



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Building the European MS Network



ANNUAL REPORT 2016

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type the shortened url
<https://goo.gl/<code>>

www.emsp.org

Cost of Illness study launched in 2016

Participants

17,000 people
living with MS

From 16
countries
across Europe

With an
average age
of 51 years

52% live with
relapsing-
remitting MS

Key findings

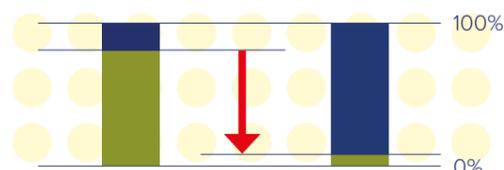
Average costs of MS:
between € 22,800/year
for mild condition to
€ 57,500/year
for severe condition

Effect on employment: work
capacity shown to have
declined from 82% to 8%

**Fatigue and cognitive
difficulties:** reported by at
least 70% of respondents
regardless of severity



COST OF ILLNESS /year
€ 22,800 – € 57,500



WORK CAPACITY
82% ↘ 8%



FATIGUE 70%
**COGNITIVE
DIFFICULTIES 37%**

MS Brain Health: Time matters in MS report launched in 2015

Participants

Group of MS
experts lead
by neurologist
Gavin

Giovannoni,
with the
participation
of EMSP's

External
Affairs Director
Christoph
Thalheim

Key findings

**Average cost of
MS relapse: € 4,000**

Loss of brain volume:
untreated MS triggers
brain atrophy at a rate
5 times higher than in
unaffected people

Average utility: people
with MS rate themselves
20% to 30% less useful to
society in comparison to
people unaffected

**Life expectancy for
people with MS: reduced
with 5 to 10 years**

Foreword

A challenging and exciting year of change lies behind us. Over the past years, a growing MS community across Europe has given us a deeper understanding about the challenges faced by people with multiple sclerosis. Looking back on our achievements, we realise how far we have progressed in building and strengthening this community by engaging on a living, breathing platform where our members and individuals affected by MS can actively participate. Our highly committed and interactive community is key to our success.

This year's annual report illustrates our organisation's maturing structure of resourceful and highly active national MS societies, young people with MS, partners and supporters – all working towards the same vision of a world without MS. The report also highlights our coordination role as the European MS Platform and our successful achievements. From raising awareness of MS and other neurological conditions to supporting our members achieve their goals, as well as working with partners to develop a comprehensive framework to keep the fight against MS ongoing, we covered a broad range of activities.

Strategically and in our day-to-day operations, we set our focus on developing and deepening the relationships with our members and the young people with MS across Europe, addressing with them the priority areas identified in the Code of Good Practice – Defeating MS Together. We showcased our strong connections with dedicated campaigns throughout the year, such as the launch and swift development of our Membership Communications Network – an efficient tool for sustained dialogue and sharing of best practice with our network of national MS societies.

Despite the step back from the health agenda that is currently impacting the European and national political engagement in the public health field and thus strongly affecting the sustainability of patients' organisations throughout Europe, EMSP will continue to push for increased investment in MS research and health budgets so that people with multiple sclerosis get the support they need. EMSP will continue to work on data collection for more 'real world' evidence-based advocacy. Through our activities, we will keep strengthening our partnerships with the MS community, businesses,

media and researchers in order to influence policies favourable for people with MS. This will be achieved by taking forward the development of the European Network of MS registries.

We believe these difficult times offer us a unique opportunity to focus our strength through more collaboration, resources sharing, growth and connectivity by better supporting each other. We will adapt the way we are leading and collaborating to improve our impact. Our closer and more targeted cooperation with the European Medicines Agency (EMA) is a good example for how we plan to go forward – one relevant approach in this sense was our outreach to members to identify and train MS advocates able to represent the patient community within EMA.

Our goal is to craft a strong and unique voice for people with MS. We have an excellent basis on which to build: our expertise and our community. We are a leading patients' organisation in Europe, expanding and being increasingly involved in relevant activities that make a real difference. In 2016, we signed a memorandum of understanding with the Board of the European Committee for Treatment and Research in Multiple Sclerosis. This memorandum provides concrete endorsements for our flagship projects MS Nurse Professional and Paving the Path to Participation.

Last year was also one of change – challenging and positive, we like to think. To meet our objectives and deliver, we restructured our Secretariat with the appointment of Elisabeth Kasilingam as our Managing Director. Our dedicated team has and will strengthen our organisation further. We would like to take this opportunity to express our gratitude to Maggie Alexander who retired as Chief Executive and Bettina Haussmann who served as interim CEO in 2016. Our thanks also go to Dr Christoph Lotter, stepping down as Vice-President, and the Swiss MS Society for their support.

In the year ahead, change will demand a lot from us as patients' organisations at European and national level. We are always aspiring to be more sustainable and to do more to progress the fight against MS. We would like to invite you to remain part of this journey as members, individuals affected by MS, supporters and partners.

To conclude, we are extending our special thanks to our Executive Committee members that keep us focused on our mission to improve the quality of life of the people with MS and secure our future; and to the entire team for their great ideas and their daily work which allows us to seize the right opportunities and keep advancing the EMSP success story.

Brussels, April 2017



Anne Winslow
EMSP President



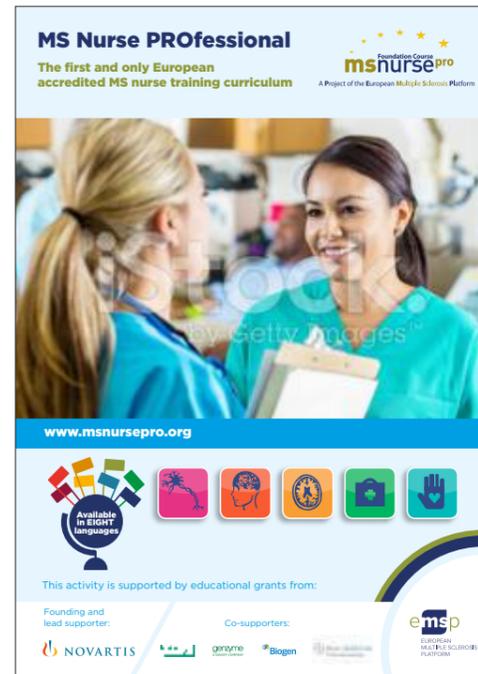
Elisabeth Kasilingam
EMSP Managing Director

Building success

In 2016 we made important progress with our flagship projects in areas of great interest for our members such as the specialisation of healthcare professionals and the workplace inclusion of young people with multiple sclerosis. We also shared crucial treatment updates together with best practice related to early intervention and unmet needs during our successful Spring Conference.

MS Nurse Professional

EMSP's project providing accredited online training to MS nurses continued its expansion in 2016. Its core goal is to improve the provision of appropriate care and support for people living with MS across Europe. [1]



MAIN ACHIEVEMENTS

- Over 3,500 registered nurses from Europe and beyond.
- Nine available languages.
- National launch in Norway.
- Official endorsement and financial support from the Board of the European Committee for Treatment and Research in MS (ECTRIMS).



