

Annual Report 2020

Building
MS communities
for change



TABLE OF CONTENTS

ABOUT EMSP



Foreword



Our Members



Our Executive
Committee

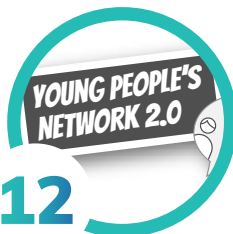


Our Team

CAPACITY BUILDING: EMPOWERING THE MS COMMUNITIES



Membership Capacity
Building Programme



Young People's Network
(YPN)



You have MS



#EMSP2020 Virtual
Conference

UNDERSTANDING THE NEEDS AND CHALLENGES OF PEOPLE AFFECTED BY MS



MS Barometer 2020



MS Data Alliance



Paediatric MS and
caregivers

BUILDING STRATEGIC ALLIANCES FOR GREATER IMPACT



Work with the European
Medicines Agency /
EUnetHTA



Shared policy initiatives
and campaigning

RESEARCH & INNOVATION: BRINGING THE NEEDS AND PERSPECTIVE OF PEOPLE WITH MS INTO THE CENTRE



N2B-Patch Project



HTx Project

IMPROVED CARE EXPERIENCE FOR PEOPLE WITH MS



MS Nurse PRO



Keep moving with MS

DIGITAL COMMUNICATIONS DURING COVID TIMES



FINANCES



ACKNOWLEDGEMENTS



FOREWORD

FROM THE PRESIDENT AND THE CEO

Dear Friends and supporters,

Looking back at 2020 takes us on an emotional roller coaster as the world has suddenly been put on hold by the COVID-19 global pandemic. If anything, the MS Community at all levels – national, European, and globally – has demonstrated how resilient, strong, and supportive it can be.

More than ever, the time is to strengthen alliances and collaborate to face the challenges of the world to be in the post pandemic era.

We started 2020 with the aim to continue working on building communities for change to pursue our mission to improve the quality of life of people affected by multiple sclerosis. Our plans and identity were shaken by the multiple crisis impacting the world in 2020 - including the impact on the access to healthcare systems, the need for racial justice, the global and European political stability - all of these, rooted in the need for better policies and sustainable administration.

Back in 2019, we reached a sustainable path that was seriously shaken during last year. We were “muted” on many levels while we needed time to adjust to the pandemic, understand the immediate repercussions and consolidate our assets towards a revised plan.

Despite the setback in the first semester, together with our member organisations and a dedicated team, we were able to support the European MS community by understanding the needs and priorities of the national MS societies and delivering a tailor-made capacity building programme, by organizing regular meetups for the young MSers to keep the community alive, and by contributing to the Global Data Sharing Initiative focusing on the COVID-19 through the MS Data Alliance project. We also had the opportunity to hold for the very first time ever, a fully virtual EMSP Annual Conference which gave us the opportunity to reach out to individuals worldwide.



Pedro Carrascal
EMSP President

The MS Barometer 2020 also gives back a strong advocacy voice for more than one million people affected by MS across Europe. It will serve to support the campaigns of the European MS community in the coming years and engage in a meaningful evidence-based dialogue with the health and social policy decision-makers.

We are proud to be part of the MS Community, which went from words to action, mobilising the communities in no time to bring change and support to the people with MS and their supporters across Europe in the present circumstances.

Our hearts go out to all those who have lost loved ones during those major crises, those who are caring for them and those who have been affected. EMSP will stand for solidarity, equal access to healthcare and for social justice and inclusion.

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 Christoph Thalheim, our former External Affairs Director and Torben Damsgaard, EMSP Vice-President who stepped down in 2020 after many years of committed services and contribution to lead EMSP where it stands today; and to the team which has shown resilience during a tough year and successfully contributed to the action



Elisabeth Kasilingam
EMSP CEO

We hope you will enjoy reading our Annual report.

ABOUT EMSP



Who we are

The European Multiple Sclerosis Platform (EMSP) is a Pan-European umbrella organisation with over 30 years of expertise. We work together with 43 members organisations from 37 countries and our partners to ensure that the more than one million people affected by multiple sclerosis (MS) in Europe, have a real voice in determining their own priorities



What we do

We raise the voice of people with MS to ensure they have a role in determining their own priorities. Their needs are the focus of our advocacy and awareness-raising campaigns to influence European decision-makers and EU policymakers. We gather data and provide knowledge and expertise to relevant stakeholders and encourage high quality research and the dissemination of excellent, evidence-based information on MS.



What makes us different?

EMSP is the only MS-specific organisation that can represent the voice of people affected by MS to influence EU policies that impact their quality of life. For the past 30 years, EMSP has been collaborating with the European Commission and European Parliament to address the challenges faced by the European MS community and we work with the European Medicines Agency.



