2021 Annual Report





Continuing to build MS communities for change

ABOUT EMSP

Who we are

Multiple sclerosis (MS) is one of the most common long-term conditions affecting the central nervous system (brain and spinal cord) and the main cause of non-traumatic disability among young adults. There are 1.2 million people living with MS in Europe.

For over 30 years, the European Multiple Sclerosis Platform (EMSP) has been the leading voice in Europe advocating for people living with MS. Together with our members, partners, and people living with MS across the EU, we strive to influence policy decisions to ensure high-quality, equitable treatment, care, and resources for people affected by MS, and their inclusion in education, employment and society at large. EMSP is also a driving force in the MS research agenda, ensuring coherence, engagement of people living with MS, and advancement towards our vision of a world without Multiple Sclerosis.





Vision

A world without MS, achieved in partnership with people living with MS, their communities across Europe, and their allies.

Mission

EMSP brings together the unique expertise of our members and partners in Europe to drive critical, state-of-the-art research and advance MS-relevant policies and treatments and possible cure. Our platform offers our members, EU decision-makers and opinion-leaders, and the wider MS community valuable evidence-based resources and tools to improve the lives of every individual living with MS in Europe.



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This report is available in web format



FOREWORD FROM THE PRESIDENT AND THE CEO

Dear Friends, Members and Partners,

While the world is assessing the impact of two years of a global pandemic crisis and now is facing the war at Europe's doorstep, in Ukraine, we can't help but be overwhelmed by a sense of compassion, urgency, and solidarity. The impact on our societies of those events goes in-depth and pushes us to rethink our priorities and question our ways.

To shed lights on the current context, we dedicate this report to all the first responders that show daily resilience, professionalism and courage to help people face those challenges and accompany them through difficult moments.

Amid a Europe marked by the continuous spread of the COVID-19, natural disasters growing in numbers and intensity over the Summer, and international political challenges; EMSP and its members thrived to develop its new Strategic Plan 2022-2024, working together for a future free of multiple sclerosis, in order to define priorities that respond to the current reality in which people with MS lived and the challenges they are facing.

The MS Barometer 2020 revealed the gaps in the health and social care management of people affected by MS across Europe. Needless to say, that this picture remains the same, and in some cases worsen: the pandemic has intensified existing inequalities in health, education, access to employment and governance.

EMSP will continue providing a robust platform for capacity building; strive for better access to treatments, therapies, and integrated care for people with MS across

Europe; promote evidence-based good practice and effective health and social care for people with MS, using digitalisation and health data; strive for equity and social inclusion and social protection of people affected by MS and support more and better investment of people and resources for MS research.

In 2021, we continued working on our flagship projects. The Annual conference marked a milestone in the efforts made through the MS Nurse PRO programme to support the MS Nursing Community and bringing it closer to the patients' community and part of the European MS movement. We also launched the MS Hive within the young people's network encouraging young people to work more closely with their national MS societies and start acting for change now through peer activities, community outreach at local level.

We are grateful for our member organisations, partners, volunteers, and corporate sponsors for joining their forces with us and continuing to build a better Europe for people affected by multiple sclerosis. A special thanks goes to the Executive Committee members, and to the team which has shown resilience during a tough year and successfully contributed to the action.

We hope you will enjoy reading our Annual report,





MEMBERSHIP



:: Full Members

Multiple Sklerose Gesellschaft
Österreich

http://www.oemsq.at/

MS Society Belarus http://msbelarus.com/

Ligue Nationale Belge de la Sclérose en Plaques

http://www.ms-sep.be/

MS Foundation Bulgaria http://www.msobg.org/

Savez Udruženja oboljelih od Multiple Skleroze Bosne i Hercegovine

Savez drustava multiple skleroze Hrvatske https://sdmsh.hr/

Unie Roska https://www.roska.eu/

Scleroseforeningen
www.scleroseforeningen.dk

Estonian Multiple Sclerosis Society

http://smk.ee/

The Finnish MS Society https://neuroliitto.fi/

Ligue Francaise contre la Sclérose en Plaques http://www.ligue-sclerose.fr/

Deutsche Multiple Sklerose Gesellschaft

https://www.dmsg.de/

Greek MS Society
https://gmss.gr/

MS Felag Islands
https://www.msfelag.is/

MS Society of Ireland https://www.ms-society.ie/

Associazione Itlaliana Sclerosi Multipla

https://www.aism.it/

Latvijas Multiplas Sklerozes
Asociacija
http://www.mslapa.lv/

Lithuanian Multiple Sclerosis Union

http://www.liss.lt/

Ligue Luxembourgeoise de la Sclerose en Plaques http://www.msweb.lu/

Tittp://www.irisweb.iu/

Multiple Sclerosis Society of Malta

http://www.msmalta.org.mt/

Multiple Sclerose Vereniging
Nederland

https://msvereniging.nl/

Multiple Sklerose Gesellschaft Österreich

http://www.oemsg.at/

National Association of Persons with MS in North Macedonia

https://msmakedonija.eu.org/

Multipel Sklerose Forbundet |
Norge

https://www.ms.no/

Polskie Towarzystowo Stwardnienia Rozsianego

https://www.ptsr.org.pl/

Asociatia Pacientilor cu Afectiuni Neurodegenerative din Romania

www.afectiunineurodegenerative.ro/

Sociedade Portuguesa de Esclerose Multipla https://spem.pt/

All Russian Public Organization (RPO) of Disabled People with MS

http://www.ms2002.ru/

Drustvo Multiple Skleroze Srbiie

https://multiplaskleroza.org.rs/

Slovensky Zvaz Sclerosis Multiplex

https://www.szsm.sk/

Zdruzenje Multiple Skleroze Slovenija (ZMSS) http://www.zdruzenje-ms.si/

Neuro Sweden https://neuro.se/

Asociación Española de Esclerosis Multiple (AEDEM-COCEMFE)

https://aedem.org/

Schweizerische Multiple Sklerose Gesellschaft (SMSG) https://multiplesklerose.ch/

The Multiple Sclerosis Society of Great Britain and Northern Ireland

https://www.mssociety.org.uk/

Associate Members

Udruženja Multiple Skleroze Republike Srpske www.uomsrs.org

Union de lutte contra la Sclerose en Plaques (UNISEP) www.unisep.org

The Hellenic Federation of Persons with Multiple Sclerosis (HfoPwMS)

MS Platforma Srbije https://msplatforma.org.rs/

MS Society of Moldova

MS Association 'Hope' Združenie Sclerosis Multiplex Nádej (ZSMN)

https://sclerosis-multiplex.sk/

Esclerosis Multiple España (EME)

www.esclerosismultiple.com

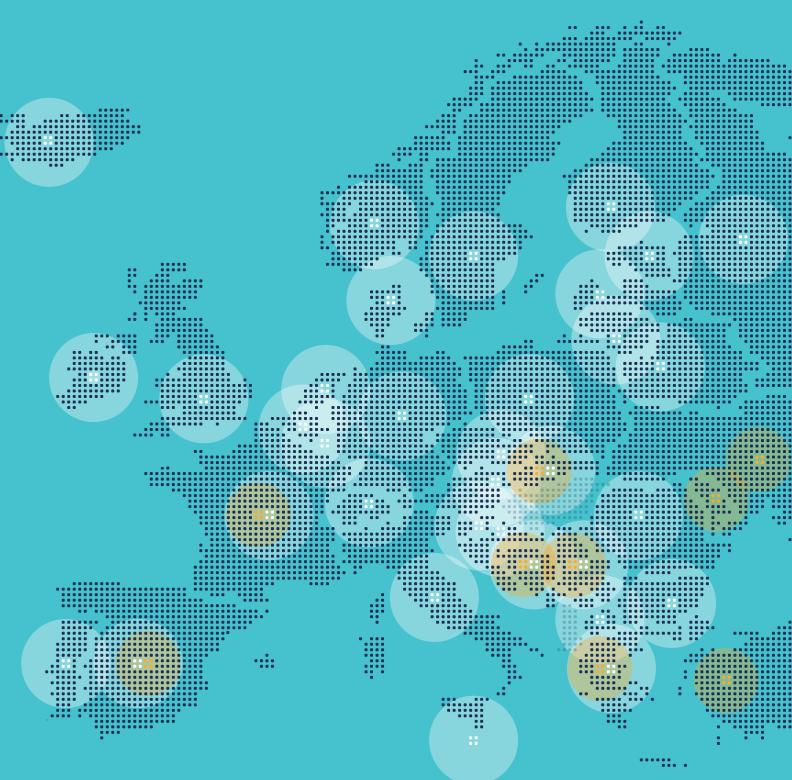
Multiple Sclerosis (MS)
Association of Turkey
www.turkiyemsdernegi.org

