

# The European MS Platform: turning policy into actions!

ANNUAL REPORT 2017





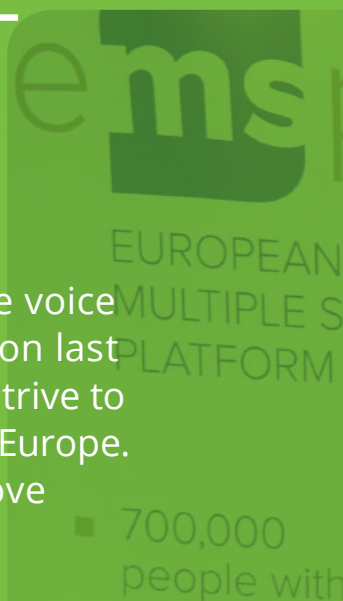
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# FOREWORD: BY PRESIDENT AND MANAGING DIRECTOR

**It is our pleasure to present to you our 2017 Annual Report.**

Over the past 29 years, we have been privileged to represent the voice of 700,000+ people affected by Multiple Sclerosis (MS). Building on last year's efforts in consolidating a strong European MS network, we strive to actively respond to the challenges faced by people with MS across Europe. This year, we've worked hard to use our existing networks to move forward and advance our work from advocacy to action.



In 2017, the health community along with civil society organizations experienced a setback. We saw the health agenda move down the priority list across Europe. We immediately recognized the urgent need to join forces with our partners and members to strengthen our voices to bring health back on the political agenda. Despite these challenges, we marched on. We advanced our work on the implementation of our 2015-2020 Strategic and Work Plan.

EMSP successfully led a campaign on the need for Real-World Evidence data to improve the decision-making processes affecting the people with MS. After more than 10 years of continuous work on the development of a European Register for MS, we have reached a major milestone by getting the support of the European Medicines Agency and setting up a plan to support MS registries for the future.

Thanks to our members who implemented our projects on Employment and MS Nurse Pro at national level, we could grow our impact and reach. It is both encouraging and humbling to see that our work and expertise through those projects has been acknowledged.

Time and time again, we recognize the power and value of youth engagement. Acknowledging the voice of young people in MS, our Young People's Network (YPN) is now stronger than ever. *We are constantly in awe of our YPN representatives, their powerful contribution and the energy they bring in shaping the MS landscape.* Hosting the first ever MS Sessions in Prague was a clear affirmation of the value of collaborating with our young advocates.

Finally, we are proud and honoured to have been invited to host a successful event during the ECTRIMS Congress 2017 in Paris to launch the rehabilitation module for the MS Nurse PRO programme.

It has been another great year thanks to the support of our member organisations, our key partners and sponsors but most of all, our own committed team of experts.

In these times of shrinking resources for civil societies and health communities, EMSP has not been spared. However, we are encouraged by the continuous growth of our activities and impactful outcome. As we celebrate our 30th anniversary next year, we hope to go from strength to strength driving meaningful change in the lives of people with MS.





**Anne Winslow**  
EMSP President

Anne Winslow



**Elisabeth Kasilingam**  
Managing Director

Kasilingam

# LETTER FROM THE PRESIDENT

**Dear Friends,**

In June 2018, I will be concluding my four-year term as EMSP's President at the Council meeting, in Bratislava. During my time as President and previously, as Vice President, I saw EMSP grow to be a well-established and key player in the MS community. Some of these notable milestones include: the growth of MS Nurse Pro across and beyond Europe, recognition as the voice of people with MS by professional organisations like ECTRIMS and RIMS, development of the Membership Communication Network as well as the Young People's Network, European MS Registries and game changing patient reported outcomes.

EMSP's name means that the importance and value of the patients' voice is now more than ever, as powerful as any other voice in the field of MS.

EMSP is a real force in the global MS Movement primarily because we are built on the energy and drive of our people. On every page of this report, you will be introduced to the true inner workings of EMSP, the engines that keep us running strong. You will see faces, smiles, curious and determined eyes, passionate hearts, and boundary-pushing minds. In short, our people. This is what makes EMSP strong.

There are many who make up the EMSP and the role we play as part of the World MS Movement. I wish to thank People affected by MS, our member societies, my fellow officers, Pedro Carrascal and Torben Damsgaard as well as all the outgoing Executive Committee members.

I also would like to take the opportunity to thank our valuable collaborators, projects partners, sister organisations, industry partners – who bring in the knowledge, expertise and means to make our mission and plans a reality!

Finally, I want to sincerely thank the EMSP Secretariat led by Elisabeth Kasilingam and supported by Christoph Thalheim, Andreea Antonovici, Yves Brand, Zilvinas Gavenas, Emma Rogan, Cherie Wee and Bettina Haussmann who acted as our External Advisor for their hard work and success.

Sincerely,

**Anne Winslow**  
EMSP President







**EMSP Executive Committee members,  
Spring Conference 2017, Athens**

# ABOUT US

Founded in 1989, EMSP is a team of experts in MS and advocates in health and social policies who represent 39 national MS patient organisations in 35 countries and the 700,000 people with MS in Europe.

As the voice of MS in Europe, our vision is a world without MS and our mission is to help our members and partners drive change: through advocacy support, training, and by pioneering ground-breaking initiatives.

We work on a three-pillar approach to ensure that people with MS have a real voice in determining their own objectives and priorities.



Encouraging research and data collection.