Vision

A world without Multiple Sclerosis

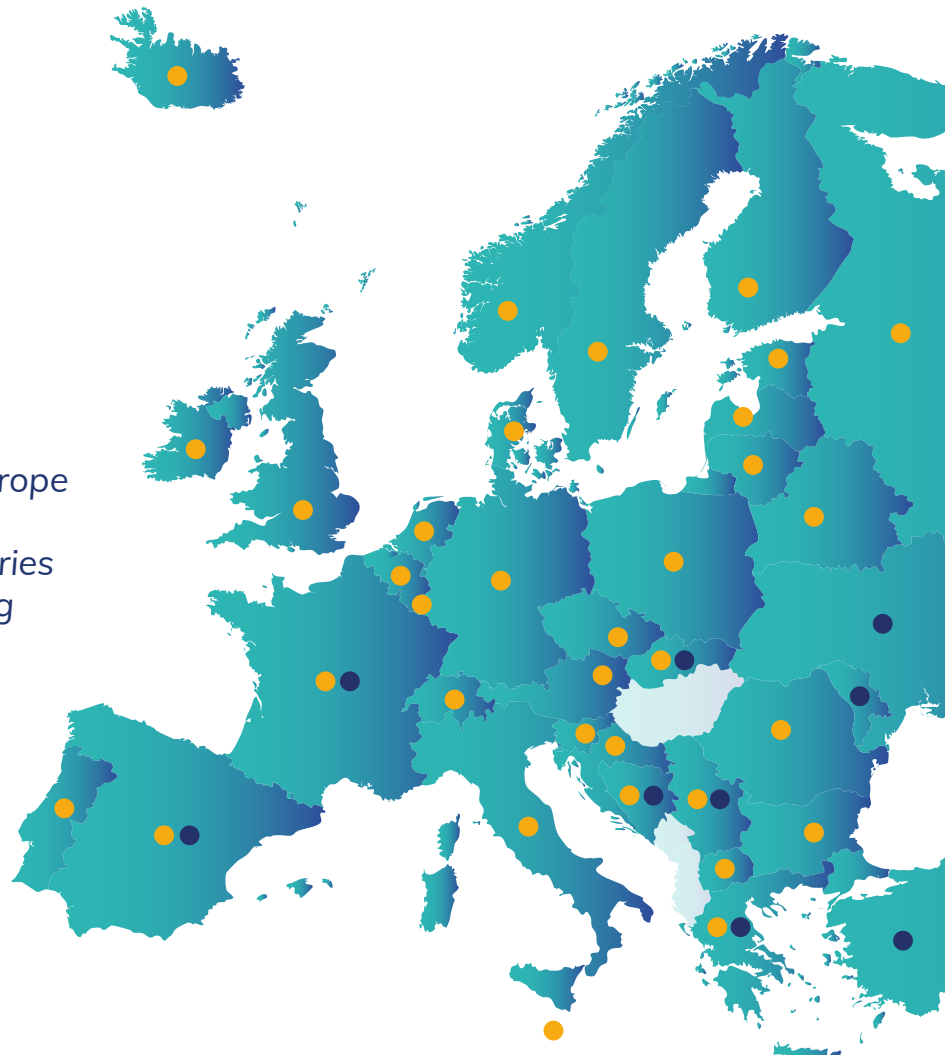


Mission

Improving the quality of life of people affected by MS through improved access to care, improved social and financial protection and societal understanding of MS.

OUR MEMBERS

EMSP has been working with and for MS Societies across Europe since 1989 – now with 43 MS Societies in 37 European countries under its umbrella and counting



Full Members ●



Multiple Sklerose Gesellschaft Österreich
<http://www.oemsg.at/>



Estonian Multiple Sclerosis Society
<http://smk.ee/>



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



MS Society Belarus
<http://msbelarus.com/>



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



Lithuanian Multiple Sclerosis Union
<http://www.liss.lt/>



Ligue Nationale Belge de la Sclérose en Plaques
<http://www.ms-sep.be/>



Ligue Française contre la Sclérose en Plaques
<http://www.ligue-sclerose.fr/>



Ligue Luxembourgeoise de la Sclérose en Plaques
<http://www.msweb.lu/>



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



Deutsche Multiple Sklerose Gesellschaft
<https://www.dmsg.de/>



Multiple Sclerosis Society of Malta
<http://www.msmalta.org.mt/>



Savez Udruženja oboljelih od Multiple Skleroze Bosne i Hercegovine



Greek MS Society
<https://gmss.gr/>



Multiple Sclerose Vereniging Nederland
<https://msvereniging.nl/>



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



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



National Association of Persons with MS in North Macedonia
<https://msmakedonija.eu.org/>



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



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



Multipel Sklerose Forbundet | Norge
<https://www.ms.no/>



Scleroseforeningen
www.scleroseforeningen.dk



Associazione Italiana Sclerosi Multipla
<https://www.aism.it/>



Polskie Towarzystwo Stwardnienia Rozsianego
<https://www.ptsr.org.pl/>

43
MS Societies

Our
members

37
Countries



**Asociatia Pacientilor
cu Afectiuni
Neurodegenerative
din Romania**
[https://www.afectiuni-
neurodegenerative.ro/](https://www.afectiuni-neurodegenerative.ro/)



**Sociedade Portuguesa
de Esclerose Multipla**
<https://spem.pt/>



**All Russian Public
Organization (RPO)
of Disabled People
with Multiple Sclerosis**
<http://www.ms2002.ru/>



**Drustvo Multiple
Skleroze Srbije**
<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
(MSG)**
<https://multiplesklerose.ch/>



**The Multiple Sclerosis
Society of Great Britain
and Northern Ireland**
<https://www.mssociety.org.uk/>



**The Hellenic Federation
of Persons with Multiple
Sclerosis (HfoPwMS)**
<https://www.poamskp.gr/>



**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
Espana (EME)**
<https://esclerosismultiple.com/>



**Multiple Sclerosis (MS)
Association of Turkey**
<https://turkiyemsdernegi.org/>



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

Associate Members



**Udruženja Multiple
Skleroze Republike Srpske**
<http://www.uomsrs.org/>



**Union de lutte contre la
Sclerose en Plaques
(UNISEP)**
<https://www.unisep.org/>

OUR EXECUTIVE COMMITTEE



Pedro Carrascal
President,
MS Society of Spain
(EME/AEDEM)



Klaus Knops
Treasurer,
MS Society of Belgium



Anne Winslow
EMSP Past-President,
MS Society of Ireland



Federica Balzani
Member,
MS Society of Italy



Jonathan Blades
Member,
UK MS Society

NEW!



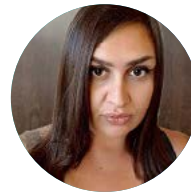
**Dominika
Czarnota-Szałkowska**
Member,
MS Society of Poland



Jana Hlaváčová
Member,
MS Society of Belarus



Dimitra Kalogianni
Member,
Greek MS Society (GMSS)



Tanja Malbaša
Member,
Croatian MS Society



Claude Mekies
Member,
MS Society of France



Herbert Temmes
Member,
MS Society of Germany



Patrik Puljić
Young People's
Representative



Peer Baneke
Observer,
MS International
Federation (MSIF)

Thank you!



Torben Damsgaard
Vice-President,
MS Society of Denmark



Georgina Carr
Member,
UK MS Society

OUR TEAM



Krystalenia Ampreu
Office Coordinator



Žilvinas Gavėnas
ICT Coordinator



Elisabeth Kasilingam
CEO



NEW!

Debianka Mukherjee
Fundraising and
Development Manager



NEW!

Cristina Munteanu
Administrative Coordinator



Emma Rogan
Campaigning and External
Engagement Officer,
(MS Ireland)



Máté Tagaj László
Senior Communications
and Membership
Coordinator



Joeri Wullens
Accountant
(Bebotax)

External project coordinators:



Stefaan De Corte
MS Nurse PRO
Project Manager



Elena Kelly
MS Nurse PRO
Scientific Project
Coordinator

Thank you!



Christoph Thalheim
External Affairs Director



Nora Kriauzaitė
Programme Coordinator

CAPACITY BUILDING

EMPOWERING THE MS COMMUNITIES

A central element of EMSP's work is supporting MS societies and people with MS to have a meaningful participation in the management of their condition and in the decision-making processes affecting their lives (including healthcare, employment, education, or policy actions). We believe in the power of empowerment as a catalyst for change.



EMSP Membership Capacity Building Programme and Membership Communications Network

The EMSP Membership Capacity Building (MCB) Programme aims at the empowerment of the national MS Societies across Europe with the goal of improving the quality of life of the people with MS in the regions of Europe.

The core objective of our MCB programme is to define the common priorities of MS organisations regionally and to set up a framework for sustainable partnerships. The programme allows us to get in-depth understanding of the activities undertaken by the MS societies, as well as the challenges they are facing at national level, and to strategise their advocacy efforts better for a greater impact.

In 2018, EMSP initiated its first capacity building programme to work in regional clusters with its member organisations to empower the MS community to raise their voices, starting with the Baltic region, followed by a focus on the Balkan regions in 2019.

In 2020, EMSP ran a survey among its members organisations identifying the impact of the global pandemic on the activities of the organisations and their needs to adjust the programme to this new situation. The programme was extended to the overall membership.

