



**30 YEARS
ANNIVERSARY**

ANNUAL REPORT 2019

30th Anniversary Special edition (1989-2019)

Since 1989

Our 30th Anniversary Annual Report is dedicated to the founders of each European MS organisation who had the strength and determination to ensure quality care for people affected by MS and the employees across Europe committed to their vision.

30

Years of advocacy &
awareness raising



1

Voice of

41

national MS Societies



19

EMSP Annual conferences



24

EMSP Projects



8000

MS nurses trained
with MS Nurse PRO



Table of contents

About EMSP



6 Foreword



8 The last 30 years



10 Our members



12 Our team

Empowerment of MS societies



14 Capacity building programme



15 YPN 2.0



16 MS Sessions



17 Clinical trials

Better quality of life for people with MS through better management of MS



18 Annual Conference 2019



19 EMA / EUneHTA



20 Campaigning

Better quality of life for people with MS through better management of MS



21 Research and Innovation



22 Paediatric MS and caregivers



23 MS Nurse PRO

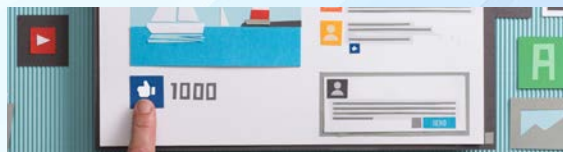
Evidence-based best practices & better cost-effective healthcare



24 MS Barometer



26 Cross-sectorial alliances



28 EMSP's Online Real Estate

Finances 2019



30 Finances 2019

Acknowledgements



38 Acknowledgements

Foreword from the President and the Managing Director

Dear Friends,

The European Multiple Sclerosis Platform has a truly remarkable journey of ensuring that people affected by multiple sclerosis (MS) have a real voice in determining their own objectives and priorities. 2019 was an important milestone for EMSP: the celebration of its 30th Anniversary.

Much has changed since EMSP was founded three decades ago. The work of the European MS Community has significantly altered how health care providers at a European and national level work toward improving the health and health care for people living with MS. In Europe, the growth in number of the newly diagnosed has added to the already strong demand for high-quality, affordable health care for everyone affected by the disease.

Since 1989, thanks to the tireless work of our organisation, our members and partners, the voice of the people affected by MS contributed to the identification of the challenges and priority areas impacting on their lives. We brought together patients, health care professionals, researchers and policy makers ensuring that we all work together towards a common goal: improving the quality of lives of the people affected by MS. We are getting closer to the establishment of a standardised data collection system across Europe every day, which can ultimately support better, data-driven decision making for better personalised care for the people with MS. We have seen an increasing number of people with MS getting access to the care they need. While our work is far from over, we are proud of what we have accomplished in the first thirty years.

In that span of time EMSP has achieved more than any of us could have ever imagined 30 years ago: founded by 21 member organisations in 1989, the organisation consisted of only a Board. The first Secretariat member joined 10 years later. EMSP has been among the lead organisations of the patients' voice in Brussels for the past 20 years. Today, EMSP is a well-established, strong advocate of the voice of people with MS in Europe, with 41 members in 36 countries, acknowledged by the European institutions and key stakeholders in the field of MS.

While EMSP returned to a path of sustainability over the past year, in 2019 we restructured our Secretariat and realigned





our overall strategic objectives in an increasingly challenging economic situation.

All that EMSP has accomplished is due to the initial grassroots efforts of European MS organisations seeking better care and a better-quality life for people affected by Multiple Sclerosis – a mission that remains in focus to this day.

On the pages of this commemorative 30th anniversary annual report, we look back at our humble beginnings and provide a summary of what we have achieved in the previous 12 months. We invite you to read more about what we have learned and what lies ahead.

As always, on behalf of our Executive Committee and Secretariat, we would like to thank all our member organisations, partners, volunteers and corporate sponsors for their continuous support and participation in this wonderful journey.

Pedro Carrascal
EMSP President

Elisabeth Kasilingam
Managing Director

About EMSP

Who we are



Pan-European umbrella organisation with 30 years of experience



41 national MS patient organisations in 36 countries

What we do



Campaigning through advocacy and awareness raising



Collecting and sharing knowledge and expertise



Encouraging research and data collection

“ We work together with our members and our partners to ensure that the more than 770,000 people living with MS in Europe who we represent, have a real voice in determining their own priorities.

Vision



A world without Multiple Sclerosis

Mission



Improving the quality of life of people affected by MS



30 YEARS ANNIVERSARY



Alberto Sainz (Spain), Princess Hélène De Merode (Belgium), Miriam Crenesse (France), Mario A. Battaglia (Italy) - founders and Presidents, acting as volunteers caring for EU funded projects, European advocacy, conferences and training seminars.





The first edition of the MS Barometer was launched, followed by the first "High Level National Roundtable", achieving agreement of the first "pure" MS Rehabilitation Centre in Slovenia.

2008



John Golding, first EMSP President who is a person with MS.

2010



2012 was marked by the launch of the Under Pressure Exhibition in the EP and the adoption of the Written Declaration on tackling MS in Europe.

2012



Under the presidency of Anne Winslow (Ireland), EMSP, launched the Believe and Achieve and the EU-funded Paving the Path to Participation projects on employment.

2014



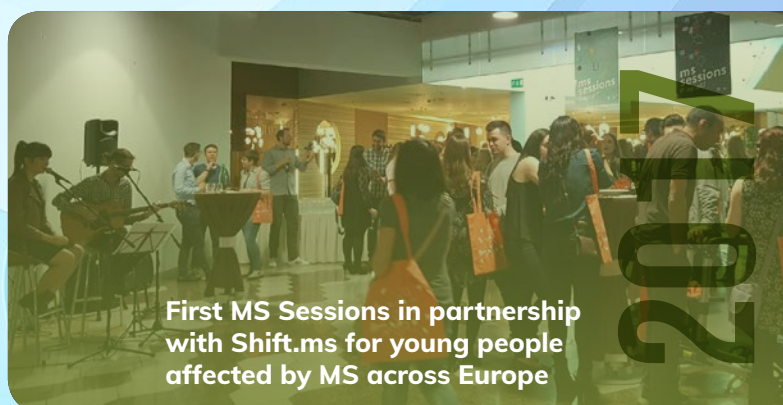
With support from MEPs, Ádám Kósa, Rosa Estaras-Ferragut and Jeroen Lenaers, EMSP launched the European Employment Pact for people with MS and other neurodegenerative diseases in the EP.