Campaigning through advocacy and awareness-raising

**EMSP drives change by**



Collecting and sharing knowledge and expertise



# 2017 AT A GLANCE: CALENDAR OF EVENTS

Annual  
Networking  
Dinner



**February**

ECTRIMS; Launch  
of MS Nurse Pro  
6<sup>th</sup> Module on  
Rehabilitation



**October**

Spring Conference in Athens;  
World MS Day at the European  
Parliament

**March**



European Parliament  
Debate on Real World  
Data and Equity of Care

**November**



MS Sessions 2017:  
Young People's  
Conference



**May**

**July**



Real World  
Evidence workshop  
at the European  
Medicines Agency  
(7<sup>th</sup> July)

# STRENGTH IN NUMBERS: OUR MEMBERS

## 39 Members in 35 countries

### Full Members

 **Multiple Sklerose  
Gesellschaft Österreich**  
[www.oemsg.at/news](http://www.oemsg.at/news)

 **MS Society Belarus**  
[www.msbelarus.com](http://www.msbelarus.com)

 **Ligue Nationale Belge de  
la Sclérose en Plaques**  
[www.ms-sep.be](http://www.ms-sep.be)


 **MS Foundation Bulgaria**  
[www.msobg.org](http://www.msobg.org)


 **Savez Udruzenja Gradana  
Oboljelih od Multiple  
Skleroze Bih Sarajevo**

 **Savez drustava multiple  
skleroze Hrvatske**  
[www.sdms-hr](http://www.sdms-hr)

 **Unie Roska**  
[www.roska.eu](http://www.roska.eu)

 **Scleroseforeningen**  
[www.scleroseforeningen.dk](http://www.scleroseforeningen.dk)

 **Estonian Multiple  
Sclerosis Society**  
[www.smk.ee](http://www.smk.ee)

 **The Finnish MS Society**  
[www.ms-liitto.fi](http://www.ms-liitto.fi)

 **Ligue Francaise contre  
la Sclérose en Plaques**  
[www.ligue-sclerose.fr](http://www.ligue-sclerose.fr)

 **Deutsche Multiple  
Sklerose Gesellschaft**  
[www.dmsg.de](http://www.dmsg.de)

 **Greek MS Society**  
[www.gmss.gr](http://www.gmss.gr)


 **MS Felag Islands**  
[www.msfelag.is](http://www.msfelag.is)

 **MS Society of Ireland**  
[www.ms-society.ie](http://www.ms-society.ie)

 **Associazione Italiana  
Sclerosi Multipla**  
[www.aism.it](http://www.aism.it)

 **Latvijas Multiplas  
Sklerozes Asociacija**  
[www.lmsa.lv](http://www.lmsa.lv)

 **Lithuanian Multiple  
Sclerosis Union**  
[www.liss.lt](http://www.liss.lt)

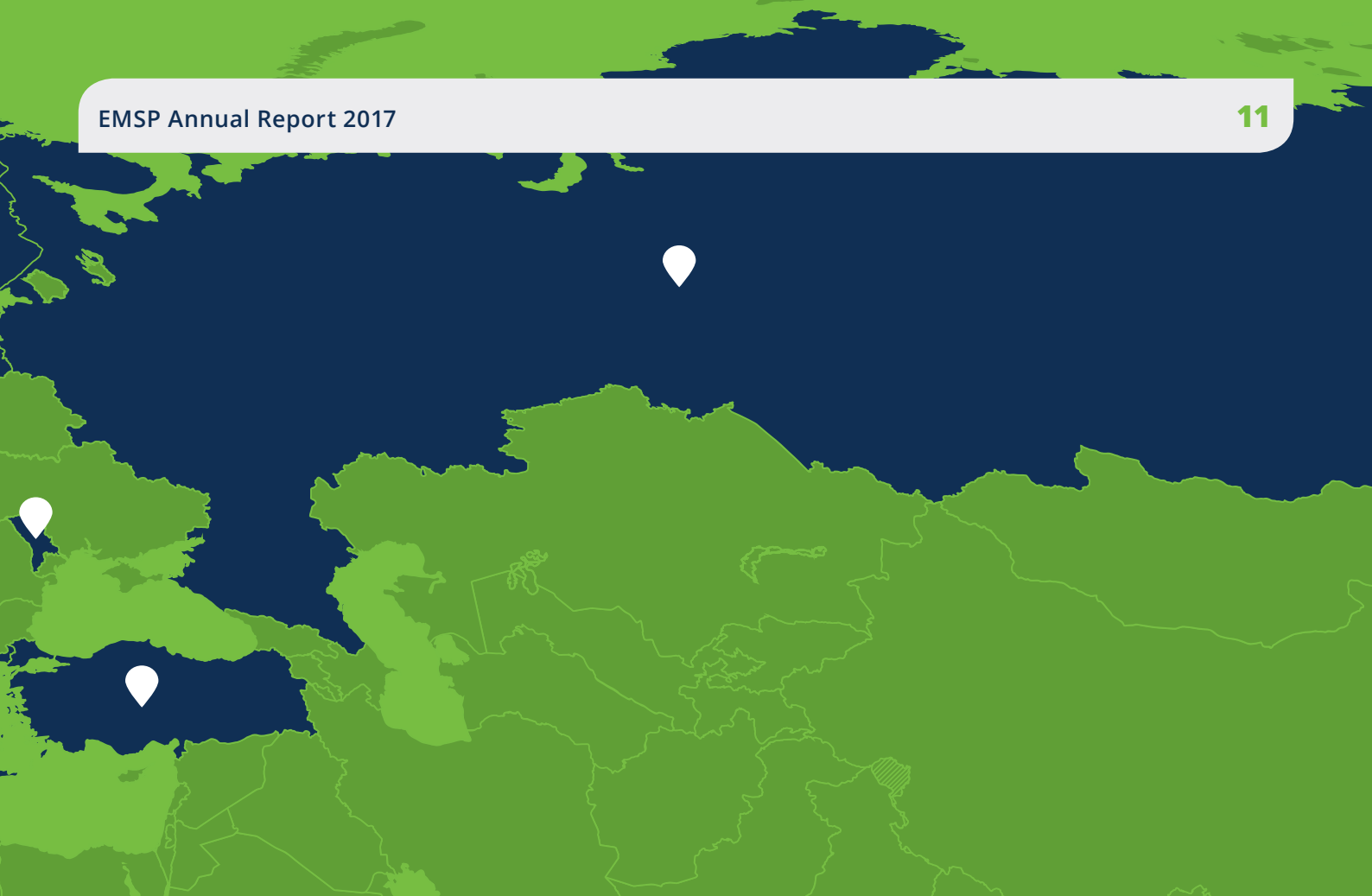
 **Ligue Luxembourgeoise  
de la Sclerose en Plaques**  
[www.msweb.lu](http://www.msweb.lu)

