



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

TOWARDS BETTER ACCESS TO DIGNIFIED AND INDEPENDENT LIFE FOR PEOPLE WITH MULTIPLE SCLEROSIS

2018

Annual Report



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and the Managing Director

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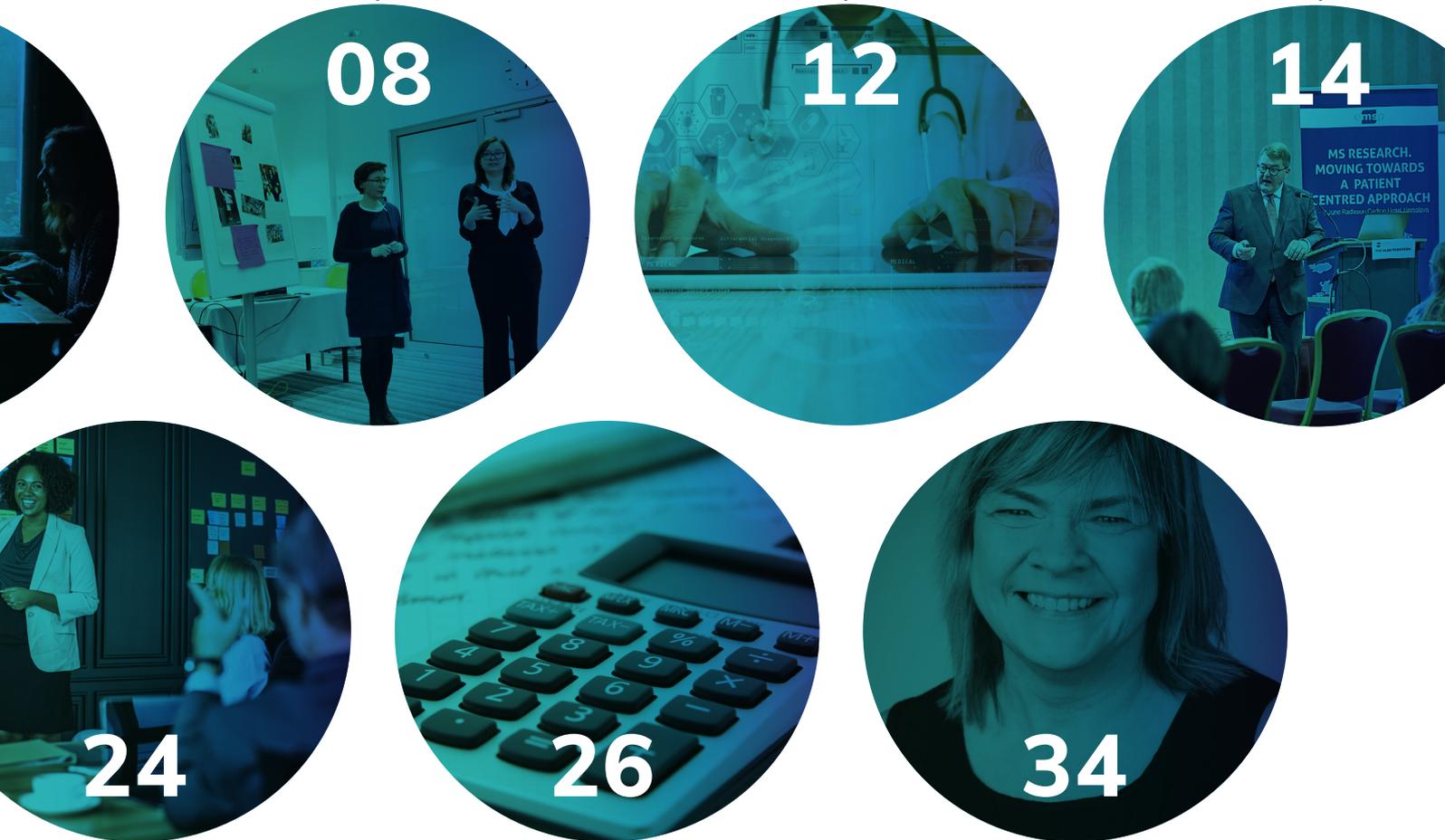
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FOREWORD

FROM THE PRESIDENT AND THE MANAGING DIRECTOR



Dear friends, 2018 has been a major transitional year for the European Multiple Sclerosis Platform (EMSP) on several fronts.

We welcomed new Executive Committee members, re-prioritised our activities to align with new challenges impacting the MS community at European level and refocused our resources to ensure the sustainability of the organisation in accordance with our current Strategic Plan 2015-2020.

In a changing political and socio-economic context in Europe, we had to adjust our work to ensure a closer alignment of our priorities to the needs of our member organisations.

We also worked to strengthen our partnership with pan-European organisations to keep advocating to improve the quality of life of people affected by multiple sclerosis (MS).

In 2018, two of our major initiatives reached milestones: the successful MS Nurse PRO project counts now more than 7,000 registered users. We renewed a long-term strategic plan for the further roll-out of the project. EMSP progressed its work on the development of the MS Data Alliance project and established a consortium of experts to push forward better data collection to support improved decision-making.

Continuing EMSP's membership growth, we had the pleasure to add two new active members from Bosnia-Herzegovina and Romania to our network.

When we look back on 2018, there is no doubt EMSP had a challenging year with the loss of public core income. To deal with this situation, EMSP restructured its Secretariat and realigned its overall strategic objectives in an increasingly challenging economic situation. In the midst of this process, the Secretariat welcomed three new skilled and enthusiastic team members.

On behalf of our Executive Committee and Secretariat, we would like to thank all our member organisations, partners, volunteers and corporate sponsors for placing their trust in us and helping us shaping a better future for people with MS.

Our goal is to raise the voice of people affected by MS to make an impact on our policy decision-makers while expanding our network and leadership through innovative projects and powerful campaigning.

ABOUT EMSP



Our Core Work

- Pan-European NGO working in health – and social policies;
- Offering a platform to exchange knowledge and expertise in the field of multiple sclerosis (MS);
- Aiming to improve quality of life as well as access to treatment, care and employment.



Our Activities

- Campaigning through advocacy, awareness raising and patient involvement;
- Collecting and sharing knowledge and expertise;
- Encouraging research and data collection.



Our Network

Founded in 1989, EMSP is a team of experts in MS and advocates in health and social policies relying on a network of 41 national MS patient organisations in 36 countries and - via those national member organisations – representing more than 770,000 people with MS in Europe. We work together to ensure that people with MS have a real voice in determining their own priorities.