2015



Introduction of Cost of Illness study, co-authored by Gisela Kobelt and the launch of the Ready for Work project.

2016



First MS Sessions in partnership with Shift.ms for young people affected by MS across Europe

2017



30th Anniversary under the Presidency of Pedro Carrascal (Spain).

2019



Membership

EMSP has been working with and for MS Societies across Europe since 1989

41 MS Societies

36 European Countries



Full Members



**Multiple Sklerose
Gesellschaft Österreich**
www.oemsg.at



MS Society Belarus
www.msbelarus.com



**Ligue Nationale Belge de
la Sclérose en Plaques**
www.ms-sep.be



**Savez Udruženja oboljelih
Od Multipla Skleroze
Bosne i Hercegovine**
www.aism.it



MS Foundation Bulgaria
www.msobg.org



**Savez drustava multiple
skleroze Hrvatske**
www.sdms.hr



Unie Roska
www.roska.eu



Scleroseforeningen
www.scleroseforeningen.dk



**Estonian Multiple
Sclerosis Society**
www.smk.ee



The Finnish MS Society
www.neuoliitto.fi



**Ligue Francaise contre
la Sclérose en Plaques**
www.ligue-sclerose.fr



**Deutsche Multiple
Sklerose Gesellschaft**
www.dmsg.de



Greek MS Society
www.gmss.gr



MS Felag Islands
www.msfelag.is



MS Society of Ireland
www.ms-society.ie



**Associazione Italiana
Sclerosi Multipla**
www.aism.it



**Latvijas Multiplas
Sklerozes Asociacija**
www.lmsa.lv



**Lithuanian Multiple
Sclerosis Union**
www.liss.lt



**Ligue Luxembourgeoise
de la Sclérose en Plaques**
www.msweb.lu



**Multiple Sclerosis
Society of Malta**
www.msmalta.org.mt



**Multiple Sclerose
Vereniging Nederland**
www.msvereniging.nl



**Multipel Sklerose
Forbundet | Norway**
www.ms.no



**Polskie Towarzystwo
Stwardnienia Rozsianego**
www.ptsr.org.pl



**Sociedade Portuguesa
de Esclerose Multipla**
www.spem.pt



**Asociatia Pacientilor cu Afectiuni
Neurodegenerative din Romania**
www.afectiuni-neurodegenerative.ro



**All Russian Public Organization
(RPO) of Disabled PwMS**
www.ms2002.ru



**Društvo Multiple
Skleroze Srbije**
www.multipleskleroza.org.rs



**Slovenský Zväz
Sclerosis Multiplex**
www.szsm.sk



**Združenje Multiple
Skleroze Slovenija (ZMSS)**
www.zdruzenje-ms.si



**Asociación Española de Esclerosis
Multiple (AEDEM-COCEMFE)**
www.aedem.org



Neuroförbundet
www.neuroforbundet.se



**Schweizerische Multiple
Sklerose Gesellschaft**
www.multiplesklerose.ch



**The Multiple Sclerosis Society of
Great Britain and Northern Ireland**
www.mssociety.org.uk



**Udruženja Multiple
Skleroze Republike Srpske**
www.uomsrs.org



**Union de lutte contre la Sclerose en
Plaques (UNISEP)**
www.unisep.org



**The Hellenic Federation of Persons
with Multiple Sclerosis (HfoPwMS)**
www.poamskp.gr



**Hungarian Federation of
People with Multiple
Sclerosis**



MS Society of Moldova



**MS Association 'Hope'
Združenie Sclerosis
Multiplex Nádej (Msah)**
www.sclerosis-multiplex.sk



**Esclerosis Multiple
España (EME)**
www.esclerosismultiple.com



**Multiple Sclerosis (MS)
Association of Turkey**
www.turkiyemsdernegi.org

Associate Members

Meet EMSP

Executive Committee

President



Pedro Carrascal
MS Society of Spain
(EME/AEDEM)

Vice-President



Torben Damsgaard
MS Society of
Denmark

Treasurer



Klaus Knops
MS Society of
Belgium

Board Member



Claude Mekies
MS Society of
France

Board Member



Dimitra Kalogianni
MS Society of Greece
(GMSS)

Board Member



**Dominika
Czarnota-Szałkowska**
MS Society of Poland

Board Member



Federica Balzani
MS Society of Italy

Board Member



Georgina Carr
UK MS Society

Board Member



New
Member

Herbert Temmes
MS Society of
Germany

Board Member



Jana Hlaváčová
MS Society of
Belarus

Board Member



Patrik Puljić
Young People's
Representative

Board Member



Tanja Malbaša
MS Society of
Croatia

EMSP Past President



Anne Winslow
MS Society of
Ireland

Observer



Peer Baneke
MS International
Federation (MSIF)

Our Team



Christoph Thalheim

External Affairs
Director



Emma Rogan

Project Coordinator
(MS Ireland)



Elisabeth Kasilingam

Managing Director



Joeri Wullens

Accountant
Bebotax



Krystalenia Ampreu

Administrative
Officer



New
Member

Nora Kriauzaitė

Programme
Coordinator



Tagaj Máté László

Communications and
Membership Officer



Žilvinas Gavėnas

ICT Coordinator



Elena Kelly

MS Nurse PRO
Scientific Coordinator



Liesbet Peeters

MS Data Alliance
Project Coordinator



Pieter van Galen

MS Data Alliance
Project Coordinator



Stefaan De Corte

MS Nurse PRO
Project Coordinator

External coordinators

Empowerment of MS societies



A central element of EMSP's work is supporting MS societies and people with MS to subserve meaningful participation in the decision-making processes affecting their lives and in the management of their condition (healthcare, employment, education or policy actions).

At EMSP, we believe in the power of empowerment as a catalyst for change. In 2019, we continued our efforts to empower the national MS societies in Europe to have a stronger, more influential role in addressing the needs of people with MS across Europe.

In addition, we also kept training young people with MS to become advocates, and encouraged them to get involved at national level in awareness-raising campaigns and advocacy activities run by national MS societies.

Capacity building programme and Membership Communications Network

In 2018, EMSP initiated a capacity building programme to work in regional clusters with its member organisations to empower the MS community to raise their voices, starting with the Baltic region. The 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 to strategize their advocacy efforts better for a greater impact.