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More details in the section
Building MS Communities

EUReMS2 EUnetMUS

In 2016 EMSP took further steps towards the efficient collection, analysis and standardisation of MS data in Europe. The ultimate plan is to make reliable patient data available to entities such as the European Medicines Agency – for drug evaluation and monitoring, and healthcare technology assessment (HTA) bodies at national level – for decisions regarding pricing and reimbursement. This outcome would also benefit our members and their national constituencies in terms of better access to treatment.

MAIN ACHIEVEMENTS

- Completed the second phase of our European Register for Multiple Sclerosis (EUReMS) project by refining findings and publishing a study poster – 'Assessing the employment status of people with MS'. [2]
- Launching the EUnetMUS project for standardisation of MS data collection. Whereas EUReMS represented the successful proof of concept in this field, EUnetMUS is looking to put this concept into practice – in the next phase – by forming a wider coalition of MS registries.



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Believe & Achieve

Our project making quality work available to young people with MS moved into a new phase last year. However its main objective remains the same: enabling independence and contribution to society through employment. [3]



MAIN ACHIEVEMENTS

- Reached a total of ten young people with MS trained across seven countries in Europe.
- Shifted focus to widening the employers' pool.
- Set the basis for collaboration with social enterprise Interns Go Pro.
- Boosted project marketing by launching two new tools: a dedicated website [3] and a brochure featuring profiles of interns.

“
I have no intention
to stop working.”

Emma Hughes – Believe and Achieve intern

Ready for Work

Voice of MS Patients

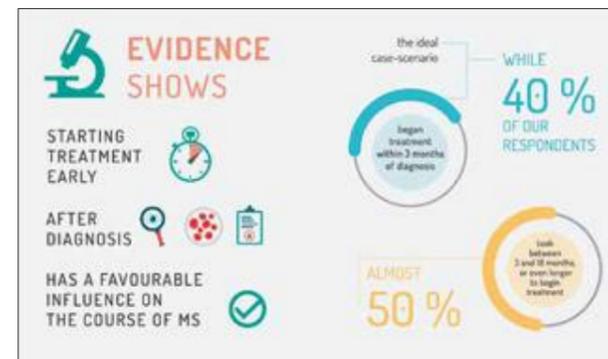
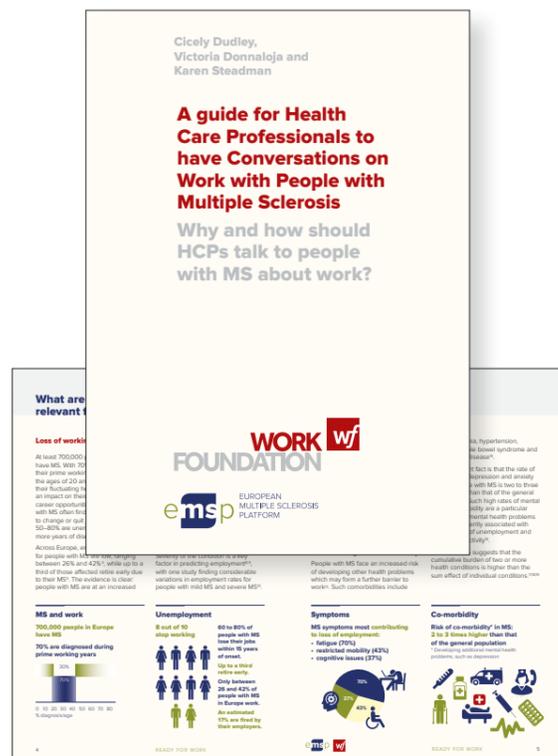
Spring Conference

photos EMSP's 2016 Spring Conference
[photo bottom] EMSP's 2016 Spring Conference coincided with the celebration of the Norwegian National Day

The relation between patients and healthcare professionals (HCPs) sparks ongoing debates within our constituency. The launch of our Ready for Work project aimed to add a new dimension to this key topic: encouraging HCPs to include employment in their dialogue with people with MS. [4]

EMSP's collaboration with members was essential in collecting, analysing and launching the results of our comprehensive Voice of MS Patients survey. Its role was to accurately assess the real needs of people living with MS in Europe in order to boost awareness-raising, policy outreach and potentially also healthcare technology assessment (HTA) processes. [6]

One of the most relevant markers of EMSP's membership outreach is our Annual Spring Conference. In 2016 the event was held in Oslo, Norway and co-hosted by the national society MS Forbundet. As in previous years, the majority of participants represented our wide network of members – from Iceland to Greece. Titled 'Growing with MS', the Conference focused on MS in children (paediatric MS) as well as the post-diagnosis life of people with MS. [8]



MAIN ACHIEVEMENTS

MAIN ACHIEVEMENTS

- Completed by 2,700 people from 33 European countries.
- Provided policy recommendations in key areas such as patient involvement, social policies and provision of care.
- Produced an innovative and easily sharable awareness-raising tool in the form of a video infographic. [7]
- Pooled and disseminated key MS employment data. [5]
- Set the stage for the 2017 launch of the employment Guide for Neurologists.

MAIN ACHIEVEMENTS

- Held a multidisciplinary panel on how to better understand and address paediatric MS.
- Introduced the biggest MS study to date – Cost of Illness (G. Kobelt).
- Provided inspiration to the MS public by giving the floor to remarkable MS advocates.
- Launched a Membership Communications Network.

[4] [5] [6] [7]

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[8]

<tdyvTR> More details in the section Building MS Communities



EMSP's main 2016 achievements stemmed from our commitment to continuously improve the capacity of our member societies and of their constituencies. Last year, we looked to achieve this key goal by working closer with our national MS societies, involving young people with MS in our activities on a more regular basis and banking on new communications tools.

Young people

In 2016 we tailored a substantial part of our activities to answer to the needs and concerns of young people living with MS across Europe.

MAIN ACHIEVEMENTS

- Organised the Young People's Conference focused on Readjustment. The conversations gravitated around the impact of the MS diagnosis. [9]
- Present at the major European Youth Event organised in the European Parliament in Strasbourg, France. Our young patient advocates focused once again on employment and spoke about their need for empowerment under the motto 'Ready, Brilliant and Able to Work'. After the Strasbourg event our MS advocate Anna Zaghi was nominated as member of the EPF Youth Group. [10]
- Fundraised for and launched two awareness-raising videos dedicated to MS disclosure. Under the title 'Dropping the Mask', the MS interviewees talked about disclosing at work and in a relationship. [11]



[9]



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[10]



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[11]



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“

The Readjustment event was an opportunity to learn from one another and share experiences so that young people with MS can have access to the information they need.