Pedro Carrascal
EMSP PRESIDENT



Elisabeth Kasilingam
MANAGING DIRECTOR

2018 PICTURE STORY

TOWARDS BETTER ACCESS TO DIGNIFIED AND INDEPENDENT LIFE FOR PEOPLE WITH MULTIPLE SCLEROSIS

At EMSP, we believe that in order to improve the quality of life of people with MS they need to have access to a dignified and independent life by:

01

Empowering people with MS to undertake an informed and active role in all decisions impacting their lives



ENGAGING WITH POLICY
DECISION MAKERS



RAISING THE CONCERNS AND
PERSPECTIVE OF PEOPLE WITH
MS IN PUBLIC CONSULTATIONS



TRAINING PATIENTS AND
THEIR REPRESENTATIVES
IN CLINICAL TRIALS



DIALOGUE WITH
HEALTH CARE
PROFESSIONALS

02

Collecting data directly from people with MS and their representatives to support shaping adequate responses to the real needs



MS DATA ALLIANCE AND PATIENT REPORTED OUTCOMES



MS BAROMETER

03

Facilitating evidence-based dialogue and projects



ANNUAL CONFERENCE 2018



MS NURSE PRO: BETTER CARE FOR PEOPLE WITH MS

04

Moving forward and supporting advocacy and campaigns to addressing social and health policies challenges



BRAIN AWARENESS WEEK



WORLD MS DAY



MS POLICY NARRATIVE – EUROPEAN BRAIN COUNCIL



EU ELECTIONS CAMPAIGN

EMPOWERING

THE MS COMMUNITY TO SPEAK UP!

At EMSP, we believe in the power of empowerment as a catalyst for change.

A key feature of EMSP's work in 2018 was the empowerment of the national Multiple Sclerosis (MS) societies to have a stronger, more influential role to address the needs and perspectives of the people with MS across Europe.

Capacity Building Programme and Membership Communications Network

To empower the MS community to raise their voices, EMSP initiated a capacity building programme to work in regional clusters with its member organisations. We began with the Baltic regions and included the following countries: Belarus, Estonia, Latvia, Lithuania and Poland. The capacity building programme allows us to get in-depth understanding of the activities undertaken by the MS societies as well as the challenges they are facing at national level and strategise better their advocacy efforts for a greater impact. As a first practical endeavour, a face-to-face capacity building workshop was organised in early 2019.

We continued the Membership Communications Network activities; it provides a platform to share EMSP's news and updates on projects and ensures ongoing identification of best practices, exchange of knowledge and information between professional staff in member societies. Key news were shared through the EMSP website under the Members sections. EMSP member organisations also supported the translations of the articles in eight languages.

We would like to take this opportunity to thank the 22 members of the Communications Network who actively contributed to our work



Educational Workshops for People with MS and their Representatives

During EMSP Annual Conference 2018 in Bratislava, we organised two educational workshops to support people with MS and their representatives to improve their influential role in the decisions affecting their quality of life. In 2018, the themes of those workshops were:

- The involvement of patients in clinical trials: the workshop was provided by Dr Marleen Verbeeck from the European Center for Clinical Trials and Research (ECCRT). The participants received a basic understanding of the drug development process as well as the role and importance of clinical research in this context.
- The involvement of patients' representatives in Health Technology Assessment (HTA): this workshop was facilitated by Jean Mossman of the London School of Economics who gave a short refresher on what HTA is and how it promotes evidence-based health policy. She shed light on the current situation around the process in Europe by giving an insight into the European HTA regulatory framework and its objectives. Finally, Ms Mossman highlighted why and how patient groups should contribute on national level, empowering them by providing a set of useful tools that could foster their meaningful involvement.

The participants of the workshops reported that the content of the workshop supported the development or improvement of their advocacy skills and provided them with new ideas to approach their national governments and thus strengthening their voice.

Youth Takes Charge!

In 2018, the voice and lived-experiences of people with MS were heard at high-level engagements with European policy-makers and parliamentarians. The Young People's Network (YPN) was actively involved in supporting the advocacy work of EMSP and the national MS societies.

In 2018, EMSP continued to encourage the members of the Young People's Network to attend trainings and workshops offered by the European Patients' Forum and the European Federation of Neurological Associations. They had the opportunity to develop their advocacy skills and better campaign and add their voices to the MS movement.

Jacobo Santamarta Barral (Spain) and Susanna Van Tonder (Luxembourg) represented EMSP at the high-level meeting of the Brain, Mind and Pain MEP interest group at the European Parliament (February 2018). Jacobo shared his experience about his diagnosis, adaptations to work and more importantly about the need for better support to ensure people living with MS have access to work.



Through awareness raising and advocating for multiple sclerosis, I had found something incredibly rewarding. Being aware that my advocacy work alongside that of other MS advocates and YPN members will have a profound impact on the lives of MSers at an EU and national level is fulfilling: being a part of change carries real meaning.

Susanna van Tonder, MS Society of Luxembourg

EMSP Young People's Representative



Patrik Puljić

Patrik Puljić from Croatia was elected as the young people's representative on EMSP Executive Committee during our Annual General Meeting, in Bratislava. Patrik was also elected to represent EMSP young people's network on the European Patient Forum Youth group.

Patrik is a 26-year-old student living in Zadar, Croatia. He was diagnosed with multiple sclerosis in 2011. In 2015, Patrik participated in the Annual Conference of EMSP in Warsaw, Poland for the first time and then in 2016 in Oslo, Norway. These experiences motivated him to devote his time to advocacy and campaigning in Croatia and in Europe. He was elected as the President of his local MS organisation in Zadar in 2016. Driven by his passion for advocacy, Patrik is dedicated to better understand the disease and fight for the protection of the rights of young people with MS at local, national and European level.

EMSP ALSO SUPPORTED THE #MAKEWORKWORK CAMPAIGN

Helen Chandler (UK) represented EMSP's Young People's Network and worked with EFNA to bring the patient-perspective to the European Academy of Neurology Congress in Lisbon. She delivered a presentation on workability and MS (June 2018).



In the last trimester of 2018 we launched a special article series based on testimonies from members of our Young People's Network.



Susanna Van Tonder

Member of the MS Society of Luxembourg and EMSP's Young People's Network. She shared with us her story of getting involved with her national organization.



Wouters Marijsser

Member of the board of the MS-Ligue Flanders. He has a special interest in empowering young people with MS.



Donna Nahal

Is actively involved in her local MS community and local MS Society - The Birmingham MS Group.

