

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

# Annua Report 2024

Empowering Lives, Shaping the Future — A Unified Approach to Multiple Sclerosis

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### About EMSP

For over 30 years, the European Multiple Sclerosis Platform (EMSP) has been Europe's leading voice for people living with Multiple Sclerosis (MS). As the umbrella organisation for national MS societies, EMSP drives the MS research agenda and builds strategic alliances across Europe to influence policy decisions to ensure equitable treatment, care, and resources for people affected by MS. Our advocacy extends beyond healthcare to promote full inclusion of people with MS in education, employment, and society at large.

In 2024, EMSP expanded its focus to include Neuromyelitis Optica Spectrum Disorder (NMOSD) and Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD) to provide advocacy and support to people with MS and related disorders.

### Foreword

The past year has again been one of immense challenges and transformations, both globally and within EMSP. As the world navigates shifting political priorities—where defence, competition, and innovation increasingly dominate policy agendas—Health and Social care risk being sidelined. Yet, at EMSP, we remain unwavering in our mission: to improve the quality of life of people affected by MS and related disorders by advocating for better health and social care systems for people living with MS across Europe.

In 2020, the EMSP MS Barometer highlighted critical gaps in care, access, and Ø policy across European nations. Our One Million Minds campaign initiative in 2024 has been a direct response to this, pushing forward key recommendations to ensure that MS care does not fall behind in times of global uncertainty. In 2024, a year of EU elections, we have called on our policymakers to prioritise investment in healthcare, to strengthen support systems, and to uphold their commitments to people living with MS and related conditions. We thank the Members of the European Parliament and our allies who endorsed EMSP Manifesto and joined their voices to our cause.

Despite the organisational and financial challenges we have faced, we are proud to say that our team and members have stood strong. Our community has mobilised in times of difficulty, demonstrating resilience, unity, and a shared commitment to making a difference. This spirit of collaboration has been the driving force behind our successes this year.

Looking ahead, we are excited to expand our outreach, integrating the voices of those affected by MS-related disorders such as Neuromyelitis Optica (NMO) and Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD) into our work. By broadening our advocacy, we reinforce our pledge to be a truly inclusive and representative platform, ensuring that no voice goes unheard.

As we present this Annual Report, we reaffirm our commitment to standing by and for our communities. In a world where priorities shift rapidly, we will continue to fight for the recognition and support that people with MS and related disorders deserve. Together, we will keep pushing for progress, because health should never take a backseat.

Herbert Temmes EMSP PRESIDENT



Elisabeth Kasilingam EMSP CEO

### Our Executive Committee







Federica Balzani VICE-PRESIDENT MS SOCIETY OF ITALY

**Aoife Kirwan** BOARD MEMBER MS IRELAND



Eduard

Andrei Pletea

**APAN ROMANIA** 



Jan van Amstel BOARD MEMBER DUTCH MS SOCIETY **BOARD MEMBER** 



#### Thank you





**Klaus Knops** TREASURER MS SOCIETY OF BELGIUM

Nataša Hlaban **BOARD MEMBER** CROATIAN MS SOCIETY



Peer Baneke OBSERVER MS INTERNATIONAL FEDERATION (MSIF)

Margarida Piçarra Navalhinhas REPRESENTATIVE YOUNG PEOPLE

Welcome



**Tania Pilz** YOUNG PEOPLE REPRESENTATIVE









Debianka Mukherjee FUNDRAISING AND DEVELOPMENT MANAGER

Mohsharif Nasrulloeva PRO JECT COORDINATOR

Elisabeth Kasilingam CEO

Patricia Moghames PROGRAMME COORDINATOR

### Thank you



Emma Rogan CAMPAIGNING AND EXTERNAL ENGAGEMENT OFFICER MS IRELAND



Simina Peterfi COMMUNITY MANAGER

Welcome





Žilvinas Gavėnas ICT COORDINATOR



Krystalenia Ampreou EXTERNAL ADMINISTRATION COORDINATOR



Kanika Kohli COMMUNICATIONS COORDINATOR

### **External Project Coordinators**



Stefaan De Corte PROJECT MANAGER MS NURSE PRO



Elena Kelly SCIENTIFIC PROJECT COORDINATOR MS NURSE PRO

Jana Hlaváčová EXTERNAL POLICY ADVISOR



Empowering Lives, Shaping the Future – A Unified Approach to Multiple Sclerosis

This report highlights our 2024 achievements in championing the European MS community. Driven by our 2022-2024 Strategic Plan and 3 core activity pillars-Advocacy, Education and Research, we've made remarkable progress across all project areas, advancing our shared vision of a world free from MS—a future we're building alongside those living with the condition.