We held five online workshops from August 2020 to January 2021 to help the organisations to pursue their activities while adapting their ways of communications to the digital transformation that happened so fast during the year:

We held five online workshops from August 2020 to January 2021 to help the organisations to pursue their activities while adapting their ways of communications to the digital transformation that happened so fast during the year:

These workshops were attended by 20 participants representing 14 MS European Societies on average.

Meanwhile, the Membership Communications Network kept running its regular meet ups to address specific issues of concerns for the European MS community while supporting further peer learning among the different national MS societies. We covered different hot topics ranging from 'COVID-19 response of patient organisations' in the beginning of the pandemic to 'Cannabinoids for medicinal use for people living with MS'. The meetings recorded especially high attendance in 2020 counting on the participation of an average of 27 representatives of at least 20 MS organisations from across Europe.

YOUNG PEOPLE'S NETWORK 2.0

YOUTH
TAKE
CHARGE!

Young People's Network (YPN)

EMSP continues its successful approach in including young MSers (from age 18 – 35) in advocacy via its Young People's Network (YPN) and further develop the YPN to become a more powerful group that supports the work of EMSP and member societies and is recognised as a powerful group of MS and Brain health advocates.

The first part of the year has been focused on providing support to the Young People with MS during the first Covid-19 wave and the lockdown that had a strong impact on the young people's mental health and wellbeing.

Between April and August 2020, we organised 12 Digital Coffee table session which offered an opportunity to discuss themes of importance for the young people, co-hosted by Patrik Puljić, Krystalenia Ampreou and special guest experts. The covered topics included MS connections, Life with MS in Australia, Discrimination and inequalities, "MS, COVID19 – Employment", Immunity system health and food, Stress management and Living with MS.

MS, Covid19 and employment

JUNE 26th
17:00 (CEST)

SPECIAL GUEST
YOLANDA
HIGUERAS

Living with MS is all about living life

JULY 27th
17:00 (CEST)

SPECIAL GUEST
TREVIS
GLEASON





Advocacy during COVID-19

JULY 3rd
17:00 (CEST)

SPECIAL GUEST
DAN
MOXON



Immunity, health and food

JULY 10th
17:00 (CEST)

SPECIAL GUEST
CONOR
KERLEY



Stress management during Covid-19 and other challenging times

JULY 17th
17:00 (CEST)

SPECIAL GUEST
SABINA
BRENNAN



Help me? Heal me? Hurt me?

OCTOBER 20th
10:30 (CEST)

PRESENTER
BIRGIT
BAUER



MS Treatments: Decisions, Benefits & risks

NOVEMBER 27th
13:00 (CEST)

PRESENTER
DR. MARCELLO
MOCCIA



15 December 2020
10:30-13:30 CET

2020

INTERNATIONAL YEAR
OF THE NURSE AND THE MIDWIFE

13



2020
INTERNATIONAL YEAR
OF THE NURSE AND
THE MIDWIFE

#SupportNursesAndMidwives



World Health
Organization

A special webinar was held on the topic of Covid-19 and resilience (mental health management).



In September 2020, EMSP launched the MS Hive – an online community of young MS leaders, activists, and individuals who want to learn how to impact their local communities on the issues that matter to them.



In partnership with Campaign Accelerator, we developed a coaching and training programme for young people to step into advocacy, get involved in the MS movement and support campaigns. This 6-week online training ‘How to be a Changemaker’ was held from September to December during 4 workshops.

If you want to be a part of the YPN or know someone who would like to become a member, contact us to tell us about yourself/themselves, what you/they do in your/their local community or the ideas you/they have for people with MS in your/their country.



You have MS

The moment of the MS diagnosis is a crucial turning point in the life of people with MS. Communication between healthcare professionals and people affected by MS often plays an important part on the quality of life of the people living with MS and their families.

Our recent initiative on carers of paediatric MS identified that parents – as legal representatives of children and adolescents diagnosed with MS – do not receive adequate information about the condition of their kids, the different treatment options and symptom management from the healthcare professionals. This is especially critical upon the time of the MS diagnosis. The issues might be the absence of the model on MS diagnosis-related communication, lack of training for healthcare professionals, lack of consultation time to allot for each patient and so forth.

To explore the details of the exact issues surrounding the provision of information by healthcare professionals upon the time of diagnosis, in 2020 we launched the 'You Have MS' project. With this initiative we aim at gathering and sharing best practice models from across Europe for MS diagnosis-related communication and provision of information by healthcare professionals (including nurses, neurologists, psychologists, etc.) involved in the care of the patients.



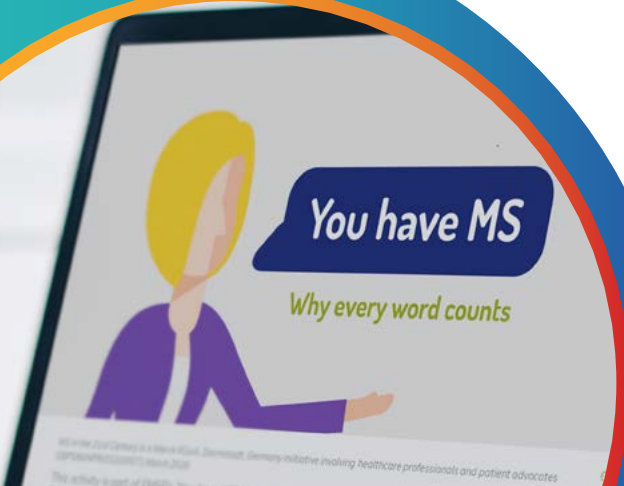
In April 2020, in collaboration with the **MS in 21st Century** initiative, we organised a webinar entitled 'You have MS: why every word counts'.

The webinar intended to show the need to improve communication between people affected by MS and healthcare professionals. Our expert panellists shared their personal experiences and existing initiatives that focus on overcoming such communication barriers. One of the important takeaways from the webinar was that by working together we can help to bridge the communication gap between patients and healthcare professionals.

Download
the slides of
the webinar



Watch
the webinar
recording



#EMSP2020 Virtual Conference: Understanding Progressive MS

For the first time ever, EMSP Annual Conference 2020 was held online on the 19th and 20th of November 2020. The theme of the conference was “Understanding progressive MS.” Over one million people are living with multiple sclerosis across Europe and 10-15% have been diagnosed with progressive forms of MS.

Over 500 participants registered from a wide range of stakeholders from people with MS, healthcare professionals to policymakers from across the Globe. The event brought together people with MS, advocacy organisations, healthcare professionals and researchers, alongside policymakers from across Europe to offer a dynamic mix of presentations, interactive sessions, and debates.

The conference addressed the importance of the diagnosis in a person's life and the following topics:

Latest developments in research: progress made in research brings hope to people with Progressive MS;

The need for a holistic approach to support people with MS in the best way possible: rehabilitation and health lifestyle;

How better policies and support from health and social care systems would enable a fulfilling life for people affected by progressive MS.





