



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

ANNUAL REPORT

2023

SHAPING SOCIAL POLICIES
AND DRIVING PROGRESS FOR
A WORLD WITHOUT MS

Table of Content

3 FOREWORD

12 FINANCES 2023

4 OUR IMPACT IN 2023:
A JOURNEY THROUGH
PURPOSE AND PROGRESS

16 EMSP MEMBERSHIP

5 DRIVING CHANGE WITH ONE
MILLION MINDS: ADVOCACY
AND CAMPAIGNING

17 OUR EXECUTIVE
COMMITTEE

11 AMPLIFYING IMPACT:
MULTI-STAKEHOLDER
PARTNERSHIP IN ACTION

18 OUR TEAM

GROWING DIGITAL REACH:
EMSP'S COMMUNICATION
IMPACT

19 ACKNOWLEDGMENTS
AND SPONSORS

About EMSP

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.

<https://emsp.org/about-emsp/>

About MS

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. Affecting 1.2 million people in Europe, MS remains a complex neurological condition for which currently there is no cure.

<https://emsp.org/about-ms/>

Foreword from the President and the CEO

Dear Friends, Members and Partners,

Moving forward in a world post pandemic, affected by significant crises in the European Region due to the war in Ukraine, and resulting in global economic challenges, EMSP has remained steadfast in its mission towards a world without MS. This report highlights our key achievements, demonstrating the collective impact of our journey.

We empowered the MS community through capacity building programmes and launched initiatives for young adults with MS, such as the Young People's Festival and "ACT! Activists Cut Through" at the European Youth Event 2023 in Strasbourg. Our annual conference in Helsinki explored "Social Policies: A Better Life for People with MS," fostering crucial discussions on employment, family support, and social inclusion. The IMSS project collected data from over 17,000 individuals, while the MS Data Alliance empowered key actors to establish MS registries and leverage real-world evidence data for improved care.

Innovative projects, such as HTx and More-EUROPA have championed a patient-centered approach to research, ensuring the needs of people with MS are prioritised. Meanwhile, MS Nurse PRO continues to train and connect MS nurses across Europe.

Securing representation in pivotal EU-funded research projects such as EBV-MS, Behind MS, and WISDOM, alongside the launch of the "One Million Minds" campaign in 2023 further solidified our position. This campaign marks a milestone in the EMSP strategic plan, aiming for better MS and neurological care on both the EU and national policy agendas ahead of the 2024 European Elections.

International collaborations combined with an unprecedented growth in our digital presence, reinforced EMSP's position as a leading advocacy voice for people affected by MS. We extend our gratitude to our members, whose commitment fuels our progress; former team members, whose dedication laid a solid foundation; partners, whose collaboration expands our reach; and our current team, whose tireless efforts and passion bring our vision to life.

As we step into 2024, our commitment to a future without MS remains unwavering. This report is a testament to the collective power of collaboration, inviting you to explore the impact of our 2023 activities. Join us on this journey towards a world without MS.



Herbert Temmes,
EMSP President



Elisabeth Kasilingam,
EMSP CEO

OUR IMPACT IN 2023: A JOURNEY THROUGH PURPOSE AND PROGRESS

This report showcases the impact of our 2023 efforts on the European MS community. Underpinned by our 2022-2024 Strategic Plan, each of our projects contributed to specific strategic objectives, demonstrating a purposeful path and driving progress for a world without MS:

- STRATEGIC OBJECTIVE 1 (SO.1):** To provide a robust platform for capacity building: to engage, educate and inspire representatives and advocates of people affected by MS to be a strong and effective voice
- STRATEGIC OBJECTIVE 2 (SO.2):** To strive for better access to treatments, therapies, and integrated care for people with MS across Europe
- STRATEGIC OBJECTIVE 3 (SO.3):** To promote evidence-based good practice and effective health and social care for people with MS, using digitalisation and health data
- STRATEGIC OBJECTIVE 4 (SO.4):** To strive for equity and social inclusion and social protection of people affected by MS
- STRATEGIC OBJECTIVE 5 (SO.5):** To support more and better investment of people and resources for MS research.



YOUNG PEOPLE'S NETWORK

Empowering young adults (18-35) with MS, the EMSP Young People's Network (YPN) connects, educates, and activates them to be catalysts for change.