Young People's Network Focus Group Meeting

In September 2018, EMSP organized a focus group meeting with members of the YPN to develop a long-term strategy and identify areas of potential activity.

The main goal of the YPN 2.0 will be to bring change in society and communities to improve the quality of life

of people with MS through the inclusion of the young people in the activities of the MS societies and the MS movement. To do so, EMSP will be working to empower young people through an increased visibility of the YPN and empowerment of local coordinators.

Meaningful Patient Engagement in Research

N2B-Patch Project

The N2B-Patch is a project funded by the European Union Horizon 2020 research and innovation programme, which brings together universities, research institutes, SMEs, industry and patients organisations. This is a research project focused on developing innovative technologies for the treatment of MS, specifically, a new 'nose-to-brain' delivery technology that will provide a minimally invasive and pharmacological use of medically-established biomaterials. This project has the potential to significantly improve treatment of MS patients. Bypassing the blood-brain barrier could lead to a more effective way of treating MS and potentially be a less invasive treatment for patients by avoiding the need for injections and oral medicine.

EMSP is proud to be involved in this European-wide project providing the expertise of patients and circulating widely the innovative outcome of this multi-stakeholder project to our members and wider society.

MULTI-ACT project / Italian MS society (AISM)

EMSP has joined the MULTI-ACT project led by the Italian MS society as a member of the External Advisory Board and Patients Forum. The EU-funded MULTI-ACT project aims to increase the impact of health research on people with brain diseases. It is going to provide a new Collective Research Impact Framework which will be translated into guidelines and tools to improve stakeholder co-accountability in health research and innovation.

This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570

This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No. 721098



COLLECTING REAL-WORLD DATA

DIRECTLY FROM PEOPLE WITH MS
AND THEIR REPRESENTATIVES
TO ENSURE ADEQUATE
RESPONSES TO THEIR NEEDS

MS Registries Mapping Exercise

This project intended to map current MS data collection as a first important step towards standardization of a new minimal dataset for all current and future national MS patient registries in Europe and beyond. A survey allowed us to assess the current MS registry landscape. This led to deeper knowledge on existing MS registries across Europe with detailed breakdown on data types, collection frequency and used measuring instruments.

A peer reviewed publication of the mapping exercise on MS registries across Europe identifying and describing 19 major MS registries in Europe was developed and published early 2019.

We would like to take this opportunity to thank all contributors of the study led by EMSP and the Karolinska Institute: Anna Glaser (Karolinska Institute, Sweden), Prof. Peter Flachenecker (Quellenhof, Germany), Prof. Maura Pugliatti (University of Ferrara, Italy), Alexander Stahmann (DMSG-MS Register), Dr. Paola Zaratina (AISM, Italy).

MS Data Alliance

Since the ECTRIMS congress 2017, EMSP played a key role in discussing with members and partners EMA recommendations on core data elements to be collected by MS registries, common procedures, consents, governance, data quality and registry interoperability.

During 2018, EMSP joined forces with the University of Hasselt and began a dedicated working group to further develop the MS Data Alliance (MSDA) project proposal.

The MSDA is based on two core components:

- The “MSDA toolbox” providing three innovative tools to registries for better data sharing; and
- The “MSDA Academy” for motivation, engagement and education of the MS community.

MSDA aims at influencing a mind-shift on the vital importance and multifaceted usability of good quality real world data - urgently needed as additional evidence for proper decision making by health authorities.

The project proposal was presented to a wider group of stakeholders during dedicated sessions. The MS Data Alliance is designed to boost research and enable better outcomes for the broader MS community with a focus on Patient Reported and Patient Relevant Outcomes (PRO).

Big Data for Better Outcomes (BD4BO) Project

The BD4BO project was a 2-year project, funded through the 'Innovative Medicines Initiative' (IMI) of the European Union's Horizon 2020 research and innovation programme. The overall goal of the BD4BO programme was 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 represented patients' perspective on the ways to share the information that clearly shows the value of including patient centred outcomes (PCO) in data collection and the development of an appropriate and informed consent documents and templates for clinical trials.

In 2018, EMSP supported gathering feedback of patient perspectives on:

- How to construct an informed consent form that is understandable for patients when providing data via clinical trials.
- On the importance of including real-world evidence in bigger data setups.

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

“
EFPIA welcomes the Public Private Partnership initiative in MS Data Alliance as a concrete step towards better connecting health data in Europe, which is a key EFPIA priority in line with the EU Health Summit recommendation supporting evidence-based care and European registries.”

Thomas Allvin, Executive Director Strategy and Healthcare Systems of European Federation of Pharmaceutical Industries and Associations (EFPIA)

MS Barometer

The MS Barometer is a comparative survey based on key MS data collected by the national MS societies. First launched in 2008, the MS Barometer raises awareness on the geographical division that underpins the difference in MS management across Europe. It also serves as a benchmarking tool outlining improvements and actions that can be adopted by national MS societies to influence the decision-makers.

The MS Barometer targets healthcare stakeholders at all levels, including MS patients, healthcare professionals, governmental institutions, insurers and other payers, politicians and financial supporters. The results from this benchmarking tool have proven to be most valuable. The information has been used in advocacy and campaigning activities directed to political decision-makers both at European and national level. Furthermore, it highlights the huge disparities in access to appropriate healthcare and healthcare professionals for people with MS and the unacceptable variations in their quality of life from one country to another.

In 2018, preparatory work to revise and adapt the survey to current needs and challenges in MS has been undertaken. The questionnaire review and development will be finalised in 2019.

FACILITATING EVIDENCE-BASED DIALOGUE AND PROJECTS FOR IMPROVING THE QUALITY OF LIFE OF PEOPLE WITH MS



EMSP Annual Conference 2018

More than 120 delegates from more than 20 European countries attended the EMSP Annual Conference 2018, 8-9th June, in Bratislava, Slovakia.

Co-hosted by the Slovakian MS Society under the theme of MS Research: Moving towards a Patient-Centred Approach, the event gave people the

opportunity to learn about the latest developments in the field of MS research, to understand the political and administrative challenges for access to treatments as well as demonstrating the importance of patients' involvement and perspective in MS research. Patient involvement is vital to ensure outcomes are focused on the real lives and needs of people with MS.



Prof. Alan Thompson,
Dean of the Faculty of Brain Sciences University College London (UCL) – Recent developments on the MS Research Agenda.

Prof. Tobias Derfuss,
Member of the ECTRIMS Executive Committee - ECTRIMS - Supported MS research programmes and current partnerships.

