opportunity to rethink the way we manage multiple sclerosis and how we deliver health care."

Gavin Giovannoni, Professor of Neurology, Barts and the London School of Medicine and Dentistry, UK





The current global public health crisis has challenged the assumption that health care needs to be delivered locally.⁷¹ COVID-19 has managed to break down barriers to adoption of crucial changes that healthcare systems had been slow to embrace. Accelerated digitalisation and innovation and increased use of telemedicine and self-monitoring applications have changed the way healthcare is delivered. The pandemic has highlighted, more than ever, the need for sustainable and resilient supply chains to safeguard patient access, the need to offer data-driven solutions beyond national boundaries and for multilateral coordination and cooperation.⁷² As continuity of care is crucial for people with MS, as well as for people with chronic conditions in general, strategies must be in place to ensure it is included in future pandemic response plans.⁷³

The landscape of multiple sclerosis is changing, with new insights on prognosis, the emergence of artificial intelligence in brain imaging, technological advances challenging knowledge on disease pathogenesis, and the identification of novel therapeutic pathways.⁷⁴ The accelerated integration of technology in clinical practice and virtual neurological assessments are likely to become the new norm after the crisis. This rapid shift signals transition toward a hybrid care model,^{75 76 77} in which providers, payers and innovators will need to properly integrate virtual and in-person care in the future and address questions arising on the reimbursement of telehealth services. While telemedicine provides numerous advantages, such as more efficient data collection resulting in a better knowledge and follow-up of patients and the possibility of self-monitoring, the use of telemedicine should be based around patients' choices and needs rather than being organisationally driven.⁷⁸ The integration of remote-based services will lead to better outcomes in people with MS only if they feel empowered and engaged in the management of their own disease.

It is evident that understanding such a complex and unpredictable disease such as MS is a mission on its own, it takes time, determination and collaboration. Rethinking the current management of MS in order to adequately provide care and support for all people with MS is needed. It is crucial that European and national policymakers focus their efforts around these priorities and take specific actions. The COVID-19 pandemic has brought opportunities to re-think integrated care models across Europe and the lessons learned from this global health emergency should lead to optimal and continuous care and treatment for all people living with MS.

THE COVID-19 PANDEMIC HAS HIGHLIGHTED THE NEED FOR:



- 1** Sustainable and resilient supply chains to safeguard patient access 
- 2** Data-driven solutions beyond national boundaries 
- 3** Multilateral coordination and cooperation 
- 4** The use of telemedicine based around patients' choices 
- 5** Patient engagement in disease management 

EXPERTS' BIOGRAPHIES

We would like to express our great appreciation to the experts for their valuable and constructive input during the development of this project.



Angela Guerra Alvarez

Senior Director, Multiple Sclerosis Medical Lead - Europe, Canada and Partner Markets - Biogen

Angela Guerra works for Biogen as the European Multiple Sclerosis Medical Lead. Chemist by training, she started her career as a scientific researcher applying artificial intelligence to optimise drug design. In 2010 Angela joined the pharmaceutical industry and during the last 10 years has been working on the neuroscience arena with the primarily focus on advancing care in MS.



Gavin Giovannoni

Professor of Neurology - Barts and the London School of Medicine and Dentistry, UK

Gavin Giovannoni is an academic neurologist based in the Blizard Institute, Barts and The London School of Medicine and Dentistry, Queen Mary University of London. His current research is focused on the Epstein Barr virus as a possible cause of multiple sclerosis, MS-related neurodegeneration, biomarker discovery & validation, and MS clinical outcomes. Gavin is also an avid reader, blogger, runner, gardener, husband, father, dog-owner, cook and wine & food lover.



George Pepper

Co-founder and CEO - Shift.ms, UK

George Pepper is the co-founder and CEO of Shift.ms – the social network for people with MS. Founded by MSers, for MSers, the charity supports many thousands of recently diagnosed people across the world as they make sense of MS. It's independent and it's free.

www.Shift.ms launched in 2009 following George's own experience of coming to terms with MS. Aged just 22, the diagnosis came at a time when George was faced with key decisions about relationships, family and career. Although diagnosis is most common when people are in their 20s and 30s, there was a lack of support for those recently diagnosed.