2023 HIGHLIGHTS

- Young People's Festival:** On 7 May, 52 participants gained tools and knowledge on career building, quality of life and self advocacy at our post-conference event in Helsinki.
- European Youth Event (EYE) 2023:** 8 YPN representatives shared their personal MS story at the EYE 2023 in Strasbourg, attended by over 10,000 European youth, including decision-makers. The YPN hosted an event discussing health, environment, and security, focusing on what matters for young people with MS before the EU Elections.
- Digital Content:** The "Let's talk MS" podcast, webinars, and youth-created digital content addressed diagnosis, community, advocacy, EMSP projects, and daily life tips.



> Let's talk MS Podcasts



IMPACT

The Young People's Network contributed to the empowerment of young people with MS via knowledge sharing, skill development, and advocacy opportunities fostering community engagement.

EXPLORE MORE

emsp.org/projects/ypn/





DRIVING CHANGE WITH ONE MILLION MINDS: ADVOCACY AND CAMPAIGNING ●

Launched in 2023, EMSP's "One Million Minds" campaign aims at mobilising the the European MS community and the communities of people with other neurological conditions for a unified voice to push MS and brain condition priorities onto the EU's policy agenda in the framework of the EU Elections 2024.

WITH THE MANIFESTO

- We call our National MS Societies to promote the recommendations from the MS Barometer and their national priorities; and our partners and supporters to mobilise themselves by endorsing the Campaign and working with us over the next five years.
- We call the Members of the European Parliament 2024-2029, other European institutions and national authorities to act for the improvement of the quality of care and lives of people with multiple sclerosis and other neurological conditions in Europe by pledging to deliver on our proposals during the next mandate.

The Campaign Manifesto - "Empowering Lives, Shaping the Future: a Manifesto for a Unified Approach to Multiple Sclerosis" is a response to urgently address the unmet needs faced by over 1.2 million individuals living with multiple sclerosis (MS) across Europe.

ENDORSE OUR MANIFESTO

SIGN OUR PETITION: "Quality Access to Care for People with Multiple Sclerosis and Neurological Conditions"

SIGN OUR
PETITION

emsp.org/one-million-minds-campaign-petition/



EVERY FIVE MINUTES,
someone, somewhere in
the world is diagnosed with MS.

The prevalence of MS
is substantial, with
37,000 NEW MS DIAGNOSES
reported across 27 European
countries in 2018.



IMPACT OF MULTIPLE SCLEROSIS SYMPTOMS

Our IMSS survey, completed by 17,151 individuals in 2023, sheds light on MS symptoms and treatment and care methods across Europe.

2023 HIGHLIGHTS

- **Comprehensive Analysis:** Survey co-developed with experts, people with MS and MS societies
- **Widespread Reach:** Promoted by EMSP, its members, and partners for maximum reach and impact.
- **Actionable Insights:** Data analysis and interpretation is underway to improve understanding of symptoms and effective management. Findings of the survey to be shared in 2024.

IMPACT

The IMSS survey became the largest-ever MS symptom study in Europe, including an unprecedented amount of data from 17,151 people living with MS. The survey will shed light on the impact of MS symptoms, raising awareness and informing policy and social support.

EXPLORE MORE

emsp.org/projects/imss/

EMSP MEMBERSHIP CAPACITY BUILDING PROGRAMME

The MCB Programme provides European MS Societies with capacity building through regional workshops and tailored support.

2023 HIGHLIGHTS

- **Baltics workshop (online):** Identified common needs and priorities.
- **Campaigning workshop (online):** Shared effective engagement techniques.
- **Western European workshop (in-person):** Discussed tools and knowledge for setting up MS registries.
- **Membership Communications Network (online):** Offered insights on digital dissemination and campaigning best practices.

IMPACT

In 2023, EMSP's Membership Capacity Building empowered societies with activities enhancing their leadership, campaigning, and research capabilities, leading to more effective advocacy efforts, increased policy influence, and stronger alliances. Shared knowledge through communication fostered awareness of EMSP initiatives and best practices, solidifying a more informed and impactful community.

EXPLORE MORE

emsp.org/projects/membership-capacity-building/



MS NURSE PRO

MS Nurse PRO is the first, free, multilingual, internationally accredited online training programme that equips nurses to excel in MS care.

