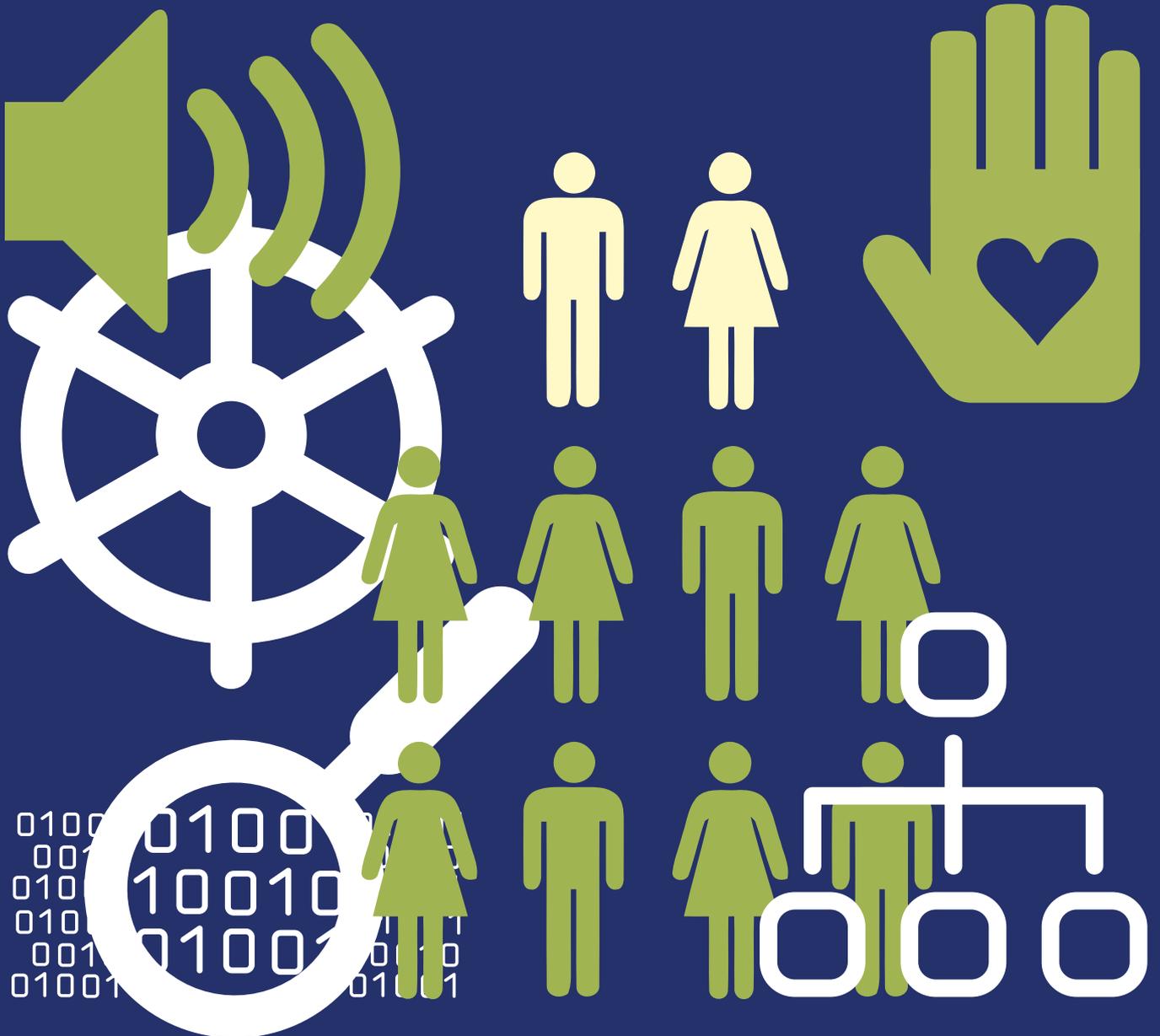


ANNUAL REPORT 2015

Maximising health and wellbeing



A world without MS
www.emsp.org/about-us

- 1 **Facts**
- 2 **Introduction**
- 4 **EMSP Constituency**
- 6 **Main Achievements**
- 8 **Breakdown of Achievements**
- 14 **EMSP Events**
- 20 **Stakeholder Events**
- 26 **Policy Report**
- 28 **Media Report**
- 30 **Financial Report**
- 36 **Organisation**
- 38 **Members**
- 39 **Acknowledgements**
- 40 **Corporate Supporters**



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM



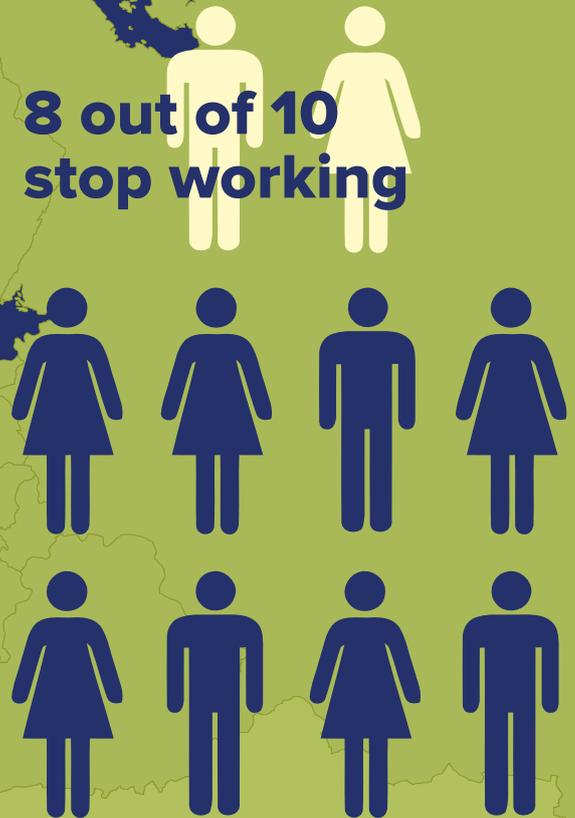
- 700,000 people in Europe have MS
- 70% diagnosed during prime working years
- 9 million people with neuro-degenerative diseases
- € 800 billion = cost of brain conditions in Europe



€ 1,500,000 per minute*
are being spent on brain conditions in Europe

* European Brain Council, *Cost of Brain Diseases in Europe*, 2010

8 out of 10 stop working



- 65% of the 1,300 respondents to our young people with MS survey said they are currently employed or doing voluntary work ...
- ... but 80% usually stop working within 15 years of the onset of the disease

* Work Foundation, *Ready to Work?*, 2011

2015–2020

Introduction

The 2015-2020 Strategic Plan sets out a comprehensive range of specific goals and milestones for EMSP together with a revised expression of our vision for a world without MS. This is backed by an unfailing commitment to improving the quality of life for the more than 700,000 people with MS across Europe.