George is passionate about the role that we, people living with the condition, can play in the management of their healthcare. Shift.ms has 40,000 members from around the world. Prior to joining Shift.ms as CEO in 2012, George worked at a marketing agency for eight years. George lives in Leeds, a city in the UK, and is married with two daughters.



Giampaolo Brichetto

Clinical Director - Italian MS Society Rehabilitation Center - AISM Liguria

Dr. Giampaolo Brichetto joined the Italian MS Society Foundation (FISM) on March 2009, where he currently holds the position of Coordinator of Research in Rehabilitation. Giampaolo is 46 years old and has 19 years of Research in Rehabilitation experience in the field of neuro-rehabilitation: Parkinson's disease, stroke, traumatic brain injury and multiple sclerosis; he worked as Physical Medicine and Rehabilitation MD and then as PhD in Neurosciences for the Department of Neurological Sciences, University of Genova, from 2000 to 2007. He is currently coordinator of research in Rehabilitation for the Italian MS Society and its Foundation, Head of Rehabilitation Service for the Italian MS Society and Vice President of Rehabilitation in Multiple Sclerosis Network (RIMS). His whole carrier effort aimed at improving neuro-rehabilitation strategies both by integrating traditional rehabilitation techniques with bio-tech devices and cognitive rehabilitation strategies and by improving rehabilitation outcome measures for clinical and research purposes. He is author of more than 70 papers in extenso, published on international peer reviewed journals.



Izabela Czarnecka

Vice President - Polish Brain Council, Poland

Izabela Czarnecka is a journalist and leader of patient organisations. She has been managing NGOs since 2001. She spent 12 years as President of the Polish Multiple Sclerosis Society, for which she won the Wolfensohn award for persons with MS who has contributed to the worldwide fight against MS.

In 2012 she founded the NeuroPozytywni Foundation, an organisation that supports people with brain disorders.

Initiator and Deputy President of the Polish Brain Council, an umbrella organisation for NGOs working with people with brain diseases, developing a strategy for such patients. Chief editor of two quarterlies published by the Foundation: the NeuroPozytywni, aimed at MS patients and their families, and the Świat Mózgu, which popularises neurobiology and knowledge of brain diseases.

She represents patients' interests in the HTA process and is an expert of the Agency for Health Technology Assessment and Tariff System (AOTMiT) on the patient side. She also represents patient organisations in the Health Ministry's National Ethical Committee for Experiments on Animals.



Jenny Freeman

Professor in Physiotherapy and Rehabilitation - University of Plymouth, UK

Jenny Freeman is a Professor in Physiotherapy and Rehabilitation, and Associate Head of Research at the School of Health Professions, Faculty of Health, University of Plymouth, United Kingdom. Her research programme centres on the development and evaluation of complex rehabilitation interventions, reflecting the priority given by health services to providing evidence based management. She has a particular interest in the field of multiple sclerosis, and more specifically on the rehabilitation of impaired mobility and balance, a key challenge for many people with MS. Her research is grounded in her longstanding clinical expertise in neurological physiotherapy and multi-disciplinary rehabilitation, for which she has an ongoing clinical commitment.

Johan van Beek

Senior Director, Head of Personalized Health Solutions,
Worldwide Medical - Biogen



Johan van Beek leads the Personalised Health Solutions group at Biogen Digital Health. In his role, he is investigating how digital tools may drive the development of evidence-based solutions to improve outcomes in people with multiple sclerosis. Trained as a neuroscientist in the field of neuroinflammation research, Johan has 20 years of experience working in the pharmaceutical industry, including positions held in drug discovery, clinical development, and medical affairs, with a number of companies committed to improving the lives of people with multiple sclerosis.