2023 HIGHLIGHTS

- Expert Exchange:** ECTRIMS Congress 2023 connected 150+ nurses with renowned speakers and offered the opportunity to share best practices.



- Annual Gathering:** 30+ nurses discussed supporting people with MS in navigating employment challenges.

- Participation at EAN 2023:** MS Nurse PRO hosted a session at the European Academy of Neurology 2023 Congress.

IMPACT

MS Nurse PRO empowered nurses specialising in MS through training and community building provided for an estimated number of 92,000 people living with MS across Europe. This impact included a rise in the number of specialised nurses, with 600 course completions. Additionally, the programme boosted the confidence of MS nurses to be a voice in the multi-disciplinary care team.

More than

7k

Users on the platform

More than

600

Completed eLearning courses annually

More than

1300

Active users on the platform per year

More than

300

Joined a live training session



91% of nurses that confirmed the training has positively changed their MS nursing practice

EXPLORE MORE

msnursepro.org/



MS DATA ALLIANCE
 acting under the umbrella of the
 European Charcot Foundation

MS DATA ALLIANCE

This project tackles challenges in transforming real-world MS data into valuable insights for better care.

2023 HIGHLIGHTS

- Webinars on “How to set up a Multiple Sclerosis Registry”: 24 participants gained insights on how to establish MS registries, advancing data advancements in the MS landscape.
- Fellowship Program: supported the MSDA Fellowship Program across the Central Eastern Europe and Balkans regions.

IMPACT

In 2023, the MS Data Alliance strengthened data sharing and research capabilities in Europe by empowering EMSP member organisations and fellowship-winner researcher Dr. Christos Bakirtzis (MD, MSc, PhD from Thessaloniki) to advocate for people with MS through research.

EXPLORE MORE

msdataalliance.com/



MS CAB

MULTIPLE SCLEROSIS COMMUNITY ADVISORY BOARD (MS CAB)

The MS CAB comprises dedicated MS community activists and patient advocates from various European countries, trained on scientific and policy matters. They offer invaluable expert patient perspectives to industry, researchers, and academics on MS research and development, patient and caregiver needs, ensuring a strong patient involvement in clinical trials design and execution, and promoting greater access to effective and affordable MS treatments.

2023 HIGHLIGHTS

- Training on Market Access & Health Technology Assessment (HTA): Trained members on navigating healthcare landscapes and contributing to informed decisions on treatments.

IMPACT

The MS CAB connects patient experts with industry and academics, which contributes towards effective interventions and improved access to care for people with MS.

EXPLORE MORE

emsp.org/projects/ms-cab/

JOINING CUTTING-EDGE MS RESEARCH PROJECTS

 Funded by the European Union



BEHIND MS

Investigating genetic and environmental factors behind MS risk and disease course.



WISDOM

Developing personalised medicine approaches for better MS management.

EBV-MS



EBV-MS

Exploring the potential role of Epstein-Barr virus in MS development and progression.

EXPLORE MORE

emsp.org/projects/



EMSP ANNUAL CONFERENCE 2023: Social Policy, A Better Life for People with MS

This Conference was co-hosted by the Finnish MS Society (Neuroliitto) taking place in Helsinki under the theme “Social Policies: A better life for People with MS” between 5-6 May 2023.

IMPACT

This year’s Annual Conference focused on improving lives through policy discussions on employment, family support, and social inclusion for individuals with MS. It addressed the unique challenges faced by marginalized groups and provided tools for advocating for MS-related issues, particularly relevant to the upcoming EU elections.

The conference aimed to empower individuals with MS to navigate challenges and fostered international

collaboration for exchanging best practices.

By discussing critical healthcare topics like palliative care, long-term care, and pandemic impacts, and offering actionable ways to address inequalities and advocate for social change, the conference aimed to drive sustainable improvements for the MS community in the field of social policies.

EXPLORE MORE

emsp.org/annual-conference-2023/



HTx PROJECT

This project aims to revolutionise Health Technology Assessment (HTA) in Europe by prioritising patient needs, social implications, and timely access to ensure fair reimbursement for innovative treatments in Europe.

2023 HIGHLIGHTS

Enhanced Dissemination: Increased digital reach to new audiences through active promotion.