Highlights

Harriet Doig,
Information Advocacy and Research Officer at the MS Society of Ireland - The Role of Patients in shaping up the Research agenda.

MS Nurse PRO: Better Care for People with MS

The MS Nurse Professional is the first and only European, CME-accredited, e-learning training curriculum for nurses progressing their career in the field of MS. It is led by the EMSP in collaboration with the International Organisation of Multiple Sclerosis Nurses (IOMSN) and Rehabilitation in MS (RIMS). The MS Nurse PRO project trains nurses working in the field of MS and contributes to improved healthcare for MS patients. With the extensive geographical outreach and the growth of registered nurses and others completing the online training modules, the project has huge potential in improving healthcare for MS patients in all regions of Europe.

At the end of 2018, this online training had over 7000 registered nurses. As well as from preparatory work that will allow the launch of the training in Denmark and Portugal, we had several minor accomplishments around the project. In December 2018, a launch event took place in Greece. Among others, the Module 4 on treatment was updated and its Polish edition was completed. EMSP has also developed a long-term strategy intended to improve the outreach and quality of the training.

An increase in registration



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 four meetings that took place in 2018.

We advocated on behalf of people with MS at the EUnetHTA meetings where we campaigned for better patient involvement in Health Technology Assessment (HTA) processes impacting the access to treatment for people affected by MS.

Moreover, in 2018 EMSP, together with 13 other patient organizations, co-signed a joint-statement to call on European Institutions to adopt appropriate measures to fully incorporate the meaningful involvement of patients and patient organizations in the European Cooperation on HTA.

“
The integration of the Rehabilitation module in the MS Nurse PRO programme highlights the important collaboration of nurses and allied health care professionals in enhancing activity, participation and autonomy of and with people with MS within their context.”
 Daphne Kos, Vice President of Rehabilitation in MS and MS Nurse PRO Steering Committee Member



MS at Work: a 360° Campaign

Multiple sclerosis is a disease that has a huge socio-economic impact, often marked with productivity losses in terms of employment. Productivity loss has enormous effects on the economy, the local community and on an individual's financial situation. MS at Work projects contribute to minimization of productivity losses that affect economy and individual financial sustainability.

EMSP brings the expertise from European to national level and responds to the needs of the EMSP member societies. We have people who have been interns on the Believe & Achieve programme, return to work experts, health care professionals, MEPs, experts from other brain health organisations, businesses, industry partners and other allies supporting the work on employment issues to ensure we are focusing on the right issues.

To raise awareness on the needs of people with MS for better access to employment and social care, EMSP developed and launched in July 2018 an online hub called MS at Work (www.msatwork.life) to facilitate access and use of the outcomes of the Employment initiatives also developed by EMSP.

The site is a focal point for any person with MS, employers, healthcare professionals or other stakeholder who needs information, wants to read how other people have dealt with issues, use readjustment tools and use EMSP and other expert documents in their work.

Through the promotion of the Believe & Achieve project for patients with MS and other chronic diseases EMSP shows what is possible and how to improve access to employment and training for young people with MS in Europe:

- Localisation of the Employer's Toolkit developed by EMSP in EU countries: EMSP provides guidance to MS societies to adapt the toolkit for local needs, taking into consideration the national specificities and needs.
- Ready for Work is a project that focuses on the workability of persons with MS through a step-by-step information booklet and conversation guide for healthcare professionals to talk about work with their patients and promote work as a clinical outcome in different countries.
- The issue of access to employment and job retention policies will be tackled through: the promotion of the Toolkit for Employers, the Employment PACT and ongoing campaigning on the issues of financial security and employment.
- EMSP has been working with MS Ireland to address the need in that country with a view that this will combine the work of employment-focused projects into a cohesive strategy that can be adjusted according to national needs.

MSatWork.LIFE
It presents our employment-focused materials in an accessible format. Believe & Achieve, Ready for Work, Paving the Path to Participation, Code of Good Practice in MS are all included.

MSat Work.LIFE





THE EFFECT OF SELF-REPORTED SYMPTOMS ON WORK CAPACITY

AN ANALYSIS OF DATA FROM A COST-OF-ILLNESS STUDY WITH 16808 PATIENTS IN 16 COUNTRIES

GISELA KOBELT, PHD

KOBELT G, THOMPSON A, BERG J, ET AL. NEW INSIGHTS INTO THE BURDEN AND COST OF MULTIPLE SCLEROSIS IN EUROPE. *MULTIPLE SCLEROSIS JOURNAL* 2017; 23: 1123-1136

SUPPLEMENT WITH METHODOLOGY AND 16 COUNTRY RESULTS *MULTIPLE SCLEROSIS JOURNAL* 2017; 23(S2): 1-216

KOBELT G, LANGDON D, JONSSON L. THE EFFECT OF SELF-ASSESSED FATIGUE AND SUBJECTIVE COGNITIVE IMPAIRMENT ON WORK CAPACITY. *MULTIPLE SCLEROSIS JOURNAL*, ONLINE MARCH 2018 [EPUB AHEAD OF PRINT]

This talk was organized and funded by Biogen

Facilitating Evidence-Based Dialogue for Better Access to Employment for People with MS

Webinars were held for members, employers and other stakeholders to support better inclusion in the workplace and healthy working environment for people affected by MS.

The first EMSP webinar on Employment took place on the 13th November and the second on 11th December with an average number of 70 participants. A wide range of stakeholders' participation was noted: member organisations, a diverse range of people with MS, and industry partners.

A summary of the webinars can be found on EMSP website and full recordings posted on EMSP YouTube channel.

“Burden and Costs of MS in Europe” Debate at ECTRIMS 2018

“New insights into the burden and costs of multiple sclerosis in Europe”, led by Professor Gisela Kobelt discussed the results of a study based on data from almost 17,000 people with MS. Study results were published and can be combined with other evidence to assess whether the different management approaches provide value to society. The cross-sectional study was conducted in 16 countries. Patients reported on their disease, health-related quality of life (HRQoL) and resource consumption.

The results of this study indicate that the 16,808 participants had a mean age of 51.5 years, and 52% had relapsing–remitting multiple sclerosis (RRMS). Work capacity declined from 82% to 8% and utility declined from normal population values to less than zero with advancing disease. Mean costs were €22,800 purchasing power parity in mild MS, €37,100 purchasing power parity in moderate and €57,500 purchasing power parity in severe disease; healthcare accounted for 68%, 47% and 26%, respectively.