Emma Rogan – EMSP Project Coordinator
📍 at the Young People's Conference

Unemployment

8 out of 10 stop working



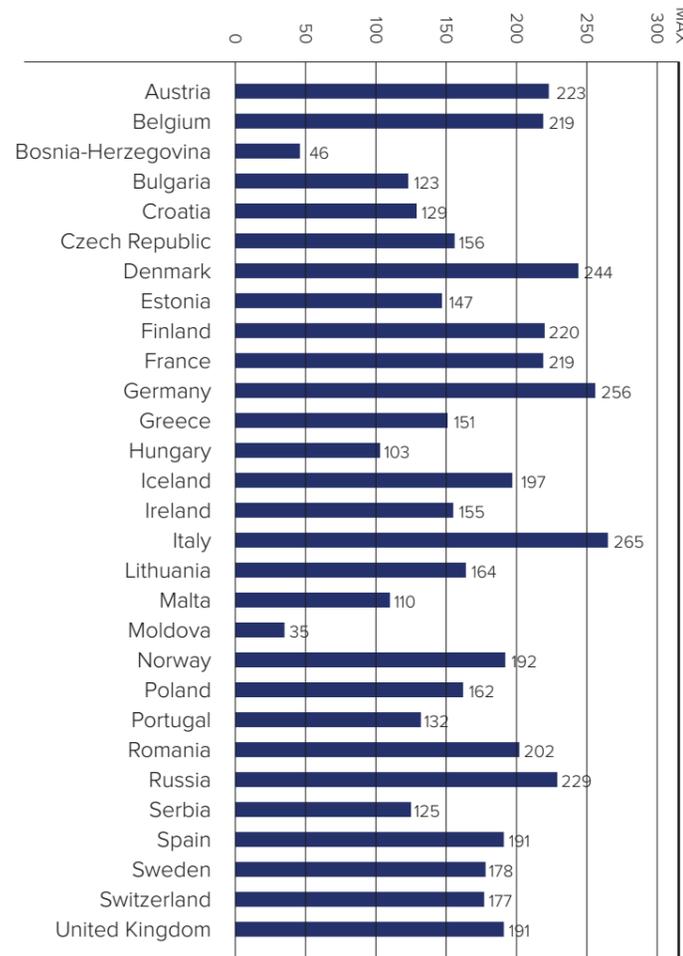
60 to 80% of people with MS lose their jobs within 15 years of onset.

Closer cooperation

Our capacity-building activities enabled members to actively participate in our flagship projects in order to deliver positive outcomes for their MS communities. We focused on key areas such as specialisation of MS nurses, workplace integration and evidence-based advocacy.

MAIN ACHIEVEMENTS

- Organised the Norwegian national launch of our MS Nurse Professional project together with the national society – MS forbundet. Our collaboration also resulted in the translation of the online training modules in Norwegian. [12]
- Worked with MS Ireland to adapt our Employment Toolkit for the use of MS patients at national level. [13]
- Collaborated with 29 national MS societies for the completion of our comprehensive questionnaire – the MS Barometer. Together we refreshed the data analysis methodology and identified four areas to summarise the main findings: access to healthcare, MS research and data collection, participation in society, and MS empowerment. We set the launch date for early 2017.
- Organised a capacity-building seminar for six national MS societies in Central and Eastern Europe. The seminar focused on the most effective fundraising and advocacy tools in relation to the needs of the MS organisations.



MS Barometer 2015 – max. overall score 314 pts.)

[12]

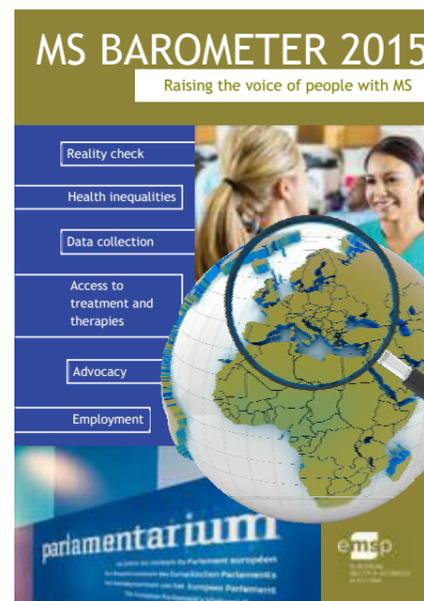


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[13]



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Communications

The ongoing collaboration with our members allowed us come to an essential conclusion: that communications underpins the efficiency of our European MS network. This is why we created new membership communications tools and channels.

MAIN ACHIEVEMENTS

- Launched a Membership Communications Network which brought more regular dialogue and sharing of best practice, and increased cooperation in the dissemination of MS information.
- Produced a quarterly Membership Newsletter with valuable contributions from member societies. [14]



[14]



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Participants at the kick-off session of EMSP's Membership Communications Network



In 2016 EMSP increased the volume and frequency of member news shared through our website, newsletters and social media channels. This was a mark of recognition for the excellent work carried out by our national MS societies and a signal of ever closer collaboration for the benefit of the wider MS communities.



SWITZERLAND

- 📌 Launch of national MS register [15]

We acknowledged the great progress in the collection and analysis of MS data at national level.

SPAIN

- 📌 150,000 made a 'splash' for MS [16]

We shared this news to serve as an example of the creative power and solidarity that nation-wide patient advocacy can generate.



REPUBLIC OF MOLDOVA

- Only 35 of 1,000 MS patients receive reimbursement [17]

We shared this article to raise awareness of a staggering lack of access to treatment and to encourage the fledgling advocacy work of one of our newest member societies.

UNITED KINGDOM

- 📌 Hundreds of people with MS are missing out on treatment [18]

We recognised the potential of patient engagement solutions – such as surveys – to influence national health and social policies.

POLAND

- 📌 MS cycling tour [19]

We shared this news to emphasise the importance of promoting key MS management solutions such as physical activity.

[15]



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[17]



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[18]



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[19]



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[20]



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Find more member news on www.emsp.org [20]

Building the MS voice

Online advocacy

In 2016 EMSP further harnessed the results of our good collaboration with members through advocacy and campaigning initiatives. In doing so we brought patients' priorities before European decision-makers, top healthcare professionals, pharmaceutical industry representatives and drug regulators.

Last year we continued to refine our online outreach focusing increasingly on meaningful engagement with our European MS public. We interacted with MS patients directly, brought them closer to healthcare professionals and involved them in our project marketing.

MAIN ACHIEVEMENTS

- Organised a series of 'Tweet chats' in the run-up to World MS Day. The overarching theme was Independence. [21]
- Launched a new blog campaign, A Day in the Life, which provides a platform for different health stakeholders to share their MS experience with our public. [22]
- Completed a social media 'Thunderclap' campaign to popularise our new Ready for Work project. [23]
More details in the section Building partnerships
- The #EMSP2016 hashtag helped us extend far beyond our established online audience by reaching over 160,000 accounts and generating almost 1 million impressions in the period around our Spring Conference (14-23 May).