IMPACT

HTx gained greater visibility by achieving record reach raising awareness of the project's patient-centered approach.

EXPLORE
MORE

htx-h2020.eu/



More-EUROPA

This project aims to improve the use of registry data for ethical, patient-centered decision-making in drug/medication research and policy decisions. EMSP got involved in this project in 2023, ensuring that the voice of people with MS is represented in case studies, which will inform specific regulatory and HTA guidance, as well as contribute to the work of the [European Health Data Space](#).

2023 HIGHLIGHTS

- Training Modules Development:** Guides creation of online and in-person courses on Registries as Real-World Data source and its benefits for patients.
- Patient Involvement:** Fostered patient involvement in the project by sharing training materials.

IMPACT

Through More-EUROPA, EMSP contributes to building capacity on ethical and patient-centered use of registry data in regulatory and HTA decision-making.

EXPLORE
MORE

emsp.org/projects/more-europa/



AMPLIFYING IMPACT: MULTI-STAKEHOLDER PARTNERSHIPS IN ACTION

Our partnerships in 2023 strengthened engagement with diverse stakeholders, driving impactful collaborations.

2023 HIGHLIGHTS

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

EMSP collaborated closely with the [European Committee for Treatment and Research in MS \(ECTRIMS\)](#), the [Multiple Sclerosis International Federation \(MSIF\)](#), the [European Brain Council \(EBC\)](#), [Rehabilitation in MS \(RIMS\)](#), and the [European Charcot Foundation \(ECF\)](#) and the [European Academy Neurology \(EAN\)](#).

EMSP is also a member of the [EFPIA \(European Federation of Pharmaceutical Industries and Associations\) Patient Think Tank](#)

EMSP is represented on the [Patient and Consumer Working Party](#) and the Committee for Medicinal Products for Human Use of the [European Medicines Agency \(EMA\)](#), and collaborating with the HTA Stakeholders' Network.

IMPACT

Through strategic partnerships in 2023, EMSP amplified its reach and impact by co-hosting a joint live session with [Rehabilitation in MS \(RiMS\)](#) at the EMSP Annual Conference, collaborating on the "One Million Minds" campaign launch with the [European Disability Forum \(EDF\)](#), actively participating in the [ECTRIMS 2023 Congress](#) and the post-event Patient Community Day, as well as by successfully advocating together with the [Multiple Sclerosis International Federation \(MSIF\)](#) to [add MS therapies to the WHO Essential Medicine List for the first time](#), demonstrating the power of collective action.

GROWING DIGITAL REACH: EMSP'S 2023 COMMUNICATION IMPACT

EMSP's online presence skyrocketed in 2023, amplifying our voice and impact. The IMSS survey fuelled website traffic, newsletter subscriptions, and social media engagement (Instagram, LinkedIn, Facebook). Despite Twitter and YouTube growth slowing down due to platform changes, EMSP's thriving digital presence lays a solid foundation for continued impact.

✉ 3,082

Newsletter Subscribers



+ 118%

👥 72,624

Website visitors



+ 86%

📷 1,118

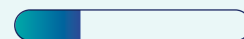
Followers on Instagram



+ 47%

in 1,670

Followers on LinkedIn



+ 28%

f 5,261

Followers on Facebook



+ 13%

🐦 4,896

Followers on Twitter (X)



+ 3%

📺 72,624

YouTube Subscribers



+ 0,5%

FINANCES: 2023

TREASURER'S REPORT

Dear EMSP Members, Supporters, and Partners,

We are pleased to present the Treasurer's report for the fiscal year 2023, a year marked by numerous successes and achievements for the European MS Community, thanks to the dedicated efforts of our team and members.

Despite the challenges posed by the post-pandemic context and economic crisis, compounded by geopolitical tensions, EMSP has persevered. Despite the impact of team changes on our operations, we commend our team for their resilience and commitment to advancing successfully EMSP's initiatives.

While 2023 brought financial difficulties, including a decrease in expected funding from the private sector and decrease of membership fees income due to the last policy change and members' financial constraints, we are encouraged by the success of three EU-funded projects applications, out of six submitted. These projects not only diversify our income streams but also position EMSP favourably for future public grant opportunities, helping to mitigate financial constraints.