Fatigue and cognitive difficulties were reported by 95% and 71% of participants respectively; both had a significant effect on the individual's utility. Costs and utility were highly correlated with disease severity but as it is frequently highlighted by EMSP, resource consumption was heavily influenced by healthcare systems organisation and availability of services.

In 2018, EMSP encouraged member organizations to use the data for advocacy purposes and co-hosted an event at the ECTRIMS Congress in Berlin to discuss specifically the impact of MS on employment of people with MS.

MOVING ON: LEADING AND SUPPORTING ADVOCACY AND CAMPAIGNS ADDRESSING SOCIAL AND HEALTH POLICIES CHALLENGES

Brain Awareness Week 2018

Brain Awareness Week is a global campaign to increase public awareness of the progress, benefits and importance of brain research. EMSP used the week to highlight different initiatives of the organisation and member societies, the activities of different advocates and to amplify the messages from member societies, partner organisations, health policy and brain health experts.

In 2018, we wanted to encourage more activity amongst our advocates. We supported young people to reach-out in their workplaces and prepare people to deliver information sessions and presentations on MS and brain health. This is an activity that we know would bring greater public awareness of the issues people with MS may face in the workplace and we encourage people to contact us for more information on how to do this.

During Brain Awareness Week 2018, we used the extensive EMSP social media network to focus people on the issues people with MS face across Europe. This was an opportunity for us to ensure valuable activities - such as the Under Pressure Project, MS Nurse Professional, employment-focused projects, data collection and the EMSP campaigning activities in the European Parliament - were amplified to a global audience focused on all activity relating to brain health.

World MS Day 2018

EMSP focused its campaign on:

- Research and Data collection using the results of the MS Barometer to call for policy decision makers and other stakeholders to invest more on health and MS research.
- Socio-economic impact and health gains of early treatment and intervention using the Value of Treatment (EBC) report. Early treatment is key in MS to slow disease activity and progression. In addition, exposure to negative lifestyle factors such as cigarette smoking, and low Vitamin D levels have been reported to decrease disease progression. Economic evidence is provided to base appropriate public health interventions to reduce the MS burden.
- Access to treatment and therapies and how can Real-World Evidence data help influence decision making processes.



worldMSday
30 MAY



MS Policy Narrative, European Brain Council Project

EMSP joined the Expert panel of the MS Policy narrative developed by the European Brain Council. This project aims to drive tangible policy changes in health and social care which can improve the lives of people living with MS across Europe.

This project is building on the Value of Treatment report:



EU-Elections Campaign

In 2018, EMSP joined forces with several broader pan-European organisations to support campaigns for access to better health for patients:



EMSP CONTRIBUTED TO THE DEVELOPMENT OF THE EU HEALTH SUMMIT MANIFESTO (#WEWONTREST)



EPF ELECTIONS MANIFESTO 2019 (#EUROPEFORPATIENTS) PUTTING WHAT MATTERS MOST FOR PATIENTS AT THE HEART OF EU HEALTH POLICY



EBC: ELECTIONS MANIFESTO FOR AN IMPROVED QUALITY OF LIFE OF PEOPLE LIVING WITH BRAIN DISORDERS

BUILDING UP BROADER CROSS-SECTORIAL PARTNERSHIPS

EMSP works for successful collaboration with our partners and allies to broaden our impact by reaching out to the wider healthcare professionals' network as well as the other stakeholders.

These include researchers, academia, other NGOs such as the European Federation of Neurological Associations or the European Patients' Forum. We will continue highlighting MS as an example of long-term, disabling, neurological condition in our campaigning and advocacy activity.

EMSP held its Annual Networking Dinner on 26 February 2018 in Brussels, Belgium. Together with our partners and sponsors, we looked back at EMSP's main achievements in 2017 and we presented EMSP's Work Plan for 2018. On behalf of EMSP's partners, Jean-Pierre Malkowski, Head of Global Ophthalmology Patient Relations of Novartis presented the opportunities and challenges for MS in 2018 and beyond.

In September 2018, we attended the ECTRIMS conference and exhibition in Berlin, being attended by almost 8000 neurologists from around the world. The ECTRIMS leadership offered the opportunity to ten patients and/or their representatives from MS societies to attend for the first time the ECTRIMS Congress. The participants reported back to respective member societies and to EMSP on their learnings.



We would like to
take this opportunity
to thank the Board
of ECTRIMS for their
generosity



ACCELERATING EMSP'S ONLINE PRESENCE: COMMUNICATIONS AT A GLANCE

+13.8%

2,960
Followers
on Facebook

+24.3%

3,430
Tweets



+14.9%

3,450
Followers
on Twitter



+44.4%

1,138
YouTube
Subscribers

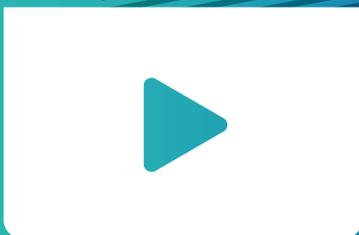


+100.3%

1,230
EMSP Newsletter
Subscribers

4

Videos
Produced



STRENGTH IN NUMBERS

OUR MEMBERS

● Full Members

● Associate Members

MS Society Belgium
ms-sep.be

MS Society Iceland
msfelag.is

MS Society UK
mssociety.org.uk

MS Society France (LFSEP)
ligue-sclerose.fr

MS Society Ireland
ms-society.ie

MS Society France (UNISEP)
unisep.org

MS Society Spain (EME)
esclerosismultiple.com

MS Society Spain (AEDEM)
aedem.org

MS Society Portugal
spem.org

MS Society Luxembourg
msweb.lu

MS Society Germany
dmsg.de

MS Society Switzerland
multiplesklerose.ch

MS Society Netherlands
msvereniging.nl

MS Society Norway
ms.no

MS Society Denmark
scleroseforeningen.dk

MS Society Poland
ptrs.org.pl

MS Society Finland
neuroliitto.fi

MS Society Sweden
neuro.se

MS Society Italy
aism.it

MS Society Malta
msmalta.org.mt

MS Society Bosnia & Herzegovina (SUOMSBiH)