A fundamental component of the plan is the implementation of the core principles included in Defeating MS Together – the revised Code of Good Practice in MS.

2015 represents the first year of this Strategic Plan and despite the lack of an EU operating grant we did not hold back from setting ambitious targets across each of the priority areas. It is encouraging to note that across almost all domains, tangible progress has been achieved. In some cases this has exceeded expectations. In a few cases work is either ongoing, or will require further attention and focus.

The overall Strategic Plan is supported by new strategies for Fundraising, Advocacy and Communications. A tangible manifestation of the new Communications Strategy includes the launch of the new EMSP website which has received consistently positive feedback from members and other key stakeholders. The Fundraising Strategy has yielded, as intended, progress towards diversification of EMSP funding. The Advocacy Strategy has focused attention on expansion of our burgeoning network of parliamentary and other high level support.

EMSP is able to cover considerably more ground than the modest and cost effective size of its Secretariat would suggest thanks to the versatility of its staff and the expertise and high level of participation of members of its Executive Committee (ExCom).

This has translated in EMSP being able to collaborate with a wide range of organisations that share common goals in relation to MS and other long-term neurological conditions; improving access to high quality care and treatment; and the wider health equalities and disabilities agenda.

During 2015, these have most notably included active participation and contribution to the European Federation of Neurological Associations (EFNA), particularly around the Brain, Mind and Pain MEP Interest Group programme; the European Brain Council (EBC) with an emphasis on their revised programme selection strategy; the European Federation of Pharmaceutical Industries Association (EFPIA) Health Collaboration Summit; the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS); the Multiple Sclerosis International Federation-led World MS Day and the European Medicines Agency Patients and Consumers Working Party.

Given that one of our strategic goals is for EMSP to be the “go-to” organisation for key European decision-makers, the depth and breadth of relevant activities to which EMSP is invited to contribute is both very encouraging and at the same time presents a real challenge in continuing to refine our prioritisation process.



A major feature of the Strategic Plan is to engage more closely and better support our members. To this end, in 2015 members of the EMSP team and Board engaged onsite with members from 14 European countries whilst carrying out a range of advocacy, PR and membership development activities.

This report also provides details about the progress that has been made with each of EMSP's flagship projects. As well as meeting the main objectives and milestones set for 2015, attention was focused on establishing the future direction for the projects and ensuring that plans are in place to secure continuity and sufficient resources for those projects that will be developed during the course of the next few years, and those that will be concluded during this period.

As well as investing in the Secretariat, toward the end of the year, following her resignation after three successful years as CEO, the ExCom turned its attention to the recruitment of a new CEO to take the place of Maggie Alexander. We sincerely thank Maggie for her inspirational leadership. In March 2016, the appointment of organisational management and communications expert Bettina Hausmann as Interim CEO will ensure the right momentum as the organisation takes up the challenge of the 2016 workplan and further progress towards the major strategic goals.

The continuous dedication and extraordinary work of our staff and member organisations, in collaboration with our sister agencies, professional colleagues and supporting organisations is much appreciated.

“A major feature of our Strategic Plan is to engage more closely and better support our members.”

Anne Winslow, *EMSP President*



Anne Winslow
President



Maggie Alexander
Chief Executive (2012-2016)

EMSP

EMSP Constituency

- EMSP is the representative voice of people living with multiple sclerosis (MS) in Europe.
- Since 1989, we have raised awareness and run advocacy projects focused mainly on access to treatment, care and employment for people with MS.
- In 2015, EMSP gained two new members: the national MS societies from Turkey and the Republic of Moldova.
- Our network numbered 40 national MS societies from 35 countries at the end of 2015.
- A priority in EMSP's 2015–2020 Strategic Plan is 'supporting members in their advocacy projects'.



A world without MS
www.emsp.org/about-us



AUSTRIA

- MS Nurse Pro launch

BELGIUM

- MS Nurse Pro launch

ESTONIA

- launch of Under Pressure video documentary
- 25th anniversary

IRELAND

- launch of The Cost of MS study
- MS costs Irish society € 400 million each year

GERMANY

- MS Nurse Pro launch
- New CEO: Susanne Schönemaier

POLAND

- EMSP 2015 Spring Conference
- 25th anniversary
- MS Nurse Pro launch

SPAIN

- most answers for Voice of MS Patients survey

SWITZERLAND

- MS Nurse Pro launch

MOLDOVA

- New member

TURKEY

- New member

TURKEY

NEW MEMBER

EMSP

Main Achievements

BETTER DATA FOR IMPROVED OUTCOMES

Upon successfully building a cross-border network of MS data registries – collections of centralised patient information – we worked towards its expansion and its potential to enhance collaboration with regulatory bodies. We also conducted our own patient surveys while supporting studies on key topics such as brain health and the cost of chronic conditions.

KEEPING PEOPLE IN WORK

We delivered on our commitment to young people with MS by creating a paid internship scheme supported by our corporate partners. Winning an EU grant also allowed us to go further and produce a well-received Pact aiming to boost employment for people with multiple sclerosis and other neurodegenerative diseases.



A collaborative initiative to improve MS research and policy across Europe

Better Outcomes with Better Data

www.eurems.eu



B&A
Believe & Achieve

Paving the Path to Participation





ACCESS TO HIGH QUALITY CARE

Throughout 2015 we stepped up our efforts in supporting the specialisation of MS nurses, who are key workers in the provision of care to people with multiple sclerosis. This resulted in thousands of nurses furthering their education in numerous European countries, and beyond.

AWARENESS-RAISING

We reshaped our mission and vision by producing a new Strategic Plan and refreshing our Communications and Advocacy strategies. Two concrete deliverables were the re-launch of our website and the establishment of a Young People's Network. Going forward, a core priority is to bring MS voices together.



available languages



MS advocates Martina Vagini (left) and Shana Pezaro



EUReMS

Better data for improved outcomes



The conclusion of our European Register for MS (EUReMS) project at end of 2014 gave EMSP the opportunity to focus on how to expand the network of MS registries solidified during this four-year initiative. Together with our partners, we identified as main priorities

- 1 collaboration between the registry network and regulatory bodies such as the European Medicines Agency (EMA) and health technology assessment (HTA) authorities, and
- 2 the focus on collection and analysis of patient-centered data.

Between April and September 2015, we conducted the Voice of MS Patients survey (PEP), a comprehensive questionnaire designed to help us and other health stakeholders better understand the specific needs of people with MS. We were glad to report nearly 3,000 respondents. The results will be made public in the first half of 2016.

Towards the end of 2015, EMSP started to centralise data for our MS Barometer – a comparative report comprising of MS data collected by our member societies. To be published in 2016, this will be a revamped edition (the fifth since 2008) aiming to obtain more detailed information from our member societies on MS management across Europe.