Massimo Filippi

Full Professor of Neurology - Vita-Salute San Raffaele University, Italy



Massimo Filippi is currently: Full Professor of Neurology at Vita-Salute San Raffaele University, Milan, Italy; Director of the Residency School in Neurology, and President of the Bachelor's Degree in Physiotherapy at the same University; Chair of the Neurology and Neurorehabilitation Units, Director of the MS Center, Director of the Neurophysiology Service, and Director of the Neuroimaging Research Unit at IRCCS Scientific Institute San Raffaele, Milan. His research activity has always focused on the definition of the mechanisms leading to progressive accumulation of irreversible physical disability and cognitive impairment in various neurological conditions. He is member of various national and international Scientific Societies and Boards where he covered or is covering institutional roles. He is author of over 1200 papers, Editor-in-Chief of the Journal of Neurology, Associate Editor of Human Brain Mapping, and member of the Editorial Boards of many international scientific journals. He is very often requested as speaker and/or chairman in national and international neurological congresses. In 2001, Prof. Filippi was awarded the Rita Levi Montalcini Prize for his outstanding contributions to the study of MS.



Maura Pugliatti

Full Professor of Neurology - University of Ferrara, Italy

Maura Pugliatti, MD, PhD is Associate Professor of Neurology at the University of Ferrara, and acting as Director of the University Hospital Unit of Clinical Neurology, S. Anna Hospital, Ferrara, Italy. She took a PhD in 2007 and was a Research Fellow in 2007-10 at the Dept. of Public Health and Primary Health Care, University of Bergen, Norway, actively coordinating a large multi-center case-control study on multiple sclerosis (MS) and environmental risk factors. She has been Visiting Professor at the University of Bergen (Erasmus Teaching Staff Mobility program to medical students, 2010-12), University of Belgrade, Serbia (to PhD student, 2015). Since 2011 she is Adjunct Professor at the Dept. of Clinical Medicine, McGill University, Montreal, Canada within collaborative research in MS epidemiology. She has been a faculty member of the PhD School in at the University of Medicine and Pharmacy, Cluj Napoca, Romania, since 2016. In 2008-14 she was Chair of the EFNS Scientist Panel of Neuroepidemiology and Public Health, and she co-chairs the same Panel for the European Academy of Neurology. Her main research areas in epidemiology are multiple sclerosis, epilepsy, amyotrophic lateral sclerosis and myasthenia gravis, through collaborative research at national and international level. She is author of 122 papers in peer-reviewed scientific journals.



Miguel Angel Robles Sanchez

Multiple Sclerosis Clinical and Research Nurse
Multiple Sclerosis Centre of Catalonia, Spain

Miguel Ángel Robles Sánchez is a MS clinical and research nurse at the Center of Multiple Sclerosis of Catalonia and attended several post-graduate courses focused on the management of people with chronic diseases as well as the Master of Health Promotion at the University of Girona. His dissertation at the end of his master's degree studies entitled "Improving quality of life and satisfaction in patients diagnosed with multiple sclerosis through a specialized nursing management" was awarded at 2014 by the Girona Biomedical Research Institute.

In 2015 he performed theECTRIMS MS Nurse Training Fellowship Programme with an international stage at The National Hospital for Neurology & Neurosurgery Queen Square London in United Kingdom linked to his PhD thesis: "A comprehensive approach to meeting the needs and demands of people with multiple sclerosis".

He currently combines his clinical activity with three projects related to the management and support of people with multiple sclerosis:

- Expert Patient Programme of Catalonia for MS population
- VisualEM Project: visual resources for people with multiple sclerosis and their caregivers
- MS Shared-decision making web for the Spanish socio-cultural setting with a decision aid



Moira Tzitzika

Psychologist - Panteion University of Social and Political Studies, Greece

Moira Tzitzika studied Psychology at the Panteion University of Social and Political Sciences. She has a PhD in Psychology and is specialised in Disability counselling and Sexual Medicine from the European Society of Sexual Medicine.

Moira Tzitzika works as a Consultant for the disabled and chronically ill. She also collaborates with Rehabilitations Centers all over Greece and is a Partner at Neurological Clinic of the "G. Genimatas" Athens General Hospital and the Sexual clinic at the Psychiatric Department of "ATTIKON" University Hospital in Athens.