Despite the negative year-end financial results and the challenges ahead for 2024, we maintain confidence in our organisation's expertise to pursue its mission. The Executive Committee and the Team are dedicated to ensuring EMSP's financial stability in the years to come, as we continue to build and support the European MS Community in achieving its objectives.

We extend our heartfelt thanks to all our members, supporters, and partners for their unwavering commitment to this journey.

Sincerely,



Klaus Knops
Treasurer,
MS Society of Belgium

DOWNLOAD
FULL REPORT

emsp.org/wp-content/uploads/2024/03/EMSP-Finances-Report-2023.pdf

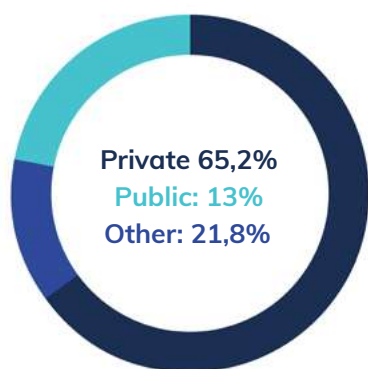
Financial Statements 2022-2023 (EUR €)

Income	2023	2022
Core funding	94.469	105.534
Conferences & events	335.487	283.500
Other Income	7.428	20.117
Project funding	911.246	751.036
Total Income	1.348.630	1.160.187
Expenditure		
Staff salaries	622.445	522.680
Outsourcing	16.722	14.878
Administrative costs	95.954	98.831
Direct costs	619.062	521.188
Total Expenditure	1.354.183	1.157.577
Profit/loss for the period	-5.553	2.610

EMSP income 2023

Industry Income	Percentage	Amount
Alexion	1,1%	10.000
Almirall	5,1%	44.500
Biogen	4,5%	39.500
Bristol Myers Squibb	4,1%	36.000
Coloplast	3,4%	30.000
Horizon Therapeutics	9,8%	86.000
Janssen	3,4%	30.000
Merck	17,1%	149.970
Novartis	19,5%	171.000
Roche	15,5%	136.000
Sandoz	2,8%	25.000
Sanofi	11,5%	101.000
Viatrix	2,3%	20.000
Total Industry Income & Percentage	65,2%	878.970

Overall proportion of Industry and non-industry income



EMSP income 2023 (continuing)

Non-Industry Income	Percentage	Amount
Public Funding	41,3%	72.341,40
Private Non-Industry Grants	1,7%	3.000
Membership	47,1%	82.555
Other Income	6%	10.490
Annual Conference	3,9%	6.839
Total Non-Industry Income & Percentage	13%	175.225
Carry forward to 2024	-13,8%	-185.996
Brought forward from 2022	35,6%	480.431

Balance Sheet 2022-2023 (EUR €)

Assets/Liabilities	2023	2022
Fixed Assets	43.291	54.348
Current Assets		
Accounts Receivable - Pharma	205.591	142.377
Accounts Receivable - Members	11.036	27.445
Prepayments	14.875	18.350
Other receivables	75.884	19.377
Total Current Assets	307.386	207.549
Bank Current Account	504.871	813.191
Total Assets	855.547	1.075.088
Funds		
Capital	13.585	13.585
Reserves B/fwd	360.636	358.025
2023 Deficit - 2022 Profit	-5.553	2.610
Total Funds	368.667	374.221
Current Liabilities		
Accounts payable	80.369	95.529
Prepayments	0	29.813
Deferred Income	277.996	480.431
Accruals & other creditors	21.950	0
Taxes & Social Security	44.330	41.227
Provision holiday pay	62.234	53.867
Total Current Liabilities	486.880	700.867
Total Liabilities	855.547	1.075.088