 **Multiple Sclerosis  
Society of Malta**  
[www.msmlta.org.mt](http://www.msmlta.org.mt)

 **Multiple Sclerose  
Vereniging Nederland**  
[www.msvereniging.nl](http://www.msvereniging.nl)

 **Multipel Sklerose  
Forbundet | Norge**  
[www.ms.no](http://www.ms.no)

 **Polskie Towarzystwo  
Stwardnienia  
Rozsianego**  
[www.ptsr.org.pl](http://www.ptsr.org.pl)



**Sociedade Portuguesa  
de Esclerose Multipla**  
[www.spem.org](http://www.spem.org)



**All Russian Public  
Organization (RPO)  
of Disabled PwMS**  
[www.ms2002.ru](http://www.ms2002.ru)



**Drustvo Multiple  
Skleroze Srbiie**  
e-mail [msserb@sbb.rs](mailto:msserb@sbb.rs)



**Slovensky Zvaz  
Sclerosis Multiplex**  
[www.szsm.szm.sk](http://www.szsm.szm.sk)



**Zdruzenje Multiple  
Skleroze Slovenija  
(ZMSS)**  
[www.zdruzenje-ms.si](http://www.zdruzenje-ms.si)



**Neuroförbundet**  
[www.neuroforbundet.se](http://www.neuroforbundet.se)



**Asociación Española  
de Esclerosis Multiple  
(AEDEM-COCEMFE)**  
[www.aedem.org](http://www.aedem.org)



**Schweizerische Multiple  
Sklerose Gesellschaft  
(9SMG0)**  
[www.multiplesklerose.ch](http://www.multiplesklerose.ch)



**The Multiple Sclerosis  
Society of Great Britain  
and Northern Ireland**  
[www.mssociety.org.uk](http://www.mssociety.org.uk)

### Associate Members



**The Hellenic Federation  
of Persons with Multiple  
Sclerosis (HfoPwMS)**  
[www.msassociationhellas.org](http://www.msassociationhellas.org)



**Union de lutte contra la  
Sclerose en Plaques  
(UNISEP)**  
[www.unisep.org](http://www.unisep.org)



**Sclerosis Multiplexes  
Betegek Orszagos  
Egyesulete (SMBOE)**  
[www.smboe.hu](http://www.smboe.hu)



**Esclerosis Multiple  
Espana (EME)**  
[www.esclerosismultiple.com](http://www.esclerosismultiple.com)



**MS Association 'Hope'  
Združenie Sclerosis  
Multiplex Nádej (Msah)**  
[www.dakujeme.sme.sk](http://www.dakujeme.sme.sk)



**Multiple Sclerosis (MS)  
Association of Turkey**  
[www.turkiyemsdernegi.org](http://www.turkiyemsdernegi.org)



**National Association of  
People with Multiple  
Sclerosis in Hungary**



**MS Society of Moldova**

# BRINGING CHANGE IN THE MS LANDSCAPE: OUR POLICY AND ADVOCACY WORK

2017 represented a year of continuous advocacy work for EMSP. We've dedicated our energy and efforts to fighting for better access to therapies and treatments for people affected by MS in various fora, from stakeholder meetings to the European Parliament, European Commission, European Medicines Agency or the EUnetHTA.

In 2017, EMSP launched the results of the latest edition of the EMSP MS Barometer, a tool that has been successfully used by EMSP members and patient advocates to lobby their national policy decision makers for better access to treatments for MS patients. We also started a series of country fact sheets at our Annual Conference in Athens to strengthen this valuable tool for our members and partners.

We successfully campaigned on access to employment for people affected by MS, with the support of the Employment Pact for People with MS and the Guide for Healthcare Professionals. Our voice was heard at the European Parliament and European Commission as well in various events hosted by partners such as the European Federation of Neurological Associations.

As a Pan-European organization, our advocacy efforts have also been effective at the national level where our member societies like Ireland, Romania and Estonia have localised the Toolkit for Employment. We also continued to advocate towards better social and employment policies in collaboration with other stakeholders and building up partnerships with other European health NGOs to strengthen the patient voice in Brussels and beyond.

2017 also marked the launch of the European Brain Council's [White Paper Towards Optimising Research and Care for Brain Disorders](#), a publication co-authored by EMSP.

Last but certainly not least, we advanced our advocacy work through our collaboration with Professor Gisela Kobelt and her research on the MS Cost of Illness. This breakthrough study which is the largest research of its kind in the field of MS, had participation from over 16.000 people with MS in Europe. The study showed us *"there is nothing like data to make policy makers sit up and listen"*.

The MS Cost of Illness Study, published in the Multiple Sclerosis Journal, provides the most up to date information on the burden of multiple sclerosis to both society and MS patients.

## Useful Links

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[MS Barometer Report](#)

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[Employment Toolkit Ireland](#)

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[MS Cost of Illness Study](#)

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## Work with the European Medicines Agency / EUnetHTA:

As a member of the Patients' and Consumers' Working Party within the European Medicines Agency, we represented our members at 4 meetings that took place in 2017. We advocated on behalf of people with MS at the EUnetHTA meetings where we campaigned for better Health Technology Assessment that impact the access to treatment for people affected by MS.

Through our continued advocacy at the EMA, concrete outcomes have allowed us to progress our work on representing our members and the patient voice at the European level as well as to advance our work on Data Registries across Europe.



**"Can real world evidence data advance equity of healthcare for MS in Europe?", European Parliament debate, 7th March 2017.**

# PIONEERS IN THE MS FIELD: CREATING PATHWAYS FOR BETTER MS CARE

People living with multiple sclerosis (MS) in the European Union could receive timelier access to safer and more efficient therapies. They could also become more important partners in the regulation and pricing of medicines. The key to turning these possible scenarios into reality is the better exploitation of Real-World Evidence (RWE) - provided by patient data which are collected outside of randomized clinical trials.

In the past decade, EMSP completed two exploratory proof of concept projects in the field of Real World data; these were the “Multiple Sclerosis – Information Dividend” (MS-ID) which ran from 2006-2009 and the [European Registry for MS \(EUREMS\) from 2011 -2017](#)).

Both MS-ID and EUREMS were EU-co-funded and served as foundation for our continuing efforts to make patient data from registries more impactful.

