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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

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

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

WORK CAPACITY
82% → 8%

FATIGUE 70%
COGNITIVE DIFFICULTIES 37%
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
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.

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).

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 EUUnetMUS project for standardisation of MS data collection. Whereas EUReMS represented the successful proof of concept in this field, EUUnetMUS is looking to put this concept into practice – in the next phase – by forming a wider coalition of MS registries.

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]

Believe & Achieve

I have no intention to stop working.

Emma Hughes – Believe and Achieve intern

[1] More details in the section Building MS Communities

[2] EUReMS2

[3] EUnetMUS


BELIEVE & ACHIEVE

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.
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]

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]

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]
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.

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]

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

[9] [10] [11]
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.

The ongoing collaboration with our members allowed us to 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]
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.

**Member news**

**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.

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**CONCLUSION**

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

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).

---

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.
Policy report

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.

Employment

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.

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)

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.

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

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

Research

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.

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

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■ 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.

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.

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

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]

Bagno Vignoni, Italy

Working in reception at a luxury hotel and spa is a good fit for Martina Vagnini, 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.

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 someone 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.”

Aversa, Italy

Working as receptionist at a luxury hotel and spa is an improvised and fulfilling option for Martina Vagnini, who had faced years of unemployment and severe depression. Her new job has allowed her to put her skills in interpretation to good use, meet many interesting people, and feel supported by her colleagues and boss. She can now set her crutches aside for long periods of the day and is hopeful for the future.
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 lead 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]

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]

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]

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

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INDIVIDUAL
- Education
- Expertise
- Equality

ORGANISATIONAL
- Experience
- Engagement

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

The 5 ‘E’-s of patient empowerment:

- Education
- Expertise
- Equality
- Experience
- Engagement

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.

MAIN ACHIEVEMENTS

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

[26] [27] [28]
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

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.

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

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

"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
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 audit 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 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 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 accounting policies 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.

Done at Brussels, 27/04/2017

[Signature]

Represented by
Ulrich De Poortere
Registered Auditor - Director
### Income

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership fees</td>
<td>79,278</td>
<td>91,194</td>
<td>84,389</td>
</tr>
<tr>
<td>Corporate core funding</td>
<td>90,000</td>
<td>129,559</td>
<td>193,216</td>
</tr>
<tr>
<td>Project funding</td>
<td>948,474</td>
<td>700,127</td>
<td>812,875</td>
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<tr>
<td>Events</td>
<td>175,381</td>
<td>104,418</td>
<td>110,230</td>
</tr>
<tr>
<td>Other income</td>
<td>17,896</td>
<td>4,137</td>
<td>57,043</td>
</tr>
<tr>
<td>Total income</td>
<td>1,311,029</td>
<td>1,089,852</td>
<td>1,257,753</td>
</tr>
</tbody>
</table>

### Expenditure

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

### Result

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Profits / losses</td>
<td>– 52,829</td>
<td>–36,023</td>
<td>–17,195</td>
</tr>
</tbody>
</table>

2016 Income: total 100% = 1,257,753 €

2016 Project funding: total 100% = 812,875 €

### Assets/Liabilities

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fixed assets</td>
<td>40,482</td>
<td>34,552</td>
<td>32,653</td>
</tr>
<tr>
<td>Current assets</td>
<td>743,790</td>
<td>610,617</td>
<td>620,078</td>
</tr>
<tr>
<td>Total debtors</td>
<td>373,833</td>
<td>328,759</td>
<td>222,029</td>
</tr>
<tr>
<td>Total bank and cash</td>
<td>370,157</td>
<td>281,858</td>
<td>398,049</td>
</tr>
<tr>
<td>Current liabilities</td>
<td>449,173</td>
<td>346,093</td>
<td>370,851</td>
</tr>
<tr>
<td>Trade creditors</td>
<td>121,552</td>
<td>57,850</td>
<td>8,688</td>
</tr>
<tr>
<td>Deferred income</td>
<td>147,500</td>
<td>146,529</td>
<td>227,402</td>
</tr>
<tr>
<td>Accruals &amp; other creditors</td>
<td>93,174</td>
<td>51,553</td>
<td>71,967</td>
</tr>
<tr>
<td>Taxes &amp; social security</td>
<td>86,977</td>
<td>90,161</td>
<td>62,794</td>
</tr>
<tr>
<td>Net current assets / liabilities</td>
<td>294,617</td>
<td>264,524</td>
<td>249,227</td>
</tr>
<tr>
<td>Total Assets</td>
<td>335,099</td>
<td>299,076</td>
<td>281,880</td>
</tr>
</tbody>
</table>