In 2019, the capacity building programme focused on the Balkan region including MS Societies from Croatia, Bosnia and Herzegovina, Slovenia, Serbia, Romania, Bulgaria, Greece and Turkey. The activities included two regional meetings to strategize regional advocacy efforts and one peer study visit hosted by the MS society, in the United Kingdom, where participants learned the best practices in organisational management and MS campaigning with experts from the UK MS Society and the Multiple Sclerosis International Federation (MSIF).

As a practical outcome, we managed to agree with

national MS associations in the region on a framework for a sustainable, long-term regional collaboration to strengthen the campaigning for improvement of the quality of life of people affected by MS. The programme also enabled us to align the priorities of MS societies and EMSP to become more influential and participative.

We also continued the Membership Communications Network activities, providing a unique internal platform to exchange best practices, as well as knowledge and information between EMSP and dedicated communication specialists from member societies.

We would like to take this opportunity to thank all the members of the Communication Network who actively contributed to our work.



YPN 2.0

Multiple Sclerosis is the most common disabling neurologic disease amongst young people. Therefore, EMSP has been actively supporting the youth from the very beginning to ensure that they have a strong voice in determining their own objectives and priorities.

In the past nine years, the Young People's Network (YPN) of EMSP has grown in numbers and strength, and today we are proud to have over 100 members from across Europe on board.

Last year we continued building on the current YPN to develop a stronger European network of young people living with Multiple Sclerosis and to increase the number of patient advocates on the continent.

We have activated the YPN 2.0 with a renewed strategy. This upgraded version of the YPN aims to bring change both on regional and European level; the quality of life of people with MS will improve through the inclusion of the young people in the governance bodies of the national MS associations by participating in the decision-making processes, which impact their lives.

YOUNG PEOPLE'S NETWORK 2.0

YOUTH
TAKE
CHARGE!



In order to make sure that young people are empowered and prepared to participate in determining their treatment choices, EMSP have organised several webinars, as well as a training workshop aiming at helping young MSers to effectively raise awareness and run advocacy campaigns.

EMSP supported throughout the years the representation of the MS voice by young people from the network through different activities. Representing the YPN in the European patients' movement, three members attended the 1st European patients congress held by the European Patients Forum (EPF) in November 2019. EMSP also continued its special article series launched in 2018, based on testimonies from members of our Young People's Network with 3 new entries:



Patrik Puljić from Croatia



Daniel Lafferty from Scotland



Helen Chandler from the UK

rs
ns
ly



In the past nine years, the Young People's Network (YPN) of EMSP has grown in numbers and strength, and today we are proud to have over 100 members from across Europe on board.



[Young people's network declaration](#)



The support provided for young people with MS unfortunately does not cover the current needs. Consequently, newly diagnosed MSers are “condemned” to isolation, unable to make personal connections with their peers.

Aiming to address this challenge, one of our most important moments of the year was undoubtedly the 2nd volume of the MS Sessions. During the two-day event, EMSP – in partnership with Shift.ms – brought together 142 young MSers in the vibrant city of Bucharest. MS Sessions 2019 provided a platform for young people and their partners and carers—from 35 different countries—to exchange their experiences, find peer support and share best practices.

We also took advantage of this opportunity to share the latest developments in the field of MS with the attendees in order to empower them to proactively manage their condition. Furthermore, we did not miss out on this unique chance to highlight the importance of young people getting involved in advocacy and campaigning opportunities, making their voice heard and ensuring they are represented by MS groups.

During the two-days festival, 22 sessions were hosted by both professional clinical experts on multiple sclerosis, as well as MSers themselves, who shared their own inspiring experiences.

Amongst the experts were

Dr. Jeremy Hobart (Consultant Neurologist - UK), Dr. Sharmilee Gnanapavan (Consultant Neurologist - UK), Dr. Sabina Brennan (Neuropsychologist - Ireland), Dr. George Radu Tanase (Director of the Physcos Institute - Romania) and Dr. Moira Tzitzika (Clinical Sexologist - Greece).

During the week post to MS Sessions, EMSP's Young People's Network received 52 requests to join the group. The reach out also allowed new entries, like Ukraine, to join the European MS movement. Individuals have arranged meetups, been in contact with their local MS Society and shared information about their local networks.

We would like to thank Shift.ms for partnering up once again with EMSP, and all EMSP member societies for their strong support in growing and encouraging young people with MS to be active. Together we are stronger, and we can achieve a greater impact on addressing challenges raised by young MSers more efficiently.

“I loved the weekend, thank you so much for giving me the opportunity to meet likeminded MSers and have lots of fun in the process. It will be unforgettable and I’m truly grateful. I’ve learnt so much and gained friends for life. Absolute magic!”

For more info look for the hashtag #MSsessions19 on Twitter & Instagram





Workshop on clinical trials

During the EMSP Annual Conference 2019 in Vilnius, we organised a professional workshop on Clinical Research facilitated by Marleen Verbeeck, coach of the European Centre for Clinical Research Training (ECCRT). Mrs. Verbeeck presented the requirements of clinical research focusing on five aspects, including ethical principles, available information, informed consent, patient centricity and digital health in the context of clinical trials.

Through an interactive workshop, the participants learned about the European clinical trials database and all the credible resources where people with MS can find more information about previous, ongoing and upcoming clinical trials.

At the end of the workshop and after several fruitful interactive group activities, we were reminded of the importance of future learning, rapid feedback loops between user and researchers, as well as how they can contribute to data driven innovation.



Digitalisation can help make information related to clinical research more user-friendly.

Digitalisation can help make information related to clinical research more user-friendly. Real world evidence can help people avoiding hospital time, meaning that virtual visits can ultimately empower people affected by multiple sclerosis to drive innovation.

Information abundantly present on the Internet can be complicated, and the overload of information can be scary. People affected by MS were reminded to always discuss all their questions with their healthcare professionals first, and to equip themselves before making a decision.

The participants of the workshop reported that the content broadened their knowledge in the field of clinical research and helped them to make more informed decisions in the future.



Striving for a better quality of life for people with MS through better management of MS



Influencing decision-makers can lead to better access to treatments and therapies for people affected by MS, and it can ultimately ensure that health systems across Europe provide the most innovative, efficient and sustainable treatment, care and support to all of them.