She is also a scientific collaborator at the outpatient Neuro-urology, Sexual Medicine and incontinence clinic at the National Rehabilitation Centre. Finally, she has introduced a series of publications (15) with MS being the basic theme and participate as a Consultant in Executive Committees in various Associations and Organizations dealing with Multiple Sclerosis and helping voluntarily groups (Vise President at the Hellenic Federation of Persons with Multiple Sclerosis, Head of Psychological Support at MS Association Hellas).



Pedro Carrascal

President - European Multiple Sclerosis Platform, Belgium

Pedro Carrascal is the CEO of EME (Multiple Sclerosis Spain); the Biscay MS Society and the MS Basque Foundation. He graduated with a Bachelor's degree in Law from the University of Deusto in 1996, Master's in Business Administration (MBA) from the University of Basque Country in 2004.

Since 2007 Pedro is board member of the MSIF (Multiple Sclerosis International Federation). In september 2012 Pedro become member of the European Multiple Sclerosis Platform (EMSP) Executive Committee, being since 2018 the president of this organisation.

Pedro has extensive knowledge and awareness of the needs of people with MS and the skills and abilities to develop and manage initiatives to meet those needs. He is also fully committed to the Spanish patient movement and one of the promoters of the Spanish "Neuroalianza" (Spanish alliance of neurodegenerative diseases) created in 2012 and "Plataforma de Pacientes" (umbrella organization for the main patients NGOS in Spain) in 2014.

Patient advocacy, management, ehealth, and social innovation are some of his skills.



Thomas Berger

President, Austrian Society of Neurology
Chair Scientific Committee, European Academy of Neurology

Thomas Berger, MD, MSc, FEAN, is Professor of Neurology and Chair, Dept. of Neurology, Medical Univ. of Vienna, Austria. He graduated in 1991 and postgraduated in 2002 in "Hospital Management and Health Economics". His career started 1992 at the Dept. of Experimental Neuropathology and Neuroimmunology (Hans Lassmann) and he was resident at the Dept. of Neurology, Univ. of Vienna from 1993-1995. In 1995 he moved to the Dep. of Neurology, Medical Univ. of Innsbruck, where he continued his academic track (1998 board certification in neurology and psychiatry, habilitation in 2003 and Vice-Director of the Dept. of Neurology from 2014-2018).

Scientific interests focus on inflammatory demyelinating CNS disorders. He has published more than 350 peer-reviewed papers/research letters/invited reviews and several books/book chapters. He was awarded several times, including by ECTRIMS and by the European Charcot Foundation and was/is principal investigator in more than 70 clinical treatment trials.

T. Berger is currently president of the Austrian Society of Neurology, serves as National MS Coordinator of the Austrian Society of Neurology and is member/chair of several international and national MS organisations and panels. Recently he was also appointed as member of the Austrian Supreme Public Health Council. T. Berger chairs with enthusiasm the Scientific Committee and is Board Member of the European Academy of Neurology. On behalf of the local organizing committees he is honored to host the virtual EAN and ECTRIMS congresses 2021 in Vienna.

ABOUT RETHINKING MS

"RETHINKING MS in times of COVID-19" is an extension to the project "RETHINKING MS in Europe", a research-driven project offering tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council. "RETHINKING MS in times of COVID-19" covers the experience of people living with multiple sclerosis (MS), their carers and health care professionals in the context of COVID-19.

Funding

The project is funded by Biogen and Bristol Myers Squibb. All outputs are non-promotional and not specific to any particular treatment or therapy.

About the European Brain Council

The European Brain Council (EBC) is a network of key players in the "brain space", with a membership encompassing scientific and professional societies, patient organisations and industry partners. A non-profit organisation based in Brussels, its main mission is to promote brain research with the ultimate goal of improving the lives of those living with brain conditions, neurological and mental alike.

For more information on "RETHINKING MS in times of COVID-19", please visit:

www.braincouncil.eu/RethinkingMS

ADDITIONAL RESOURCES

MS Barometer

The MS Barometer is a comparative survey collecting key information on Multiple Sclerosis (MS) in over 30 countries in Europe. It serves as a benchmarking tool to provide an accurate picture of MS management across Europe.