Make YOUR VOICE count!

THE VOICE OF MS PATIENTS
Only 10 minutes!

If you are a person with MS, we invite you to complete this survey and tell us about your situation.

The survey is open until the 30th September and available in 28 languages.

Not just another survey: Help us better understand MS

EMSP's aim with this survey is to find new solutions for the challenges facing people with multiple sclerosis (MS) in Europe.

This is not just a standard questionnaire. It is meant to help us better understand the specific needs of people with MS.

We will use the survey results to:

- 1) Encourage policy-makers and other stakeholders to push for concrete solutions to improve the quality of life for people with MS.
- 2) Identify better ways of managing MS and contribute to the search for a cure.

www.emsp.org/tools/ms-patient-survey

Data protection
The survey is anonymous. Your privacy will be respected. The individual data gathered through the survey will be stored and analysed by the Goettingen University (Germany) and will only be accessible to EMSP. Only the results of the survey analysis will be published.

Transparency
The survey is funded by TEVA, in accordance with EMSP's Code of Conduct which safeguards the best interest of all individuals.

EMSP represents the voice of 700,000 MS patients in 36 countries and works to achieve its goals of high quality equitable treatment and support for them.

www.emsp.org

Because we believe in close collaborations and strong partnerships, we added our support to a number of external initiatives. Among them: the report launched in October 2015 by the MS Brain Health initiative: MS Time Matters, championed by neurologist Gavin Giovannoni; and the ongoing Cost of Illness study, carried out by health economist Gisela Kobelt.

Four B&A interns conveyed their experience through video messages viewable on EMSP's YouTube account 'emspvideos'.

video screenshots clockwise from top left
Emma Hughes
Sorin Nicu
Anna Zaghi
Ioanna Christodoulidou

Our Believe & Achieve (B&A) project, coordinated by MS advocate Emma Rogan, managed to send a strong message to health stakeholders in Europe and beyond: young people with multiple sclerosis are capable and willing to work.

B&A Believe & Achieve



During 2015, B&A enabled seven people with MS in their 20s and 30s to access paid employment with our corporate partners Novartis and Biogen. In doing so, we engaged MS communities in six European countries: the Czech Republic, Greece, Ireland, Italy, Portugal and Spain.

Paving the Path to Participation



With the help of an EU grant for our Paving the Path to Participation project, we were able to launch and promote an European Employment Pact for people with MS and other neurodegenerative diseases. We promoted the Pact in the European Parliament between March and May 2015, gaining support from more than 50 Members of the European Parliament and a significant number of patient organisations and advocates.

Under Pressure



2015 marked the successful completion of the video documentaries gallery from our multimedia Under Pressure (UP) project, which artistically captures the many different aspects of living with MS across Europe. In March 2015, our Estonian MS Society launched the last of the UP documentaries – telling the stories of three people with MS in Estonia. Find all 600 UP pictures and 9 videos at www.underpressureproject.eu.

YouTube channel

📺 Captures from 'Under Pressure Estonia – Short documentary video on living with MS'.

VIDEO LURDES R. BASOLÍ

Resilience is the common attitude towards life of the main characters from this short documentary.

Despite the obstacles, they believe they are now better people than before having MS.

Photo gallery

📍 Armelle Bugand
Paris, France
02/2012
PHOTO LURDES R. BASOLÍ

📍 Martina Vagini
Buonconvento, Italy
02/2012
PHOTO CARLOS SPOTTORNO

📍 Helga Káradóttir
and Jón Þórðarson
Reykjavik, Iceland
10/2011,
PHOTO FERNANDO MOLERES





MS Nurse Professional



EMSP's MS Nurse Professional online training tool enjoyed its most successful year in 2015. We were able to work together with our national members and launch the project in five new countries: Austria, Belgium, Germany, Poland and Switzerland. More than 2,500 MS nurses were registered at the summit of 2015. The programme also gained global appeal, with participating nurses coming from countries as geographically spread as the United States, Australia, India, South Africa and Saudi Arabia.

How does MS Nurse PROfessional work?

Online course setting a benchmark for MS nursing practice and nursing care across Europe



There are five distinct modules available. The modular curriculum focuses on core competencies of MS nurses including advocacy, health education, symptom and treatment management

- 
Understanding MS
- 
Clinical Presentation
- 
Diagnosis and Assessment
- 
Treatment
- 
Care and Support
- 
COMING SOON

Currently available in EIGHT languages



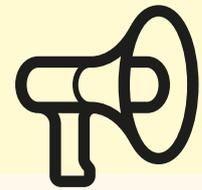
MS Nurse PROfessional is a widely endorsed and accredited programme both at a local and European level

Programme includes an online accreditation test of which a pass mark of 75% or more must be obtained to be eligible for the certificate of credit



WHY IS MS NURSE PRO IMPORTANT?

Nurses remain pivotal in promoting independence and self-care for people with MS. The project was developed as a result of the MS-Need survey conducted in 2009, which highlighted the disparity of access, availability and standards of specialised MS nursing care across Europe. Find more on the dedicated website www.msnursepro.org



Online publications have become a key tool in awareness raising, and EMSP fully acknowledged this trend by re-launching emsp.org in September 2015.

But raising awareness takes so much more than web tools. It takes people. This is why EMSP has gathered a number of impressive MS advocates around its new Young People's Network. The initiative kicked-off during our 2015 Spring Conference in Warsaw under the coordination of two remarkable MS champions: Shana Pezaro and Trishna Bharadia, pictured above, in the centre of the image.

The new website better responds to member needs and stakeholder requirements: the link with target audiences is straightforward, EMSP's visual ID is embedded and easily distinguishable, project information is one click away and the main documents are centralised in one section.



HIGHLIGHTS

2015 Spring Conference



TWO NEW MEMBERS

EMSP's Annual General Meeting meeting which preceded the Conference approved the request of two national MS societies to become associated members: the Turkish MS Society and the MS Society of the Republic of Moldova. They brought the total number of MS organisations under EMSP's umbrella to 40 societies in 35 European countries.



EMSP's 2015 Spring Conference was organised with the great support of the Polish MS Society (PTSR), which celebrated its 25th anniversary.

WORLD MS DAY MESSAGE

EMSP's 2015 Annual Conference was an official World MS Day event (www.worldmsday.org), furthering the collaboration between our organisation and the MS International Federation (MSIF). In preparation for World MS Day 2015, EMSP's former President and powerful MS advocate John Golding (pictured) recorded a video* message emphasising the importance of striving for better ACCESS for people with multiple sclerosis: access to healthcare, jobs and treatment.