Ukrainian Community of people with Multiple Sclerosis (UCMS)
https://ucms-help.org/en/









EMSP is the voice of more than 1.2 million people with MS across Europe. We represent them through our growing network of 43 MS Societies in 37 European countries including 34 Full Members and 9 Associate Members (and still counting).



OUR EXECUTIVE COMMITTEE



Dimitra Kalogianni



MS Society of

Greece (GMSS)

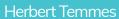


Treasurer MS Society of Belgium

MS Society of Belarus

Federica Balzani

Jonathan Blades





Szałkowska

Board Member MS Society of Poland



Board Member MS Society of Italy

MS Society of

France (LFSEP)



Board Member MS Society of the UK



Board Member MS Society of Germany

Anne Winslow

Dominika Czarnota-

EMSP Past-

Klaus Høm

Peer Baneke

Tanja Malbaša



President MS Society of Ireland



MS Society of Denmark

New member



MS International Federation (MSIF)



Board Member MS Society of Croatia

Patrik Puljić



Young People's Representative

OUR EXECUTIVE COMMITTEE





OUR TEAM

Debianka Mukherjee



Fundraising Development Manager

Emma Rogan

Krystalenia Ampreou



Campaigning and External Engagement Officer



Administrative



Communications and Membership Coordinator



New member Assistant **Project** Coordinator

Simina Peterfi





.c. Coordinator



Joeri Wullens

Cristina Munteanu



Accountant (Bebotax)



Thank you! Administrative Coordinator Stefaan De Corte

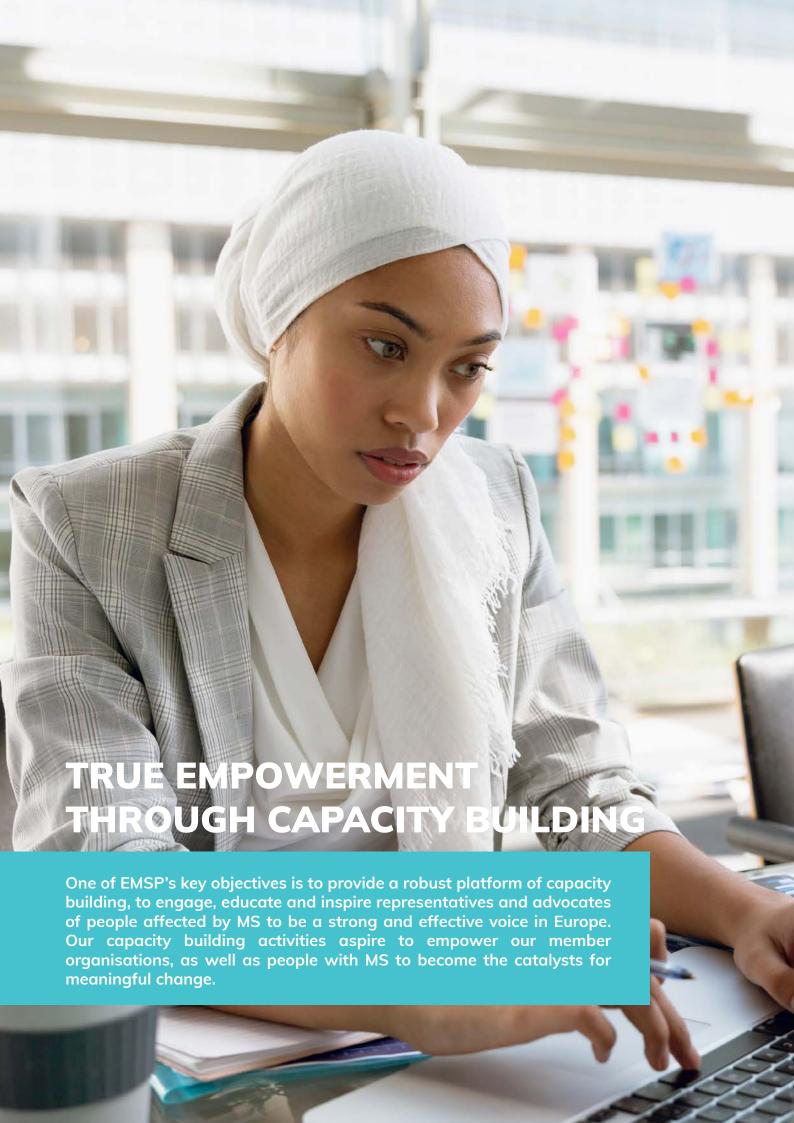




MS Nurse PRO Scientific Project Coordinator

EXTERNAL PROJECT COORDINATORS

OUR TEAM



EMSP MEMBERSHIP CAPACITY BUILDING PROGRAMME

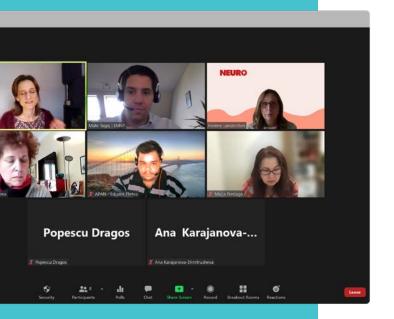
The EMSP Membership Capacity Building (MCB) Programme aims at empowering national MS Societies across Europe taking a regional approach to provide tailored support to the organisations - working in 2018 with the Baltic states and in 2019 with the Balkans. In 2020, due to the COVID-19 outbreak, the planned activities were adjusted and extended to the entire EMSP Membership in order to help member organisations to readjust their activities during the pandemic.

The core objective of our capacity building programme is to define the common priorities of MS organisations regionally and to set up a framework for sustainable partnerships to maximise their advocacy efforts for a greater impact.

In 2021, EMSP continued to pursue its regional capacity-building approach with online activities supporting specifically the Western Mediterranean, Balkan and Baltic regions.

In the framework of the 2021 programme, we held four online workshops to help the organisations to strengthen their activities. On 7 October we held a discovery workshop for our member organisations from France, Italy, Portugal, and Spain. This workshop aimed to equip the national MS societies and MS ambassadors to foster collaboration and build out the solidarity in the Western Mediterranean region, which was highly affected by the COVID-19 pandemic. We focused on discovering regional commonalities - common needs and challenges in the region - as well as supporting best practices sharing and peer support, acknowledging easier implementation, given the sociocultural and regional similarities.