With this goal in mind, in 2019, EMSP has been leading joint advocacy and campaigning activities with its member organisations at a national/regional level and other umbrella organisations at an EU level.

On the other hand, we kept raising awareness on the specific needs of people with MS, ensuring their involvement in research and kept equipping MS nurses and informal carers with the skills and knowledge they need and the recognition they deserve.

At last, our special 30 years anniversary Annual Conference provided a unique platform to exchange experiences and ideas in the field of digital health in MS management.

Annual Conference 2019: Digital health in MS Management

This year was a special EMSP's Annual Conference, since the organisation also celebrated its 30th Anniversary. Throughout the years, this event has become a 'to-go-to' meeting for patients, healthcare professionals, industry, patients' organisations, policy and decision-makers and key opinion leaders in the field of MS.

In 2019, the EMSP Annual Conference brought together 172 delegates from 32 European countries between 9-11th May, in Vilnius, Lithuania. It provided a platform to engage in a dialogue on the needs of the people with MS, and how the issue should be addressed politically both at European and national level.

This year's Conference theme was Digital Health in MS Management, raising the following topics:

What would digital innovation bring for people with MS?

Developments on electronic recording and better evaluation of the symptoms;

Progress on supporting care management by the patients within a multi-disciplinary approach framework;

Developments on data collection systems.

Currently, the means used to follow and treat MS are not optimized. The patient assessment relies on a score coming from medical standards tests (MSFC, EDSS, etc.), which are hard and lengthy to conduct and present several limitations. We strongly believe that connecting health data across Europe to support evidence-based care will bring a difference in the quality of care received by MS patients. Furthermore, digital applications and health records empower individuals to better understand and manage their health and well-being. Technologies and digital tools are allowing healthcare professionals to deliver services remotely, thus improving access and facilitating communication between patients and healthcare professional.



Sabina Brennan
Psychologist &
Neuroscientist Trinity
College Dublin, Ireland



Daphne Kos
Vice President of Rehabilitation
in Multiple Sclerosis



Nicola Bedlington
European Patients Forum
(EPF)



Susanna Van Tonder
MS Society of Luxembourg



Marcello Moccia
University College London &
Federico II University of Naples

How digital health
can improve patients'
involvement in MS
research

A multi-disciplinary
approach in
rehabilitation and
benefits of digital
health

The latest priorities
on digital health
policies at European
level

A young person's
perspective on
digital health in MS
management

The latest key
developments
in research and
innovation

Work with the European Medicines Agency / EUnetHTA

EMSP is a member of the [Patient and Consumer Working Party](#) and the Committee for Medicinal Products for Human Use of the European Medicines Agency (EMA). By being an active member within EMA, EMSP is looking to extend an intensive cooperation between MS patients and the EMA to involve people with MS in all possible procedures within EMA. Patients' contribution is very important also for pharmacovigilance, e.g., adverse drug reaction reporting, as well as pushing national authorities to implement all rules of the Pharmacovigilance Directive. Another major

issue in which EMSP is involved is risk/benefit assessment and the communication towards the patients on this issue.

EMSP is a collaborating partner of EUnetHTA, an EU Commission established initiative to create an effective and sustainable network for Health Technology Assessment (HTA) across Europe. EMSP provides support in terms of effectiveness of HTA models, and fights for better patient involvement in processes impacting the access to treatment for people affected by MS.





Shared policy initiatives and campaigning

At the year of the 9th European Parliamentary Elections, a broader alliance with patient organisations enabled us to bring up the priorities of the MS community on the political agenda.

Our pre- and post-electoral campaign allowed us to raise awareness on the political priorities that impact the lives of people with MS, including digital health as a mean to influence decision making processes, Health Technology Assessment, as well as the promotion of the use of Real-World Evidence for improved, patient-centred decision-making.

In 2019, we joined forces with several broader pan-European organisations to support campaigns for access to better healthcare for patients and greater public understanding of brain health in general, and MS in particular:

Endorsement

MEP Interest Group on Brain, Mind & Pain - Book of Evidence (2019-2024) setting a strategic vision on policy action to deliver better care for people with neurological and chronic pain disorders in the EU



Contribution

EMSP contributed to the development of the EU Health Summit manifesto and to the work of the EU Health Coalition

Endorsement

EPF elections manifesto 2019 (#europeforpatients) putting what matters most for patients at the heart of EU health policy



EBC
Election
Manifesto

EBC: elections manifesto for an improved quality of life of people living with brain disorders



Research & Innovation: Bringing the needs and perspective of people with MS into the centre

Supporting research in the field of MS remained one of our three pillars after 30 years. With our active involvement in the EU-funded scientific project of Nose-to-Brain-patch (N2B-patch), we enabled the [inclusion of patients' perspectives](#) at an early stage of this scientific project. The new generation of researchers ask the persons affected by any disease about products that the scientists intend to develop for those affected by the disease. In 2019, we did exactly that. We made sure to bring the questions and expertise of MS community to the table, as well as kept our members and wider society informed about the innovative outcome of this multi-stakeholder project.

The N2B-patch project is a European Union's Horizon 2020 Research and Innovation programme-funded project that has received funding under the grant agreement No. 721098 and started in January 2017.

N2B-patch stands for “Nose-to-Brain-patch”. The consortium aims to develop an innovative technology for multiple sclerosis (MS) treatment by developing a ‘nose to brain’ delivery system which will avoid the need for injections and oral medicine. The direct transport route from the nasal cavity to the brain, bypassing the blood-brain barrier, could potentially offer an innovative method for central nervous system drug delivery. The long-term objective is to improve treatment of people with MS. Science, industry and patients’ representatives work hand in hand in order to achieve the project objectives and maximise impact for patients and their relatives, healthcare professionals and European industries.



More about the project
<https://n2b-patch.eu>



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

Paediatric MS and caregivers: addressing policy and action gaps to support children and adolescents with MS and their carers better

The International Paediatric MS Study Group states that an increasing number of cases of Multiple Sclerosis (MS) in children and adolescents have been recorded worldwide. Between 3-11% of MS cases are now diagnosed before the age of 18. With the increasing number of paediatric MS cases, there is a growing need for the provision of care for children and adolescents with MS.

However, due to the recency of an emerging need and lack of data on paediatric MS, there is a vacuum in policy and action regarding how to support best those children and adolescents with MS and their families who are key carers.