## In 2017, EMSP consequently



Finalized phase 2 of EUREMS project: four studies were completed (in the fields of Epidemiology, Disease-Modifying Drugs and Patient Reported Outcomes) and a summary report was prepared for publication in 2018.



Campaigned on the need for real world evidence (RWE) data in the healthcare decision-making by organizing a debate in the European Parliament co-hosted by the MEP Cristian Busoi, on the 7th March 2017.



Completed a mapping exercise on MS registries across Europe, identifying and describing 25 major MS registries in Europe. This survey allowed us to assess the current MS registry landscape as vital preparatory step for the intended efforts on harmonization of parts of the data collection – a peer reviewed publication will follow in 2018.



Lobbied for the inclusion of MS into the “Patient Registries Initiative”<sup>\*</sup> of the European Medicines Agency (EMA) and was chosen by them as one of only two pilot diseases. First key result of this collaboration between EMA and EMSP was a very well attended multi-stakeholder workshop on MS Registries hosted by EMA in July 2017, with a detailed report being published [here](#).

<sup>\*</sup>EMA's Patient Registry Initiative is an ongoing project which aims to understand ways of expanding the use of patient registries in the benefit-risk evaluation of medicines within the European Economic Area. EMSP's mapping of existing MS registries across Europe showed wide gaps among the levels of usability of existing registries for regulatory purposes.





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**COMPARING DATA FROM DIFFERENT COUNTRIES WILL BE OF GREAT BENEFIT TO MS PATIENTS. EUREMS GOES BEYOND THE NATIONAL BORDERS. IT IS A COMPREHENSIVE ANALYSIS.**

Karoline Buckow (co-lead, Study 1),  
IT Professional, Department of  
Information Technology Medical  
University Centre, Gottingen, Germany

Since the ECTRIMS congress 2017, EMSP played a key role in discussing with members and partners those EMA recommendations on core data elements to be collected by MS registries, common procedures, consents, governance, data quality and registry interoperability, ultimately leading to the start in 2018 of a new data access and harmonization project, the **MS Data Alliance** (MSDA).

MSDA is based on two core elements: The “MSDA toolbox” providing three innovative tools to willing registries for better data sharing and the “MSDA Academy” for inspiration and motivation of the MS community, creating a mind-shift on the vital importance and multifaceted usability of good quality real world data - desperately needed as additional evidence for proper decision making by health authorities.

## MS Nurse Pro

The MS Nurse Professional is the first and only European, CME-accredited, focused, e-learning training curriculum for nurses progressing their career in the field of MS. It is led by the European Multiple Sclerosis Platform (EMSP) in collaboration with the International Organisation of Multiple Sclerosis Nurses (IOMSN) and Rehabilitation in MS (RIMS). To date, more than 5,200 nurses have undertaken the program in 11 languages.

2017 was a remarkable year for MS Nurse Pro. We kicked the year off with our 10th national launch in Bucharest, [Romania](#) in April where we had more than 50 stakeholders from patients, patient advocates, healthcare professionals, decision-makers and nurses.

Subsequently, we hosted a pre-launch of the Greek version of MS Nurse Pro at EMSP's Annual Conference in Athens. MS Nurse Vicki Matthews provided a great presentation about the situation of MS nurses in Europe and Greece stressing the importance of proper education and training for MS nurses.

Additionally, we improved the benchmarking survey for MS Nurse Pro and have successfully engaged over 5,200 nurses in the programme – a total of 1,700 more registrations in 2017.

Last but not least, EMSP proudly launched the newly developed [6<sup>th</sup> module](#) of the programme on rehabilitation at ECTRIMS in Paris. EMSP developed the new module in collaboration with ECTRIMS, RIMS and IOMSN and received the support and endorsement of ECTRIMS President, Professor David Miller who provided remarks at the launch. The event included a panel discussion to a packed auditorium with neurologists, nurses and patients about the key role of the MS nurses in Europe. With many more translations along the way, we hope to launch more versions of MS Nurse Pro in Portuguese and Danish among others.

[msnursepro.org](https://msnursepro.org)







**SPECIALIST NURSES OFFER UNPARALLELED, HIGH-QUALITY CARE AND SUPPORT FOR PEOPLE WITH MS AND THEIR FAMILIES. MS NURSE PROFESSIONAL IS A VITAL STEP TOWARDS UNIFICATION AND RECOGNITION OF THE MS NURSE ROLE THROUGHOUT EUROPE, AND WE HAVE ALREADY SEEN THE POSITIVE IMPACT IT IS HAVING ON PATIENTS AND FAMILIES ALIKE.**

Vicki Matthews (Rehabilitation in MS Committee Member, MS Trust Representative and MS Nurse PROfessional Steering Committee Member)

#### Highlights:

#### An increase in registration:

+48.6%

**3,500**

**5,200**

2016

2017



**Launch of the 6<sup>th</sup> module  
on rehabilitation  
at ECTRIMS**

**MS Nurse Pro Launch  
in Romania**

**Pre-launch  
in Greece**





## Horizon2020: N2B Patch Project

The N2B-Patch is a project funded by the European Union, which brings together universities, research institutes, SMEs, industry and patients organisations. The main aim of this research-project is to explore the possibility to have treatments in MS that would bypass the blood-brain barrier.

Bypassing the blood brain barrier could lead to a more effective way of treating MS – and potentially also be a less invasive treatment for patients, avoiding for instance the need for injections and oral medicine to treat MS.

EMSP is proud to be involved in this European-wide project to provide the expertise of patients and to disseminate the innovative outcome of this multi-stakeholder project to our members.



*This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 721098.*



“

**THIS ‘BIG DATA’ HAS THE POTENTIAL TO DELIVER INSIGHTS THAT WILL ALLOW HEALTHCARE SYSTEMS TO ENSURE THAT THE PATIENT IS TRULY AT THE CENTRE OF DECISION-MAKING, WITH OUTCOMES THAT MATTER AND RESOURCES FOCUSED ON TREATMENTS THAT REALLY MAKE A DIFFERENCE.**

Big Data for Better Outcomes,  
European Research project, IMI2

## **Innovative Medicines Initiative (IMI) BD4BO Do-it Project**

The DO-IT project is a 2-year project, funded through the ‘Innovative Medicines Initiative’ (IMI) of the EU. The overall goal of the Big Data for Better Outcomes (BD4BO) programme is to facilitate the use of ‘big data’ to promote the development of value-based, outcomes-focused healthcare systems in Europe.