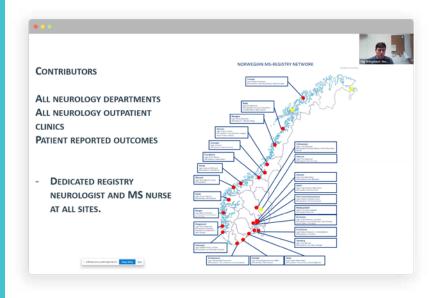


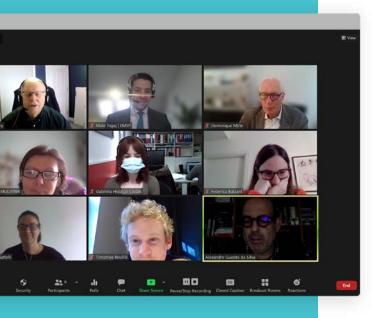


Stella Pearson Helplines Partnership

Another successful online workshop took place on 27 October for our member organisations from Belarus, Latvia, Lithuania, Northern Macedonia. Romania Estonia. and Sweden. The online training led by **Stella Pearson** – Trainer and Assessor from Helplines Partnership – provided tangible support for the leadership of the MS Societies in the Baltics to establish their needs for a helpline, their purpose and remit, to identify what channels they want to offer, what is needed to set up and run their service, how to ensure their helpline service is safe and to formulate an action plan for next steps.

On 19 January 2022 we had guest speakers from the MS Registries of **Italy** and **Norway**, who presented the story of their registries supporting the development of MS registries in the Balkan region. The main objective of the workshop was to support MS Societies in their







Graham Halsey from Well Working Matters led our last workshop on the 24th February 2022. The event counted on the presence of EMSP member organisations from the Western Mediterranean region. We were focusing on how priority areas changed for people living with Multiple Sclerosis in terms of employment during the COVID era. Together the MS Societies and EMSP assessed the current national and European policies and worked on a regional policy case to put spotlight on specific challenges that have come to the surface in terms of employment for people with MS during the pandemic.



EMSP Membership Communications Network & Online Engagement Platform

In 2021, the Membership Communications Network kept running its regular meet ups to foster two-way communications and to learn from regional best practices. We made sure that our members stayed up-to-date with ongoing and upcoming initiatives, to improve the contact between EMSP and its members, and to provide a network of peer support connecting the MS societies, young people, active volunteers and MS ambassadors.

On average, we counted on the presence of 19 representatives from 16 member organisations during bi-monthly our membership meet-ups. We addressed different 'hot' topics such as COVID-19 Real-Word Vaccination and MS and. Evidence Data.

In addition, EMSP launched its Membership Engagement Platform integrated on the recently redesigned emsp.org website, where the representatives of MS Societies can now: Communicate in a more efficient way with EMSP and with each other:

Interact with and support each other by sharing best practices via direct messages, groups & forum discussions:

Download the documents related to EMSP activities; and

Upload & share your own resources via Download Centre.

To learn more visit: www.emsp.org



YOUNG PEOPLE'S NETWORK (YPN)

The <u>EMSP Young People's Network (YPN)</u> is dedicated to the empowerment and involvement of young people living with MS in the work of the organisation. The members of the YPN (between the ages of 18-35) are passionate about advocating for their needs and making a change in our society, contributing to the European MS movement.

MS Hive: A creative space for social innovation

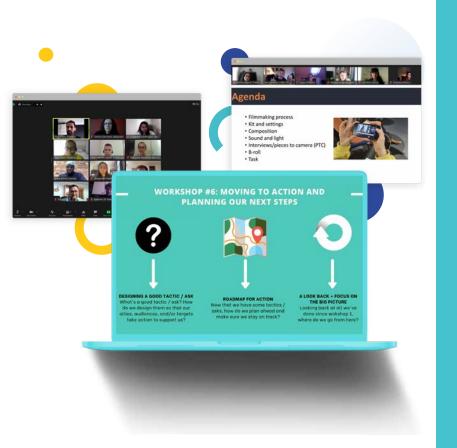
In 2021, EMSP developed a new project dedicated to the Young People's Network, the MS Hive. The MS Hive is a creative space for social entrepreneurship, with young people with MS, their allies and friends and people from all areas of life to work on innovative projects. EMSP envisions the MS Hive as an incubator, a place for the creation and development of projects based on social entrepreneurship and collaborative practices.

information please visit: emsp.org/projects/ms-hive/



Within the framework of the MS Hive, EMSP hosted an Advocacy & Campaigning learning program with six interactive workshops in collaboration with Campaign Accelerator for both YPN members and member MS societies. During the program participants were collaborating to design initiatives or events for young people with MS. Currently, different projects are being developed in 3 countries: Slovenia, Ukraine and the UK, all addressing different needs of





Empowerment of local young coordinators

In 2021, EMSP continued training young people with MS within its community building and advocacy programme. Namely, through a Webinar on Mental Health hosted in collaboration with Mental Health Europe, as well as the different webinars organised by EMSP addressing issues relevant to young people with MS, where YPN members were given a place to share their thoughts and ideas on the matters at hand. The YPN members were also given a storytelling platform by writing blogs and participating in wider EMSP campaigns.





How to get involved with the EMSP Young People's Network





This event helped us to understand the broader healthcare ecosystem and support the further development of the European MS nursing community. The conference also bridged the communication between the patients and the healthcare professionals for an improved understanding of the needs and personalized care of people with MS.

The EMSP Annual Conference 2021 specifically focused on the context of the global pandemic that has enhanced existing issues and at the same time fast forward the adaptation of health care and services through digitalization.

The world is changing in the light of a worldwide pandemic and MS care is challenged on many levels. The 2021 edition of EMSP's Annual Conference acknowledged this under the theme of MS Care in a Changing World in a virtual format.

#EMSP2021 ANNUAL CONFERENCE: MS CARE IN A CHANGING WORLD

The EMSP Annual Conference was held on the 9th to 11th June 2021 virtually in the context of the global pandemic. The event set up a milestone in EMSP engagement to support the MS nursing community to join its effort improving the care of the people with MS.

A mix of interactive sessions and highly inspiring speakers addressed the challenges highlighted in the <u>MS</u> <u>Barometer</u> and faced by patients and nurses in terms of access to quality, timely and personalised care.

This was a great opportunity to meet with other MS nurses and experts, people with MS and connect, learn and discover with others from across Europe and beyond.

Topics included: Sleep disorders in MS, MS nursing in a global pandemic, results for the MS Hackathons, Dealing with Fatigue, Disease Modifying Treatments, COVID-19 & MS and more! There was a special focus on MS Nursing, improving the future of MS Care as well as information on the MS Nurse PRO online training programme.

Access the recordings of all the sessions here:

https://youtube.com/playlist?list=PLh5_ s8Tjx9xbfuLFF-j8rzRQcn7HtqBAS





MS BAROMETER

The MS Barometer is a comparative survey based on key MS data collected by the national MS societies analysing MS management and care in Europe periodically since 2008. It provides an important framework for identifying the most persistent and challenging gaps in care, understanding how MS management has changed over time and fundamentally, how the lives of people with MS are impacted by decisions made at local, national and EU level. It also serves as a benchmarking tool outlining improvements and actions that can be adopted by national MS societies to influence decision-makers.



We see issues across the continent in access to appropriate healthcare, health professionals and social support for people with MS and their carers. National systems that fail to provide quality care are failing their MS communities.

In 2021, Brain Awareness Week (15-21 March) was all about the launch of the MS Barometer report and country factsheets for EMSP, through an overarching social media campaign joining forces with our members to make an impact together.



The MS Barometer uses 5 indicators of health and social care systems including:

Health care service delivery, including the number of MS health facilities and the number of MS related health workers

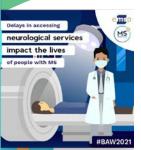
Health information, including MS epidemiology, MS data collection and MS research

Access to treatments, including access to disease modifying drugs (DMDs) and symptomatic medical treatments and therapies

Governance, leadership, and health financing, including existing MS-relevant policies, patient engagement, and health financing

Participation in society, including education/ employment opportunities for people with MS and social supports available to people with MS and their carers







On July 22nd, we dedicated World Brain Day 2021 to Multiple Sclerosis, and we were delighted to announce the launch of the interactive MS Barometer platform including:

- (1) Key findings on the state of MS Care in Europe
- 2° A comparison tool to highlight differences between countries
- Advocacy Toolkit with key messages and assets
- National information sheets translated into all the European languages
- 5° And much more!