*the video is available on our 'emspvideos' YouTube channel



👤 Anne Winslow *EMSP President*
👤 FROM LEFT TO RIGHT
Fabio Carlucci and Ioanna Christodoulidou *B&A Interns*,
Antonella Moretti *former EMSP Vice-President*,
Anna Zaghi *B&A Intern* and *MS advocate Shana Pezaro*

YOUNG PEOPLE'S CONFERENCE

EMSP organised a parallel session involving young people with MS from across Europe: the Young People's Conference.

This special event tackled the important topic of identity in relation to multiple sclerosis, benefiting from the contribution of three outstanding MS advocates: Trishna Bharadia, George Pepper and Shana Pezaro.

COOKING SHOW

Our Spring Conference also featured for the first time an interactive cooking demonstration and workshop where participants had the chance to learn how to prepare tasty, healthy food which can enhance their well-being.

More information on our 2015 Conference is available on www.emsp.org under EMSP News



HIGHLIGHTS

2015 Spring Conference



🕒 FROM LEFT TO RIGHT
EMSP CEO Maggie Alexander,
EMSP President Anne Winslow and
MS advocate Alina Popa
👥 EMSP staff together with the
enthusiastic Young People's Network



MS advocacy in the European Parliament



EMSP organised two Parliament events in 2015, on 24 March and 26 May to present and raise support for our European Employment Pact.

THE PACT

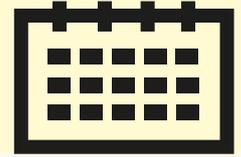
Supporters signed the Pact for improvements in employment policy, recruitment, equal opportunities, training and awareness in the workplace. Some of those requested: reasonable accommodations, flexible hours, rest areas, accessibility, and return-to-work policies.



EMSP asked fellow patient organisations, national and European decision-makers and employers to support the Pact.



The events were supported by Members of the European Parliament Adam Kosa (pictured), Rosa Estaras-Ferragut and Jeroen Lenaers, among others.



Member outreach

MARCH

Our Estonian MS Society (ESMUL) marked their 24th anniversary with a multi-stakeholder conference organised in Tallinn, on 20 March.

APRIL

EMSP CEO Maggie Alexander visited the Finnish Neuro Society to exchange information and discuss concrete ideas for future collaboration between our two organisations.

OCTOBER

EMSP and the organisations representing multiple sclerosis societies in Belgium launched the French and Flemish language training modules of MS Nurse Professional, our educational programme dedicated to European MS nurses.

EMSP President Anne Winslow attended the 25th anniversary of the Latvian MS Society and reinforced

MAY

EMSP and our German MS Society (DMSG) collaborated for the creation and launch of an interactive online tool for people with multiple sclerosis: *Treating MS*. English version available on our website: www.emsp.org/tools/treating-ms/.

SEPTEMBER

EMSP addressed a letter to the Polish Ministry of Health to ask for support in the area of access to innovative therapies.

JULY

EMSP President Anne Winslow, CEO Maggie Alexander, and Programme Manager Elisabeth Kasilingam had a joint meeting with Ed Holloway from the UK MS Society to look into areas where EMSP could prioritise / deprioritise.

NOVEMBER

EMSP's CEO Maggie Alexander was present for a special event – *Music at the Brain* – organised by the Maltese MS Society at national level. Furthermore, she discussed the possibility to launch *MS Nurse Pro* in Malta.

EMSP addressed a letter to the Bulgarian Ministry of Health expressing high concern about the limited treatment options available.

The German MS Society's (DMSG) long-serving Secretary General Dorothea Pitschnau-Michel retired, being replaced in the role by Susanne Schönemeier.

cooperation in order to best represent the interests of people with MS, both at national and European level.

EMSP's member society MS Ireland has launched a new report – *Societal Cost of MS* – which highlights the need of tackling the huge financial burden inflicted by MS on those affected and their families.

stakeholders

ECTRIMS 2015

Over 9,000 participants from 96 countries attended the 31st Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held between 6 and 10 October in Barcelona, Spain.

As in previous editions, EMSP had a booth installed in the exhibition hall and was represented by speakers and delegates at presentations and scientific sessions.

Top on our ECTRIMS agenda was the promotion of the MS Nurse Pro online training tool improving the specialisation of MS Nurses.



EMSP's representatives at ECTRIMS 2015 took this opportunity to visit the MS Centre of Catalonia, Cemcat, and reconnect with the crew members of the Oceans of Hope boat which has circumnavigated the world manned by people with multiple sclerosis.