Using our extensive experience on MS registry projects, EMSP represents patients’ perspective

on how to share healthcare data on the value of including patient centred outcomes (PCO) and the development of an appropriate informed consent template for clinical trials. In addition, EMSP supports the communication and dissemination of the project outcomes.

**The project results are expected for the end of 2018.**



*This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 116055. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA*

# EMPOWERMENT IN ACTION: YOUTH AND EMPLOYMENT

MS usually affects people between the ages of 20 and 50 and is known as a Young People's disease. This year, we made a commitment to focus on Youth and Employment as a pillar of our work plan. We grew our Young People's Network, launched the first ever Festival for young people with MS in Prague and published breakthrough guidelines on keeping young people in the workforce.

We believe that people with MS deserve support for progressing their aspirations. From farming to hospital surgeries to businesses, universities and art studios, people with MS are part of all sectors of the European workforce.

In 2017, we continued advocating for change and providing solutions through our projects on youth and employment.

## Cost of Illness and Fatigue:

As the Burden and Cost of Illness Study from Gisela Kobelt et al highlighted, having MS has a serious socio-economic impact on the individual, their family and the society they live in.

As important is the finding that the availability of services and the adequacy of the healthcare systems are major factors in the cost of MS.

## Toolkit for Employers:

Last year, EMSP released the [Practical Toolkit for Employers: Working out MS in the Workplace](#) in response to the prevailing work status of people with MS in Europe.

Acknowledging the divergence in economies across Europe, this toolkit provides a clear framework for modern, responsive and solution-focused recommendations to employers how to better support people with MS in their workforce.

### These include:

- How to assess the current workforce
- Internal policies that support staff
- Changing attitudes with staff education
- Preventative, cost saving activities
- Securing staff commitment, lowering staff turnover and cost saving

Developed to be the 'go to' document for supporting both employers, our Estonian and Irish members have translated and localised the Toolkits to lobby their governments on the issues people with MS face in the workplace.





## Ready for Work:

The [Ready for Work Guidelines for Healthcare Professionals](#) is a method of early intervention endorsed by the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS). Together with the Work Foundation, we co-developed and published the guideline in 2017.

Healthcare professionals have a unique role in helping people with MS understand and manage their condition. Moreover, effective communication has been shown to have an impact on adherence – the degree to which a patient follows the advice of the healthcare professional. Through this publication, we hope to empower people with MS with the tools and motivation they need to lead an independence life and the added value of work.

### European Patient's Forum (EPF) Taskforce on Discrimination in the Workforce:

EMSP worked on the EPF Taskforce to ensure the common issues faced by people with MS such as social isolation, financial insecurity and poverty were included in the development of resources for people with chronic conditions and recommendations for policy decision-makers.

### Together, we successfully developed these materials for our members:

- A [collection of patient organisation initiatives](#) to promote patient-led actions and promote EPF member action on this topic and take-up of existing materials. EMSP projects included are in Paving the Path to Participation, the Employment Pact, the Believe and Achieve Internship programme and other employment-focused initiatives.
- [Recommendations targeting policy makers](#) – on how they can promote better inclusion of people with chronic conditions in the workplace in the context of the European Pillar of Social Rights;
- A [digital leaflet for employers](#) on how to foster inclusive work places and better inclusion of people with chronic conditions. The Practical Toolkit for Employers is a fine example for businesses wanting to build a workplace that matches the changing demographics of the workforce in Europe.

**Photo from MS Sessions,  
Prague 2017**



## Young People's Network

This year was a highlight in the development of the EMSP Young People's Network. Thanks to the support of our member societies and partners, the network has grown from the small group of strangers who gathered together in Stuttgart (2010) to a powerful group of knowledgeable and experienced advocates.

Across Europe, there are more than 80 young people involved with member societies, taking part in events, giving their energy to campaigns and do what they can to make a difference.

Young people were very well represented at the Spring Conference in Athens as volunteers helping all the delegates, presenting their perspective on life with MS and having their opinions heard.





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**I HAD SUCH AN AMAZING TIME IN PRAGUE. IT'S BEEN A LIFE CHANGING, EMOTIONAL, INFORMATIVE, FUNNY AND INSPIRING WEEKEND. BIG THANK YOU TO THE EMSP, SHIFT MS AND ALL THE BEAUTIFUL FELLOW MSERS THAT ATTENDED. ENERGY AND LOVE AROUND THE PLACE WAS TRULY OVERWHELMING #MSSESSIONS2017”.**

Donna Nahal, MS Sessions participant

## European Patients Forum Youth Group and MS Sessions 2017

Anna Zaghi has been representing young people with MS on the EPF Youth Group. A capable and excellent representative, Anna stood down from the position at the end of the year. We wish her every success in her next endeavours and look forward to welcoming other MS advocates to represent young people with MS at European level.

Without a doubt, one of the highlights of the year was MS Sessions. Over the course of three days in Prague, in partnership with [Shift.ms](#), EMSP welcomed young people from across Europe. The enthusiasm and passion was exhilarating. We hope that MS Sessions is only the beginning of many more possibilities to come.

For the EMSP team, MS Sessions is a perfect example of why it's that much more necessary to include young voices in our advocacy work. We returned with renewed motivation to grow the Young People's Network. Thank you to all EMSP member societies for your support and encouragement in growing the YPN at European level and nourishing young people with MS through national events and groups.

**SMile**

@CentrulSMile



#Msers take over the #MSSessions2017!  
Sharing is caring and these young inspirational people share their experiences to motivate others!