On 15 March the msbarometer.eu site went live allowing everyone to download the key highlights of the latest edition of the MS Barometer. The campaign was a huge success reaching over 37,000 people in Europe and with the online resources downloaded approximately 1,000 times from different corners of the continent.

To learn more visit: **msbarometer.eu**

In addition, EMSP has been actively involved at national level advocacy initiatives by giving presentations at member events with top level decision-makers in Ukraine and Poland.

We also hosted a webinar to introduce the platform to our members and multiple stakeholders.





MS DATA ALLIANCE

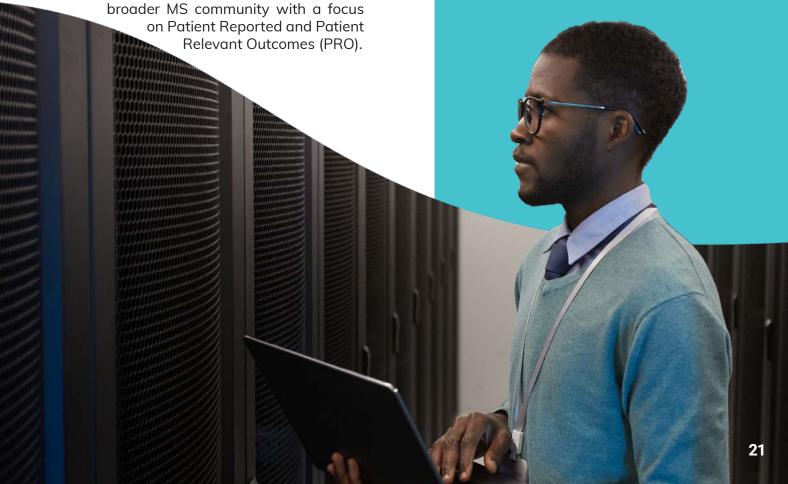
The <u>Multiple Sclerosis Data Alliance</u> (MSDA) is a multi-stakeholder collaboration working to accelerate research insights for innovative care and treatments for people with MS. The MS Data Alliance envisage a patient-centred learning health system in which all stakeholders contribute and use big data to co-create the innovations needed to advance the timely treatment and care of people with MS.

One of the main objectives of the 'Multiple Sclerosis Data Alliance' (MSDA) is the implementation of a minimal data set and quality standards, approved by the European Medicine Agency (EMA), in as many MS data registries and cohorts as possible. Improving the collection and analysis of real-world evidence can lead to better research outcomes and better informed policies for decision-makers, regulators and patients

MSDA aims to influence a mindshift on the vital importance and multifaceted usability of good-quality real world data - urgently needed as additional evidence for proper decision making by health authorities. It is designed to boost research and enable better outcomes for the broader MS community with a focus

MS DATA A L L I A N C E

MSDA was originally initiated by EMSP, the University of Hasselt and several project partners as a follow-up of EMSP's long-lasting efforts to harmonize MS data collection in Europe. Today, the MSDA is an independent multi-stakeholder initiative under the umbrella of the European Charcot Foundation (ECF) with ECF acting as the legal entity, and EMSP acting as one of the 6 main partners.



EMSP's main role in the project is to contribute to the development and promotion of the MSDA educational program. The educational program aims at providing resources to the MS patients, advocates and individual people with MS, their family and other stakeholders on MS data, its use, the methods of data collection and its ultimate impact on improving the quality of lives of people with MS.

In 2021, EMSP supported the project by providing the patient perspective in broader consultations online and by supporting the recruitment of national registries. Additionally, MS hosted a meeting with the European MS societies on the "Design and data considerations for MS registries" in January 2021 (moderated by Professor Dipak Kalra) and another meeting in the framework of the EMSP Membership Communications Network in May 2021.

In July-August 2021 MSDA collaboration with EMSP conducted Needs Assessment with all the stakeholder groups. To contribute to this assessment from the patients' perspective, EMSP collected from people living with MS and their caregivers via an online survey. The final report of that is available via this link: MSDA Stakeholder Focus Group Report

data sharing initiative Find out more Because data can tran people with Multiple Science

COVID-19

Facilitate future collaborations by aligning data collection

In order to facilitate possible future collaborations between different MS registries/initiatives regarding research on COVID-19 vaccinations, we did a mapping exercise and composed a recommended minimal dataset on COVID-19 vaccinations.

More information can be found HERE.

Learn more visiting: https://msdataalliance.com/

EMSP also played a central role in drafting an educational programme for patients to raise awareness about the importance of research using real-world MS data.



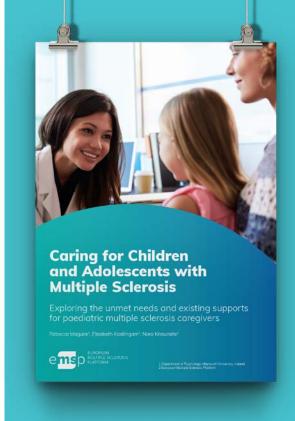
RECOMMENDATIONS FOR CAREGIVERS OF PAEDIATRIC MS

The "Recommendations for Caregivers of Paediatric MS" project aims to identify existing resources and unmet needs for caregivers of paediatric MS patients.

Our objective is to develop a set of recommendations to improve the support received by caregivers and specialised healthcare professionals and to raise awareness and influence positive change in current systems to improve support for caregivers of paediatric MS across Europe.

Ultimately, our goal is to provide better care for children and adolescents with MS . In 2019, EMSP completed and published its report of the rapid systematic review of the literature into the unmet needs of those who care for children and adolescents with MS. The survey aimed at gathering information on the available supports and resources for caregivers completed by national MS societies and experts in the area of paediatric MS.

In June 2021, EMSP organised a workshop with an expert group discussing the fact that many countries lack an MS registry, and even those that do have a registry do not include those aged under 18. The experts and practitioners who participated in the workshop noted that more information is required on the



longer-term social outcomes for children and adolescents living with MS, using cohort studies, rather than retrospective evidence, as well as data on the experiences encountered when transitioning from child to adult services.

As a result of our collaboration with the expert group, in September and October 2021 we updated our Recommendations for Caregivers of Children and Adolescents with MS, which was also approved by the group of experts and practitioners. The publication of the updated recommendations is planned during early 2022.





MULTIPLE SCLEROSIS COMMUNITY ADVISORY BOARD (MS CAB)







Patient Community Advisory Boards (CABs) are groups established and operated by patient advocates and facilitated by EURORDIS, Rare Diseases Europe and EUPATI Spain, a patient education specialist. CAB members are people living with a specific condition, a close family member or carer, and a member of a patient organisation that works with the disease.

In December 2021, EMSP launched a new initiative called the Multiple Sclerosis Community Advisory Board (MS CAB), through which we intend to become a positive and constructive partner in the research and development of safe, effective, and tolerable treatments for MS.

CABs facilitate discussions on the latest developments and challenges related to medical research, as well as procedures in our disease area with the sponsors of clinical research (a pharmaceutical or biotechnology company, or a hospital or university research team). The discussions are held in a neutral setting and are structured around the principles of confidentiality, transparency, sharing, openness, optimisation of research and development, and a joint action plan as an outcome of the discussions.