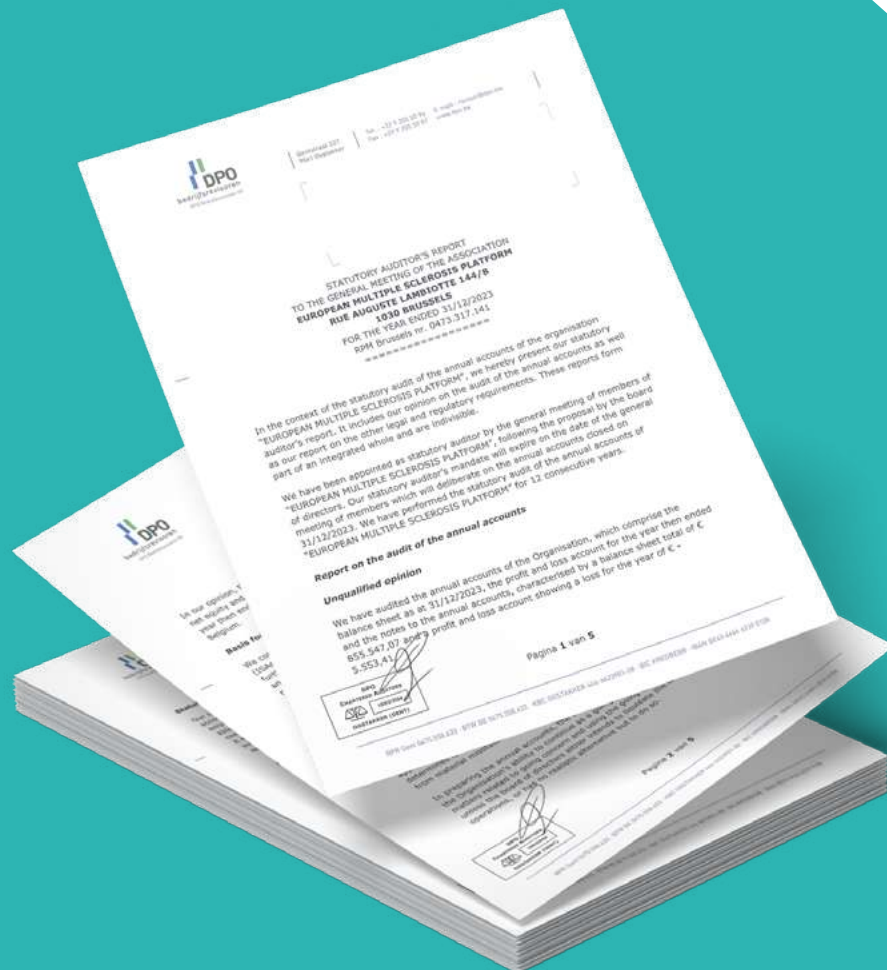
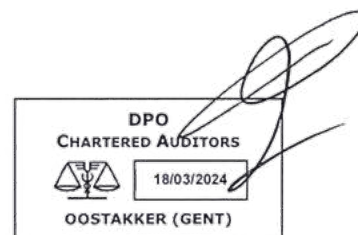
AUDITOR'S REPORT

Extract from the Auditor's Report to the Board of Members on the Financial Statements for the year ended 31 December 2023

"We have audited the annual accounts of the Organisation, which comprise the balance sheet as at 31/12/2023, the profit and loss account for the year then ended and the notes to the annual accounts, characterised by a balance sheet total of € 855.547,07 and a profit and loss account showing a loss for the year of € 5.553,41. In our opinion, the annual accounts give a true and fair view of the Organisation's net equity and financial position as of 31/12/2023, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium."