MS Society Serbia
multiplaskleroza.org.rs

MS Society Bosnia & Herzegovina (UOMSRS)
uomsrs.org

OUR CURRENT TEAM

MS Society Czech Republic
roska.eu

MS Society Estonia
smk.ee

MS Society Latvia
mslapa.lv

MS Society Lithuania
liss.lt

MS Society Russia
ms2002.ru

MS Society Austria
oemsg.at

MS Society Belarus
msbelarus.com

MS Society Slovakia
szsm.sk

**MS Society Slovakia
(ZSM Nádej)**
sclerosis-multiplex.sk

MS Society Slovenia
zdruzenje-ms.si

MS Society Hungary
msmba.hu

MS Society Croatia
sdmsh.hr

MS Society Moldova

MS Society Romania
afectiuni-neurodegenerative.ro

MS Society Bulgaria
msobg.org

MS Society Turkey
turkiyemsdernegi.org

MS Society Greece (GMSS)
gmss.gr

MS Society Greece (POAMSKP)
poamskp.gr

Our Executive Committee

Pedro Carrascal, President,
MS Society of Spain (EME/AEDM)

Torben Damsgaard, Vice-President, MS Society of Denmark

Klaus Knops, Treasurer, MS Society of Belgium

Claude Mekies, Member, MS Society of France (LFSEP)

Dimitra Kalogianni, Member, Greek MS Society (GMSS)

Dominika Czarnota-Szałkowska, Member, MS Society of Poland

Georgina Carr, Member, UK MS Society

Hendrik Schmitt, Co-Optee: Herbert Temmes,
Member, MS Society of Germany

Federica Balzani, Member, MS Society of Italy

Jana Hlaváčová, Member, MS Society of Belarus

Tanja Malbaša, Member, MS Society of Croatia

Patrik Puljić, Young People's Representative

Anne Winslow, EMSP Past-President, MS Society of Ireland

Peer Baneke, Observer, MS International Federation (MSIF)

Our Team

Krystalenia Ampreou, Administrative Officer

Žilvinas Gavėnas, ICT Coordinator

Elisabeth Kasilingam, Managing Director

Nora Kriauzaitė, Programme Coordinator

Tagaj Máté László, Communications and Membership Officer

Christoph Thalheim, External Affairs Director

Emma Rogan (MS Ireland), Project Coordinator

Joeri Wullens (Bebotax), Accountant

External Projects Coordinators

MS Data Alliance Project:
Dr Liesbet Peeters, Pieter Van Galen,

MS Nurse PRO: Stefaan De Corte, Elena Kelly

FINANCES

2018

Treasurers Report

After a year with a surplus in 2017, we are closing 2018 with a slight loss (€ -14,351) but which nevertheless has an impact on our reserves.

Income declined seriously in 2018, as a result of the decrease of funding from our current sponsors. We were only able to realize 71% of the budgeted income, reducing the financing for projects. Due to the adequate action of the management, expenditure was reduced in a timely manner, as a result of which the loss remained smaller than budgeted (€ 19,427). Restructure of the Secretariat started at the end of 2017, also impacted the fundraising and planned projects activities.

EMSP's members paid € 95.168 in membership fees in 2018 – a little more than 12% of the total income.

Although we have seen a decreased income from the pharma industry, the companies remain major funders and supporters of EMSP's projects.

EMSP's financial statements since 2011 show a downward trend in income. To reverse this phenomenon, we will have to acquire new sources of financing in the coming years.

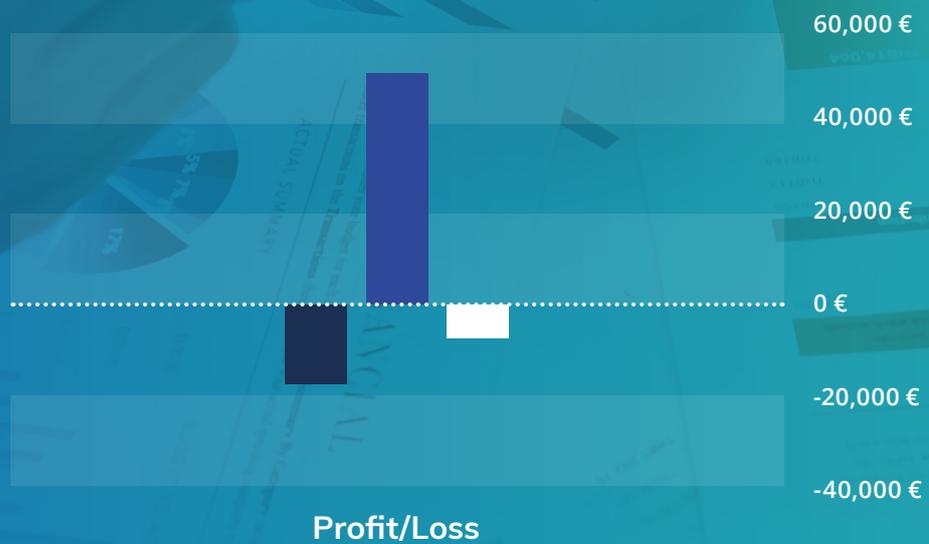
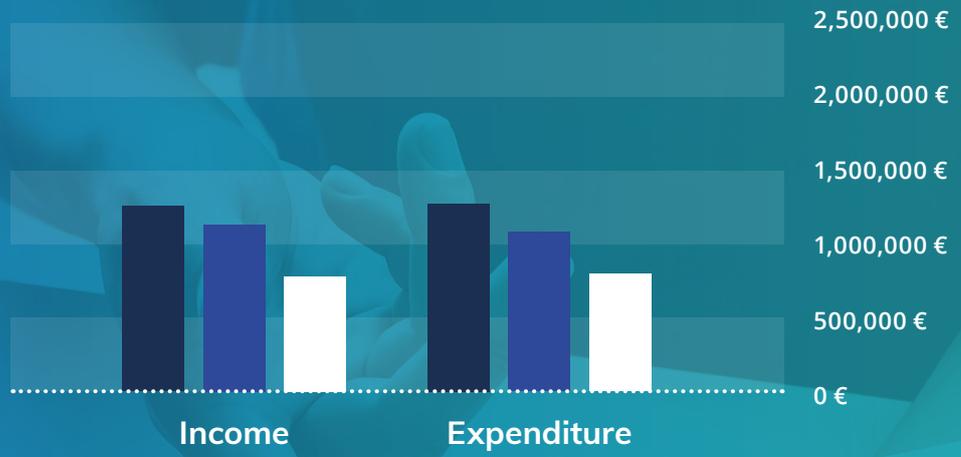
The Secretariat is focusing on finalising the restructuration to fully get back on track to successfully realizing its important assignment for people with MS.