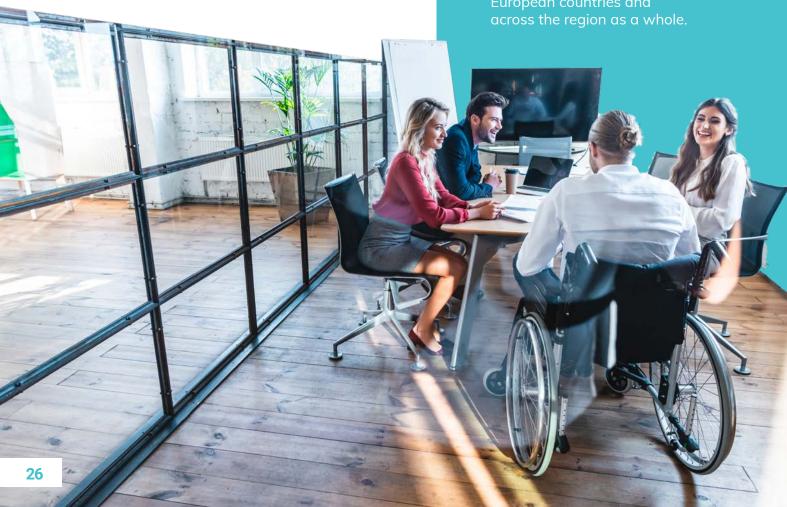
The MS CAB is a representative group of dedicated MS community activists and patient advocate members from different European countries, who have knowledge of scientific, as well as policy-related issues. It offers a pool of patient experts with the aim of meeting with companies, researchers and other stakeholders to provide expert knowledge. Activities might include providing advice to optimize clinical trials for better and faster results, accelerate treatments, or a possible cure.

Through the MS CAB we would like to bring the MS patient perspective via a structured and independent platform to contribute in development of initiatives and research that impact directly the people living with MS.

In 2021, EMSP managed to set up the MS CAB by identifying interested volunteers from The Netherlands, Ireland, Spain, Portugal, Italy, Romania and Croatia. We provided the training to become patient experts equipped to give advice to industry and research partners in their field of activities on a regular basis. It also helps co-create patient driven agenda for a meaningful and impactful outcome.

In the coming years, the MS CAB will offer the following opportunities:

- To influence the research and development pipeline for multiple sclerosis treatments so that it better meets the needs of patients and carers.
- To increase access to, and reimbursement of, multiple sclerosis treatments across Europe.
- To improve awareness and understanding of multiple sclerosis, both nationally and across Europe, within the healthcare system, academia, industry, and EU institutions, and among the public.
- To recruit, train and support more individual patient advocates and experts to work within individual European countries and



N2B-PATCH PROJECT

Effective drugs for the treatment of diseases of the central nervous system such as multiple sclerosis do exist. However, the blood-brain barrier, which protects the brain as the body's control centre, makes it especially difficult for therapeutic biomolecules to pass through. Thus, researchers from an international consortium – including EMSP representing the patient perspective – have spent the last 4.5 years developing a novel system in the N2B-patch EU funded research project that can be used to bypass this barrier.

Placing medications as close as possible to the site of the disease: this sounds completely believable in theory but is unfortunately not so simple in practice. While this works well for many drugs via the bloodstream or the digestive tract, it does not apply to the brain. In this case, special protective mechanisms such as the blood-brain barrier ensure that foreign substances from outside – and thus therapeutic agents and, above all, highly effective biomolecules – can reach this so important organ only with great difficulty and to a significantly reduced extent. However, especially for diseases of the central nervous system (CNS), it is crucial that the drugs reach this organ as efficiently as possible. One example is the treatment of multiple sclerosis, in which the pharmaceuticals must unfold their effect primarily in the CNS.



During the last 4.5 years, an international consortium of eleven partners including EMSP, set the task of providing a more efficient, alternative option for the therapy of multiple sclerosis and other CNS diseases as a platform technology.

With success: the international consortium developed a nasal delivery system for biopharmaceuticals via the olfactory mucosa, the regio olfactoria.

A gentle form of administration for treatments through the nose

For this reason, the European Union's Horizon 2020 Research and Innovation programme-funded N2B-Patch ("Nose-to-Brain-patch") project – that received funding under the grant agreement No. 721098 – was carried out between January 2017 and June 2021.

In contrast to treatment by nasal spray or intravenous injection directly into the bloodstream, this innovative "nose-to-brain" approach enables an active ingredient to bypass the path through the bloodstream and reach the brain directly. This is because the brain is separated from the nasal cavity only by the perforated ethmoid bone and a few additional cell layers so that the drugs can easily penetrate this barrier and reach the CNS directly over a short distance.





Check out the final video of the project: https://youtu.be/BZ81wXhwb51

Future platform technology for a wide range of indications

The novel delivery system is so promising that a patent application is to be filed shortly. For the active ingredient itself can be stably formulated using the new system and can thus even be stored for days and weeks at room temperature.

Since the novel system is designed to be flexible, the method can also be used in the future as a platform technology for other CNS diseases – for example, for the therapy of strokes and

Preclinical studies convincing

With the new system, the active ingredient is administered continuously and reliably to the brain over a period of up to two weeks. After that, another application must be made.

However, surveys conducted by the consortium have shown that patients do not perceive this as a burden. By enabling repeated use in a safe way for the patient, the system is suitable for long-term or even lifelong treatment. The system cannot be self-administered but must be applied by a physician or trained personnel who have appropriate skill and experience – similar to a Corona swab.

EMSP closely accompanied the project as a partner through the entire duration and thus regularly involved those affected by MS through events, campaigns or interviews.

Ended with a symposium, but research continues

In June 2021, the project officially ended with a virtual final symposium attended by experts from science and industry, but also patients and the interested public.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 721098.





HTX PROJECT

EMSP joined forces to support EURORDIS and other partners of the **HTx project** that envisions a new generation of healthcare decision-making. The main aim of HTx is to create a framework for the Next Generation Health Technology Assessment (HTA) to support patient-centred, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

Complex Decisions and Real World Evidence (RWE)

Healthcare professionals decide on the best therapies for their patients diagnosed with MS. They also determine in which moment and in which combination different treatments will offer the highest benefit.

However, clinical research doesn't always answer the questions of healthcare professionals and decision-makers about standards of care or reimbursement of therapies.

The HTx project will test methods to combine all the data available from clinical research and real-world medical practice into artificial intelligence (AI) models, assessing therapeutic pathways on a personalised basis.

Such an Al-powered web application will allow healthcare professionals to identify the best therapeutic pathway for people with MS, based on their characteristics, in real-time, discussed with them during a consultation. This will also prove useful for health authorities that decide on the reimbursement of certain therapies. This tool is meant to assess the combination of MS treatments, that are most probable to prevent relapses for a person living with MS, based on personal characteristics.



HTx is a project that received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825162, commenced in January 2019 and lasting for 5 years.