ECTRIMS 2015 FIGURES

150 Chairs & Speakers

SCIENTIFIC PROGRAMME

1,889 Abstracts

94 Orals

1,053 Poster

247 Poster

495 Rejected

EXHIBITION & SPONSORING

1,818 m² Exhibition with 42 Exhibitors

11 Satellite Symposia

APPLICATION

3,161 Congress mobile app users

WEBSTATISTICS

153,684 Visits

415,724 Page views

ECTRIMS @ SOCIAL MEDIA

5,222 Tweets

1,044 Contributors

2,038,568 Audience



📍 The ECTRIMS 2015 exhibition hall

🏥 The MS centre of Catalonia, CEMCAT



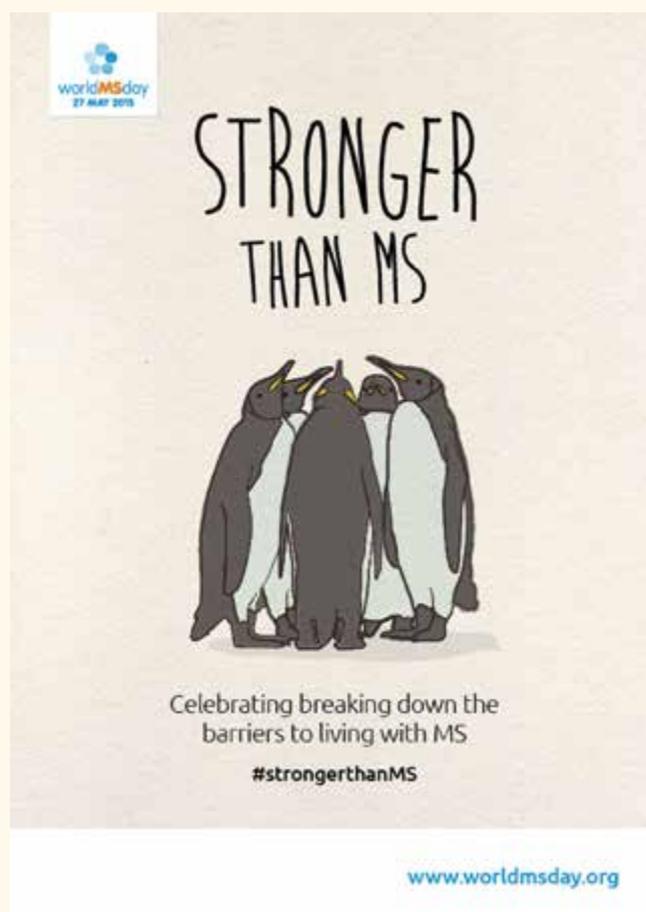
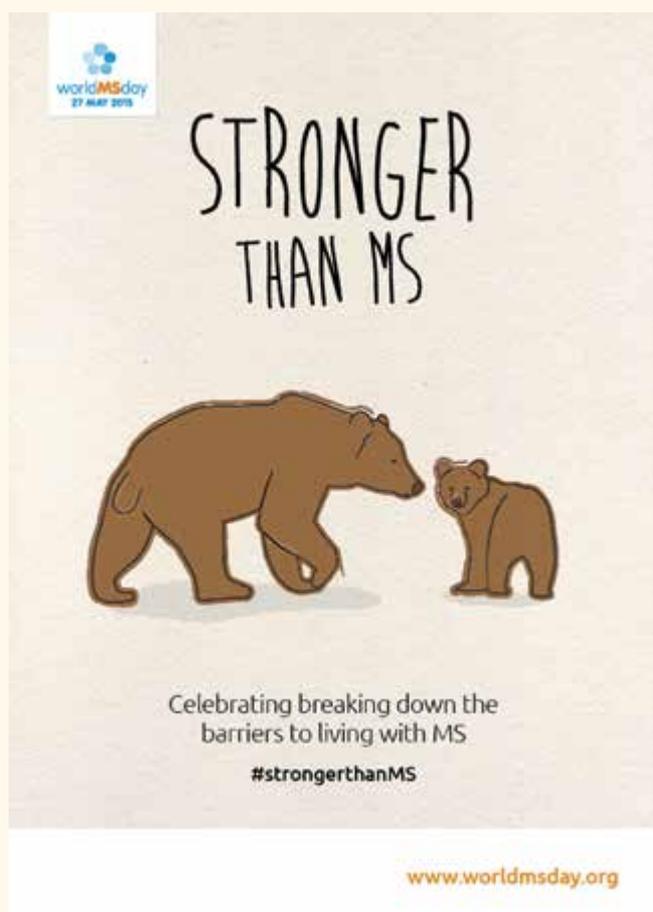


#strongerthanms

Our partners from the Multiple Sclerosis International Federation (MSIF) dedicated the theme of their yearly global awareness-raising campaign World MS Day to access and breaking down the barriers to living with MS.

The campaign motto was 'Stronger than MS' and EMSP joined in by branding our Spring Conference as a World MS Day event.

EMSP's Poland Conference was among an estimated **275 World MS Day events in 67 countries worldwide.**



worldMSday
27 MAY 2015



Our partners from the European Federation of Neurological Associations (EFNA) organised an Advocacy Awards ceremony on 13 October, in Brussels, Belgium.

EMSP'S YOUNG PEOPLE'S REPRESENTATIVE SHANA PEZARO WAS AMONG THE WINNERS.

Upon receiving the award for her outstanding work on multiple sclerosis (MS) advocacy, Shana Pezaro stressed that the daily lives of people with chronic conditions such as MS are affected in many different ways

The other three awards handed out at EFNA's event went to: Jeroen de Schepper for raising awareness of Huntington's disease, Prof Cristina Tassorelli for her research in headache disorders and former Member of the European Parliament Gay Mitchell for his support for epilepsy advocacy.



“On top of access to medication, rehabilitation, welfare, and social care, there are other problems which massively impact our lives: identity, sexuality, body image, social isolation and relationships. And crucially: the matter of having a professional career.” SHANA PEZARO



During 2015, EMSP supported the launch of three new European Parliament Health Interest Groups, created to improve the representation of patients' voice in the EU policy-making process.



WHAT IS AN INTEREST GROUP?

Interest Groups are informal cross-party, cross-country groups, providing a forum for debate and initiating policy action. They bring together Members of the European Parliament (MEPs) with a common interest in a specific policy field to discuss European policy development and take initiatives that can lead to or influence policy developments.

ACCESS TO HEALTHCARE

MEPs launched on 27 January the Access to Healthcare Interest Group, focused on ensuring more commitment from EU institutions for the patients' cause.

BRAIN, MIND AND PAIN

EMSP's partners from the European Federation of Neurological Associations (EFNA) joined by the European Pain Alliance have launched on 24 February the Interest Group on Brain, Mind and Pain. Currently, 1 in 3 Europeans are affected by a brain disorder and 1 in 5 by chronic pain. These figures are rising due to the ageing population.

EUROPEAN PATIENTS' RIGHTS AND CROSS-BORDER HEALTHCARE

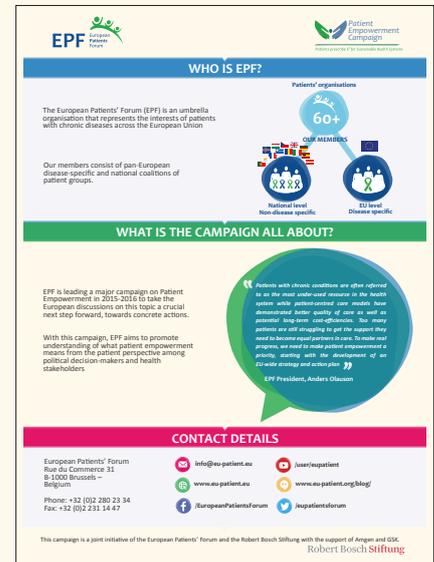
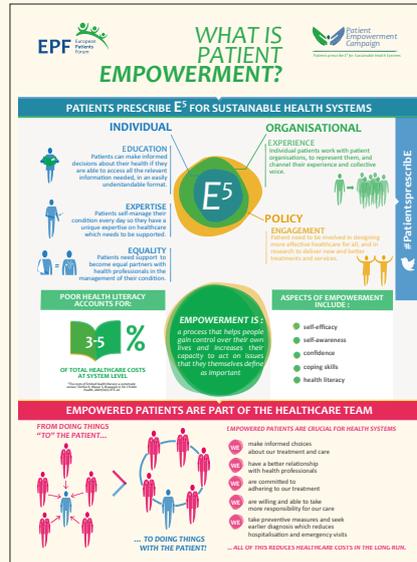
A group of 20 MEPs have launched on 2 December an MEP Interest Group on "European Patients' Rights and Cross-Border Healthcare" following the request of around 100 civic and patient organisations to recognise the importance of citizens' initiatives in policy-making.

stakeholders

EPF: Patient Empowerment



EMSP's partners from the European Patients' Forum (EPF) launched a major one-year campaign on Patient Empowerment in May 2015. The objective is to promote understanding of patient empowerment from the patient perspective among political decision-makers and health stakeholders.



stakeholders

EBC: Call to Action for Brain Health



MEP Jerzy Buzek, an EBC Honorary Member, was present at the event and stated that tackling brain disorders requires strategic thinking, model solutions and exchange of good practices.