Developing a better understanding and treatment of paediatric MS, as well as supporting and empowering MS carers, have been identified as key priority actions within EMSP's Code of Good Practice.

To address the emerging needs, in 2018, EMSP initiated the [project "Recommendations for Caregivers of Paediatric MS"](#) that aims at improving the quality of care received by children and adolescents with MS and address the challenges faced by caregivers.

On 20 November, 2019, World Children's Day, EMSP published the "Caring for Children and Adolescents with Multiple Sclerosis: Exploring the unmet needs and existing supports for paediatric multiple sclerosis caregivers" report, which identified that families of children and adolescents with MS ask for:

To amplify the needs of those affected by paediatric MS, in 2019, EMSP launched a video-campaign that received outstanding attention by reaching out to 150,000 people.

In order to drive the European Union and the national governments in Europe to reform the health and social care systems to address these policy and action gaps related to paediatric MS, EMSP launched a [petition](#) to ensure the wellbeing of children and adolescent with MS and those who care for them.



Adequate information from healthcare professionals on paediatric MS treatment options and symptom management

Psychological support, especially during the time of MS diagnosis

Stronger social support from networks to cope with caregivers' challenges

Better financial support to undertaking caring responsibilities

Support from educational providers to address the challenges of paediatric MS, such as fatigue and cognitive impairment



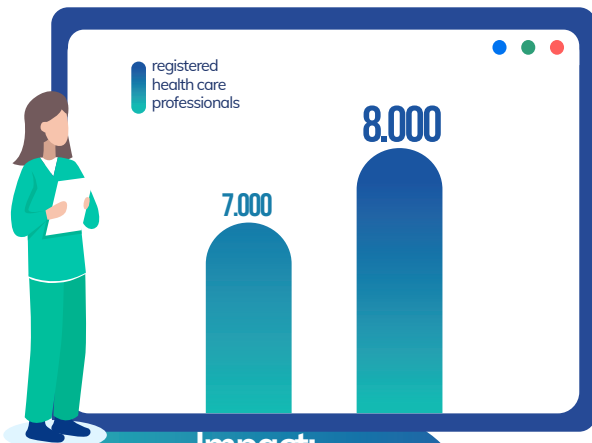
MS Nurse PROfessional: Improving care for people with MS

The MS nurse is key in the provision of expertise and consistent information, support and advice for people with MS. From the moment of diagnosis and throughout the disease trajectory, the nurse ensures a shared and coordinated approach to care. Across Europe, the role, skillset and professional development of MS nurses varies. This leads to inequity of access to expert nursing care and advice, and inequality of patient care experience.

MS Nurse PROfessional (MS Nurse PRO) is the first and only online foundation education programme for nurses working in the field of MS. It is led by EMSP in collaboration with the International Organisation of Multiple Sclerosis Nurses (IOMSN) and Rehabilitation in MS (RIMS). MS Nurse PRO successfully trains qualified nurses who work in the field of MS, contributing to improved healthcare for people with MS in all regions of Europe and beyond. By equipping MS nurses with the skills and knowledge they need, the MS Nurse PRO will create a positive change in MS care that extends across the entire multi-disciplinary care team.



An increase in registered health care professionals



Impact:
Over 60% of nurses indicate that the programme increased their confidence in answering patients and colleagues' questions on Multiple Sclerosis.

Source: Survey to all registered HCP's, 192 answered, May 2018

In 2019, MS Nurse PRO was launched in [France](#) and [Portugal](#). It is now available in 12 languages and was launched and works actively in 15 European countries. At the end of 2019, MS Nurse PRO had approximately 8,000 registered nurses from Europe and across the globe.

With this increasing outreach, growth of registered nurses and accelerated activities around the e-learning platform, EMSP aspires to ensure that adequate numbers of MS nurses are employed to provide appropriate support to all people with MS.

EMSP is also working collaboratively with the MS nursing community across Europe to develop a European MS nurse community that will promote and share their best evidence-based practices, advances in MS care and exchange of peer group support and professional development.



Promotion of evidence-based best practices and better health and social care for people affected by MS

In previous years, EMSP has been working towards the development of tools to collect reliable health and socio-economic data from MS societies. This work is important to monitor patients' disease management, to highlight existing discrepancies in the access to treatment, health and social care and employment.

The MS Barometer and MS Data Alliance projects were

specifically designed to foster reliable and effective information from people with MS and MS societies through data collection. These tools were designed to contribute to evidence-based decision-making and to raise awareness through focused campaigning across Europe on the needs and the issues faced by people affected by MS in their daily lives.

MS Barometer: tracking MS management within the European health systems

For the last decade, the MS Barometer served to track MS management in our health and social systems: collecting data on how health and social systems are performing, indicating areas for improvement - just like an exercise performance tracking tool that tells you what to improve. EMSP, together with its Member Organisations, collected the data and used this tool for European and national advocacy efforts to strengthen health and social systems that should serve by improving the quality of life of people affected by MS.

Data collection was launched in the last quarter of 2019

The 6th edition of the MS Barometer with the new features will be launched in 2020.

In preparation for the new edition in 2019, EMSP reviewed the MS Barometer concept and questionnaire in order to update the tool for the evolving health and social systems, and the better measurement of MS management outcomes that impact the quality of life of people affected by MS.

The new MS Barometer is inspired by the overarching health vision of the World Health Organisation (WHO) in which "all people have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers are motivated, skilled and operate in a supportive environment".



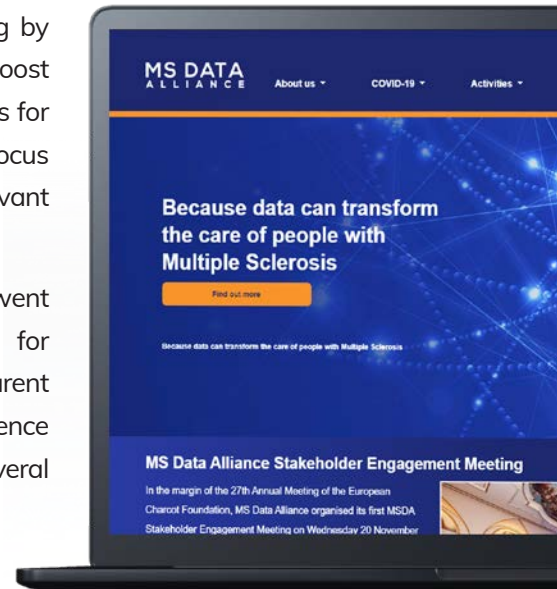
MS DATA ALLIANCE

One of the main objectives of the 'Multiple Sclerosis Data Alliance' (MSDA) is the implementation of a minimal data set and quality standards, approved by the European Medicine Agency (EMA), in as many MS data registries and cohorts as possible. Improving the collection and analysis of real-world evidence can lead to better informed policy and decision makers, regulators, patients and better research outcomes.