Shared Decision Making in Health Technology Assessment

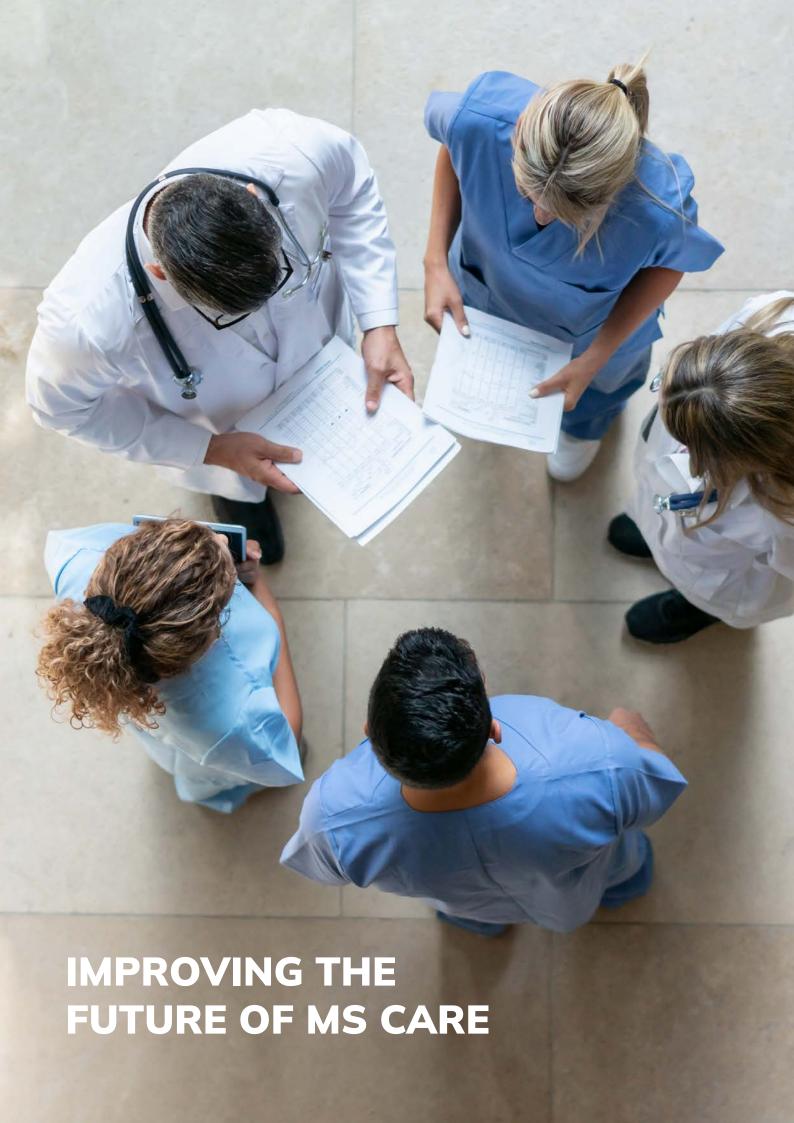
On 29 November 2022 we ensured meaningful patient involvement at the HTx workshop held under the title of "Shared Decision Making". The objective of the event was to compile ways in which clinicians and patients can use Real-World Evidence (RWE) to explore expectations regarding the outcome(s) of treatment and to make shared decisions.

People with MS have the possibility to influence the drivers of this research by interacting with project experts and making those tools fit their needs. This is an opportunity to shape the new decision-making models and decide the role patients can play in the future.

If you are a person with
MS and would like to
engage in the HTx project,
please contact us via email
at projects@emsp.org

If you would like to learn more, please visit HTx website: https://www.htx-h2020.eu/





MS NURSE PRO: SETTING THE STANDARD FOR MS NURSING PRACTICE ACROSS EUROPE

MS Nurse PROfessional (MS Nurse PRO) is the first European online foundation education programme for nurses working in the field of multiple sclerosis (MS). It is led by the EMSP in collaboration with the International Organisation of Multiple Sclerosis Nurses (IOMSN) and Rehabilitation in MS (RIMS).

MS Nurse PRO successfully trains qualified nurses who work in the field of MS, contributing to improved healthcare for people with MS in all regions of Europe and beyond. By equipping MS nurses with the skills and knowledge they need, MS Nurse PRO will create a positive change in MS care that extends across the entire multi-disciplinary care team.

The MS nurse is key in the provision of expert and consistent information, support, and advice for people with MS. From the moment of diagnosis and throughout the disease course, the nurse ensures a shared and coordinated approach to care. Across Europe, the role, skillset, and professional development of MS nurses varies. This leads to inequity of access to expert nursing care and advice, and inequality in the patients' care experience.

Since its launch in 2012, more than 7,500 nurses have joined the e-learning programme. Currently available in 12 languages and launched in 15 European countries, MS Nurse PRO is an online training programme that is accredited for 30 International Continuing Nursing Education Credits by the International Council of Nurses and 20 learning credits by the Birmingham City University (United Kingdom). It is also endorsed by over 25 national and international organisations.



Visit the MS Nurse PRO e-learning platform here: http://msnursepro.org/

With this increasing outreach, growth of registered nurses and accelerated activities around the e-learning platform, EMSP aspires to ensure that there are adequate numbers of MS nurses employed to provide appropriate support to all people with MS.



MS Nurse PRO is also an active community of nurses that strive for harmonized minimal standards of care for people living with MS across Europe to empower those people and their carers. The mission of MS Nurse PRO is to provide both at the European and the national level, online and offline educational content, sharing and networking opportunities for nurses working with people with MS in Europe.

In 2021, a new MS Nurse PRO e-platform was officially launched, adding new community and engagement features. Moreover, the module on Rehabilitation was also translated into German and all the relevant national and international accreditations have been renewed. In terms of events, two online educational sessions were conducted in Romania and Germany over the course of the year.

Furthermore, MS Nurse PRO launched the integration of the e-learning platform in the educational curriculum at the Birmingham City University and the MS Nurse Syllabus Committee undertook the preparatory work for the new module on MS nursing and research. The development of the MS nurse research module will be initiated in 2022 in collaboration with the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS).

32



7000+

registered users

new members

yearly from all

regions of the

800+

courses annually

completed

world

ADVOCACY AND CAMPAIGNING: ONE MILLION MINDS CAMPAIGN

OneMillion Minds

Under the umbrella of the multiannual "One Million Minds" campaign EMSP will lead two main awareness raising activities in the coming years: further amplification of the information from the MS Barometer and a campaign promoting better social inclusion of persons with disabilities. The purpose of EMSP campaigns is to ensure that the supporters of the organisation are motivated to continue engaging with EMSP, to garner further supporters to the voice of people affected by MS and to prompt engagement from potential allies across all sectors of society.

In order to achieve our mission of improving the quality of life of people affected by MS, we adopted a multi-stakeholder approach to engage the MS community and broaden the reach to the general public. For this purpose, we developed a European engagement campaign - vital in a very crowded EU Community.

It is a way for EMSP to translate our activities into messaging that will help reaching new supporters and challenge us to refine our efforts to those that make maximum impact.





MULTIPLYING IMPACT: STRENGTHENING STRATEGIC ALLIANCES

In 2021, we continued working together in a multistakeholder environment to ensure successful and effective outreach and engagement to MS patients and carers and ensuring impactful recommendations for the decision-makers.

EMSP kept its contribution in broader alliances to ensure the voice of the people affected by MS is represented, with the aim of increasing visibility of neurological diseases on the political agenda through the inclusion of MS as an example in broader campaigns and initiatives.

EMSP collaborates closely with the European Brain Council (EBC) and the Multiple Sclerosis International Federation (MSIF)





EMSP is a member of the European Patients' Forum (EPF), the European Disability Forum (EDF) and the European Federation of Neurological Associations (EFNA)







EMSP regularly collaborates with healthcare professionals and the scientific community, such as Rehabilitation in MS (RiMS), the European Committee for Treatment and Research in MS (ECTRIMS) or the European Charcot Foundation







EMSP is also a member of the EFPIA Patient Think Tank. EMSP has also a Memorandum of Understanding with Caritas Norway.