The Barometer results will serve to improve the health and social care systems by outlining areas for improvement and encourage decision-makers to take actions to improve the quality of life of people affected by multiple sclerosis.

REFERENCES

1. Montalban X, Gold R, Thompson AJ, Otero-Romero S, Amato MP, Chandraratna D, et al. ECTRIMS/EAN Guideline on the pharmacological treatment of people with multiple sclerosis. *Multiple Sclerosis Journal*. 2018;24(2):96-120.
2. Giovannoni G, Butzkueven H, Dhib-Jalbut S, Hobart J, Kobelt G, Pepper G, et al. Brain health: time matters in multiple sclerosis. *Multiple Sclerosis and Related Disorders*. 2016;9:S5-S48.
3. Feys P, Giovannoni G, Dijsselbloem N, Centonze D, Eelen P, Lykke Andersen S. The importance of a multi-disciplinary perspective and patient activation programmes in MS management. *Multiple Sclerosis Journal*. 2016;22(2 Suppl):34-46.
4. Montalban X, Gold R, Thompson AJ, Otero-Romero S, Amato MP, Chandraratna D, et al. ECTRIMS/EAN Guideline on the pharmacological treatment of people with multiple sclerosis. *Multiple Sclerosis Journal*. 2018;24(2):96-120.
5. Giovannoni G, Butzkueven H, Dhib-Jalbut S, Hobart J, Kobelt G, Pepper G, et al. Brain health: time matters in multiple sclerosis. *Multiple Sclerosis and Related Disorders*. 2016;9:S5-S48.
6. Multiple Sclerosis International Federation. Atlas of MS 2013 2013
Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>
7. Whicher C, Kriauzaite N, Albane T, Kasilingam E, Taylor A, Ratchford D, Merkel C., editor LB1256: New findings from the 2020 MS Barometer on MS prevalence, practicing neurologists and use of disease-modifying drugs across Europe. MS Virtual 2020 - 8th joint ACTRIMS-ECTRIMS meeting; 2020 11-13 September 2020; Virtual
8. Kanavos P, Tinelli M, Efthymiadou O, Visintin E, Grimaccia F, Mossman J. Towards better outcomes in multiple sclerosis by addressing policy change: the international multiple sclerosis study (IMPrESS). London; 2016
9. Cerqueira J, Compston D, Gherdes R, Rosa M, Schmierer K, Thompson A, et al. Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? *J Neurol Neurosurg Psychiatry*. 2018;89(8):844-50.
10. Pugliatti M, Moroni M, Antonovici A, Hausmann B, Hellwig K, Quoidbach V, et al. Averting multiple sclerosis long-term societal and healthcare costs: early intervention and lifestyle choices as key to success. Brussels, Belgium; 2017.
11. Kobelt G, Thompson A, Berg J, Gannedahl M, Eriksson J, Group MS, et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2017;23(8):1123-36.
12. Chalmer TA, Buron M, Illes Z, Papp V, Theodorsdottir A, Schäfer J, et al. Clinically stable disease is associated with a lower risk of both income loss and disability pension for patients with multiple sclerosis. *J Neurol Neurosurg Psychiatry*. 2020;91(1):67-74.
13. Giovannoni G, Butzkueven H, Dhib-Jalbut S, Hobart J, Kobelt G, Pepper G, et al. Brain health: time matters in multiple sclerosis. *Multiple Sclerosis and Related Disorders*. 2016;9:S5-S48.
14. Kanavos P, Tinelli M, Efthymiadou O, Visintin E, Grimaccia F, Mossman J. Towards better outcomes in multiple sclerosis by addressing policy change: the international multiple sclerosis study (IMPrESS). London; 2016.
15. Cerqueira J, Compston D, Gherdes R, Rosa M, Schmierer K, Thompson A, et al. Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? *J Neurol Neurosurg Psychiatry*. 2018;89(8):844-50.
16. Montalban X, Gold R, Thompson AJ, Otero-Romero S, Amato MP, Chandraratna D, et al. ECTRIMS/EAN Guideline on the pharmacological treatment of people with multiple sclerosis. *Multiple Sclerosis Journal*. 2018;24(2):96-120.