MSDA aims to influence 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. It 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).

During 2019, MS Data Alliance went online and developed the topics for promoting trustworthy and transparent practices in the way Real World Evidence (RWE) is used. In this respect, several educational sessions helped the MS community to have a better understanding of these subjects.



The recruitment of registries was ongoing throughout the year. As a result of which, 4 new registries have accepted to take part in the MSDA initiative. The meta-data of 10 registries is now available and a minimal data set has been defined and is being tested for 2 pioneering registries.

On 20 November 2019, a Stakeholder Engagement Meeting was held in Baveno, Italy, gathering 100 stakeholders. These included the MS community represented by individual people with MS, MS Societies, researchers, clinicians, data custodians, industry representatives and regulatory decision makers. Besides raising awareness about the importance of research using real-world MS data, **coming together in Baveno helped the MSDA to lay down its organisational foundations for the next years to come.**



msdataalliance.com

Shared policy initiatives and campaigning in cross-sectorial alliances

EMSP's success lies in the effective outreach and engagement to the MS patients and the caretakers whom we serve, and the major stakeholders in the field. The support of the EMSP membership network and our relevant partnerships both at a European and national level have

been the key factor in our success so far. As part of its activities supporting outreach and visibility, EMSP continued its presence at these forums, with the aim of increasing visibility of neurological diseases on the political agenda through the inclusion of MS as an example in broader campaigns and initiatives.

EMSP collaborates closely with the European Brain Council, the Multiple Sclerosis International Federation and Shift.ms

EMSP has also a Memorandum of Understanding with Caritas Norway



EMSP regularly collaborates with healthcare professionals and the scientific community, like the Rehabilitation in MS, the European Committee for Treatment and Research in MS or the European Charcot Foundation





EMSP is a member of the European Patients' Forum, the European Disability Forum and the European Federation of Neurological Associations



In February 2019, we took a fresh approach to the [EMSP Annual Networking Dinner](#). At an exclusive roundtable meeting attended by industry, our key partners and our organization, we enjoyed an extensive and meaningful exchange on the pathway for stronger future collaborations. We looked back at EMSP's main achievements in 2018 and outlined our common priorities for 2019 and beyond. This was a great opportunity to celebrate 30 years of strong partnerships that have contributed to the strength and longevity of EMSP.

We would like to seize this occasion to express our appreciation to the Board of **ECTRIMS** for their generosity.

In September 2019, we brought the [N2B-patch](#), [MS Data Alliance](#), [Caregivers of Paediatric MS](#), [MS Barometer](#) and [MS Nurse PRO](#) projects to the ECTRIMS Congress in Stockholm. The world's largest annual international conference devoted to basic and clinical research in MS hosted over 9,300 delegates from around the world. Yet again, 10 patients and/or their representatives from MS societies received a unique opportunity to attend the event for the first time, and thus, to follow the latest developments in the field of Multiple Sclerosis.

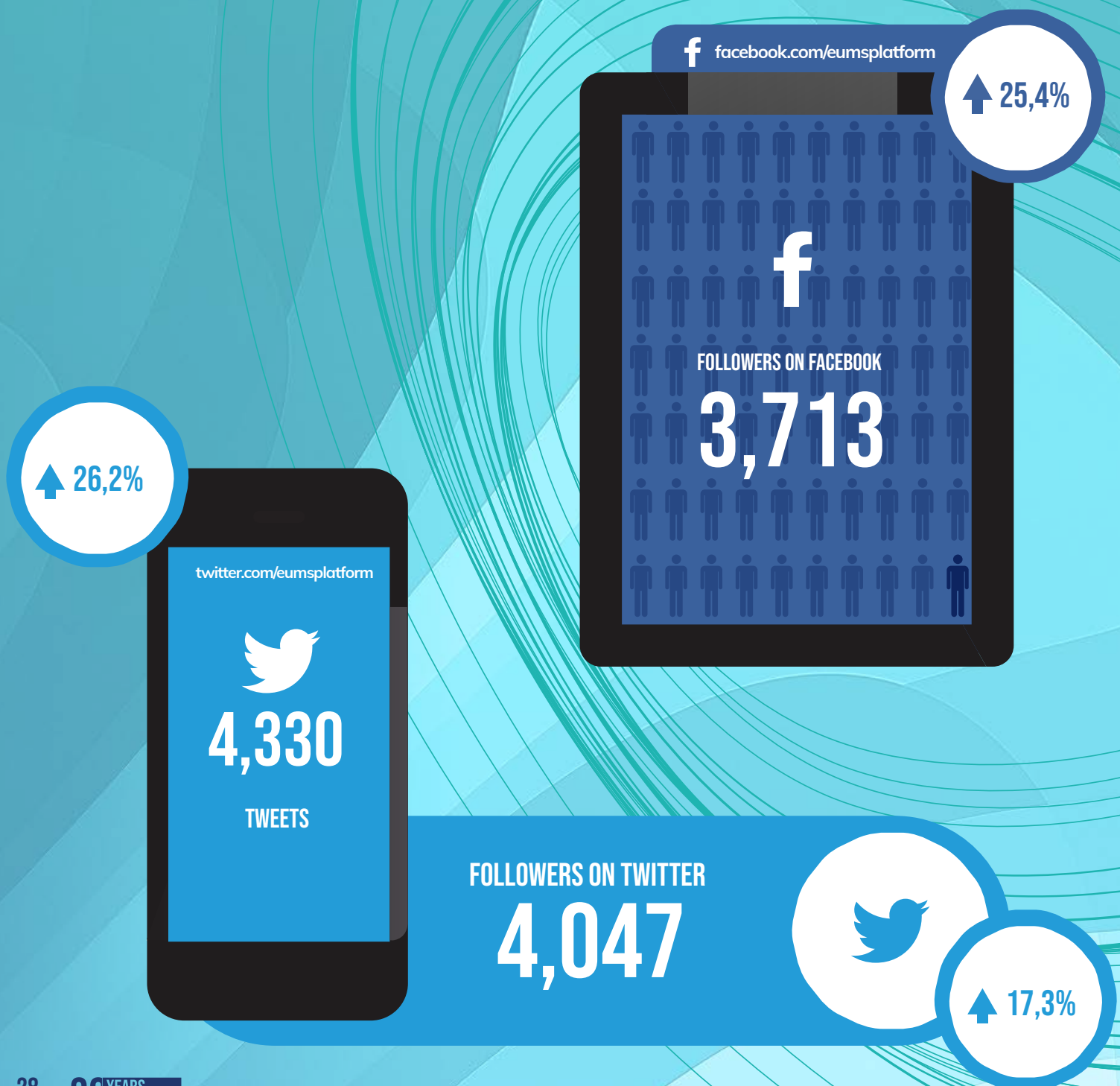
At last, in the beginning of October, EMSP was represented at the [European Health Forum Gastein](#), widely known as 'Davos for Public Health', the leading health policy conference in Europe. Our Director of External Affairs, Mr. Christoph Thalheim had the opportunity to participate in discussions on the benefit and risk balance on new therapies.