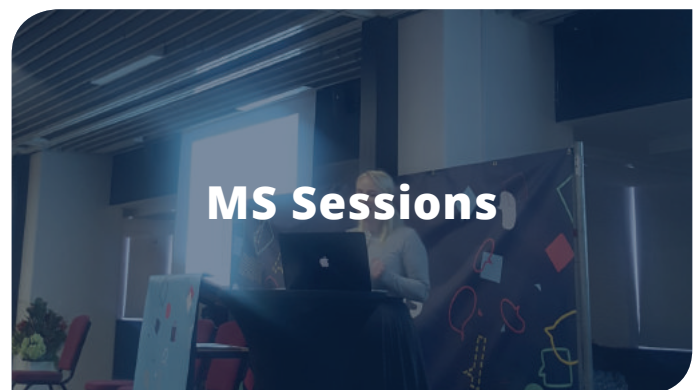
# COMMUNICATING FOR CHANGE AND IMPACT: COMMUNICATIONS BY THE NUMBERS



# STRENGTHENING OUR NETWORK: PARTNERSHIPS, EXTERNAL RELATIONS AND EVENTS

At EMSP, collaboration is a foundation for the work that we do. In 2017, we signed a memorandum of agreement with Caritas Norway and with Travel4All, a Canadian accessible travel agency. With these partnerships, we hope to strengthen our network and bring more support to our members.

## Events in 2017





# FINANCES: 2017



## Treasurer's Report

### Torben Damsgaard

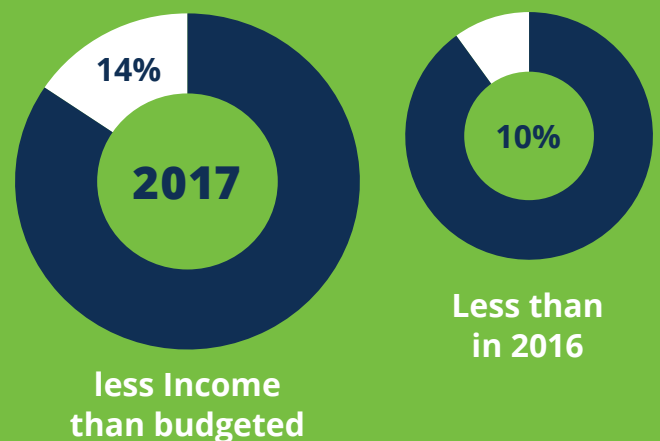
The financial result of EMSP's activities in 2017 is very satisfactory. After three consecutive years of deficits and reduced reserves, **2017 shows a surplus of 50.307€ which is 23.995€ more than budgeted.** As a result, the reserves have increased from 281.880€ in 2016 to 332.187€ at year-end 2017.

The total income of **1.134.296€ in 2017 was 14% less than budgeted and 10% less than in 2016.** Although we have seen a decreased income from the pharma industry, the companies remain major funders and supporters of EMSP's projects. Two projects funding were significantly reduced in 2017: the MS Nurse PRO and the EUnetMUS (MS registries project). However, we had considerable success in raising funds for both the Spring Conference in Athens and the MS Sessions (first-ever MS festival for young people with MS across Europe).

EMSP's members paid **81.868€ in membership-fees in 2017 – a little more than 7% of the total income**, and at the same level as in 2016. We continued our efforts to diversify the organisation's income from other sources, but that is a long and challenging process. In 2017, we applied once again for core funding from the European Union which was not granted like many other umbrella/patients' organisations. Shifting priorities of the European Commission reduces considerably the opportunities of getting core funding from the EU in the early years to come.

Given the current market and conditions for EMSP's fundraising, we think that the current level of income at 1.1 – 1.2 mill € annually is realistic for EMSP for now and the near future.

In 2017, we have had focus on expenses, and our staff worked hard to deliver on our projects with less manpower and cost. **Total expenses of 1.083.989€ was 203.199€ less than budgeted**, mainly due to the readjustment of projects spending to the reduced income received by projects. The EUREMS project ended in 2016, which gave us significantly lower project spending in 2017 compared to 2016, but the two successful conferences in 2017 - gathering more than 100 participants from our member societies and the wider MS community across Europe - partly abrogated that.



# Auditor's Report



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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 31/12/2017  
RPM BRUSSELS nr. 0473.317.141  
=====

In the context of the statutory audit of the annual accounts of the organisation "EUROPEAN MULTIPLE SCLEROSIS PLATFORM", we hereby present our statutory auditor's report. It includes our opinion on the audit of the annual accounts as well as our report on the other legal and regulatory requirements. These reports form part of an integrated whole and are indivisible.

We have been appointed as statutory auditor by the general meeting of members of "EUROPEAN MULTIPLE SCLEROSIS PLATFORM", following the proposal by the board of directors. Our statutory auditor's mandate will expire on the date of the general meeting of members which will deliberate on the annual accounts closed on 31/12/2019. We have performed the statutory audit of the annual accounts of the organisation EUROPEAN MULTIPLE SCLEROSIS PLATFORM for 7 consecutive years.

## **Report on the audit of the annual accounts**

### **Unqualified opinion**

We have audited the annual accounts of the Organisation, which comprise the balance sheet as at 31/12/2017, the profit and loss account for the year then ended and the notes to the annual accounts, characterised by a balance sheet total of € 607.962,46 and a profit and loss account showing a profit for the year of € 50.307,02.





## Auditor's Report (cont)



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In our opinion, the annual accounts give a true and fair view of the Organisation's net equity and financial position as at 31/12/2017, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.

### ***Basis for unqualified opinion***

We conducted our audit in accordance with International Standards on Auditing (ISAs) as applicable in Belgium. Our responsibilities under those standards are further described in the 'Statutory auditor's responsibilities for the audit of the annual accounts' section in this report. We have complied with all the ethical requirements that are relevant to the audit of annual accounts in Belgium, including those concerning independence.

We have obtained from the board of directors and the officials of the Organisation the explanations and information necessary for performing our audit.

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

### ***Responsibilities of the board of directors for 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.

In preparing the annual accounts, the board of directors is responsible for assessing the Organisation's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the board of directors either intends to liquidate the Organisation or to cease operations, or has no realistic alternative but to do so.



## Auditor's Report (cont)



Burgerlijke Vennootschap onder vorm van een BVBA

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### **Statutory auditor's responsibilities for the audit of the annual accounts**

Our objectives are to obtain reasonable assurance about whether the annual accounts as a whole are free from material misstatement, whether due to fraud or error, and to issue a statutory auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these annual accounts.