### Funds

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reserves</td>
<td>335,099</td>
<td>299,076</td>
<td>281,880</td>
</tr>
<tr>
<td>Capital</td>
<td>13,585</td>
<td>13,585</td>
<td>13,585</td>
</tr>
<tr>
<td>Reserves b’fwd</td>
<td>354,343</td>
<td>301,514</td>
<td>265,490</td>
</tr>
<tr>
<td>Designated funds – dev. countries</td>
<td>20,000</td>
<td>20,000</td>
<td>20,000</td>
</tr>
<tr>
<td>Profit/Loss</td>
<td>– 52,829</td>
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<td>–17,195</td>
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<tr>
<td>Total Funds</td>
<td>387,927</td>
<td>335,099</td>
<td>281,880</td>
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</table>

all figures in euros

### Income

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<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership fees</td>
<td>79,278</td>
<td>91,194</td>
<td>84,389</td>
</tr>
<tr>
<td>Corporate core funding</td>
<td>90,000</td>
<td>129,559</td>
<td>193,216</td>
</tr>
<tr>
<td>Project funding</td>
<td>948,474</td>
<td>700,127</td>
<td>812,875</td>
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2014–2016 Financial statements

2014–2016 Balance

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<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>1,500,000 €</td>
<td>1,250,000 €</td>
<td>1,000,000 €</td>
</tr>
<tr>
<td>Expenditure</td>
<td>750,000 €</td>
<td>500,000 €</td>
<td>250,000 €</td>
</tr>
<tr>
<td>Result</td>
<td>– 250,000 €</td>
<td>– 250,000 €</td>
<td>– 250,000 €</td>
</tr>
<tr>
<td>Total Funds</td>
<td>1,250,000 €</td>
<td>1,000,000 €</td>
<td>750,000 €</td>
</tr>
<tr>
<td>Net current assets</td>
<td>– 250,000 €</td>
<td>– 250,000 €</td>
<td>– 250,000 €</td>
</tr>
</tbody>
</table>
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.

EMSP Secretariat and Board

SECRETARIAT [38]
Andreea Antonovici
Public Affairs and Event Coordinator
Yves Brand
External Affairs Coordinator
Claudiu Barbece
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 Titley
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
[3] Constantinos Michalakis
Member
[4] Dr Oliver Heinzlef
Member
[5] Bettina Hausmann
Interim EMSP Chief Executive 2016
[6] Torben Damsgaard
Treasurer
[7] Dr Christoph Lotter
MS Society of Switzerland
[8] Klaus Knops
Co-optee
[9] Georgina Carr
Member UK MS Society
[10] Pedro Carrascal
Co-optee MS Society of Spain EME

(sitting from left to right)
Member MS Society of Poland
[12] Anne Winslow
EMSP President
MS Society of Ireland
Member MS Society of Latvia
[14] John Golding
EMSP President 2010-2014
MS Society of Norway
[15] Federica Balzani
Member MS Society of Italy
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), geomgs (Greece), Katharina Ossenberg (Germany). A special ‘thank you’ goes out from kind volunteers such as Daniela Shikova (Bulgaria), Georganina Carr (UK), Hanriet Dog (Ireland), Madeleine Cutting and Jacobo Santamarta Barral (Spain), Marc Lutz (Switzerland), Marta Szantoch (Poland), Pedro Palitzsch Christensen (Denmark), Stanca Potra (Romania) and Labinot Demi (Kosovo). We are also grateful for support and inspiration provided by a number of international MS advocate 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), Demina Paslaru (Romania), Joanna Christoudelidou (Greece), Jana Hlavacova (Czech Republic), Patrik Puljic (Croatia) and Alma 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 Ossenberg (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.