Work with the European Medicines Agency / EUnetHTA

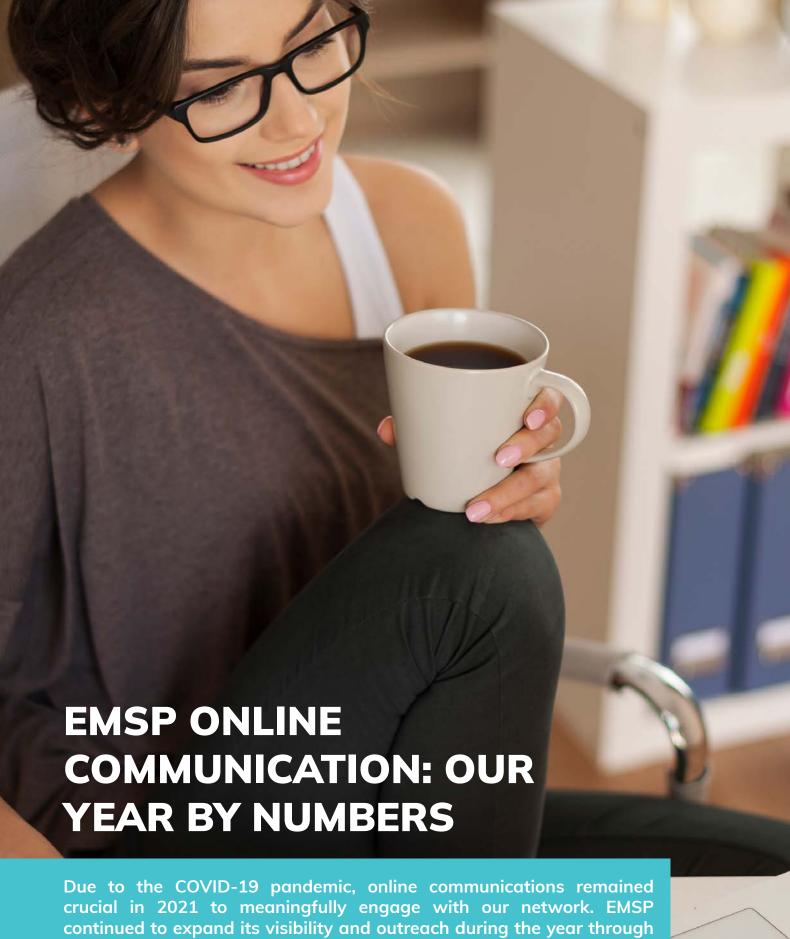
EMSP is a member of the Patient and Consumer Working Party and the Committee for Medicinal Products for Human Use of the European Medicines Agency (EMA). By being an active member within EMA, EMSP is looking to extend an intensive cooperation between MS patients and the EMA to involve people with MS in all possible procedures within EMA. Patients' contribution is particularly important for pharmacovigilance, e.g., adverse drug reaction reporting, as well as encouraging national authorities to implement all rules of the Pharmacovigilance Directive. Another major issue in which EMSP is involved is risk/ benefit assessment and the communication towards patients on this issue.

In February 2021, we organised our Annual Networking Event, attended by industry, our key partners, and members organisations, to discuss our plans and future collaboration opportunities. We looked back at EMSP's main achievements in 2020 and outlined our common priorities for 2021 and beyond.



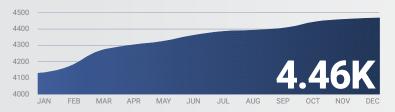
EMSP is a collaborating partner of EUnetHTA, a EU Commission-established initiative to create an effective and sustainable network for Health Technology Assessment (HTA) across Europe. EMSP provides support in terms of effectiveness of HTA models, and strives for better patient involvement in processes impacting the access to treatment for people affected by MS.





Due to the COVID-19 pandemic, online communications remained crucial in 2021 to meaningfully engage with our network. EMSP continued to expand its visibility and outreach during the year through its channels. Thanks to the launch of our redesigned and technically optimized website, we managed to register a significant increase in traffic at our digital headquarters. Overall, our metrics are maintaining a solid growth in terms of online followership and engagement.

Facebook followers



0 8,2%

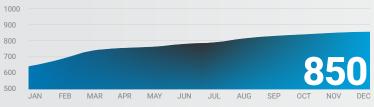


Twitter followers



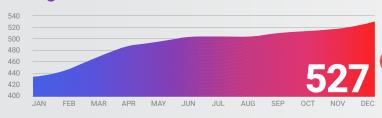


LinkedIn followers



850 **45,8**%

Instagram followers



O 21,1%



Youtube subscribers



O 13,9%



Website visitors







Treasurer's Report

In 2021, at EMSP, we felt the impact of the measures taken to help contain the global pandemic. In March last year, the container ship Ever Given got stuck in the Suez Canal, causing a complete standstill for shipments of goods transiting through the canal. This had major economic consequences for international trade. In a way, the corona measures have had the same effect on our processes: project sponsors are slower to advance and are more careful with the resources available; therefore, impacting the implementation and planning of our projects. Despite another year of constraints and associated difficulties in delivering projects as planned, our CEO and her team managed to close the year, once again, on a balanced balance sheet.

In Belgium, the entire non-profit association legislation was reformed in 2019 with the requirement for new associations to immediately comply with the new law. For existing associations, such as EMSP, the law came into effect on January 1, 2020, with the requirement to amend their statutes. In 2021, EMSP proceeded to the revision of its statutes that were approved by the Council during the Extraordinary General Meeting held virtually on June 18th.

On the same occasion, the Membership Committee presented

the review of EMSP membership policy. Membership of EMSP is a voluntary commitment taken by each national MS society, which goes with duties and obligations, to support the European MS movement. This is offset by obligations, including the payment of membership fee, which must be fulfilled. However, taken in consideration the last years, the rationale behind the new policy was adapted to ensure that the membership fee policy is in line with the changes in the financial capacity of the members. The new Membership Fee policy was also approved on the 18th of June and will be applied as of 2022.

As the COVID19 pandemic is slowly getting under control, and that we are quietly returning to a pre-corona modus operandi, 2022 brings its own challenges. Despite the war in Ukraine, our focus should remain not only on ensuring that the people affected by MS continue to receive adequate and timely care, but also on gradually getting back on track projects that were delayed due to corona and picking up speed to reach our objectives according to plan. For that reason, we carry forward a larger amount than usual of our funding from one budget year to the coming working year, with the approval of our financial partners.







Financial Statements 2019-2020

Income	2021	2020
Core funding	180.842	119.516
Conferences & events	205.002	183.854
Other Income	43.419	6.857
Project funding	446.703	661.353
Total Income	875.966	971.580
Expenditure		
	398.027	302.926
Staff salaries	398.027 1.027	302.926 90.175
Staff salaries Outsourcing		
Expenditure Staff salaries Outsourcing Administrative costs Direct costs	1.027	90.175
Staff salaries Outsourcing Administrative costs	1.027 71.655	90.175

Project funding Income N2B-patch 1,8% ... ··· MS Data Alliance 2,2% Paediatric MS Caregivers 3,2% MS Nurse Pro 38,5% **MS CAB 2,8% Project funding 51,0%** Core funding 20,6% **Membership Capacity** Conferences & events 23,4% Building 11,1% **Other Income 5%** Young People's Network 12,3% MS Barometer / Campaigning / Socialis 28,0%

Balance Sheet 2020-2021 (EUR)

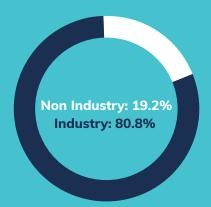
A		0004	2000
Assets/Liabilities		2021	2020
Fixed Assets		43.686	29.348
Current Assets	Accounts Receivable - Pharma	102.749	13.302
	Accounts Receivable - Members	30.299	16.613
	Prepayments	22.316	21.431
	Other debtors	0	0
	Accrued income	0	0
	Other receivables	2.651	24.798
Total Current Assets		158.015	76.145
	Bank Current Account	725.947	594.522
Total Assets		927.648	700.015
Funds		2021	2020
Capital		13.585	13.585
Reserves B/fwd		344.098	341.623
2021 - 2020 Profit		13.927	2.475
Total Funds		371.610	357.683
Current Liabilities		2021	2020
	Accounts payable	64.658	77.483
	Prepayments	76	0
	Deferred Income	410.831	169.173
	Accruals & other creditors	15.884	74.033
	Taxes & Social Security	27.761	21.643
	Provision holiday pay	36.827	0
Total Current Liabilit	ties	556.037	342.332
Total Liabilities		927.648	700.015