As part of an audit in accordance with ISAs, we exercise professional judgment and maintain professional skepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the annual accounts, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Organisation's internal control;
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the board of directors;
- Conclude on the appropriateness of the board of directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Organisation's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our statutory auditor's report to the related disclosures in the annual accounts or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our statutory auditor's report. However, future events or conditions may cause the Organisation to cease to continue as a going concern;
- Evaluate the overall presentation, structure and content of the annual accounts and whether the annual accounts represent the underlying transactions and events in a manner that achieves fair presentation.





## Auditor's Report (cont)



Burgerlijke Vennootschap onder vorm van een BVBA

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We communicate with the board of directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identified during our audit.

### ***Report on other legal and regulatory requirements***

#### ***Responsibilities of the board of directors***

The board of directors is responsible for the compliance with the legal and regulatory requirements regarding bookkeeping, as well as for compliance with the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations, and with the Organisation's by-laws.

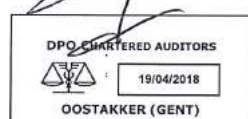
#### ***Responsibilities of the statutory auditor***

In the context of our mandate and in accordance with the Belgian standard (Revised in 2018) which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, it is our responsibility to verify, in all material aspects, compliance with certain provisions of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations and with the by-laws, as well as to report on these elements.

We do not express any form of assurance whatsoever on the other information contained in the annual report.

### ***Statement related to independence***

- Our audit firm did not provide services which are incompatible with the statutory audit of annual accounts, and we remained independent of the Organisation throughout the course of our mandate.
- No additional work services which implicated fees and which are compatible with the statutory audit of annual accounts as referred to in article 17 of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations, which refers to article 134 of the Company Code, has been carried out.

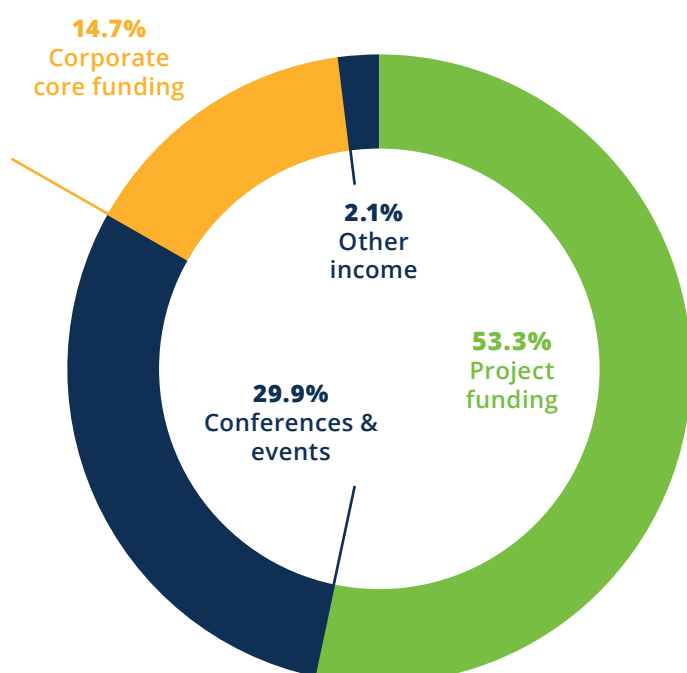


## Financial Statements

	2017 Actual	2016 Actual
<b>Income</b>		
Corporate core funding	167,055	283,353
Conferences & events	338,882	110,230
Other Income	23,368	36,414
Project funding	604,991	827,756
<b>Total Income</b>	<b>€1,134,296</b>	<b>€1,257,753</b>
<b>Expenditure</b>		
Staff & office	477,129	582,191
Outsourcing	76,938	105,277
Office expenses	41,241	61,271
Governance	11,438	11,169
Conferences/Events	208,256	94,737
PR & communication	12,949	12,082
Project expenditure	256,038	408,221
<b>Total Expenditure</b>	<b>€1,083,989</b>	<b>€1,274,948</b>
<b>Profit/loss for the period</b>	<b>€50,307</b>	<b>-€17,195</b>