“There is a life after being diagnosed with MS. You remain a person and you have to live the present.”

Christiane Tihon, Secretary General
of the Belgian National MS Ligue

A session dedicated to young people with MS was held to address the mental health support for the young people with MS.

THE LAND OF HOPE

Dr Fabiola García-Vaz set the scene with a presentation on Dealing with life with MS by managing your mental health.

One of the final messages she left was based on the idea that all of us live in the Land of Hope. This is an active space where young people work on the control and regulation of their own minds.

What does hope mean in my current circumstances

- “Emotional state that helps us move towards what we want” (G. Kuhmann)
- However, hope is not a feeling, but a decision
- Hope is an active attitude to achieve my goals
- Believe that I can do something for a better present and future
- Accept that there will be hard challenges and that it will not always be easy to overcome
- Accept that there will be different ways to achieve my goals, even when I may need to adapt the target or the ways to reach them, creatively.

The two-hour session was an opportunity to focus on the issues most important to young people with MS.

Read the full summary of
the virtual conference here

Summary



Access the recordings
of all the sessions here

Recordings



UNDERSTANDING THE NEEDS AND CHALLENGES OF PEOPLE AFFECTED BY MS

In previous years, EMSP has been working towards the development of tools to collect reliable health and socio-economic data from patients and MS societies. This work is important to monitor patients' disease management, to highlight existing discrepancies in the access to treatment, health and social care and employment. The MS Barometer and MS Data Alliance projects were specifically designed to foster reliable and effective information from people with MS and MS societies through data collection.

MS Barometer 2020

The MS Barometer is a comparative survey collecting key information on MS in 35 countries. It serves as a benchmarking tool to provide an accurate picture of MS management across health and social care systems. The Barometer results will serve to campaign for sustainable and integrated care by outlining areas for improvement and encourage decision-makers to take actions to improve the quality of life of people affected by multiple sclerosis.



The 2020 MS Barometer uses 5 indicators of health and social care systems including:

1. Health care service delivery, including the number of MS health facilities and the number of MS related health workers
2. Health information, including MS epidemiology, MS data collection and MS research
3. Access to treatments, including access to disease modifying drugs (DMDs) and symptomatic medical treatments and therapies
4. Governance, leadership, and health financing, including existing MS-relevant policies, patient engagement, and health financing.
5. Participation in society, including education/employment opportunities for people with MS and social support available to people with MS and their carers

The results outline areas for improvement to be addressed by policy decision makers in the field of personalised care, social and financial protection, and quality of life for people affected by MS.

The new MS Barometer is an improved questionnaire inspired by the World Health Organisation vision:

“...all people [to] have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers [to be] motivated, skilled and operate in a supportive environment”.

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

To quantify and benchmark performance, results of the MS Barometer are scored, reinforcing the message that inadequate standards of care cannot and will not be accepted.

The MS Barometer survey has been 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.

The MS Barometer 2020 key highlights were launched during a Webinar co-hosted by MEP Tilly Metz, on the 3rd of December 2020 – the International Day of Persons with Disabilities.

Watch
back the
webinar



Highlights



MS
Barometer
website



MS Data Alliance

The Multiple Sclerosis Data Alliance (MSDA) is a multi-stakeholder collaboration working to accelerate research insights for innovative care and treatments for people with MS. The MS Data Alliance envision 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 informed policy and decision makers, regulators, patients, and better research outcomes.

MSDA aims to influence a mind-shift 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 on Patient Reported and Patient Relevant Outcomes (PRO).

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 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.

In 2020, as the COVID-19 pandemic unfolded across the globe, the demand for data on the impact of the novel coronavirus on people with multiple sclerosis (MS) was growing rapidly. This information is crucial for people with MS and clinicians to make evidence-based decisions on how to manage their condition during the pandemic or in case of a COVID-19 infection.

Consequently, MS Data Alliance and the MS International Federation (MSIF) have teamed up to set up a **Global Data Sharing Initiative** and called for individuals and organisations across the global MS movement to get involved.

MSDA and MSIF are currently working with 22 data partners and have collected data on over 7,000 people with MS from 60 countries.

The initial focus is on understanding the impact of different disease-modifying therapies for MS on the severity of COVID-19 outcomes.

They are looking at this because the national registries have, so far at least, not been sufficiently powered to answer this question. They currently have 1591 clinician reported COVID-19 cases in people with MS included in the global dataset and they are updating their results weekly here:

Results



MS
Data
Alliance



COVID-19 & MS
Global Data
Sharing Initiative

20

#MSCOVID19



MS DATA
ALLIANCE

MS DATA
ALLIANCE

Paediatric MS and caregivers: addressing policy and action gaps to better support children and adolescents with MS and their carers

The International Paediatric MS Study Group states that an increasing number of cases of Multiple Sclerosis (MS) in children and adolescents have been recorded worldwide. Between 3-11% of MS cases are now diagnosed before the age of 18. With the increasing number of paediatric MS cases, there is a growing need for the provision of care for children and adolescents with MS.

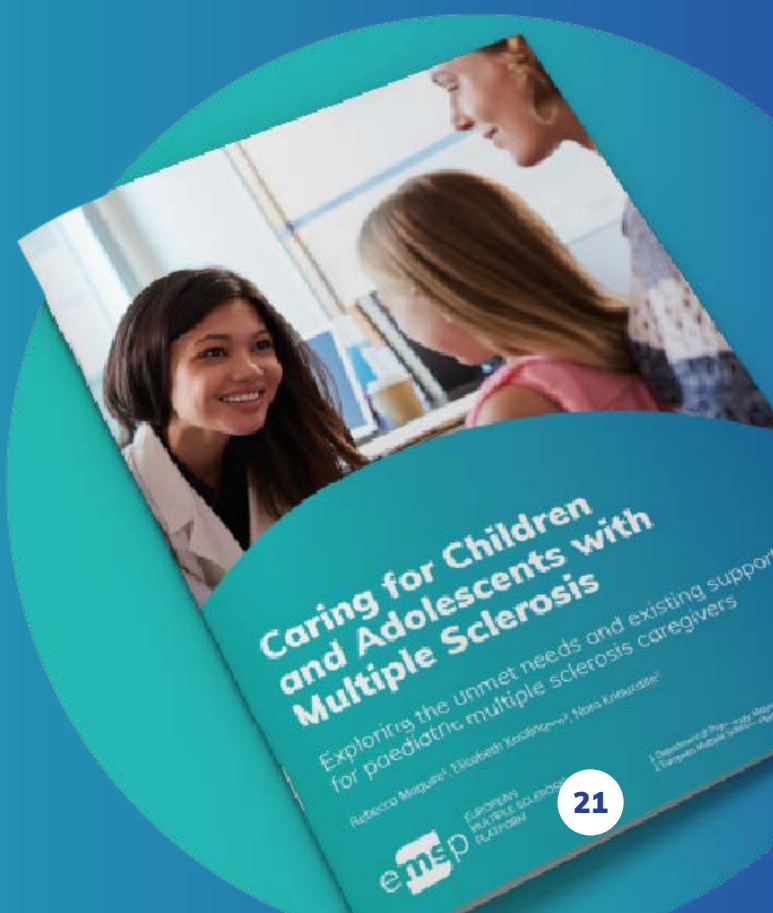
However, due to the recency of an emerging need and lack of data on paediatric MS, there is a vacuum in policy and action regarding how to support best those children and adolescents with MS and their families who are key carers (caretakers).