EMSP's partners from the European Brain Council (EBC) launched a Call to Action for the creation of a European plan, as well as separate national plans to address brain health.

"I agree with the recommendation of EBC – each member state should develop a comprehensive strategy for brain diseases. It would also be very important to have a general European strategy." MEP JERZY BUZEK

This initiative was welcomed by a mixed audience of policymakers, patient advocates and industry partners present at the launch event organised on 17 November, in Brussels, Belgium.



policy

EMSP Policy Report

EMSP has a strong position on the European health scene – by speaking with one voice on behalf of more than 700,000 people with MS in Europe, EMSP acts as an “interface” between its national members and European bodies such as the European Parliament, the European Commission, the European Medicines Agency, the European Federation of Neurological Associations and many other European stakeholders. The network we have created reflects our multiple collaborations and recognition we enjoy from the scientific community.

EMSP’s work is shaped by its over-arching goal of involving people with MS in all areas of EU policy, programmes and projects with an impact on health and disability. EMSP and its partners will work closely to provide expert policy support and use MS as an exemplar of long-term, disabling, neurological conditions.



*By Andreea Antonovici
(Public Affairs Coordinator)
and Yves Brand (External
Affairs Coordinator)*





In 2015, considerable progress was made in the following areas:

IMPROVING ACCESS TO TREATMENT AND THERAPY FOR PEOPLE WITH MS

EMSP continued to represent the voice of patients affected by long-term neurological conditions in relevant health fora (e.g. EMA, EUnetHTA). We also continued to expand our current projects designed to ensure that the quality of life of people with MS will improve.

SUPPORTING RESEARCH INITIATIVES IN LINE WITH PERSON-CENTRED PRIORITIES

EMSP continued to develop and increase its role in the political arena as well as within the scientific and healthcare community through reinforced partnerships and development of relevant alliances.

BREAKING DOWN THE BARRIERS ON ACCESS TO EMPLOYMENT FOR PEOPLE WITH MS

In 2015, EMSP launched the Pact of Employment for People with MS and a related Call to Action to raise awareness of neurodegenerative diseases in the workplace and support access to meaningful employment.

INCREASING COOPERATION

EMSP worked with patients, healthcare professionals and policy-makers to improve responses to neurodegenerative and chronic conditions. EMSP also maintained its involvement in the EUnetHTA project, which focuses on collaboration with patients within improved health technology assessment (HTA) processes.

media

EMSP Media Report



EMSP EMPLOYMENT PACT COVERAGE

Our Employment Pact for people with MS and other neurodegenerative diseases received a two-page report in the EU Neurological Review, in the summer 2015 edition.



Breaking the barriers: A European Employment Pact for Multiple Sclerosis

In March this year, the European Multiple Sclerosis Platform (EMSP) launched its *European Employment Pact* for people with multiple sclerosis (MS) and other neurodegenerative conditions. A Call to Action for the *Pact* follows in May. EMSP is inviting all relevant stakeholders, from businesses to decision-makers, to pledge support.

Find the Pact at www.emsp.org.

Why support the Pact?

- Business leaders** - to demonstrate their commitment for creating a healthy workplace for all. Health-focused workplace policies improve an individual's quality of life while promoting increased productivity.
- Decision-makers** - to prove their resolve in tackling key challenges such as youth unemployment, workplace discrimination and health inequalities.
- Patient organisations and other NGOs** - to enable the creation of a cross-border movement dedicated to improving employment for people with disabilities.

"Discrimination is a very important issue because people with MS are at a disadvantage in accessing employment. There is lack of active policies which can ensure that these people remain at work."

MEP Rosa Estarás-Ferragut (left) next to EMSP's CEO Maggie Alexander, 24 March 2015, EMSP's Pact launch in the European Parliament.

The European Employment Pact is part of EMSP's EU-funded project Paving the Path to Participation.

emsp
EUROPEAN MULTIPLE SCLEROSIS PLATFORM

65% from 1,300 respondents to EMSP's 2014 survey for young people with MS said they are employed or doing voluntary work...

...but **80%** usually stop working within 15 years of the onset of the disease

700,000 people currently live with MS in Europe

70% are diagnosed during their prime working years

EMSP IN THE PARLIAMENT MAGAZINE

EMSP published an advert focused on our Pact for Employment in the May 2015 edition of *The Parliament Magazine*. The publication goes out monthly to thousands of stakeholders within the European Union, from Members of the European Parliament (MEPs) to trade organisations.



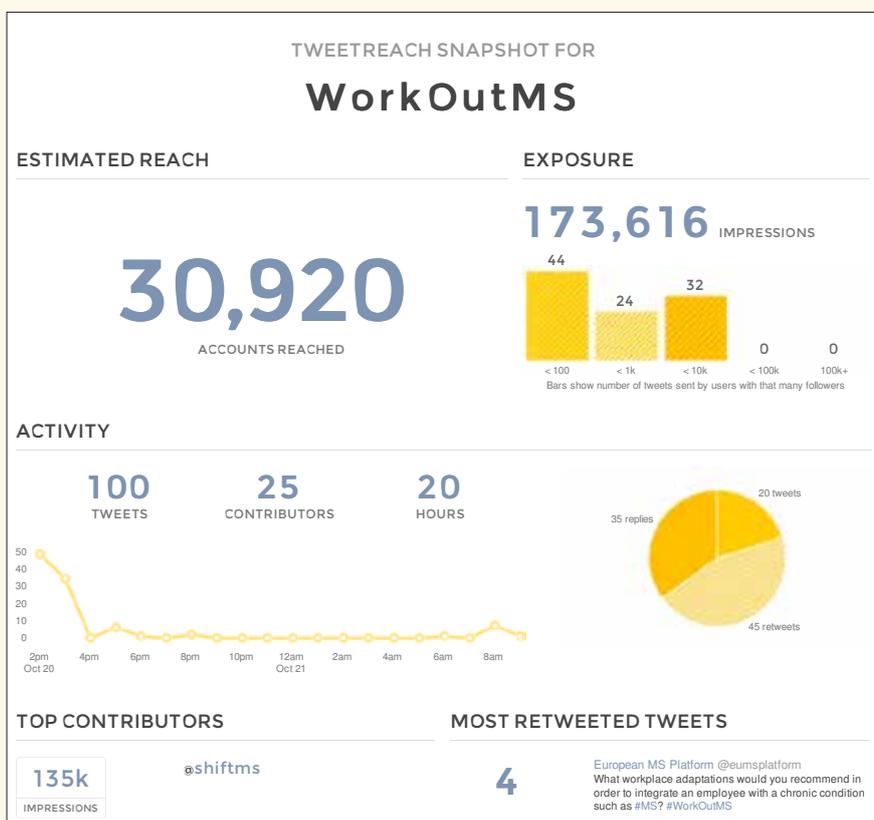
150,000 PEOPLE REACHED ON SOCIAL MEDIA

Between September and October 2015, EMSP carried out a social media 'Thunderclap' campaign in order to increase awareness of the MS Nurse Pro project – aiming to promote the specialisation of MS nurses across Europe. Concluded during ECRIMS 2015, the Thunderclap reached over 150,000 people on Twitter and Facebook.