# Strategic Objectives

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

# Activity Pillars



### Advocacy: A Year of Campaigning

# **Driving Change**

In 2024, EMSP launched its ambitious <u>One Million Minds</u> campaign in conjunction with the European elections, strengthening its advocacy to ensure health systems across Europe provide innovative, efficient, and sustainable care for all MS patients.



The campaign leveraged strategic events to build momentum throughout 2024:









#### Achievements:

- Evidence-Based Policy Advocacy: Building on the findings of the MS Barometer 2020, we presented targeted recommendations to Members of the European Parliament (MEPs) for the 2024-2029 term. The OMM Campaign Manifesto established clear priorities for MS care, successfully securing formal commitments from 21 European Parliament candidates.
- Grassroots Mobilisation: The campaign secured over 700 <u>petition signatures</u>, building public awareness and empowering patients and families to actively participate in advocacy efforts.

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- Strategic Alliance Building: We formed strategic alliances with partner organisations, including the <u>Euro-</u> <u>peanDisabilityForum, MSIF, European</u> <u>Brain Council</u>, and <u>ECTRIMS</u>, building unified collaborations around health, social policy, and equitable care priorities while expanding our advocacy reach.
- Enhanced Engagement: The campaign strengthened the capacity of national MS societies to advocate effectively with local policymakers, ensuring a coordinated approach across multiple levels of governance.

### **Looking Forward**

The One Million Minds campaign has established a strong foundation for continued advocacy under the new EU mandates. Our future focus includes further integrating MS Barometer data into policy development, maintaining engagement with newly elected representatives, expanding partnerships across health equity issues, and increasing public awareness of social exclusion challenges faced by the MS community.

# Towards Sustainable and Healthier Systems in Europe

The EMSP Annual Conference 2024 convened in Brussels during a pivotal European election year, bringing together MS societies, patients, healthcare professionals, researchers, and policymakers under the theme "Towards Sustainable and Healthier Systems in Europe."

By facilitating meaningful dialogue among diverse stakeholders during this politically significant period, the conference has established a solid foundation for advancing MS priorities within the European health policy agenda for the coming term.





## **Strengthening Evidence to Improve Quality of Care**



EMSP's flagship Impact of Multiple Sclerosis Symptoms Survey (IMSS) marks a crucial advancement in evidence-driven advocacy for MS care across Europe. By capturing comprehensive patient-reported evidence, the survey establishes a compelling foundation for policy and practice changes grounded in authentic lived experiences.

#### 2024 Achievements:

- Unprecedented Scale: IMSS has emerged as one of Europe's largest MS symptom studies, reaching more than 17,000 people with MS across 22 countries.
- Strategic Collaboration: The project forged partnerships with 24 MS societies to ensure comprehensive geographical coverage and cultural relevance.
- The study findings have been disseminated at major platforms including:
  - EMSP Annual Conference
  - RIMS Annual Meeting
  - MS Initiatives event
  - ECTRIMS



# Advancing Patient-Centered Health Technology Assessment



- EMSP successfully contributed to the <u>HTx project</u> that concluded in 2024. This initiative funded under the EU's Horizon 2020 program created a patient-centred framework for Healthcare Technology Assessment (HTA) that integrates real-world data and novel methodologies to enhance access and reimbursement decisions throughout Europe.
- As a key subcontracted partner through <u>EURORDIS</u>, EMSP played a vital role in ensuring MS patient perspectives were incorporated into HTA methodologies.

The groundbreaking HTx methodologies took center stage at EMSP's 2024 Annual Conference, offering attendees insight into the future of personalised MS treatment:



**Al-Powered Decision Support:** HTx scientists demonstrated how artificial intelligence and real-world data analytics can inform precise treatment decisions tailored to individual MS progression stages.



**Interactive Treatment Optimisation:** Professor Georgia Salanti and her team from the University of Bern unveiled an innovative interactive tool that identifies optimal treatment options based on specific patient characteristics and preferences.

**Transformative Clinical Applications:** Conference participants experienced a hands-on demonstration illustrating how these innovative HTA approaches could revolutionise patient consultation experiences in clinical settings.

These presentations highlighted the tangible ways advanced methodologies can bridge research innovations with practical clinical applications, ultimately improving personalised care for people living with MS.