To address the emerging needs to ensure appropriate policy and action are undertaken to support best pediatric MSers and their carers, EMSP initiated the project "Recommendations for Caregivers of Paediatric MS" that aims at improving the quality of care received by children and adolescents with MS and address the challenges faced by caregivers.

We continued our work in 2020 by conducting a systematic review aiming at identifying the needs and experiences of children with MS and their carers, as well as services and supports related to their needs with a group of experts in the field. The review is currently pending publication and will serve to develop recommendations and a roadmap for future policy actions to improve the quality of care received by young people affected by MS and their caregivers.



Project
page



BUILDING STRATEGIC ALLIANCES FOR GREATER IMPACT

More than ever, 2020 has shown the need to continue working together in a multi-stakeholder environment to ensure successful and effective outreach and engagement to the MS patients and the caretakers and 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 is a member of the **European Patients' Forum (EPF)**, the **European Disability Forum (EDF)** and the **European Federation of Neurological Associations (EFNA)**
- EMSP collaborates closely with the **European Brain Council (EBC)**, the **Multiple Sclerosis International Federation (MSIF)**
- EMSP regularly collaborates with healthcare professionals and the scientific community, like the **Rehabilitation in MS (RiMS)**, the **European Committee for Treatment and Research in MS (ECTRIMS)** or the **European Charcot Foundation (ECF)**
- EMSP has also a **Memorandum of Understanding with Caritas Norway**
- EMSP is also a member of the **EFPIA Patient Think Tank**.

In February 2020, 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 2019 and outlined our common priorities for 2020 and beyond.

emsp

EPF
European
Patients
Forum

EUROPEAN
DISABILITY
FORUM

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

EBC
European Brain Council

ms
international
federation

RIMS
REHABILITATION IN
MULTIPLE SCLEROSIS
European network for best practice and research

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

European
Charcot
Foundation

Caritas
Norge

efpia
PATIENT
THINK TANK

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 also for pharmacovigilance, e.g., adverse drug reaction reporting, as well as pushing 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 the patients on this issue.

EMSP is a collaborating partner of EUnetHTA, an 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 fights for better patient involvement in processes impacting the access to treatment for people affected by MS.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH



Shared policy initiatives and campaigning

In 2020, we joined forces with several broader pan-European organisations to support campaigns for access to better healthcare for patients and greater public understanding of brain health in general, and MS in particular.

EMSP contributed to the development of the EU Health Coalition - a multi-stakeholder initiative looking at mapping the future of healthcare in Europe to make the most of the innovation at our fingertips, and the role of the European Union in addressing the challenges we face and critically at how different sectors can converge to deliver the best outcomes for patients in Europe.



EMSP contributed to the Rethinking MS in Europe project, led by the European Brain Council on the development of a manuscript "Rethinking MS in Europe: Prioritising timely services for people with multiple sclerosis"



EMSP is represented on the Patient Forum of the MULTI-ACT project, led by the Italian MS society.

To learn more about the other initiatives, EMSP is involved in, please visit our website

EMSP
website



RESEARCH & INNOVATION:

BRINGING THE NEEDS AND PERSPECTIVE OF PEOPLE WITH MS INTO THE CENTRE

N2B-Patch Project

The N2B-patch project is a European Union's Horizon 2020 Research and Innovation programme-funded project that has received funding under the grant agreement No. 721098 and started in January 2017. N2B-patch stands for "Nose-to-Brain-patch". The consortium aims to develop an innovative technology for multiple sclerosis (MS) treatment by developing a 'nose to brain' delivery system which will avoid the need for injections and oral medicine.

The direct transport route from the nasal cavity to the brain, bypassing the blood-brain barrier, could potentially offer an innovative method for central nervous system drug delivery. The long-term objective is to improve treatment of people with MS.



Science, industry, and patients' representatives work hand in hand to achieve the project objectives and maximise impact for patients and their relatives, healthcare professionals and European industries. With our active involvement in the EU-funded scientific project of Nose-to-Brain-patch (N2B-patch), we enabled the inclusion of patients' perspectives at an early stage of this scientific project. The new generation of researchers ask the persons affected by any disease about products that the scientists intend to develop for those affected by the disease.

Due to the pandemic, the project was extended till 2021.

N2B-
patch
website



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. (Link) The main aim of HTx is to create a framework for the Next Generation Health Technology Assessment (HTA) to support patient-centered, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

What is the value of such a research endeavour for people with multiple sclerosis (MS)?

The University of Bern, who is one of the Consortium partners in HTx project, is working on this shared patient and doctor decision-making model. A team of researchers is working to create a framework that incorporates evidence from clinical studies and real-world data from large groups of patient participants. By applying statistical models, they aim to identify the most optimal treatment option that minimises the relapse rates for the relapsing-remitting form of multiple sclerosis, after considering the characteristics of the studied participants with MS. The methodology is under development, but early applications in comparing the effectiveness of three drugs show promising results.

HTx
website



If you are a person with MS and would like to be part of the HTx project and serve on the “MS patient expert pool,” please **contact us**.



Objectives of the
project

HTx
will facilitate
the development
of methodologies to
deliver more customized
information on the
effectiveness and cost-
effectiveness of complex and
personalised combinations
of health technologies.

HTx
will provide
methods to
support personalised
treatment advice that
will be shared with
patients and their
physicians.

HTx will in close
collaboration with
the European Network
for HTA (EUnetHTA) and
its stakeholders pilot the
implementation of these
methods in Europe.



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

IMPROVED CARE EXPERIENCE FOR PEOPLE WITH MS

MS Nurse PRO

Setting a benchmark for MS nursing practice and nursing care across Europe

MS Nurse PROfessional (MS Nurse PRO) is the first and only, online foundation education programme for nurses working in the field of multiple sclerosis. 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, the MS Nurse PRO will create a positive change in MS care that extends across the entire multi-disciplinary care team.