17. Giovannoni G, Butzkueven H, Dhib-Jalbut S, Hobart J, Kobelt G, Pepper G, et al. Brain health: time matters in multiple sclerosis. *Multiple Sclerosis and Related Disorders*. 2016;9:S5-S48.
18. MS International Federation. Global MS Employment Report 2016. London; 2016.
19. MS Society. MS Essentials: adaptations and your home. London; 2014.
20. Fantoni-Quinton S, Kwiatkowski A, Vermersch P, Roux B, Hauteceur P, Leroyer A. Impact of multiple sclerosis on employment and use of job-retention strategies: the situation in France in 2015. *J Rehabil Med*. 2016;48(6):535-40.
21. Oreja-Guevara C, Miralles A, Garcia-Caballero J, Noval S, Gabaldon L, Esteban-Vasallo M, et al. Diseño de una vía clínica para la atención a los pacientes con esclerosis múltiple. *Neurologia*. 2010;25(3):156-62.
22. Kobelt, G. and Pugliatti, M. (2005), Cost of multiple sclerosis in Europe. *European Journal of Neurology*, 12: 63-67. <https://doi.org/10.1111/j.1468-1331.2005.01193.x>
23. Walton C, King R, Rechtman L, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. *Mult Scler*. 2020;26(14):1816-1821. doi:10.1177/1352458520970841
24. Whicher C, Kriauzaite N, Albane T, Kasilingam E, Taylor A, Ratchford D, Merkel C., editor LB1256: New findings from the 2020 MS Barometer on MS prevalence, practicing neurologists and use of disease-modifying drugs across Europe. MS Virtual 2020 - 8th joint ACTRIMS-ECTRIMS meeting; 2020 11-13 September 2020; Virtual
25. Walton C, King R, Rechtman L, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. *Mult Scler*. 2020;26(14):1816-1821. doi:10.1177/1352458520970841
26. Walton C, King R, Rechtman L, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. *Mult Scler*. 2020;26(14):1816-1821. doi:10.1177/1352458520970841
27. Kobelt, G, Thompson A, Berg J, and Gannedahl M, et al. "New Insights into the Burden and Costs of Multiple Sclerosis in Europe." *Mult Scler* 23 (2017): 1123-1136.
28. <http://www.emsp.org/projects/ms-barometer/>
29. Giovannoni G. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
30. Hellwig K. 2018. Interview with Christine Merkel at The Health Policy Partnership and Vinciane Quoidbach at the European Brain Council [Telephone]. 21/08/18
31. Magyari M. 2018. Interview with Christine Merkel at The Health Policy Partnership and Vinciane Quoidbach at the European Brain Council [Telephone]. 05/09/2018
32. Sirbu C. 2018. Interview with Christine Merkel at The Health Policy Partnership and Vinciane Quoidbach at the European Brain Council [Telephone]. 19/11/18
33. Boneschi FM. 2018. Interview with Vinciane Quoidbach at the European Brain Council [Telephone]. 14/09/2018
34. Matthews V. 2019. Interview with Christine Merkel and Catherine Whicher at The Health Policy Partnership [Telephone]. 25/07/2019
35. Pugliatti M. 2018. Interview with Christine Merkel at The Health Policy Partnership and Vinciane Quoidbach at the European Brain Council [Telephone]. 27/08/2018
36. Giovannoni G. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
37. A Survey conducted in July 2020 found that most patients had still not been asked to self-monitor prior to their appointment. Giovannoni G. MS COVID-19 Have a say about your COVID-19 MS Service. Barts MS Research Blog. 2020. <https://multiple-sclerosis-research.org/2020/06/mscovid19-have-a-say-about-your-covid-19-ms-service/>
38. Giovannoni G. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
39. <https://blogs.bmj.com/bmj/2020/09/14/covid-19-induced-changes-in-the-management-of-multiple-sclerosis/>
40. Giovannoni G. 2021. Interview by Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021