DOWNLOAD
FULL REPORT

emsp.org/wp-content/uploads/2024/03/EMSP-2023-Auditors-Report.pdf



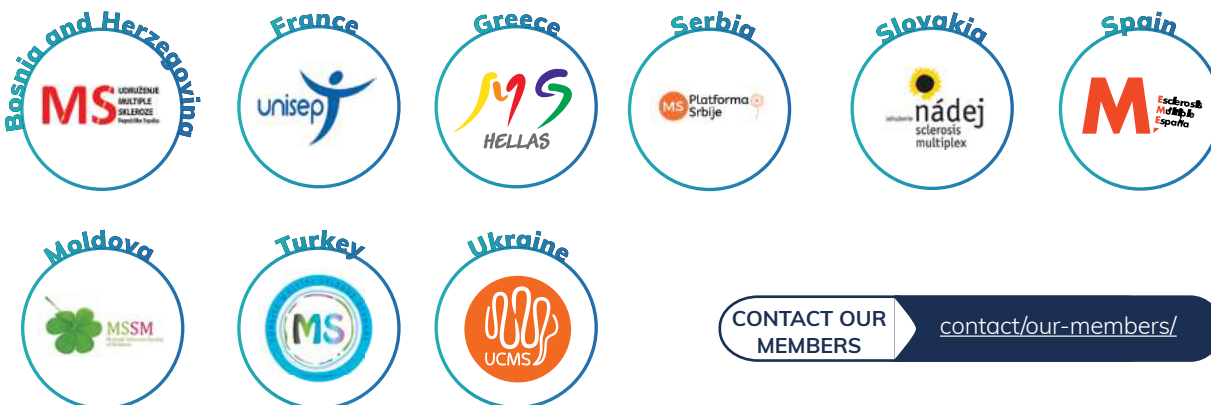
EMSP Membership

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).

FULL MEMBERS



ASSOCIATE MEMBERS



CONTACT OUR MEMBERS [contact/our-members/](https://www.emsp.eu/contact/our-members/)

Our Executive Committee



Herbert Temmes
President
MS SOCIETY OF
GERMANY



Federica Balzani
Vice-President
MS SOCIETY OF ITALY



Klaus Knops
Treasurer
MS SOCIETY OF BELGIUM



Aoife Kirwan
Board Member
MS SOCIETY OF
IRELAND



Eduard Andrei Pletea
Board Member
APAN ROMANIA



Jan van Amstel
Board Member
MS SOCIETY OF THE
NETHERLAND



Nataša Hlaban
Board Member
MS SOCIETY OF
CROATIA



Susanna van Tonder
Board Member
MS SOCIETY OF
LUXEMBOURG



**Margarida Piçarra
Navalhinhas**
YOUNG PEOPLE'S
REPRESENTATIVE



Peer Baneke
Observer
MS INTERNATIONAL
FEDERATION (MSIF)



Our Team



Debianka Mukherjee
Senior Partnership
and Development
Manager



Elisabeth Kasilingam
CEO



Emma Rogan
(MS Ireland)
Campaigning and
External Engagement
Officer



Katarzyna Gorszewska
Office Manager



Mokhsharif Nasrulloeva
Project Coordinator



Patricia Moghames
Programme
Coordinator



Simina Peterfi
Youth engagement
and Community
Manager



Žilvinas Gavėnas
ICT Coordinator



Jana Hlaváčová
Interim CEO

**Thank
you!**



Máté László Tagaj
Senior Communications and
Membership Coordinator

External Collaborators



Stefaan De Corte
MS Nurse PRO
Project Manager



Elena Kelly
MS Nurse PRO
Scientific Project
Coordinator



Joeri Wullens
(Bebotax)
Accountant

ACKNOWLEDGEMENTS

In 2023, EMSP's success relied heavily on the invaluable contributions of many. We especially thank Jana Hlaváčová for her exceptional leadership as interim CEO during Elisabeth Kasilingam's leave and Máté László Tagaj for his dedicated work.

Deep appreciation goes to the MS community, including members with special thanks to the Finnish MS Society - Neuroliitto - co-host of our Annual Conference in Helsinki, Finland; the members of the MS Nurse PRO Steering Committee and Syllabus Committee; the IMSS Scientific Working Group and Lead Investigators, GfK - Growth for Knowledge (Spain), MS CAB members, the MSDA team, the Young People's Network, as well as our More-EUROPA, WISDOM and HTx project consortium partners. Their expertise enriched our projects and delivered exceptional resources.

We are also deeply enriched by the collaborative partnerships with leading organisations who helped us amplify our reach and impact. Our sincere thanks go to the [ECTRIMS](#), [EDF](#), [RIMS](#), [MSIF](#), [ECF](#), [MSDA](#), [EPF](#), [EFNA](#), [EBC](#), and the [International Organisation of MS Nurses \(IOMSN\)](#).

Additionally, we would like to thank Bettina Hausmann, Istvan Nagy, Rob Camp, Jimmy Smyth, Liesbet Peeters, Ilse Vermeulen, Peter Feys, Daphne Kos, Elisabetta Lilli, the [One](#) campaign, Statik and many others for their instrumental support in 2023.

Sponsors and Donors

EMSP has continued to benefit from the substantial support of corporate partners, as well as the Horizon Europe programme of the European Union providing funding for key projects:





EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

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