[21]



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[22]



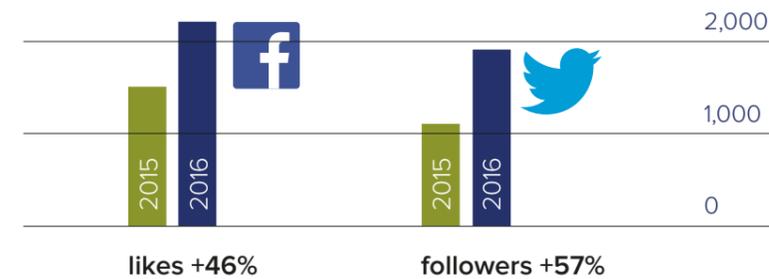
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[23]



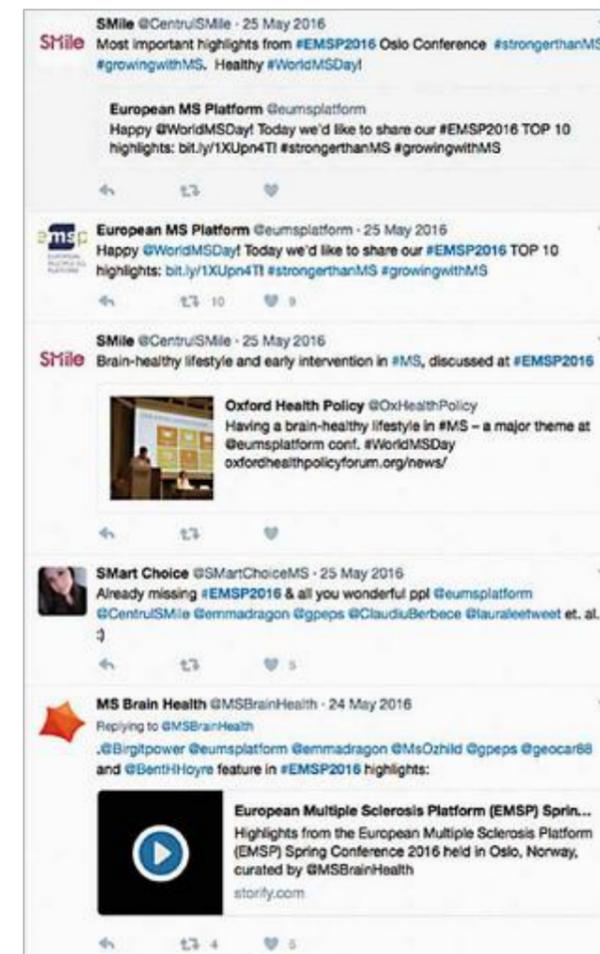
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	Facebook	Twitter
December 2015	1,500 page likes	1,100 followers
December 2016	2,200 page likes	1,900 followers



“
Social media is not the reign of technology but a service to community.”

Conclusion from the European Medicines Agency's (EMA) September 2016 workshop on the benefits and challenges of social media in a healthcare context



In 2016 EMSP’s policy priorities were determined by our overarching goal to improve the quality of life of people with MS. Our collective efforts led to positive outcomes in three main areas: employment, research and technology.

As this topic remains high on the agenda, we continued our Call to Action on Access to Employment.

Breaking down the employment barriers
EMSP campaigned in the European Parliament – in Brussels and Strasbourg – and ensured support from more than 70 MEPs. We also launched the Practical Toolkit for Employers – a guide that enables employers to build their policies for recruitment, attendance management and return-to-work procedures. The guide has been successfully used and localised by some of our member societies and the work is ongoing. EMSP has also contributed to the European Commission (EC) Consultation on the European Pillar of Social Rights. We were able to do so after consulting our members.

Three of the most pressing issues our members identified:

DISCRIMINATION

- A common bad practice in the workplace sees some employers taking advantage of the vulnerability of people with disabilities and failing to provide them with equal opportunities. When such practices occur they make it even harder for people with disabilities to reach their potential and contribute to society.

FINANCIAL SUPPORT

- The lack of a commonly accepted and policy relevant definition of ‘disability’ across Europe makes it difficult for those affected to become eligible for maintenance income or similar forms of financial state support. Employers often exploit this ambiguity and find legislative ‘loopholes’ to the detriment of people with disabilities.

EDUCATION

- In order to successfully complete their studies and access the job market, young people with disabilities need to be provided with increased support from all relevant stakeholders.

In 2016 EMSP and the European Committee for Treatment and Research in MS (ECTRIMS) signed a memorandum of understanding, formalising our longstanding collaboration.

Increasing scientific collaboration

In this context, during the ECTRIMS 2016 congress, EMSP also facilitated the first ECTRIMS – EMA dialogue, looking at ways to enhance collaboration.

EMPLOYMENT RECOMMENDATIONS FOR EMSP MEMBERS

- Localise the Practical Toolkit for Employers in your country and disseminate it to the employers (Contact the Estonian and Irish MS societies for best practice in implementing this recommendation)

RESEARCH RECOMMENDATIONS FOR EMSP MEMBERS

- Develop partnerships and collaborations with other organisations and scientific bodies
- Use the EMSP platform to develop and enhance partnerships with sister organisations and experts in the field

EMSP CALLS ON ALL EMPLOYERS AND POLICY DECISION-MAKERS TO

- Recognise the work skills and abilities of people affected by MS and other neurodegenerative diseases
- Help people to stay in, and return to work for their personal, psychological and financial wellbeing
- Provide sustainable employment for people with MS



Last year EMSP continued to represent the voice of people with MS as a member of the EUnetHTA stakeholder pool and the related joint action (JA2 and JA3). The main effort by EMSP and other patient advocates was focused on meaningful and sustainable patient involvement in HTA processes both on national and European level. We were also involved in the London School of Economics HTA Summit as one of the patient organisation representatives.

EMSP CALLS FOR

- More public funding available for the set-up of disease specific patient registries
- Existing MS registries to adopt the same protocols of data pooling and analysis for all those cases where national data collection is insufficient
- Closer cooperation between the HTA bodies and the patient community
- More transparent communication about the decision-making processes at national level

Health Technology Assessment

As a member of the Patients and Consumers Working Group (PCWP) within the European Medicines Agency (EMA), EMSP maintained its active involvement in all areas that could support our members' activities. For instance, we took part in the EMA Adaptive Pathways workshop.

The adaptive pathways concept is an approach to medicines approval that aims to improve patients' access to medicines in cases of high unmet medical needs. [24]

EMSP also contributed to the EC Public consultation on strengthening EU cooperation on Health Technology Assessment, together with the colleagues from the European Patients' Forum. Our vision is that we need better data for better outcomes. It is of crucial importance for the HTA bodies to have access to more and better data to guarantee the assessment is backed by solid evidence, including patient reported outcomes.

HTA RECOMMENDATIONS FOR EMSP MEMBERS

- Support the involvement on patients in the HTA processes at national level
- Empower patients and increase knowledge and expertise in the HTA field (see the EUPATI programme – www.eupati.eu)
- Set up national MS patient registries where none exist and liaise with EMSP to include them in a soon-to-be-built European Network of MS Registries

[24]



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Aversa, Italy

Stefania Salzillo works independently as a lawyer; having MS has increased her empathy for clients trying to cope with unjust situations. "Often, I come across people whose basic rights have just been 'cancelled' by other people, by a certain situation, or by the world in general. I try to be as close as possible to people's situation; sometimes, I choose to work on a case for no fees because it feels right to help someone else."