2016

2017

2018



Auditor's Report



Gentstraat 337
9041 Oostakker

Tel. : +32 9 255 50 96 E-mail : revisor@dpo.be
Fax : +32 9 255 50 87 www.dpo.be

AUDITOR'S REPORT
FOR THE YEAR ENDED 31/12/2018
EUROPEAN MULTIPLE SCLEROSIS PLATFORM
RUE AUGUSTE LAMBIOTTE 144/8
1030 BRUXELLES
RPR BRUSSELS NR. 0473.317.141
=====

We hereby present our audit report on the financial statements per 31/12/2018.

We have been appointed as statutory auditor by the general meeting of 18/05/2017, following the proposal formulated by the board of directors. Our statutory auditor's mandate expires on the date of the general meeting deliberating on the financial statements closed on 31/12/2019. We have performed the statutory audit of the financial statements of the Organization "EUROPEAN MULTIPLE SCLEROSIS PLATFORM" for 8 consecutive years.

Report on the audit of the financial statements

Unqualified opinion

We have audited the financial statements of the Organization, which comprise the balance sheet as at 31/12/2018, the profit and loss account for the year then ended and the notes to the financial statements, characterized by a balance sheet total of € 480.225,34 and a profit and loss account showing a loss for the year of € 14.350,98.

In our opinion, the financial statements give a true and fair view of the Organization's net equity and financial position as at 31/12/2018, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.



Auditor's Report (cont)



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RPR Brussels nr. 0473.317.141

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 financial statements' section in this report. We have complied with all the ethical requirements that are relevant to the audit of financial statements in Belgium, including those concerning independence.

We have obtained from the board of directors and organization officials 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 financial statements

The board of directors is responsible for the preparation of financial statements 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 financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the board of directors is responsible for assessing the Organization'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 Organization or to cease operations, or has no realistic alternative but to do so.

Statutory auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements 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.



Auditor's Report (cont)



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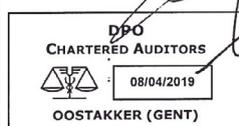
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RPR Brussels nr. 0473.317.141

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 financial statements.

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 financial statements, 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 Organization'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 Organization'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 financial statements 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 Organization to cease to continue as a going concern;
- Evaluate the overall presentation, structure and content of the financial statements and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.



Auditor's Report (cont)



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RPR Brussels nr. 0473.317.141

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.

Done at Oostakker (Ghent)
Date 8 April 2019




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

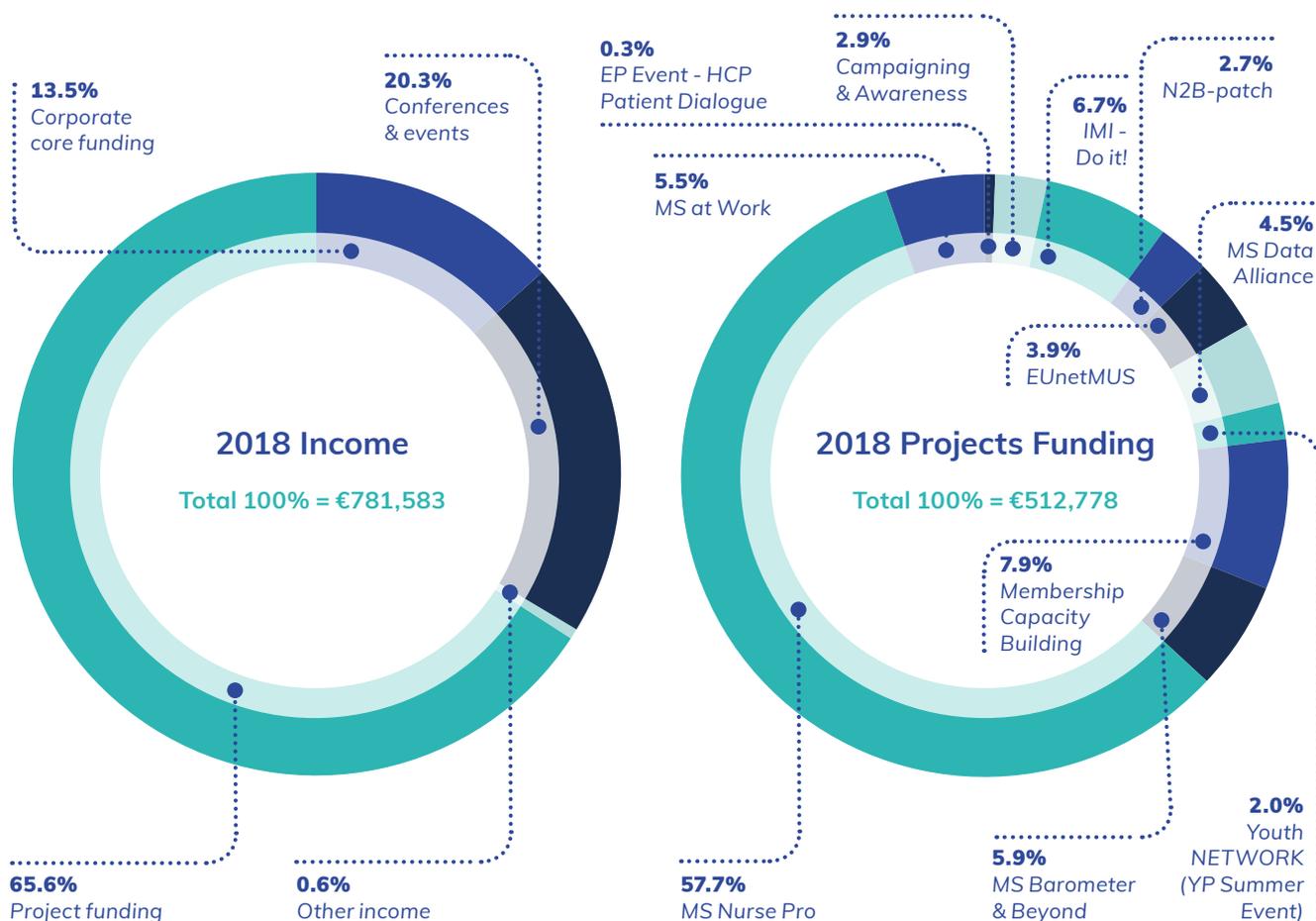


Financial Statements

	2018	2017
Income	Actual	Actual
Corporate core funding	105,168	167,055
Conferences & events	158,809	338,882
Other Income	4,828	23,368
Project funding	512,778	604,991
Total Income	€781,583	€1,134,296