END OF YEAR STATS

www.emsp.org
1,600 users
Facebook
1,500 pages likes
Twitter
1,100 followers



#WORKOUTMS

In October 2015, EMSP marked another social media breakthrough: our Tweet Chat titled #WorkOutMS attracted great interest from our followers generating a total outreach of over 30,000 people.

finances

Treasurer's Report

The results for the year ending on December 2015 show a deficit of € 36,023 against a budget deficit of € 15,530. The original budget for 2015 that was approved by Council showed a surplus of € 4,470, but during the year the Executive Committee approved an amended budget showing a reduction of € 20,000 against forecast income.

The support of our members has enabled us to mitigate the challenging circumstances, and whilst the final deficit is a little more than what was planned, the staff were able to reduce expenditure where necessary and concentrate on maintaining relationships with our funders to ensure that activity with new and planned projects was not disrupted.

When setting the budget for the year, the expenditure is calculated against the income that we expect to receive – if the income target is not reached, certain activities are delayed. Some expenditure against projects will take place in 2016.

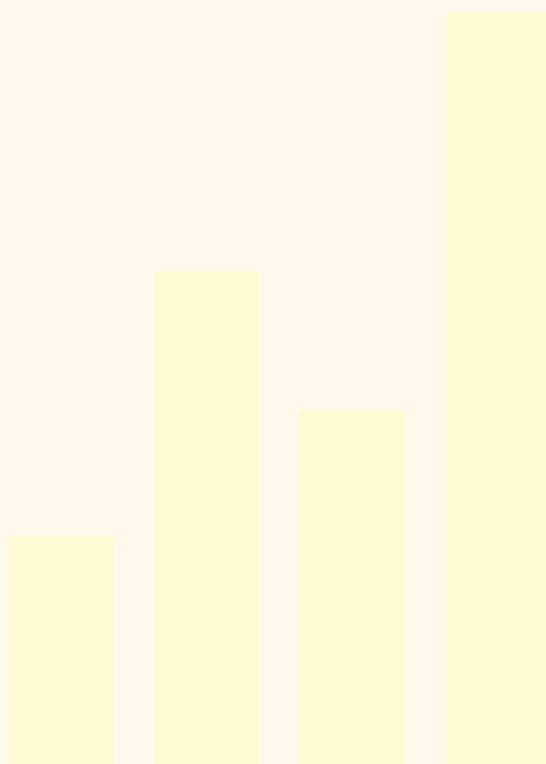
The summary of project expenditure shows that 65% of our total income was spent on activities relating to the varied projects, with the remainder on core activities and events.

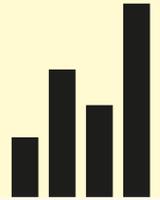
Staff costs show a total increase of 7% against the previous year, primarily due to the cost of employer contributions to the pension scheme that was introduced midway during the year in 2014.

Our planning for 2016 includes various new projects that are dependent on funding, and we have several large fundraising bids in the pipeline.

In the meantime we are concentrating our efforts on sustaining the level of income required for the year to ensure our reserves and support our membership.

Torben Damsgaard – *Treasurer*
April 2016





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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 31/12/2015
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 31/12/2015, 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 31/12/2015, which show a balance sheet total of € 746.509,90 and a loss for the year of € 36.023,10.

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.



Pagina 1 van 3

finances

Auditor's Report cntd.



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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.

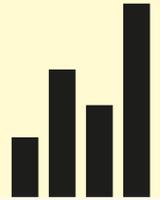
We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

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 31/12/2015, and of the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.



Pagina 2 van 3



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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 8th 2016

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



Pagina 3 van 3

finances

2015 Financial Statements

Income	2013	2014	2015
Membership fees	79,553	79,278	91,141
Corporate core funding	110,000	90,000	129,559
EU Operating grant	278,417	–	–
Member donations	–	–	60,470
Project funding	862,918	948,474	700,127
Events	137,250	175,381	104,418
Other income	5,780	17,896	4,137
Total income	1,473,918	1,311,029	1,089,852

Expenditure	2013	2014	2015
Staff costs	498,741	592,971	651,617
External fees	77,743	34,914	49,912
Office and other costs	101,614	132,662	90,273
Events	122,376	158,695	70,420
Project expenditure	614,773	444,616	263,653
Total expenditure	1,415,247	1,363,858	1,125,875