WWW.UNDERPRESSUREPROJECT.EU © WALDER ASTRADA



Bagno Vignoni, Italy

Working in reception at a luxury hotel and spa is a good fit for Martina Vagini, who admits that her previous unemployed status led to a severe depression. Now she has the opportunity to use her training as an interpreter and meets many interesting people. Her colleagues and boss are supportive, and the pace of the work is manageable: she can set her crutches aside for long periods of the day.

WWW.UNDERPRESSUREPROJECT.EU © CARLOS SPOTTORNO

Building partnerships

Last year we marked important progress in our collaboration with fellow patient organisations. Working together with various associations and federations dedicated to the wellbeing of patients and their communities provided us with additional knowledge and expertise to be utilised for the benefit of our members.

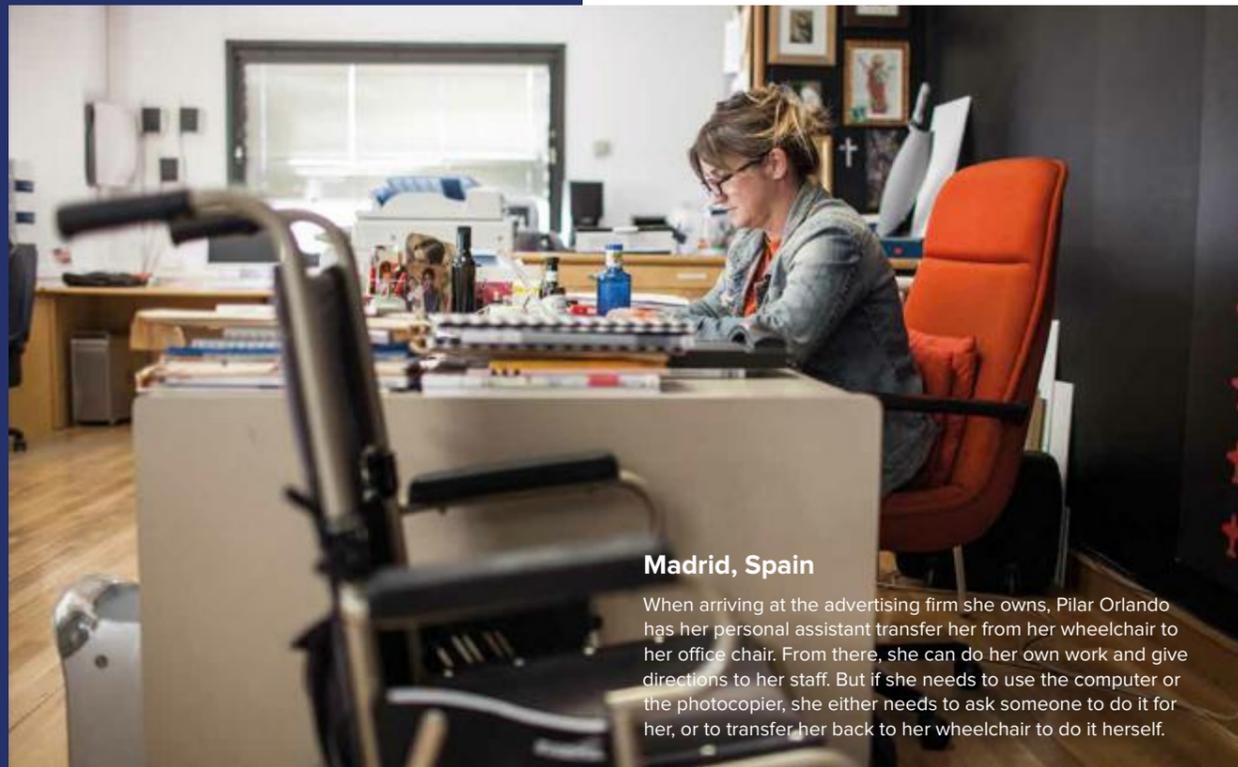
The Work Foundation

Our collaboration led to the launch of the Ready for Work project focused on supporting people with MS into employment by shaping their dialogue with healthcare professionals. www.theworkfoundation.com [25]

MAIN ACHIEVEMENTS

- Promoted the concept of employment as a clinical outcome.
- Ran a social media 'Thunderclap' campaign on #workability that reached over 140,000 people on Twitter and Facebook.

Find out more about our collaboration with fellow organisations on www.emsp.org [26]



Madrid, Spain

When arriving at the advertising firm she owns, Pilar Orlando has her personal assistant transfer her from her wheelchair to her office chair. From there, she can do her own work and give directions to her staff. But if she needs to use the computer or the photocopier, she either needs to ask someone to do it for her, or to transfer her back to her wheelchair to do it herself.

WWW.UNDERPRESSUREPROJECT.EU © LURBES R. BASOLI

European Brain Council

EMSP was involved in the European Brain Council's (EBC) Value of Treatment (VoT) project aiming to bridge the treatment gap in Europe. Our support for VoT was underpinned by our determination to address a startling reality in the healthcare landscape: only about a third of European patients receive the medication and therapy they need. EMSP also provided communications support to EBC. [27]



MAIN ACHIEVEMENTS

- Supported the VoT MS Working Group by contributing to the 'patient journey' narrative with specific feedback from leading MS advocates.
- Helped EBC produce and implement their Communications Strategy.

European Patients' Forum

As a founding member of the European Patients' Forum (EPF), we continued to support this organisation's commitment to high quality, equitable patient-centred healthcare. Throughout 2016 this meant – in particular – helping promote and conclude the 'Patient prescribe E5' project dedicated to patient empowerment. [28]

The 5 'E'-s of patient empowerment:

INDIVIDUAL

- Education
- Expertise
- Equality

ORGANISATIONAL

- Experience

POLICY

- Engagement

MAIN ACHIEVEMENTS

- Promoted – through different communications channels such as newsletters and social media – solutions to achieving sustainable healthcare systems.

[25]



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[26]



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[27]



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[28]



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Building resilience

By working closely with our members we learned the importance of offering hope to build resilience. In 2016 we endeavoured to provide this key 'ingredient' to overcoming the challenges of MS. We therefore carried out a variety of initiatives: we were involved in multi-stakeholder studies and publications, we disseminated treatment updates and we collected and shared inspiring stories.



“
The ‘Cost of Illness’ study provides a photograph of the status quo of MS populations in terms of their quality of life, daily activities, healthcare and support.

Gisela Kobelt, *Health Economist*,
 at EMSP's 2016 Spring Conference

Studies and publications

EMSP supported the progress and promotion of two remarkable initiatives in the field of MS and brain disorders: the Cost of Illness study and the Brain Health guide.

MAIN ACHIEVEMENTS

- We introduced the Cost of Illness study during our 2016 Spring Conference. Co-author Gisela Kobelt described it as the 'biggest ever' study on MS, referring to the 17,000 participants from 16 European countries. Find a related interview on our YouTube channel. [29]
- We received permission from Cost of Illness authors and data owners to share the study results with our national members and wider constituency starting with 2017.
- We promoted the MS Brain Health Guide for people with multiple sclerosis [30] It is meant to help those with MS understand how they can keep their brains as healthy as possible and request the highest possible standard of care.