REFERENCES

41. Brichetto G. 2021. Interview by Dominika Suchonova from the European Brain Council [Videoconference]. 11/05/2021
42. Havla J, Warnke C, Derfuss T, et al. 2016. Interdisciplinary Risk Management in the Treatment of Multiple Sclerosis. *Dtsch Arztebl Int* 113(51-52): 879-86
43. Feys P, Giovannoni G, Dijsselbloem N, et al. 2016. The importance of a multi-disciplinary perspective and patient activation programmes in MS management. *Multiple Sclerosis Journal* 22(2 Suppl): 34-46
44. Soelberg Sørensen P, Giovannoni G, Montalban X, et al. 2018. The Multiple Sclerosis Care Unit. *Multiple Sclerosis Journal* 25(5): 627-36
45. Oreja-Guevara C, Miralles A, Garcia-Caballero J, et al. 2010. Diseño de una vía clínica para la atención a los pacientes con esclerosis múltiple. *Neurología* 25(3): 156-62
46. Giovannoni G. 2021. Interview by Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
47. Berger T. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 30/03/2021
48. Pugliatti M. 2021. Interview by Frédéric Destrebecq from the European Brain Council [Videoconference]. 01/04/2021
49. Sánchez M. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 04/03/2021
50. Freeman J. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 12/03/2021
51. Filippi M. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 25/02/2021
52. Filippi M. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 25/02/2021
53. <https://www.healthparliament.eu/current-edition/>
54. Freeman J. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 12/03/2021
55. Brichetto G. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 11/05/2021
56. <https://hbr.org/2020/11/balancing-virtual-and-in-person-health-care>
57. <https://journals.sagepub.com/doi/full/10.1177/1355819620975069>
58. RETHINKING MS in Europe: Prioritising integrated services for people with multiple sclerosis
59. Pepper G. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 31/03/2021
60. Jelinek GA, De Livera AM, Marck CH, et al. 2016. Associations of lifestyle, medication, and sociodemographic factors with disability in people with multiple sclerosis: an international cross-sectional study. *PLoS One* 11(8): e0161701
61. Riemenschneider M, Hvid L, Stenager E, et al. 2018. Is there an overlooked «window of opportunity» in MS exercise therapy? Perspectives for early MS rehabilitation. *Mult Scler* 24(7): 886-94
62. Dalgas U, Stenager E. 2012. Exercise and disease progression in multiple sclerosis: can exercise slow down the progression of multiple sclerosis? *Ther Adv Neurol Disord* 5(2): 81-95
63. Freeman J. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 12/03/2021
64. Wanless, D., Securing Good Care for Older People: Taking a long-term view, King's Fund, 2006, accessible at: <https://www.kingsfund.org.uk/publications/securing-good-care-older-people>
65. <https://journals.sagepub.com/doi/full/10.1177/1355819620975069>

REFERENCES

66. Sánchez M. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 04/03/2021
67. Czarnecka-Walicka I. 2018. Interview with Christine Merkel at The Health Policy Partnership and Vinciane Quoidbach at the European Brain Council [Telephone]. 23/08/2018
68. Mitrečić D. 2019. Personal communication by email: 08/09/19
69. Sánchez M. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 04/03/2021
70. Giovannoni G, Butzkueven H, Dhib-Jalbut S, et al. 2016. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord* 9: S5-S48
71. Giovannoni G. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
72. <https://www.healthparliament.eu/current-edition/>
73. <https://journals.sagepub.com/doi/full/10.1177/1355819620975069>
74. [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(20\)30441-5/fulltext?rss=yes](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(20)30441-5/fulltext?rss=yes)
75. Giovannoni G. 2021. Interview with Frédéric Destrebecq from the European Brain Council [Videoconference]. 03/03/2021
76. Freeman J. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 12/03/2021
77. Pepper G. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 31/03/2021
78. Freeman J. 2021. Interview with Dominika Suchonova from the European Brain Council [Videoconference]. 12/03/2021




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