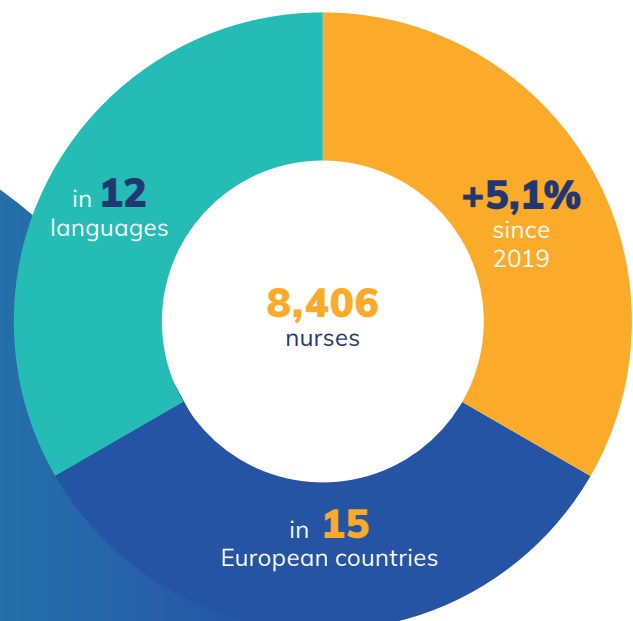
The MS nurse is key in the provision of expert and consistent information, support, and advice for people with MS. From the moment of diagnosis and throughout the disease trajectory, the nurse ensures a shared and coordinated approach to care. Across Europe, the role, skillset, and professional development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



Since its launched in 2012, more than 8,406 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 that has international accreditation and endorsement from national and international patient and professional groups.

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.

EMSP is also working collaboratively with the MS nursing community across Europe to develop a European MS nurse community that will promote and share their best evidence-based practices, advances in MS care and exchange of peer group support and professional development.



In 2020, the global pandemic affected the activities around the MS Nurse PRO. We successfully managed to turn this around by focusing on digital opportunities:

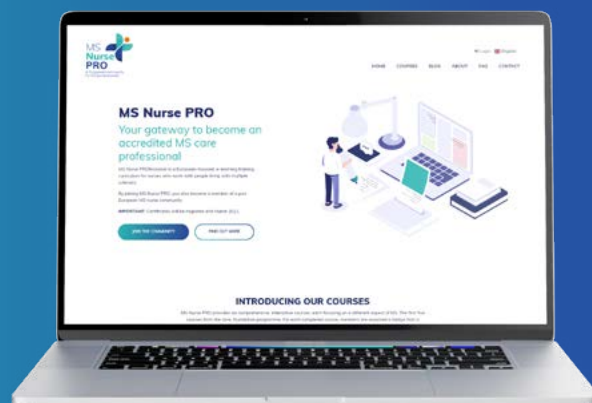


We launched the rebranded MS Nurse PRO digital platform to host the online training and to support the community building for nurses caring for persons affected by MS.



We switched from in-person to virtual meetings, organizing a webinar with key stakeholders for increased outreach across Europe.

MS Nurse
PRO



Thank
you!

We would like to give a special thanks to Victoria Matthews, member of the Steering Committee of the MS Nurse PRO initiative. Since its very beginning, her expertise, drive, and support have been key in the development of the MS Nurse PRO programme during the past years. Her commitment as an MS Nurse ambassador has been an inspiration to us all.



Keep moving with MS

Response to the negative impact of the COVID-19 pandemic on rehabilitation

During the COVID-19 pandemic thousands of people with MS remained without rehabilitation and physiotherapy sessions. This could have negative effects on their physical and mental health during and after this period. They are in (even greater) danger of suffering from anxiety, stress and depression due to the sudden impact of the situation on their daily lives.

Research supports and underlines the benefits of exercise and staying physically active for people living with Multiple Sclerosis, both in terms of disease and symptom management or quality of life.

In order to ensure that we keep the expected collateral damage of the lockdown to the minimum, EMSP partnered up with MoveToSport – a Flemish non-profit organisation providing rehabilitation and physiotherapy services for people with MS – and Almirall, to encourage people affected by MS to remain active by making the “Keep Moving with Multiple Sclerosis” online MS exercise program (created by the MoveToSport team) accessible across Europe.

With the in-kind contribution of Almirall, the video-exercises of MoveToSport – initially available only in Flemish and English – were translated to 10 additional languages and disseminated by EMSP and its member organisations to support and motivate people with MS to stay as active as possible, within their own possibilities during and after the lockdown.

Watch the exercise programme in English here:



The translated versions are available here:

-  1. Dutch
-  2. English
-  3. German
-  4. Greek
-  5. French
-  6. Polish
-  7. Italian
-  8. Portuguese
-  9. Romanian
-  10. Russian
-  11. Spanish
-  12. Turkish



DIGITAL COMMUNICATIONS DURING COVID TIMES

THE CROSS-CUTTING ACTIVITY

EMSP's Outreach in 2020

More than ever, 2020 required a focus on our Communications to ensure that our contact with the European MS community and our network remain engaging and meaningful. Therefore, EMSP adapted its digital engagement using the latest digital communication tools to expand and strengthen the relationship between its organisation and the MS community.

Website visitors
34,600

+4,8%



Followers on Twitter
4,396

+8,6%



Followers on Instagram
435

+61,7%



Videos produced
93

+320%



Followers on Facebook
34,130

+11,2%



Followers on LinkedIn
583

+102%



YouTube Subscribers
61,787

x30 times increase



FINANCES: 2020

Treasurer's Report

The technology makes it possible to ship parcels anywhere in the world in no time. But malicious viruses also travel with them and have thus seriously disrupted "normal life" all over the world. EMSP was not spared, we strongly feel the impact of the measures taken to contain the pandemic. Project sponsors are more careful with the resources available. Everyone lives in their own bubble and we only see each other and the world through the computer screen.

2021 was marked by the departure of our long-term External Affairs Director (fundraiser). Our newly hired fundraiser got off to a rock-solid start, showing a lot of refreshing creativity. Our long-term sponsors confirmed their continuous support throughout the year, allowing EMSP to adapt its work to the global context. We were also pleased to welcome new pharmaceutical companies interested in supporting EMSP projects. As a result, we performed reasonably good in project sponsorship: we realized 93% of the budget.

Delays in securing funding that were confirmed at a late stage in the financial year and the impact of the pandemic delaying the implementation of our key projects (especially Caregivers for Pediatric MS initiative, MS Barometer and the Young people's Network) have resulted in postponing the use of committed funds in early 2021 with the approval of our financial partners.

Apart from the reserves that EMSP is legally obliged to build up, EMSP strives in using as many resources as possible to improve the quality of life of people with MS and the benefits of its member organisations.

On the expenditure front, a cautious policy was applied with close monitoring of the external circumstances and regular readjustments of the activities, to close the financial year as close to zero surplus as possible. As a result, our CEO managed to end the financial year with a positive balance of € 2.475.

EMSP's members had to pay € 91.124 in membership fees – just a little more than 9% of the total income. However, we must conclude that a growing number of our members are unable to pay the membership fees. This prompted us to review our membership fee policy. Although it could be preferable to lower the membership fee in EMSP budget, as a patient organisation we must guarantee that our independence from the Pharmaceutical industry by not exceeding a certain ratio and moreover ensure EMSP's eligibility to potentially apply for EU funding in the future. In order to potentially consider further reduction of EMSP membership fees, we should first diversify our source of sustainable funding to cover the operational costs. This is certainly quite a great challenge for our fundraiser.