EMSP's Online Real Estate: Communications in a digital age

At EMSP we are keen on connecting more with our community. For a meaningful digital engagement, EMSP is using the latest digital communication tools to expand and strengthen the relationship between its organisation and the MS community.

Digital media is transforming our lives and we recognise the importance of digital communication in engaging more effectively with people with MS, MS Societies, researchers, healthcare professionals, industry representatives, decision-makers and our partner organisations.



www.emsp.org

emsp EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

33K

WEBSITE VISITORS

↑ 26,9%

youtube.com/emspvideos

YOUTUBE
SUBSCRIBERS

2,066

↑ 81,5%

VIDEOS PRODUCED

29

FIRST ONLINE PETITION TO SUPPORT
THE CAREGIVERS OF PAEDIATRIC MS

1,277

Signatures



FINANCES 2019

Treasurer's Report

In 2019, we performed well in project sponsorship. Although our fundraiser made very ambitious predictions, the 2019 income budget was revised downwards to diverge not too far from the previous year's reality. But we performed 7% better than the project budget. In practice, however, commitments are sometimes only made late in the year, so that realizations must be moved partly to the next working year. As a result, a good 10% of the project sponsorship is carried over to the next working year, and a comparable part of the previous financial year was transferred to 2019.

Regarding expenditure, a cautious policy was applied, which allowed us to close the financial year with a positive balance of € 37.372, which is € 27.700 more than budgeted for. As a result, the reserves have increased from € 317.836 in 2018 to € 355.208 at year-end 2019.

EMSP's members paid € 94.903 in membership fees – a little less than 8% of the total income. However, we must conclude that a growing number of our members are unable to pay the membership fees. This should prompt us to review our membership fee policy.

EMSP's financial statements since 2011 show a downward trend in income. To reverse this phenomenon, we had to acquire new sources of financing in the coming years. In 2019 we were able to acquire just over 6% from new sources. While we note that income from pharmaceutical industry is under further pressure, the companies remain major funders and supporters of EMSP's projects.

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



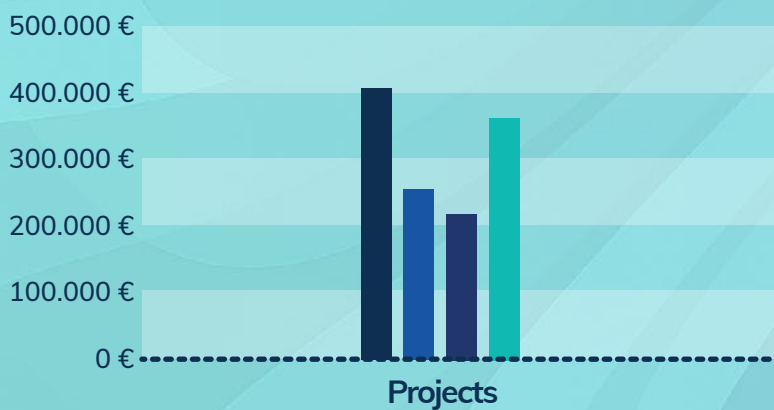
Klaus Knops
Treasurer

2016

2017

2018

2019



AUDITOR'S REPORT
FOR THE YEAR ENDED 31/12/2019
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 31/12/2019.

We have been appointed as statutory auditor by the general meeting, 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 9 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 31/12/2019, the profit and loss account for the year then ended and the notes to the financial statements, characterized by a balance sheet total of € 642.804,96 and a profit and loss account showing a profit for the year of € 37.371,81.

In our opinion, the financial statements give a true and fair view of the Organization's net equity and financial position as at 31/12/2019, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.



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.



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.