Industry income 2020 (EUR)

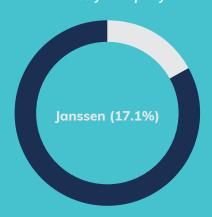


	ercentage of verall budget	Amount (90-100%)	
Actual Income 2021	100,0%	854.212	
Pharma Support			
Alexion	1,1%	10.000	
Almirall	1,1%	10.000	
Biogen	13,4%	117.000	
Bristol Myers Squibb	12,6%	110.196	
Coloplast	2,3%	20.000	
Janssen	17,1%	150.000	
Merck	10,3%	90.000	
Novartis	16,0%	140.000	
Sanofi-Genzyme	4,2%	37.016	
Roche	14,8%	130.000	
Viatris/Mylan	4,6%	40.000	
Total Pharma		854.212	
Total percentage on the overall budget for 2021	80,8%	707.712	
Total rest	19.2%	168.254	





Percentage of the highest contribution from a single Industry Company







STATUTORY AUDITOR'S REPORT
TO THE GENERAL MEETING OF THE ASSOCIATION
EUROPEAN MULTIPLE SCLEROSIS PLATFORM
RUE AUGUSTE LAMBIOTTE 144/8
1030 BRUXELLES
FOR THE YEAR ENDED 31/12/2021
RPM BRUSSELS nr. 0473.317.141

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In the context of the statutory audit of the annual accounts of "EUROPEAN MULTIPLE SCLEROSIS PLATFORM" (the Organisation), we hereby present our statutory auditor's report. It includes our opinion on the audit of the annual accounts as well as our report on the other legal and regulatory requirements. These reports form part of an integrated whole and are indivisible.

We have been appointed as statutory auditor by the general meeting of members of "EUROPEAN MULTIPLE SCLEROSIS PLATFORM", following the proposal by the board of directors. Our statutory auditor's mandate will expire on the date of the general meeting of members which will deliberate on the annual accounts closed on 31/12/2022. We have performed the statutory audit of the annual accounts of "EUROPEAN MULTIPLE SCLEROSIS PLATFORM"for 11 consecutive years.

Report on the audit of the annual accounts

Unqualified opinion

We have audited the annual accounts of the Organisation, which comprise the balance sheet as at 31/12/2021, the profit and loss account for the year then ended and the notes to the annual accounts, characterised by a balance sheet total of \leqslant 927.647,76 and a profit and loss account showing a profit for the year of \leqslant 13.927,39.

DPO BEDREFSREVESOREN

02/04/2022

OOSTAKKER (GENT)



RPM Brussels nr. 0473.317.141

In our opinion, the annual accounts give a true and fair view of the Organisation's net equity and financial position as at 31/12/2021, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.

Basis for unqualified opinion

We conducted our audit in accordance with International Standards on Auditing (ISAs) (as applicable in Belgium). Our responsibilities under those standards are further described in the 'Statutory auditor's responsibilities for the audit of the annual accounts' section in this report. We have complied with all the ethical requirements that are relevant to the audit of annual accounts in Belgium, including those concerning independence.

We have obtained from the board of directors and the officials of the Organisation the explanations and information necessary for performing our audit.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Responsibilities of the board of directors for the annual accounts

The board of directors is responsible for the preparation of annual accounts that give a true and fair view in accordance with the financial reporting framework applicable in Belgium, and for such internal control as the board of directors determines is necessary to enable the preparation of annual accounts that are free from material misstatement, whether due to fraud or error.

In preparing the annual accounts, the board of directors is responsible for assessing the Organisation's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the board of directors either intends to liquidate the Organisation or to cease operations, or has no realistic alternative but to do so.





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Fax: +32 9 255 50 87 www.dpo.be

RPM Brussels nr. 0473.317.141

Statutory auditor's responsibilities for the audit of the annual accounts

Our objectives are to obtain reasonable assurance about whether the annual accounts as a whole are free from material misstatement, whether due to fraud or error, and to issue a statutory auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these annual accounts.

As part of an audit in accordance with ISAs, we exercise professional judgment and maintain professional skepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the annual accounts, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Organisation's internal control;
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the board of directors;
- Conclude on the appropriateness of the board of directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Organisation's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our statutory auditor's report to the related disclosures in the annual accounts or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our statutory auditor's report. However, future events or conditions may cause the Organisation to cease to continue as a going concern;

Evaluate the overall presentation, structure and content of the annual accounts and whether the annual accounts represent the underlying transactions and events in a оро выплания achieves fair presentation.

02/04/2022 OOSTAKKER (GENT)



RPM Brussels nr. 0473.317.141

We communicate with the board of directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identified during our audit.

Report on other legal and regulatory requirements

Responsibilities of the board of directors

The board of directors is responsible for the compliance with the legal and regulatory requirements regarding bookkeeping, as well as for compliance with the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations, the Company and Associations Code and with the Organisation's bylaws.

Responsibilities of the statutory auditor

In the context of our mandate and in accordance with the Belgian standard (Revised in 2018) which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, it is our responsibility to verify, in all material aspects, compliance with certain provisions of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations the Company and Associations Code and with the by-laws, as well as to report on these elements.

Statement related to independence

- Our audit firm did not provide services which are incompatible with the statutory audit of annual accounts, and we remained independent of the Organisation throughout the course of our mandate.
- No additional work services which implicated fees and which are compatible with the statutory audit of annual accounts as referred to in article 3:65 of the Company and Associations Code has been carried out.





RPM Brussels nr. 0473.317.141

Other statements

- Without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- There are no transactions undertaken or decisions taken in breach of the by-laws or of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations and the Company and Associations Code that we have to report to you.

Done at Oostakker (Ghent

April 2nd, 2022

DPO Bedrijfsrevisoreh Statutory Auditor

Represented by Ulrich De Poortere

Registered Auditor - Director

ACKNOWLEDGEMENTS

We would like to express our gratitude to everyone who provided their support to successfully achieve our objectives in 2021, including EMSP member organisations, Executive Committee members, partners, and sponsors.

We would also like to take this opportunity to thank the MS advocates and experts that contribute to the development of EMSP's projects and help us to deliver high-quality resources for people with MS, including the MS Nurse PRO Steering Committee and Syllabus Committee members, the members of the MS Data Alliance working group and the members of the Young People's Network.



EMSP's reach and impact is enhanced by the close cooperation with many other European organisations. Among others: Rehabilitation in Multiple Sclerosis (RIMS); MS International Federation (MSIF); European Patients' Forum (EPF); European Federation of Neurological Associations (EFNA); European Brain Council (EBC); the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS); the European Disability Forum (EDF) and the International Organisation of MS Nurses (IOMSN).

A heartfelt thank you also goes to our external consultants who supported the work of the EMSP Secretariat in 2021: Downtown Europe team (Professional Conference Organiser), Dr Rebecca Maguire, Health Policy Partnership team, Campaign Accelerator team, Andrés Martínez Ricci, Donna Cardillo, Amy Perrin Ross, Baron Charles van der Straten Waillet, MEP Kateřina Konečná, MEP Tilly Metz, Impact Media team, Istvan Nagy and many others that accompany us on our journey.



CORPORATE PARTNERS AND DONORS

EMSP has continued to benefit from the substantial support of corporate partners who have provided funding for key projects:























This report was compiled by Mate Tagaj with the support of the EMSP Team.

Graphic design by Boostern

This report has been designed in line with best practice guidelines of visual accessibility.

We welcome your feedback on the contents and design and suggestions for making our publications more useful and accessible.

Please email your comments to mate.tagaj@emsp.org



European Multiple Sclerosis Platform aisbl

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Registered Legal Entity: 0473.317.141

secretariat@emsp.org www.emsp.org