Find out more about our collaboration with fellow organisations on www.emsp.org [33]

[29]



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[30]



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[31]



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[32]



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New treatments

EMSP disseminated the latest treatment updates originating from the most reliable sources and worked to further popularise the crucial role of the European Medicines Agency (EMA).

MAIN ACHIEVEMENTS

- Our participation in the 2016 Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) allowed us to collect and disseminate reliable treatment updates. [31]
- We continued to raise awareness on EMA's role in evaluating and monitoring medicines approved at EU level. In this sense we created a temporary EMA Treatment Updates section on the homepage of our website. [32] We also shared a higher number of EMA updates through our monthly newsletters.

“
EMSP continues to make a difference and we have to keep offering hope for people with MS.

Anne Winslow – EMSP President

Overcoming challenges

↓ The united crews of EMSP and Oceans of Hope, preparing for a boat tour of the Oslo fjords during our 2016 Spring Conference'

Storytelling is recognised as a source of inspiration and motivation for many people with MS. Therefore in 2016 EMSP continued its work to identify and share moving MS stories.

MAIN ACHIEVEMENTS

- Hosted MS advocate Lori Schneider at our 2016 Spring Conference where she talked about her experience of becoming the first person with MS to scale Mount Everest. In a subsequent interview she offered more insight into how she overcomes her MS challenges. Find the interview on our YouTube channel. [34]
- Promoted the movie adaptation of a real MS story: told upon this MS diagnosis that he would barely be able to walk, Ramon Arroyo went on to complete the ultimate sporting challenge – an Ironman race. [35]
- Encouraged a group of people with MS present at our 2016 Conference to embark on their own personal MS stories. We did this by organising a sailing trip on the popular Oceans of Hope boat which had completed the world circumnavigation in 2015. [36]



Find more inspiring MS stories on www.emsp.org [37]

[34] [35] [36] [37]

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“ I had to give myself permission to live life despite my MS. ”

Lori Schneider – MS advocate

The results for the year ending December 2016 show a small deficit of €17,195 against an original budget surplus of €28,860.

Whilst the year proved to be more challenging than expected, not only for EMSP but also for our members, the amount of income raised shows an increase against the previous year of €168,000 being 15% of the total income for 2015.

During the year we aimed to diversify more of our income, and we will continue to do this during 2017. The financial support for our projects is a benchmark of the high regard for our work and the outcomes that can be achieved with the collaboration of our members and other organisations.

We were able to increase our earned income by reimbursements and speaker's fees for staff, and at the same time showcase the work of EMSP at important events, in order to reach a wider audience for possible future funding. Expenditure for the year shows a significant decrease in staff costs, although part of this saving is offset by an increase in external fees which also includes recruitment costs.

We were also able to reduce our office costs to allow us to increase direct spending on our various projects to €408,221 – an increase of 55% against 2015. Many of our projects involve a considerable amount of staff costs, and this figure represents only other costs that are directly attributable to the projects.

Despite the final result being in deficit, the indications for 2017 are positive, with new and exciting work already underway and continuing support from our funders.

Torben Damsgaard – *Treasurer*
April 2017



DPO
bedrijfsrevisoren
Burgerlijke Vennootschap onder vorm van een BVBA

Gentstraat 337
9041 Oostakker

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www.dpo.be

**STATUTORY AUDITOR'S REPORT
TO THE GENERAL MEETING OF THE ASSOCIATION
EUROPEAN MULTIPLE SCLEROSIS PLATFORM
RUE AUGUSTE LAMBIOTTE 144/8
1030 BRUXELLES
FOR THE YEAR ENDED 31/12/2016
RPM BRUSSELS nr. 0473.317.141
=====**

As required by law and the association's by-laws, we report to you in the context of our appointment as the association's statutory auditor. This report includes our opinion on the annual accounts, as well as the required additional statements. The annual accounts include the balance sheet as at 31/12/2016, the income statement for the year then ended, and the disclosures.

Report on the annual accounts - Unqualified opinion

We have audited the annual accounts of the association "EUROPEAN MULTIPLE SCLEROSIS PLATFORM" ended 31/12/2016, which show a balance sheet total of € 652.731,53 and a loss for the year of € 17.194,70.

Responsibility of the board of Directors for the preparation of the annual accounts

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

DPO CHARTERED AUDITORS



27/04/2017

OOSTAKKER (GENT)

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RPR Gent 0475.558.633 - BTW BE 0475.558.633 - KBC OOSTAKKER 446-6623901-08 - BIC KREDBEBB - IBAN BE58 4466 4239 0108

RPM BRUSSELS nr. 0473.317.141

Responsibility of the statutory auditor

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing (ISAs). Those standards require that we comply with the ethical requirements and plan and perform the control to obtain reasonable assurance about whether the annual accounts are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the statutory auditor's judgment, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the statutory auditor considers the association's internal control relevant to the preparation of annual accounts that give a true and fair view, in order to design control procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of valuation rules used and the reasonableness of accounting estimates made by board of Directors, as well as evaluating the overall presentation of the annual accounts.

We have obtained from board of Directors and association officials the explanations and information necessary for our audit.

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

Unqualified opinion

In our opinion, the annual accounts of the association "EUROPEAN MULTIPLE SCLEROSIS PLATFORM" give a true and fair view of the association's equity and financial position as at 31/12/2016, and of the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

DPO CHARTERED AUDITORS

27/04/2017

OOSTAKKER (GENT)

Pagina 2 van 3

RPR Gent 0475.558.633 - BTW BE 0475.558.633 - KBC OOSTAKKER 446-6623901-08 - BIC KREDBEBB - IBAN BE58 4466 6239 0108

RPM BRUSSELS nr. 0473.317.141

Report on other legal and regulatory requirements

The board of Directors is responsible for the compliance with the Law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations, with the by-laws and with the legal and regulatory requirements regarding bookkeeping.

In the context of our mandate and in accordance with the Belgian standard which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, our responsibility is to verify, in all material respects, compliance with certain legal and regulatory requirements. On this basis, we make the following additional statements, which do not modify the scope of our opinion on the annual accounts:

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

Done at Oostakker (Ghent)
April 27th 2017

DPO Bedrijfsrevisoren BVBA
Statutory Auditor
Represented by
Ulrich De Poortere
Registered Auditor - Director

RPR Gent 0475.558.633 - BTW BE 0475.558.633 - KBC OOSTAKKER 446-6623901-08 - BIC KREDBEBB - IBAN BE58 4466 6239 0108

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2016 Financial Statements

2016 Balance sheet

Income	2014	2015	2016
Membership fees	79,278	91,194	84,389
Corporate core funding	90,000	129,559	193,216
Member donations	–	60,470	–
Project funding	948,474	700,127	812,875
Events	175,381	104,418	110,230
Other income	17,896	4,137	57,043
Total income	1,311,029	1,089,852	1,257,753

Expenditure	2014	2015	2016
Staff costs	592,971	651,617	582,191
External fees	34,914	49,912	105,277
Office and other costs	132,662	90,273	84,522
Events	158,695	70,420	94,737
Project expenditure	444,616	263,653	408,221
Total expenditure	1,363,858	1,125,875	1,274,948