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 2 April 2020



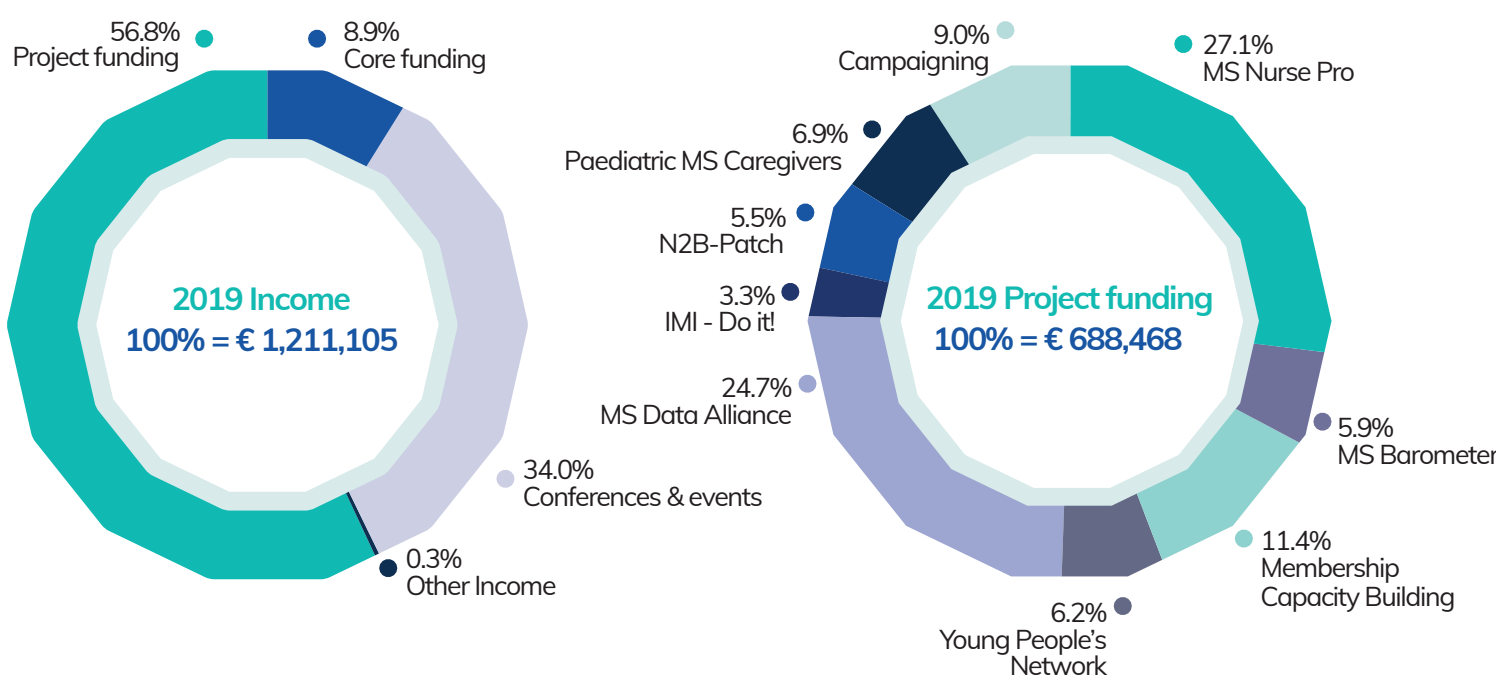
DPO Bedrijfsrevisoren BV
Statutory Auditor
Represented by
Ulrich De Poortere
Registered Auditor - Director

Financial Statements

Income	2019	2018
Core funding	€ 107,206	€ 105,168
Conferences & events	€ 412,257	€ 158,809
Other Income	€ 3,173	€ 4,828
Project funding	€ 688,468	€ 512,778
Total Income	€ 1,211,105	€ 781,583

Expenditure	2019	2018
Staff salaries	€ 263,180	€ 275,278
Outsourcing	€ 131,496	€ 64,504
Administrative costs	€ 74,313	€ 65,587
Direct costs	€ 704,743	€ 390,565
Total Expenditure	€ 1,173,733	€ 795,934

Profit/loss for the period	€ 37,372	€ -14,351
-----------------------------------	-----------------	------------------



Balance Sheet

Assets/Liabilities	2019	2018
Fixed Assets	€ 25,294	€ 30,775
Current Assets		
Accounts Receivable - Pharma	€ 195,965	€ 215,709
Accounts Receivable - Members	€ 21,453	€ 12,219
Prepayments	€ 23,239	€ 11,243
Other Debtors	€ 0	€ 16,590
VAT	€ 21,478	€ 9,848
Bank Current Account	€ 355,375	€ 183,843
Total Assets	€ 642,805	€ 480,225

Funds	2019	2018
Capital	€ 13,585	€ 13,585
Reserves B/fwd	€ 304,251	€ 318,602
2018 Deficit - 2017 Profit	€ 37,372	€ -14,351
Total Funds	€ 355,208	€ 317,836

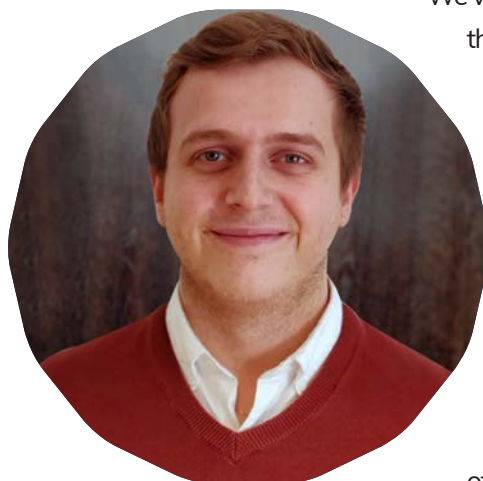
Current Liabilities	2019	2018
Accounts payable	€ 118,792	€ 45,874
Deferred Income	€ 133,000	€ 89,870
Accruals & other creditors	€ 2,621	€ 850
Taxes & Social Security	€ 33,184	€ 25,794
Total Current Liabilities	€ 287,597	€ 162,388
Total Liabilities	€ 642,805	€ 480,225

ACKNOWLEDGEMENTS

On the very outset of this report, we would like to express our gratitude to all who provided their support to EMSP and its Secretariat to successfully achieve its objectives in 2019, including EMSP member organisations, sponsors and Executive

Committee members.

Our sincere appreciation goes to the Lithuanian MS Union (LISS) and their enthusiastic group of volunteers for co-hosting the #EMSP Annual Conference 2019.



We would like to also 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 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 Georgina Carr, former Head of Campaigning and External Relations at the UK MS Society, as well as Hendrik Schmitt, former CEO of the German MS Society during their EMSP Executive Committee mandate. We wish them luck in their future endeavour. A warm welcome goes to our NEW Executive Committee members, namely Herbert Temmes, current CEO of the German MS Society and Jonathan Blades, who is replacing Georgina as Head of External Relations at the UK MS Society.

CORPORATE PARTNERS AND DONORS

We would like to thank the ACW 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 our external consultants who supported the work of the EMSP Secretariat in 2019.

Annual Conference Manager and MS Nurse PRO Project Coordinator: Stefaan de Corte

MS Nurse PRO Scientific Coordinator: Elena Kelly

MS Data Alliance Project Coordinators: Pieter Van Galen and Dr Liesbet Peeters





This report was compiled by
the team of EMSP Brussels Office.



Graphic design by IST1 Freelance Services
www.ist1.dev

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

Please email your comments to
mate.tagaj@emsp.org
© 2020 EMSP

This content is also available in web format

Visit www.emsp.org/annualreport or use the QR code to access