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Education and Capacity Building: A Year of Empowerment

### Membership Capacity Building: Uniting MS Communities Across Europe

EMSP's Membership Capacity Building (MCB) program delivered a strategic series of workshops in 2024 focused on enhancing advocacy capabilities and fostering deeper collaboration among MS societies throughout Europe. These initiatives were carefully designed to address the evolving challenges faced by the MS community while building on previous efforts.

#### March 2024

#### EU Policy Navigation Workshop

EMSP and RPP, a public affairs consultancy, co-led an online workshop titled "Driving Impact: Uniting for MS Policy Change" with 13 member organisations. This session focused on:

- Navigating EU systems.
- Enhancing advocacy strategies through digital channels and alliance building.
- Utilising case studies like the "Right to be Forgotten" initiative to address discrimination.

During the workshop, participants learned practical approaches to influence EU policy while addressing national implementation.

#### April 2024

#### Leadership & Advocacy Workshop

EMSP organised an inperson strategic planning workshop following the Association General Meeting, bringing together 42 participants from MS organisations across Europe.

This collaborative session with Association by Design:

- Identified community challenges.
- Built a shared vision for future objectives.
- Gathered insights to inform EMSP's 2025–2029 Strategy development.

#### October 2024

#### Advocacy Sustainability Workshop

EMSP hosted an online workshop on "Sustaining Advocacy Momentum" with 12 national MS societies to build upon the One Million Minds campaign manifesto. Discussions centered on leveraging advocacy toolkits to influence newly elected MEPs, responding to EU political shifts, and implementing successful cross-national collaboration strategies.



# Young Voices, Strong Impact





### Empowering the Next Generation of MS Advocates

The EMSP Young People's Network unites 41 young people with MS (aged 18-35) across 19 European countries, creating a vibrant community where members share experiences, build lasting connections, and advocate for their generation's needs.

#### Key Achievements:

- **Campaign Leadership:** Spearheaded youth engagement in the One Million Minds campaign, bringing fresh perspectives to MS advocacy.
- European Representation: Secured seats at influential policy tables through representation in:
  - European Patient Forum Youth Group
  - European Federation of Neurological Associations Community Advisory Board
- Leadership Development: Cultivated the next generation of MS community leaders through the European Patient Forum's specialised advocacy training program.
- Community Engagement: Organised the MS Awareness Run featuring 21km and 7km distance options, reaching 3,800 people through targeted social media campaigns while successfully raising funds for EMSP initiatives.
- Innovative Communication: Launched the Let's Talk MS podcast series providing a platform for young people with MS to engage in candid conversations with experts about overlooked aspects of living with MS, with three episodes released in 2024 covering intimacy, relationships, and community building.



### Empowering MS Care Professionals



MS Nurse PRO continues to transform MS nursing care across Europe through comprehensive education and professional development. The program's reach now extends to 16 countries, directly impacting 150,000 people with MS annually.

#### 2024 Highlights:

- Welcomed 300+ new nurses to the program.
- Executed critical workload management survey which emerged as a key challenges for nurses.
- Renewed accreditation from International Council of Nursing.
- Updated and translated core courses into 13 languages.
- Conducted two successful webinars on digital skills (32 participants) and biosimilars (21 participants).

### Enhancing Evidence for Better MS Treatments



Launched in January 2023, More-EUROPA united 14 organisations across 7 EU countries to transform how Real-World Data (RWD) complements clinical trials in drug development. This project aims to strengthen research methodologies, ensure ethical data governance, enhance cost-effectiveness, and accelerate patient access to new medicines.

EMSP leads Work Package 4, "Ethical perspectives and patient empowerment for RWD use," ensuring that patient voices remain central in shaping responsible real-world data practices that advance MS treatment innovations while protecting patient interests.

2024 Highlights:

### Making Patient Voices Count

- Led development of comprehensive e-learning and face-to-face training modules on "Real-World Data and its contribution to scientific and medical knowledge.
- Ensured direct MS community representation with a person living with MS on the project's Advisory Board.
- Facilitated interviews with 22 people living with MS and patient representatives from across Europe for the study on "Patient considerations for participation in registries".
- Participated in the discussions over the MS case study involving four European MS registries (Swedish, Czech, Danish, and Italian) examiningrituximabtreatmentcomparedto dimethyl fumarate using Real-World Data.

### **Research: A Year of Collaboration**

# **Brain Health: Time Matters**



In 2024, EMSP CEO, Elisabeth Kasilingam and External Policy Advisor, Jana Hlaváčová, contributed to the updated "<u>Brain Health — Time</u> <u>Matters</u>" report. This publication expanded beyond its 2015 MS focus to include related neuroimmune conditions like NMOSD and MOGAD, presenting evidence-based recommendations for health policymakers.