Result	2014	2015	2016
Profit/Loss for the period	– 52,829	–36,023	–17,195

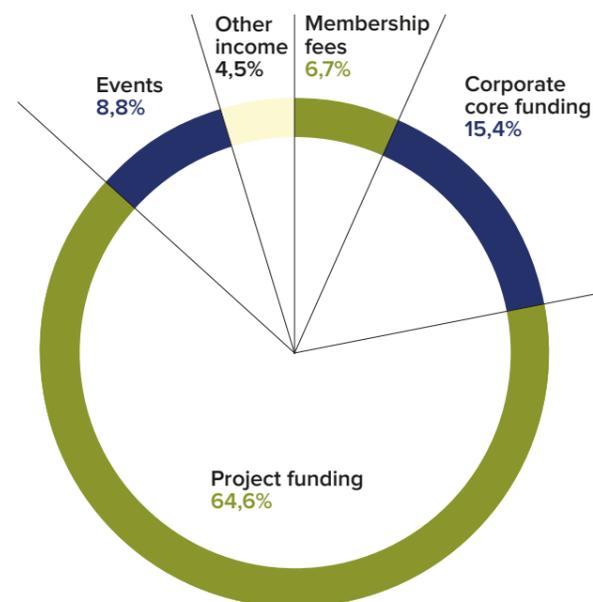
all figures in euros

Assets/Liabilities	2014	2015	2016
Fixed assets	40,482	34,552	32,653
Current assets	743,790	610,617	620,078
Total debtors	373,633	328,759	222,029
Total bank and cash	370,157	281,858	398,049
Current liabilities	449,173	346,093	370,851
Trade creditors	121,552	57,850	8,688
Deferred income	147,500	146,529	227,402
Accruals & other creditors	93,174	51,553	71,967
Taxes & social security	86,977	90,161	62,794
Net current assets / (Liabilities)	294,617	264,524	249,227
Total Assets	335,099	299,076	281,880

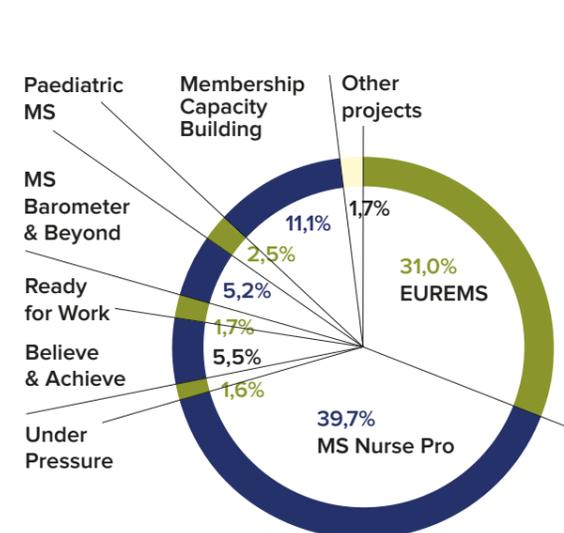
Funds	2014	2015	2016
Reserves	335,099	299,076	281,880
Capital	13,585	13,585	13,585
Reserves b'fwd	354,343	301,514	265,490
Designated funds – dev. countries	20,000	20,000	20,000
Profit/Loss	– 52,829	–36,023	–17,195
Total Funds	387,927	335,099	281,880

all figures in euros

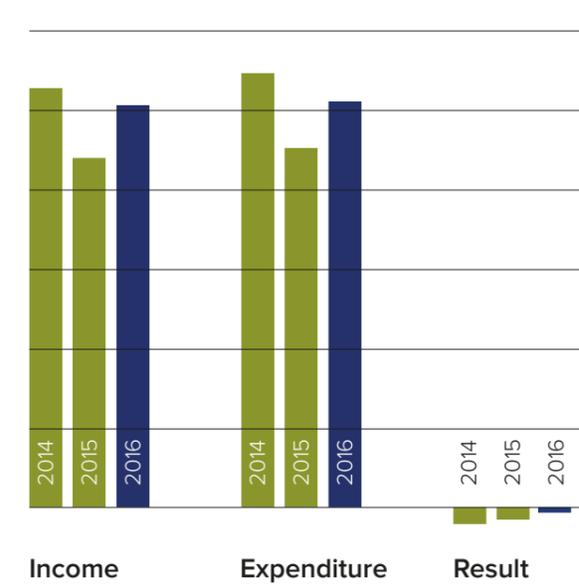
2016 Income
total 100% = 1,257,753 €



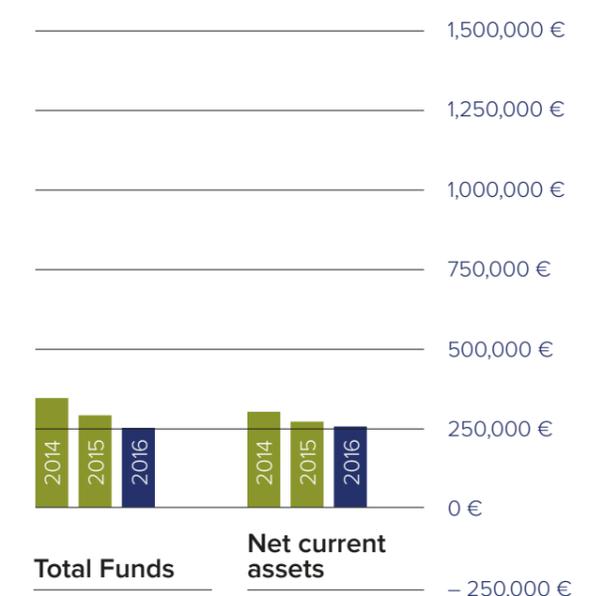
2016 Project funding
total 100% = 812,875 €



2014–2016 Financial statements



2014–2016 Balance



EMSP Secretariat and Board

The people who work at EMSP form a dedicated, hard-working, committed and versatile team. Their invaluable contribution to meeting all the key milestones for the year is gratefully acknowledged.