EMSP's financial statements since 2011 show a downward trend in income. To reverse this phenomenon, we are constantly looking for new and sustainable sources of financing in years to come. In 2020, we were able to acquire just over 5% from new sources. While we note that income from pharmaceutical industry is under further pressure, the companies remain major funders and supporters of EMSP's projects.



Klaus Knops
Treasurer,
MS Society of Belgium

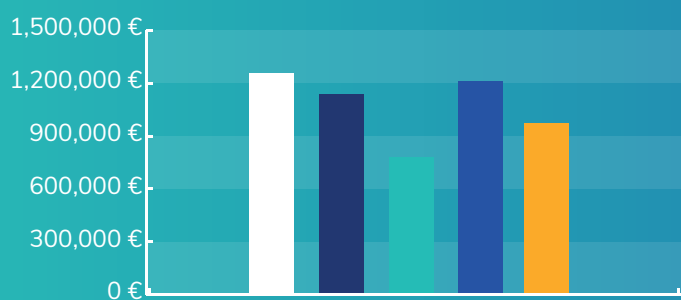
2016

2017

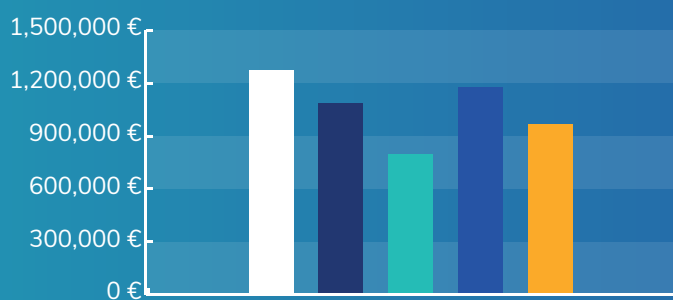
2018

2019

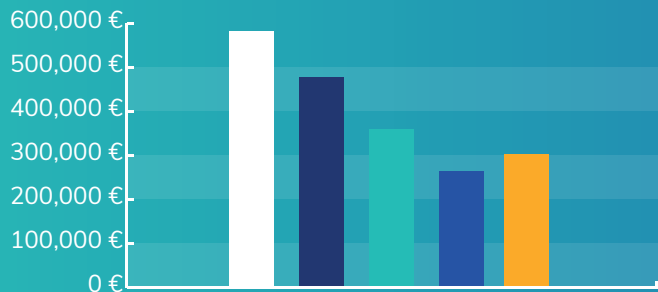
2020



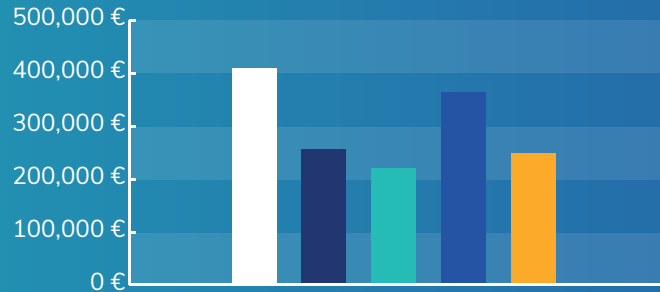
Income



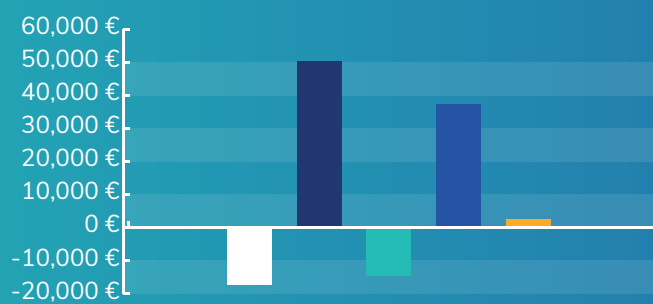
Expenditure



Staff



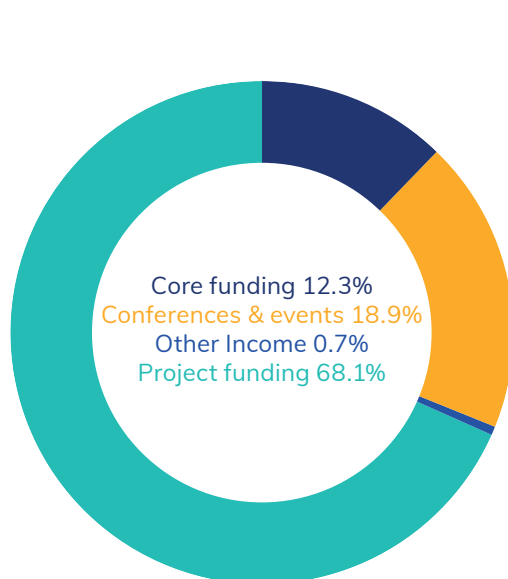
Projects



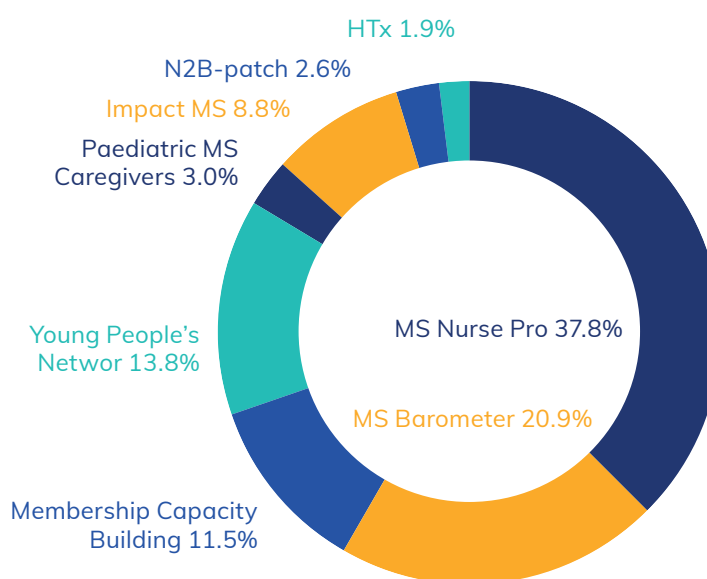
Profit/Loss

Financial Statements 2019-2020

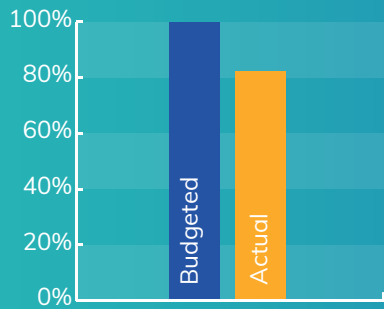
Income	2020	2019
Core funding	119,516	107,206
Conferences & events	183,854	412,257
Other Income	6,857	3,173
Project funding	661,353	688,468
Total Income	971,580	1,211,105
Expenditure	2020	2019
Staff salaries	302,926	263,180
Outsourcing	90,175	131,496
Administrative costs	90,845	74,313
Direct costs	485,159	704,743
Total Expenditure	969,105	1,173,733
Profit/loss for the period	2,475 €	37,372 €