EMSP's participation ensured patient perspectives remained central to the report, which now serves as a crucial advocacy tool for EMSP and member organisations working to influence healthcare policies and improve outcomes across Europe.

# **Advancing MS Understanding**

The <u>EBV-MS</u> and <u>BEHIND-MS</u> projects represent complementary research initiatives investigating the critical role of the Epstein-Barrvirus in Multiple Sclerosis development and progression. Through clinical trials, advanced research methodologies, and innovative models, these projects aim to transform our understanding of MS triggers and develop targeted prevention and treatment strategies.

In EBV-MS, EMSP integrates patient perspectives through its MS Community Advisory Board to shape clinicaltrialprotocols.ForBEHIND-MS,EMSPleadstheCommunicationandDisseminationWorkPackage, translating complex research into accessible formats.

#### Achievements



- Patient-Centered trial design: MS Community Advisory Board consultation provided critical insights to researchers, refining trial consent forms and addressing participation feasibility.
- **Protocol enhancement:** Patient feedback improved recruitment and retention strategies, making trials more relevant to the MS community.
- Increased visibility: Amplified project at major events including RIMS Annual Conference, ECTRIMS, and ECTRIMS Patient Community Day.

"I was very impressed by the professionalism and insights from the consultation group (CAB expert patients). Their inputs and perspectives were instrumental in shaping and improving on the study design". — Professor Øivind Torkildsen, EBV-MS, Deputy Project Coordinator

#### Achievements



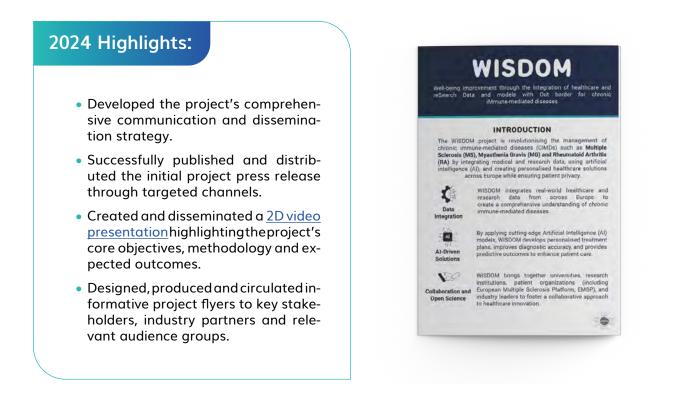
- Research-Patient connection: Featured principal investigator at EMSP's Annual Conference, creating direct dialogue between researchers and the MS community.
- Accessible communication: Developed dual-version brochures for scientific and non-expert audiences and created an engaging video explaining the EBV-MS connection.
- Strategic dissemination: Established coherent narrative through regular blogposts while pioneering inclusive communication through EMSP's accessibility guidelines.
- **Community engagement:** Distributed materials at major MS events including RIMS Annual Conference, ECTRIMS 2024, and ECTRIMS Patient Community Day.

# Transforming MS Care Through Data Integration



WISDOM (Well-being Improvement through the Integration of healthcare and re-Search Data and models withOut border for chronic iMmune-mediated diseases) is an EU healthcare initiative using AI to improve immune disease management by integrating patient data, developing cross-border record sharing, creating predictive models, and validating these tools clinically.

EMSP contributes through research in WP1, conducting surveys on patient and clinician perspectives on AI and ethics. EMSP also co-leads on WP6 to ensure patient representation via the MS Community Advisory Board and managing communications and stakeholder engagement. The project aims to enhance personalised treatment while building public trust in medical data usage.



"Using AI, we will transform complex biological information from existing data sources into clinically applicable models. If we can identify and treat patients with chronic inflammatory diseases at an earlier stage, there is a good chance of slowing the progression of the disease and reducing symptoms and relapses. An improved prediction of disease severity would also allow for better use of current treatments to avoid both over and under treatment." — Ingrid Skelton Kockum, WISDOM, Project Coordinator

# EMSP 2024



# **EMSP** Membership

 $\underline{Our\,membership}\,comprises\,43\,members\,including\,34\,full\,and\,9\,associated\,members\,across\,37\,European\,countries.{}^3$ 



<sup>1</sup>In 2024, the two French MS societies merged to form a single organisation, which is now a full member.