SECRETARIAT [38]

Andreea Antonovici
Public Affairs and
Event Coordinator

Yves Brand
External Affairs Coordinator

Claudiu Berbecu
Membership and
Communications Coordinator

Žilvinas Gavėnas
IT Coordinator

Elisabeth Kasilingam
Managing Director

Emma Rogan
Project Coordinator

Christoph Thalheim
External Affairs Director

Cristiano Pisani
External Affairs Assistant

EXTERNAL CONSULTANT
Susan Tilley
Financial Adviser

EMSP would like to especially thank:

Bettina Hausmann interim CEO in 2016
Maggie Alexander former CEO
Christoph Lotter former Vice-President
Ed Holloway former ExCom Member
Francis Smets former Finance Manager

EXECUTIVE COMMITTEE [39]

[standing from left to right]

- [1] **Jana Hlavacova**
Young People's Representative
- [2] **Peer Baneke**
Co-optee
MS International Federation (MSIF)
- [3] **Constantinos Michalakis**
Member
MS Society of Greece (GMSS)
- [4] **Dr Olivier Heinzlef**
Member
MS Society of France (LFSP)
- [5] **Bettina Hausmann**
Interim EMSP Chief Executive 2016
- [6] **Torben Damsgaard**
Treasurer
MS Society of Denmark
- [7] **Dr Christoph Lotter**
MS Society of Switzerland
- [8] **Klaus Knops**
Co-optee
MS Society of Belgium
- [9] **Georgina Carr**
Member UK MS Society
- [10] **Pedro Carrascal**
Co-optee MS Society of Spain EME

[sitting from left to right]

- [11] **Magdalena Fac-Skirtladze**
Member MS Society of Poland
- [12] **Anne Winslow**
EMSP President
MS Society of Ireland
- [13] **Maija Pontaga**
Member
MS Society of Latvia
- [14] **John Golding**
EMSP President 2010-2014
MS Society of Norway
- [15] **Federica Balzani**
Member MS Society of Italy

[38]



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[39]



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Acknowledgements

The success and impact of EMSP's work is built on the effective partnerships and cooperative work with a very wide range of stakeholders whose contributions are gratefully acknowledged.

EMSP Member organisations

2016 has seen a consistent two-way flow of information, expertise and good practice from the majority of our 40 member societies.

The launch of our common Membership Newsletter is a good example of effective collaboration and we thank all the participants – with special consideration for Daniela Shikova (Bulgaria), Georgina Carr (UK), Harriet Doig (Ireland), Madeleine Cutting and Jacobo Santamarta Barral (Spain), Marc Lutz (Switzerland), Marta Szantoch (Poland), Pedro Godinho and Susana Protasio (Portugal), Peter Palitzsch Christensen (Denmark), Stanca Potra (Romania) and Labinot Demi (Kosovo). We also address a special 'thank you' to the Norwegian MS Society who was instrumental in the organisation of our 2016 Spring Conference.

MS advocates, specialists and volunteers

We especially recognise the great support and inspiration provided by a number of international MS advocates and specialists, with Birgit Bauer, Lori Schneider, Shana Pezaro, Vicki Matthews and Alan Thompson among them.

We cannot forget the members of our Young People's Group, in particular Anna Zaghi (Italy), Denisa Paslaru (Romania), Ioanna Christodoulidou (Greece), Jana Hlavacova (Czech Republic), Patrik Puljic (Croatia) and Alina Verbni (Republic of Moldova).

We are also extremely grateful for the unconditional help received from kind volunteers such as Pieter van Galen (Belgium) and Katharina Ossenber (Germany).

Interim CEO

A special 'thank you' goes out to our External Adviser Bettina Hausmann who stepped in as an Interim CEO after Maggie Alexander's departure and ensured a smooth, extremely professional transition.

Partner organisations

EMSP's reach and impact is greatly enhanced by the close cooperation with a number of 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), the International Organisation of MS Nurses (IOMSN) and Interns Go Pro.

Supporters

EMSP would also like to acknowledge the support received from legal representative Thomas Martens, but also from the Crowne Plaza Hotel in Brussels.

EMSP Members

Full Members

-  Multiple Sklerose Gesellschaft Österreich
www.msgoe.at
-  MS Society Belarus
www.msbelarus.com
-  Ligue Nationale Belge de la Sclérose en Plaques
www.ms-sep.be
-  MS Foundation Bulgaria
www.msobshtestvo.org
-  Savez Udruzenja Gradana Oboljelih od Multiple Skleroze BiH Sarajevo
www.suomsbih.ba
-  Savez drustava multiple skleroze Hrvatske
www.sdmsmh.org
-  Unie Roska
www.roska.eu
-  Scleroseforeningen
www.scleroseforeningen.dk
-  Estonian Multiple Sclerosis Society
www.smk.ee
-  The Finnish MS Society
www.ms-liitto.fi
-  Ligue Francaise contre la Sclérose en Plaques
www.lfsep.fr
-  Deutsche Multiple Sklerose Gesellschaft
www.dmsg.de
-  Greek MS Society
www.gmss.gr
-  Hungarian Multiple Sclerosis Society
www.smtarsasag.hu
-  MS Felag Islands
www.msfelag.is
-  MS Society of Ireland
www.ms-society.ie
-  Associazione Italiana Sclerosi Multipla
www.aism.it
-  Latvijas Multiplas Sklerozes Asociacija
www.lmsa.lv
-  Lithuanian Multiple Sclerosis Union
www.liss.lt
-  Ligue Luxembourgeoise de la Sclérose en Plaques
www.msweb.lu
-  Multiple Sclerosis Society of Malta
www.msmlta.org.mt
-  Multiple Sclerose Vereniging Nederland
www.msvereniging.nl
-  Multipel Sklerose Forbundet I Norge
www.ms.no
-  Polskie Towarzystwo Stwardnienia Rozsianego
www.ptsr.org.pl
-  Sociedade Portuguesa de Esclerose Multipla
www.spem.org
-  All Russian Public Organization (RPO) of Disabled PwMS
www.ms2002.ru
-  Društvo Multiple Skleroze Srbije
e-mail msserb@sbb.rs
-  Slovensky Zvaz Sclerosis Multiplex
www.szsm.szm.sk
-  Zdruzenje Multiple Skleroze Slovenija (ZMSS)
www.zdruzenje-ms.si
-  Neuroförbundet
www.neuroforbundet.se
-  Asociación Española de Esclerosis Multiple (AEDEM-COCEMFE)
www.aedem.org

-  Schweizerische Multiple Sklerose Gesellschaft (9SMSGO)
www.multiplesklerose.ch
-  The Multiple Sclerosis Society of Great Britain and Northern Ireland
www.mssociety.org.uk

Associate Members

-  The Hellenic Federation of Persons with Multiple Sclerosis (HfoPwMS)
www.msassociationhellas.org
-  Union de lutte contra la Sclérose en Plaques (UNISEP)
www.unisep.org
-  Sclerosis Multiplexes Betegek Országos Egyesulete (SMBOE)
www.smboe.hu
-  Federación Española para la Lucha contra la Esclerosis Multiple (EME)
www.esclerosismultiple.com
-  MS Association 'Hope' Zdruzenie Sclerosis Multiplex Nádej (Msah)
www.dakujeme.sme.sk
-  Multiple Sclerosis (MS) Association of Turkey
www.turkiyemsdernegi.org
-  National Association of People with Multiple Sclerosis in Hungary
-  MS Society of Moldova



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Corporate supporters

EMSP has continued to benefit from the substantial support of corporate partners who between them have provided funding for key projects including MS Nurse Professional, Believe and Achieve and Ready for Work.



<AuoQZS>

All EMSP activities supported via unconditional grants from corporate sponsors are subject to the conditions stipulated in EMSP's Code of Conduct

A world without MS



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

This report was designed with reference to best practice guidelines of visual accessibility. We welcome your feedback on the contents and format, and suggestions in making our publications more useful and accessible.

This report was produced by EMSP Communications Coordinator Claudiu Berbecu. Please send your comments to secretariat@emsp.org

graphic design: Jan van Son



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

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