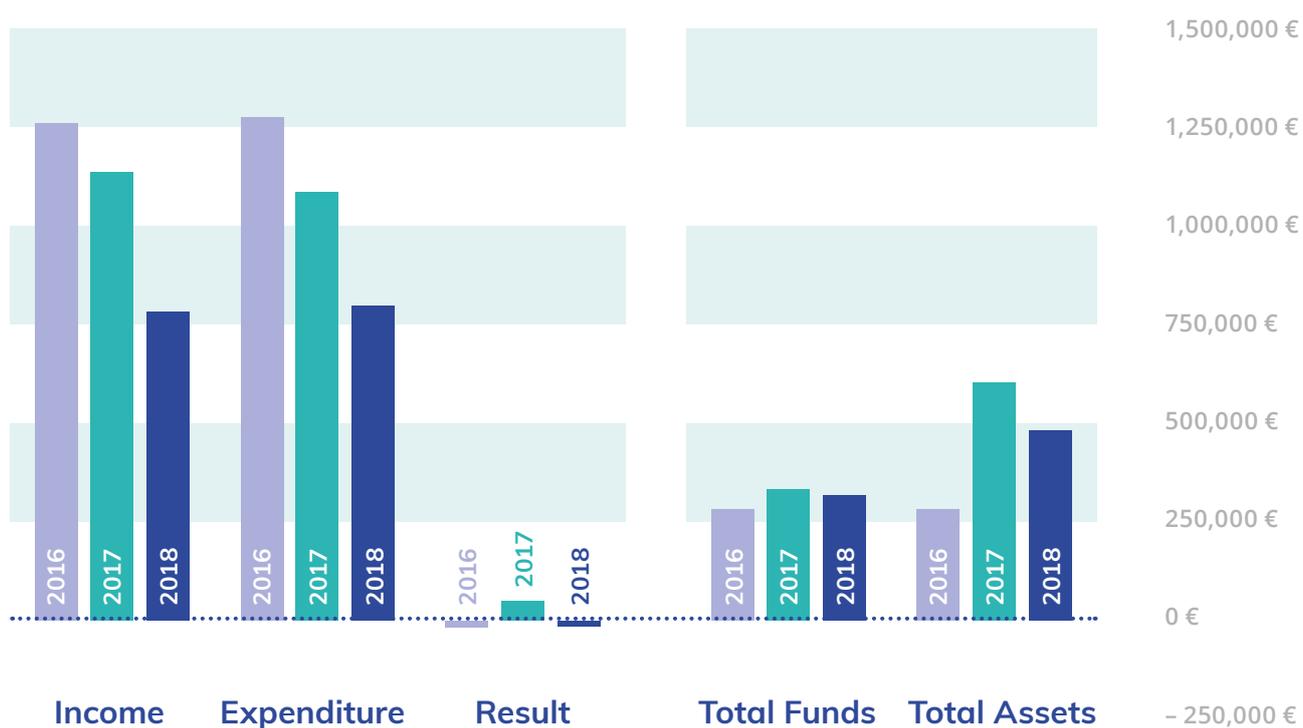
	2018	2017
Expenditure		
Staff & office	275,278	477,129
Outsourcing	64,504	76,938
Office expenses	61,045	41,241
Governance	4,542	11,438
Conferences/Events	127,098	208,256
PR & communication	43,926	12,949
Project expenditure	219,541	256,038
Total Expenditure	€795,934	€1,083,989

Profit/loss for the period	-€14,351	€50,307
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Balance Sheet

Assets/Liabilities	2018	2017
Fixed assets	30,775	29,366
Current assets		
Accounts Receivable - Pharma	215,709	170,285
Accounts Receivable - Members	12,219	7,907
Prepayments	11,243	2,244
Other Debtors	16,590	0
Accrued income	0	40,000
VAT	9,848	172
Bank Current Account	183,843	353,040
Total Current Assets	€480,225	€603,014
Current liabilities		
Trade creditors	45,874	5,217
Deferred income	89,870	18,243
Accruals & other creditors	850	172,113
Taxes & social security	25,794	75,254
Total Current Liabilities	€162,388	€270,827
Total Assets	€480,225	€603,014
Funds	2018	2017
Capital	13,585	13,585
Reserves B'fwd	318,602	268,295
2018 Deficit - 2017 Profit	-14,351	50,307
Total Funds	€317,836	€332,187



ACKNOWLEDGEMENTS

We would like to express our appreciation to all those who provided their support to EMSP and its Secretariat to successfully achieve its activities in 2018 including EMSP member organisations, sponsors, Executive Committee members.

A special thanks goes to the Slovakian MS Society and their enthusiastic group of volunteers for co-hosting the Spring Conference 2018.

We will take this opportunity to thank the MS advocates and experts that contribute to the development of EMSP's projects and help us to deliver high-quality resources for the people with MS including the MS Nurse PRO Steering Committee members, the members of the MS Data Alliance working group and the members of the Young people's Network.

We would like to acknowledge the valuable contribution of the outgoing Executive Committee members during the four-year mandate and we wish them well in their future endeavour. A special thanks to EMSP past-President Anne Winslow whose commitment to EMSP and people with MS has been invaluable and her leadership remarkable during critical moments.

We would like to extend our gratitude to the Member of the European Parliament Kateřina Konečná for supporting our cause, Sue Tilley, Jan van Son, ACW, Thomas Martens and the Crowne Plaza (Brussels).

EMSP's reach and impact is greatly enhanced by the close cooperation with many other European organisations. Among them: Rehabilitation in Multiple Sclerosis (RIMS); MS International Federation (MSIF); European Patients' Forum (EPF); European Federation of Neurological Associations (EFNA); European Brain Council (EBC); the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS); the European Disability Forum (EDF), the International Organisation of MS Nurses (IOMSN).

A heartfelt thank you also goes to the members of EMSP Secretariat who left EMSP in 2018.

Communications and Membership Coordinator:

- Cherie Wee

External Affairs Coordinator:

- Yves Brand

Public Affairs Coordinator:

- Andreea Antonovici



With deepest sadness on the passing of Nicki Abel, member of the MS Nurse PRO Steering Committee who we've lost in August 2018, we dedicate our achievements to Nicki, recognizing her commitment to improve the life of people with MS and support the MS Nurse community across Europe.

In Loving Memory of Nicki Abel

MEMBER OF THE MS NURSE
PRO STEERING COMMITTEE

CORPORATE PARTNERS AND DONORS

EMSP has continued to benefit from the substantial support of corporate partners who have provided funding for key projects.



European Multiple Sclerosis Platform aisbl

Rue Auguste Lambiotte 144/8
1030 Brussels | Belgium
telephone +32 2 304 5015
secretariat@emsp.org

Graphic Design and Artwork
ACW, London, UK



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