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), Demina Paslaru (Romania), Joanna Christoudelidou (Greece), Jana Hlavacova (Czech Republic), Patrik Puljic (Croatia) and Alma 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 Ossenberg (Germany).

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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.msfgo.at
- MS Society Belarus www.msbelarus.com
- Ligue Nationale Belge de la Sclérose en Plaques www.mls-sep.be
- MS Foundation Bulgaria www.msobnistsvo.org
- Savez Udruženja Gradana Oboželjih od Multiple Skleroze BiH Sarajevo www.suomihobi.ba
- Savez drustava multiple skleroze Hrvatske www.smsh.org
- Unie Roska www.roska.eu
- Sclerosisforeningen www.scleroseforeningen.dk
- Estonian Multiple Sclerosis Society www.smek.ee
- The Finnish MS Society www.ms-ltta.fi
- Ligue Française contre la Sclérose en Plaques www.iflep.fr
- Deutsche Multiple Sklerose Gesellschaft www.dmg.de
- Greek MS Society www.gms.gr
- Hungarian Multiple Sclerosis Society www.smtransag.hu
- MS Felag Islands www.msfelag.is
- MS Society of Ireland www.ms-society.ie
- Associazione Italiana Sclerosi Multipla www.asim.it
- Latvijas Multiplas Sklerozes Asociacija www.mmsa.lv
- Lithuanian Multiple Sclerosis Union www.iss.lt
- Ligue Luxembourgeoise de la Sclérose en Plaques www.msweb.lu
- Multiple Sclerosis Society of Malta www.mssetta.org.mt
- Multiple Scleroze Vereniging Nederland www.msvvereniging.nl
- Multipel Sklerose Forbundet i Norge www.msf.no
- Polskie Towarzystwo Stwardzenia Rozsianego www.potsr.org.pl
- Societé Portugaise de Escleroses Multiplas www.spepm.org
- All Russian Public Organization (RPO) of Disabled PwMS www.ms2002.ru
- Drustvo Multiple Skleroze Srbije e-mail mssetb@bb.rs
- Slovensky Zvaz Sclerosis Multiplex www.szsm.sz.sk
- Združenje Multiple Skleroze Slovenija (ZMSS) www.zdruzenje.si
- Neuroforbundet www.neuroforbundet.se
- Asociación Española de Esclerosis Multiple (AEDEM-COCEMFE) www.aedem.org
- Schweizerische Multiple Sklerose Gesellschaft (9SMSG) www.multiplesklerose.ch
- The Multiple Sclerosis Society of Great Britain and Northern Ireland www.msociety.org.uk

Associate Members

- The Hellenic Federation of Persons with Multiple Sclerosis (HtPsPwMS) www.msis associationhelas.org
- Union de lutte contre la Sclérose en Plaques (UNISEP) www.unisep.org
- Sclerosis Multiplexes Betegrek Orszagos Egyesulete (SMBOE) www.smbole.org
- Federación Española para la Lucha contra la Esclerosis Multiple (FEMP) www.esclerosismutilpe.com
- MS Association ‘Hope’ Zdruzenie Sclerosis Multiplex Nádeje (MSah) www.dokjema.smo.sk
- Multiple Sclerosis (MS) Association of Turkey www.turkysmdeve.org
- National Association of People with Multiple Sclerosis in Hungary
- MS Society of Moldova

Supporters

- Organisation (RPO) of Disabled PwMS www.ms2002.ru
- Drustvo Multiple Skleroze Srbije e-mail mssetb@bb.rs
- Slovensky Zvaz Sclerosis Multiplex www.szsm.sz.sk
- Združenje Multiple Skleroze Slovenija (ZMSS) www.zdruzenje.si
- Neuroforbundet www.neuroforbundet.se
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- Schweizerische Multiple Sklerose Gesellschaft (9SMSG) www.multiplesklerose.ch
- The Multiple Sclerosis Society of Great Britain and Northern Ireland www.msociety.org.uk

EMSP Members
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.

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

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

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