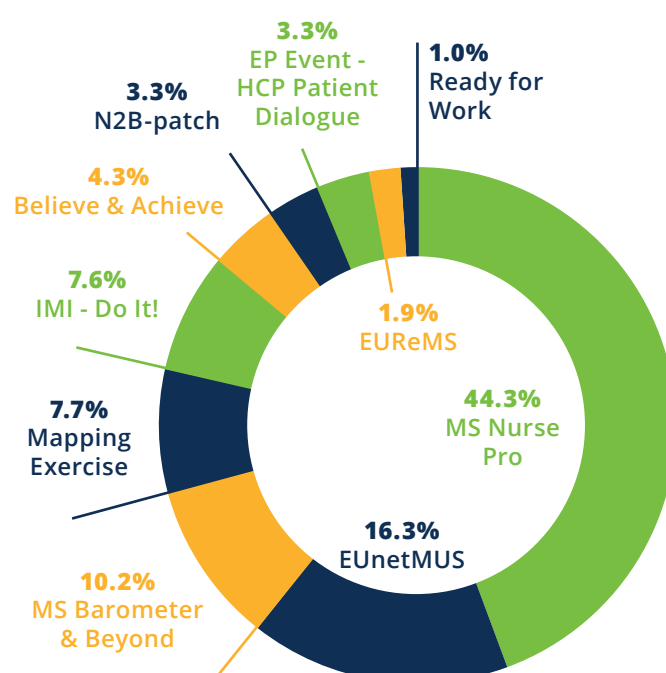
### 2017 Income

total 100% = €1,134,296



### 2017 Projects funding

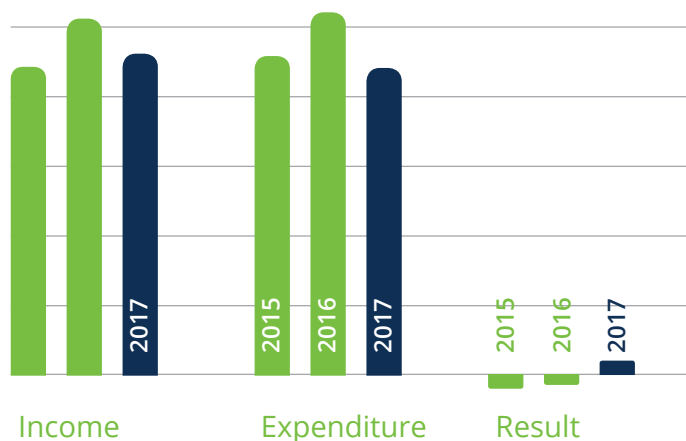
total 100% = €604,991



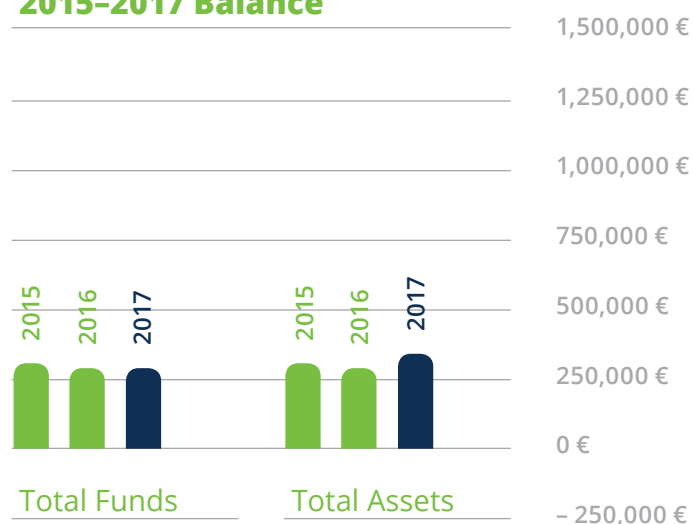
## Balance Sheet

Assets/Liabilities	2017	2016
<b>Fixed assets</b>	<b>29,366</b>	<b>32,653</b>
<b>Current assets</b>		
Accounts Receivable - Pharma	170,285	190,637
Accounts Receivable - Members	7,907	22,907
Prepayments & Other Debtors	2,244	8,485
Accrued income	40,000	0
VAT	172	0
Bank Current Accounts	353,040	398,049
Bank Guarantee Account	0	0
<b>Total Current Assets</b>	<b>€573,648</b>	<b>€620,078</b>
<b>Current liabilities</b>		
Trade creditors	5,217	8,688
Deferred income	18,243	71,967
Accruals & other creditors	172,113	227,402
Taxes & social security	75,254	62,794
<b>Total Current Liabilities</b>	<b>€270,827</b>	<b>€370,851</b>
<b>Total Assets</b>	<b>€332,187</b>	<b>€281,880</b>
<b>Funds</b>	<b>2017</b>	<b>2016</b>
Capital	13,585	13,585
Reserves B'fwd	268,295	265,490
Designated funds - developing countries	0	20,000
2017 Profit - 2016 Deficit	50,307	-17,195
<b>Total Funds</b>	<b>€332,187</b>	<b>€281,880</b>

### 2015–2017 Financial statements



### 2015–2017 Balance



# ACKNOWLEDGEMENTS

## Thank you, Merci, Dank U, Hvala, Dziękuję Ci, Tack!

They say that team work makes the dream work, EMSP's success is thanks to the support of our collaborators. We'd like to say a million thanks to all of you have contributed to our work. You are the building blocks for our continued success!

### EMSP Member organisations

In 2017 EMSP benefitted once again from the expertise of its member organisations and support to implement successfully its activities. A special thanks goes for the members of EMSP Communications network for their valuable input.

We would like to address a huge thank you to The Hellenic Federation of Persons with Multiple Sclerosis (HfoPwMS) and The Greek MS Society (GMSS) for their support in the preparation of the Spring Conference 2017 and their enthusiastic group of volunteers.

**EMSP receives a continuous support from a number of international MS advocates and specialists who bring their expertise to progress the MS movement:** Jacobo Santamarta-Barral (AEDEM, Spanish MS Society), Birgit Bauer, Lori Schneider (Empowerment through Adventure), Pieter Van Galen and the members of the MS Nurse PRO Steering Committee.

### Partners:

EMSP's reach and impact is greatly enhanced by the close cooperation with many other European organisations. Among them: Shift.ms, 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), Asociatia Pacientilor cu Asociatia Neurodegenerative din Romania (APAN), Ogilvy FTI Consulting (Brussels) and Mather. We extend our thanks to the Member of the European Parliament Katerina Konecna for hosting our event in 2017.

And we also would like to thank our **longtime supporters:** Sue Tilley, Bettina Hausmann, Jan van Son, Thomas Martens and the Crowne Plaza (Brussels).

### EMSP Secretariat:

A heartfelt thank you also goes to the members of EMSP Secretariat who left EMSP in 2017.

**Communications and Membership Coordinator:** Claudiu Berbece

**External Affairs Assistant:** Cristiano Pisani

**Finances Officer:** Jiska Bolhuis

### EMSP Current Team

**Managing Director:** Elisabeth Kasilingam

**External Affairs Director:** Christoph Thalheim

**External Affairs Coordinator:** Yves Brand

**Public Affairs Coordinator:** Andreea Antonovici

**Communications and Membership Coordinator:** Cherie Wee

**Project Coordinator:** Emma Rogan

**IT Coordinator:** Žilvinas Gavėnas

**Financial Advisers:** Susan Tilley and Joeri Wullens



## Corporate Partners and Donors:

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.

### Members of the Executive Committee:

**Member, MS Society of Italy:** Federica Balzani

**Co-optee, MS International Federation (MSIF):**  
Peer Baneke

**Member, UK MS Society:** Georgina Carr

**Co-optee, MS Society of Spain EME:** Pedro Carrascal

**Treasurer, MS Society of Denmark:**  
Torben Damsgaard

**Co-optee, MS Society of Poland:**  
Magdalena Fac-Skhirtladze

**Member, MS Society of France (LFSP):**  
Dr Olivier Heinzlef

**EMSP President 2010-2014, MS Society of Norway:**  
John Golding

**Young People's Representative:** Jana Hlavacova

**Co-optee, MS Society of Belgium:** Klaus Knops

**Member, MS Society of Greece (GMSS):**  
Constantinos Michalakos

**Member, MS Society of Latvia:** Maija Pontaga

**EMSP President, MS Society of Ireland:**  
Anne Winslow







EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

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