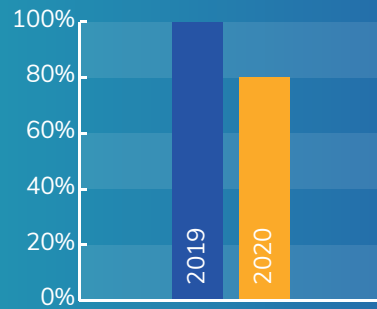
Income



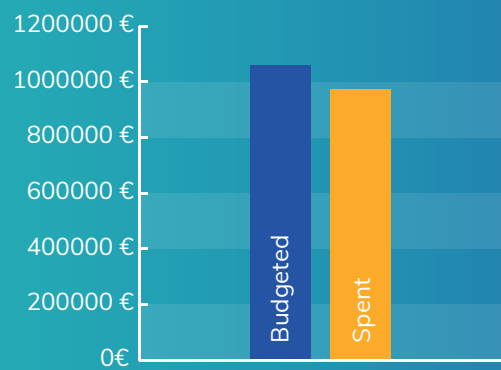
Project funding



Less income than budgeted (2020)



Less income than in 2019



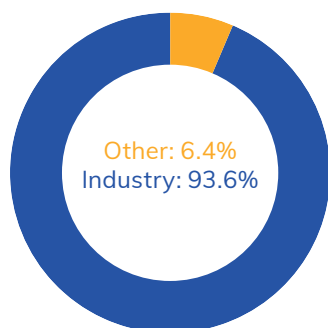
Expenditure budget (2020)

Balance Sheet 2019-2020

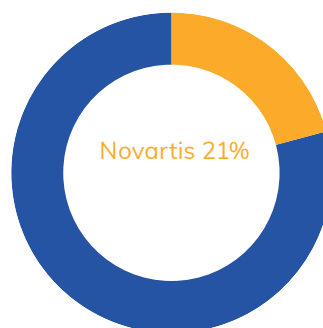
Assets/Liabilities	2020	2019
Fixed Assets	29,348	25,294
Current Assets		
Accounts Receivable - Pharma	13,302	195,965
Accounts Receivable - Members	16,613	21,453
Prepayments	21,431	23,239
Other Debtors	0	0
Accrued income	0	0
VAT	24,798	21,478
Bank Current Account	594,522	355,375
Total Assets	700,015 €	642,805 €
Funds	2020	2019
Capital	13,585	13,585
Reserves B/fwd	341,623	304,251
2020 Profit - 2019 Profit	2,475	37,372
Total Funds	357,683 €	355,208 €
Current Liabilities		
Accounts payable	77,483	118,792
Deferred Income	169,173	133,000
Accruals & other creditors	74,033	2,621
Taxes & Social Security	21,643	33,184
Total Current Liabilities	342,332	287,597
Total Liabilities	700,015 €	642,805 €

Industry Income 2020

Actual Income 2020	971,580	100.0%
Pharma Support		
Almirall	11,000	1.1%
Biogen	101,667	10.5%
Bristol Myers Squibb	197,910	20.4%
Coloplast	30,000	3.1%
Icometrix	5,000	0.5%
Merck	98,000	10.1%
Mylan	25,000	2.6%
Novartis	203,570	21.0%
Roche	130,000	13.4%
Sanofi-Genzyme	107,016	11.0%
TOTAL PHARMA	909,163	93.6%
TOTAL REST	62,417	6.4%



Overall proportion of
Industry and Other
income



Percentage of the highest
contribution from a
single Industry Company

AUDITOR'S REPORT
FOR THE YEAR ENDED 31/12/2020
EUROPEAN MULTIPLE SCLEROSIS PLATFORM
RUE AUGUSTE LAMBIOTTE 144/8
1030 BRUXELLES
RPR BRUSSELS NR. 0473.317.141
=====

We hereby present our audit report on the financial statements per 31/12/2020.

We have been appointed as statutory auditor by the general meeting, following the proposal formulated by the board of directors. Our statutory auditor's mandate expires on the date of the general meeting deliberating on the financial statements closed on 31/12/2020. We have performed the statutory audit of the financial statements of the Organization "EUROPEAN MULTIPLE SCLEROSIS PLATFORM" for 10 consecutive years.

Report on the audit of the financial statements

Unqualified opinion

We have audited the financial statements of the Organization, which comprise the balance sheet as at 31/12/2020, the profit and loss account for the year then ended and the notes to the financial statements, characterized by a balance sheet total of € 700.014,81 and a profit and loss account showing a profit for the year of € 2.474,81.

In our opinion, the financial statements give a true and fair view of the Organization's net equity and financial position as at 31/12/2020, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.



RPR Brussels nr. 0473.317.141

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 financial statements' section in this report. We have complied with all the ethical requirements that are relevant to the audit of financial statements in Belgium, including those concerning independence.

We have obtained from the board of directors and organization officials 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.

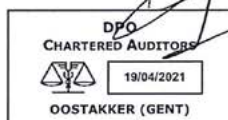
Responsibilities of the board of directors for the financial statements

The board of directors is responsible for the preparation of financial statements 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 financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the board of directors is responsible for assessing the Organization'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 Organization or to cease operations, or has no realistic alternative but to do so.

Statutory auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements 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.



RPR Brussels nr. 0473.317.141

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 financial statements.

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 financial statements, 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 Organization'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 Organization'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 financial statements 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 Organization to cease to continue as a going concern;
- Evaluate the overall presentation, structure and content of the financial statements and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.



RPR 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.

Done at Oostakker (Ghent)
Date 19 april 2021


DPO Bedrijfsrevisoren BV
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 2020, 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.

We would like to acknowledge the committed and valuable contribution of Torben Damsgaard, EMSP Vice-President who served on EMSP Executive Committee during the past 12 years contributing to its strategic development with the people we serve in mind.

EMSP's reach and impact is enhanced by the close cooperation with many other European organisations. Among them: 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 2020: Downtown Europe team (Professional Conference Organiser), Dr Rebecca Maguire, Health Policy Partnership team, Campaign Accelerator team, Chrissy Curtin, Jon Strum, Impact Media, IST1 and many others that accompany us in our journey.

With deepest sadness on the passing of Gerardo García Perales, President of the Spanish MS Society (AEDEM-COCEMFE) who we lost in September 2020, we dedicate our achievements to Gerardo, recognizing his commitment to give visibility and improve the quality of life of people with Multiple Sclerosis in Spain.



**In loving memory of
Gerardo García Perales,
former President of the Spanish MS Society
(AEDEM-COCEMFE)**

Corporate Partners and Donors

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



CREDITS



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



Graphic design by Boostern Hungary
www.boostern.com

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 ways of making
our publications more useful and accessible.
Please email your comments to
mate.tagaj@emsp.org

European Multiple Sclerosis Platform aisbl
Rue Auguste Lambiotte 144/8,
B-1030 Schaerbeek, Belgium
Registered Legal Entity: 0473.317.141
Secretariat@emsp.org
www.emsp.org