<sup>2</sup>As of 2025, the UK and Swedish MS societies are no longer members of EMSP. We extend our sincere gratitude to both organisations for their valuable contributions and dedicated support throughout their years of membership.

<sup>3</sup>Please note that the membership roster represents our total membership capacity as recorded for the 2024 calendar year.

### **Treasurer's Report**

The European Multiple Sclerosis Platform (EMSP) concludes the fiscal year 2024 with a financial deficit, as anticipated in our planned budget 2025. Despite the deficit, our financial performance remains within the expected parameters, reflecting a well-managed approach to our financial strategy amidst a challenging funding landscape.

The year 2024 has presented significant financial challenges, notably the continued decline in funding from our industry supporters and the absence of EU operating grant funding. These constraints have necessitated careful financial planning and resource allocation to ensure EMSP remains on course with its mission and strategic objectives.

In response to these financial pressures, EMSP has leveraged its ongoing research initiatives through EU projects, which have provided an essential source of funding. This has enabled us to diversify our funding while maintaining the organisation's financial capacity and continuing to advance our strategic priorities, ensuring that we uphold our commitments to the MS community.

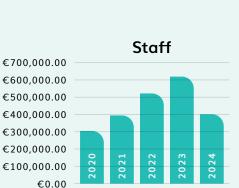
Despite major staff turnover during 2024, EMSP team has demonstrated remarkable resilience. The dedication of the team, coupled with the invaluable support and commitment of former staff members stepping in, has allowed us to successfully implement our planned activities and deliver on our objectives.

As we move into the next fiscal year, securing diversified and sustainable funding remains a key priority.EMSP will continue to explore alternative revenue streams, strengthen partnerships, and advocate for renewed EU funding opportunities. Through prudent financial management and strategic foresight, we remain committed to ensuring the long-term stability and impact of EMSP's work. To this effect, EMSP is working on setting itself to be potentially eligible for EU Operating Grants in the future.

I extend my sincere gratitude to the EMSP team, Executive Committee members, and supporters for their continued dedication and commitment in thesechallenging times. Together, we will navigate the evolving financial landscape and continue making a meaningful difference for people affected by multiple sclerosis across Europe.

Income €1,600,000.00 €1,400,000.00 €1,200,000.00 €1,000,000.00 €800,000.00 €600,000.00 €400,000.00 2020 2022 2023 €200,000.00 €0.00

Expenditure €1,600,000.00 €1.400.000.00 €1,200,000.00 €1,000,000.00 €800,000.00 €600,000.00 €400,000.00 2020 2021 €200,000.00 €0.00



2023



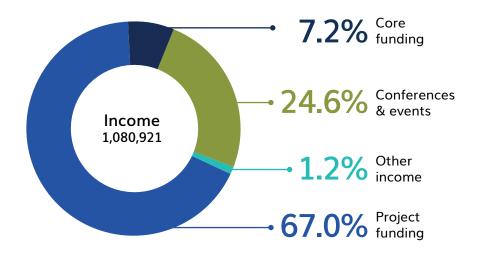


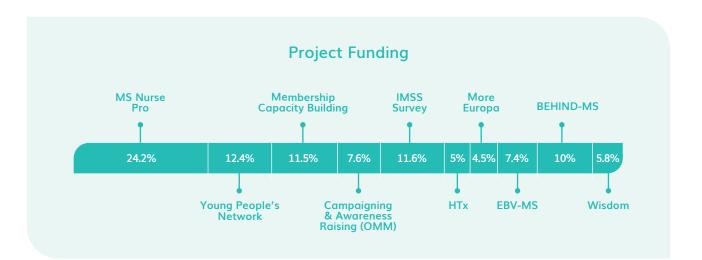


### Financial statements 2023–2024, EUR €

Income	2024	2023
Core funding	78,026	94,469
Conferences & events	265,747	335,487
Other Income	12,803	7,428
Project funding	724,345	911,246
TOTAL:	1,080,921	1,348,630

Expenditure	2024	2023
Staff salaries	399,728	622,445
Outsourcing	27,747	16,722
Administrative costs	97,616	95,954
Direct costs	589,447	619,062
TOTAL:	1,114,539	1,354,183
Profit/loss for the period	-33,618	-5,553





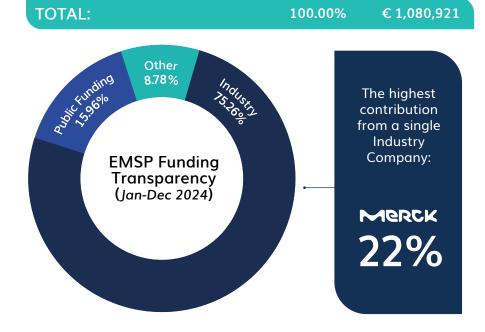
### **EMSP** Income Representation 2024, EUR €