Result	2013	2014	2015
Profit/Loss for the period	58,671	– 52,829	–36,023

all figures in euros

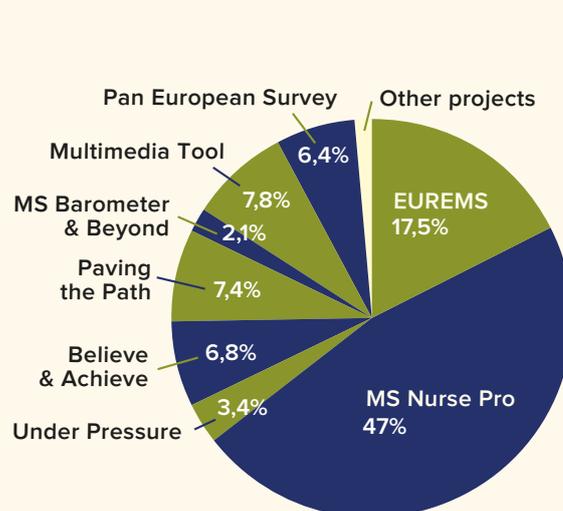
2015 Income

total 100% = 1,089,852 €



2015 Project funding

total 100% = 700,127 €



finances

2015 Balance sheet



Assets/Liabilities

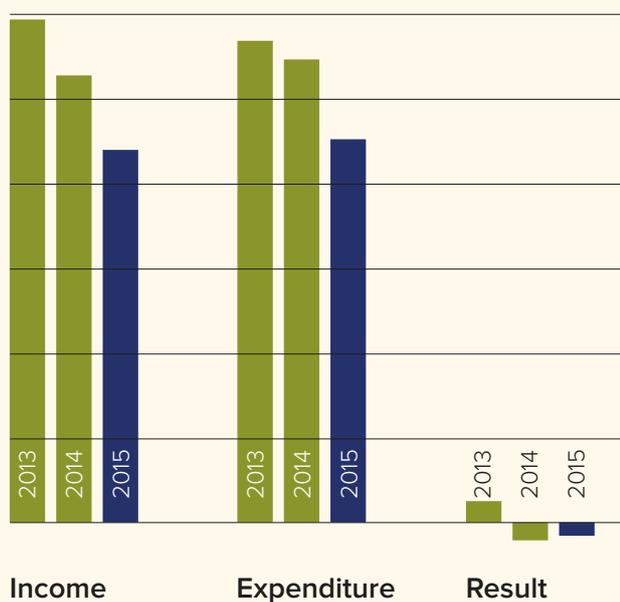
	2013	2014	2015
Fixed assets	41,727	40,482	34,552
Current assets	582,183	743,790	610,617
Total debtors	319,660	373,633	328,759
Total bank and cash	262,523	370,157	281,858
Current liabilities	235,983	449,173	346,093
Trade creditors	12,846	121,552	57,850
Deferred income	111,078	147,500	146,529
Accruals & other creditors	58,912	93,174	51,553
Taxes & social security	53,147	86,977	90,161
<i>Net current assets / (Liabilities)</i>	<i>346,200</i>	<i>294,617</i>	<i>264,524</i>
Total Assets	387,927	335,099	299,076

Funds

	2013	2014	2015
Reserves	387,927	335,099	299,076
Capital	13,585	13,585	13,585
Reserves b'fwd	295,671	354,343	301,514
Designated funds – dev. countries	20,000	20,000	20,000
Profit/Loss	58,671	– 52,829	–36,023
Total Funds	387,927	335,099	299,076

all figures in euros

2013–2015 Financial statements



2013–2015 Balance



EMSP Executive committee

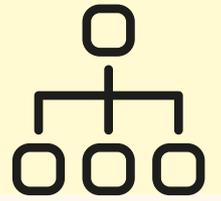
EMSP has a very experienced Executive Committee which contributes to the full range of governance activities. The ExCom Officers Group in particular provides a link, when necessary, to a rapid response decision-making body and essential support for the CEO in maximising use of the organisation's resources.

Executive Committee

- [1] **Christoph Lotter**
EMSP Vice-President
Swiss MS Society
- [2] **Magdalena Fac-Skhirtladze**
Member Polish MS Society
- [3] **Pedro Carrascal**
Co-optee MS Society of Spain (EME)
- [4] **John Golding**
EMSP President 2010-2014
MS Society of Norway
- [5] **Maggie Alexander**
EMSP Chief Executive
2012-2016
- [6] **Antonella Moretti**
EMSP Vice-President
2014-2015
- [7] **Anne Winslow**
EMSP President
MS Society of Ireland
- [8] **Torben Damsgaard**
Treasurer
MS Society of Denmark

- [9] **Shana Pezaro**
EMSP Young People's Representative
missing from picture
- [10] **Maija Pontaga**
Member
MS Society of Latvia
- [11] **Klaus Knops**
Co-optee
MS Society of Belgium
- [12] **Dr Olivier Heinzlef**
Member
MS Society of France (LFSP)
- Ed Holloway**
Member 2014-2015
UK MS Society
- Constantinos Michalakis**
Member
MS Society of Greece (GMSS)
- Peer Baneke**
Co-optee
MS International Federation (MSIF)





EMSP Team

The people who work at EMSP make up a dedicated, hard-working, committed and versatile team and their invaluable contribution to meeting all the key milestones for the year is gratefully acknowledged. EMSP also thanks the volunteers who gave freely of their time and expertise in helping us to deliver our objectives.

EMSP Secretariat

- [1] Žilvinas Gavėnas
IT Coordinator
- [2] Andreea Antonovici
Public Affairs Coordinator
- [3] Yves Brand
External Affairs Coordinator
- [4] Maggie Alexander
Chief Executive 2012–2016

- [5] Christoph Thalheim
Deputy CEO and Director of External Affairs
- [6] Elisabeth Kasilingam
Programme Manager
- [7] Claudiu Berbece
Communications Coordinator

- missing from picture*
- Emma Rogan**
Project Coordinator
- Tsveta Schyns-Liharska**
Scientific Project Coordinator
UNTIL DECEMBER 2015
- Ralf Lehmsberg**
Finance and Office Manager
UNTIL APRIL 2015

- External Consultants**
- Bettina Hausmann**
Senior Communications Adviser
- Susan Tilley**
Financial Adviser

SECRETARIAT

CEO

EUReMS Scientific Project





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.sdmsih.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 Sclerosis 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

Drustvo Multiple
Skleroze Srbiie
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
Orszagos 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

Turkish MS Society

MS Society of the
Republic of Moldova



Acknowledgements

The success and impact of EMSP's work is built on the effective partnerships, cooperative working and close collaborations with a very wide range of stakeholders whose contributions are gratefully acknowledged. In particular, we would like to recognise and note our appreciation for the support we have received from the following groups:

EMSP Member organisations

2015 has seen a consistent two-way flow of information, expertise and good practice from the majority of our 40 member societies. EMSP has supported members in a number of advocacy campaigns for access to optimal treatment and services, and via EMSP members have generously shared their learning and advocacy tools with others in similar positions. EMSP members have also been enthusiastic contributors to the key surveys and consultations that are crucial for EMSP's plans and priorities.

Volunteers and MS advocates

We especially recognise the great support and inspiration provided by a number of international MS advocates – Lori Schneider (photo), Trishna Bharadia, George



MS advocate Lori Schneider, the first person with multiple sclerosis to reach the summit of Mount Everest

Pepper and Birgit Bauer among them. We also like to express our appreciation for the tireless help offered by young Polish volunteers at our 2015 Spring Conference in Warsaw.

Corporate supporters

EMSP has continued to benefit from the unconditional support from corporate partners who between them have provided part-funding for each of EMSP's key projects including the MS Nurse Professional, Believe and Achieve, the Voice of MS Patients survey and Under Pressure.

EMSP Executive Committee (ExCom)

EMSP has a very experienced Executive Committee which contributes to the full range of governance activities.

EMSP Team

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

Partner organisations

EMSP's reach and impact is greatly enhanced by the close cooperation with a number of other European organisations that share complimentary aspirations and values and which include: Rehabilitation in Multiple Sclerosis (RIMS); MS International Federation (MSIF); European Patients' Forum (EPF); European Federation of Neurological Associations (EFNA); European Brain Council (EBC); EUneHTA; European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) and the European Disability Forum (EDF).

Corporate supporters



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



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

This report was compiled by
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Claudiu Berbece

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This report has been designed
with reference to best practice
guidelines of visual accessibility.
We welcome your feedback on
the contents and design and
suggestions for ways of making
our publications more useful
and accessible.

Please email your comments to
claudiu.berbece@emsp.org



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MULTIPLE SCLEROSIS
PLATFORM

European Multiple Sclerosis Platform aisbl

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