Industry Income	%	AMOUNT
Alexion	5.0%	€ 36,000.00
BMS	2.8%	€ 20,000.00
Coloplast	4.1%	€ 30,000.00
Amgen	9.1%	€ 66,000.00
Merck	22.1%	€161,000.00
Novartis	15.3%	€ 111,000.00
Roche	18.7%	€ 136,000.00
Sandoz	3.4%	€ 25,000.00
Sanofi	13.9%	€ 101,000.00
Viatris	5.6%	€ 41,000.00
Total Industry Income	100%	€ 727,000.00

Non-Industry Income	%	AMOUNT
Public Funding	74.2%	€ 272,895.00
Private Non-Industry Grants	0.9%	€ 3,452.00
Membership Fees	18.5%	€ 67,927.00
Other Income	3.5%	€ 12,803
Annual Conference Participation Fee	2.9%	€ 10,747
Total Non-Industry Income	100%	€ 367,824
Total Industry Income	67.26%	€ 727,000
Total Non-Industry Income	34.03%	€ 367,824
Carry forward to 2025	-18.49%	-€ 199,899
Brought Forward from 2024	17.21%	€ 185,996

100.00%

€ 1,080,921



### Balance Sheet 2023–2024, EUR €

Assets	2024	2023
Fixed Assets	32,478	43,291
Current Assets		
Accounts Receivable — Pharma	98,456	205,591
Accounts Receivable — Members	9,371	11,036
Prepayments	28,106	14,875
Other receivables	55,523	75,884
Bank Current Account	522,427	504,871
TOTAL:	746,360	855,547

Liabilities	2024	2023
Funds		
Capital	13,585	13,585
Reserves B/fwd	355,082	360,636
2024 Deficit – 2023 Deficit	-33,618	-5,553
Total Funds	335,049	368,667
Current Liabilities		
Accounts payable	118,636	80,369
Deferred Income	199,899	277,996
Prepayments	88	0
Accruals & other creditors	36,159	21,950
Taxes & Social Security	13,313	44,330
Provision holiday pay	43,217	62,234
<b>Total Current Liabilities</b>	411,311	486,880
TOTAL:	746,360	855,547



#### **Auditor's Report**

"We have audited the annual accounts of the Organisation, which comprise the balance sheet as at 31/12/2024, the profit and loss account for the year then ended and the notes of the annual accounts, characterised by a balance sheet total of €746.359,72 and a profit and loss account showing a loss for the year of € -33.618,09".

DPO CHARTERED AUDITORS Ø

### **Remembering Professor Giancarlo Comi**

The passing of Professor Comi's in 2024 was a devastating blow to the scientific community and everyone working within MS research. As the European Charcot Foundation's President, his brilliant leadership fostered crucial collaborations between scientific, academic, and industrial partners. EMSP was privileged to work alongside him on the MS Data Alliance and PROMS initiative, where his passion and expertise proved invaluable. His legacy lives on through the researchers he mentored and the patients whose lives he improved. EMSP remains committed to advancing the work to which he dedicated his life.



Professor Giancarlo Comi NEUROLOGIST

### Acknowledgements

In 2024, EMSP's success relied heavily on the invaluable contributions of many. We thank our member organisations, especially the Belgian MS Society, co-host of EMSP Annual conference 2024; 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, EUPATI Spain, the Young People's Network and all project consortiums.

We also would like to acknowledge the support received through strong partnerships with the key stakeholders in the field of MS advocacy and patients organisations: <u>Rehabilitation in Multiple Sclerosis</u> (<u>RIMS</u>); <u>MS International Federation (MSIF</u>); <u>European Charcot Foundation</u>, <u>MS Data Alliance (MSDA</u>) <u>European Patients' Forum (EPF); European Federation of Neurological Associations (EFNA); European BrainCouncil (EBC); the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS); the <u>European Disability Forum (EDF</u>) and the <u>International Organisation of MS Nurses (IOMSN</u>).</u>

A special thank you to EMSP collaborators: Mate Tagaj (Boostern), Nicola Bedlington and Jenna Piriyatharsan.

### **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:



This report was created by Kanika Kohli with the support of the EMSP Team. Graphic design by <u>Boostern</u>. 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 <u>kanika.kohli@emsp.org</u>



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