

ANNUAL REPORT 2014



**25 years  
of patient  
advocacy**

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*cover*

*Quellenhof Centre, Bad Wildbad, Germany, 12/2011*

• Ergotherapist Ingrid Weissinger leads Ernst Friedrich Bieringer through a series of exercises to improve his mobility. The Centre's multi-disciplinary approach is driven by the needs and desires of people with MS.

*photo Carlos Spottorno | [www.underpressureproject.org](http://www.underpressureproject.org)*

# Facts

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

**€ 1,5 million per minute\***

are being spent on brain conditions in Europe

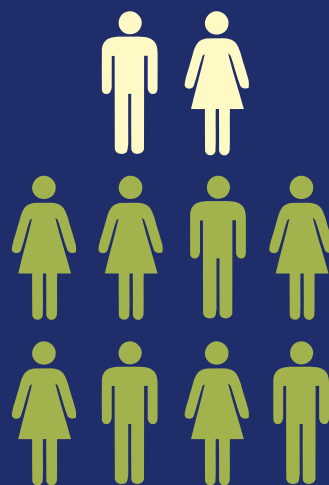


\* European Brain Council, Cost of Brain Diseases in Europe, 2010

**65% of the 1,300 respondents to our young people with MS survey said they are currently employed or doing voluntary work ...**

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

**Activity in the workplace for young people with MS**



**8 out of 10 stop working\***

\* Work Foundation, Ready to Work?, 2011

# EMSP vision and mission: A world without MS

Firmly committed to its ultimate vision of a world without multiple sclerosis, the European Multiple Sclerosis Platform (EMSP) works on a three pillar approach to ensure that people with MS have a real voice in determining their own objectives and priorities: campaigning through advocacy and awareness-raising, collecting and sharing knowledge and expertise, encouraging research and data collection.

EMSP brings together MS activists from across Europe, relying on a growing network of 39 member organisations from 34 European countries. We are the only MS specific organisation that can influence health and other EU policies. This capacity was proven again in 2014, when EMSP received a European Commission grant to produce and promote a Pact for Employment supporting people with MS and other neurodegenerative diseases. It shows our potential to adapt to new expectations from EU decision-makers that patient organisations should be relevant to more than one disease area.

At the same time, EMSP continues to strengthen ties with other patient organisations and federations – such as the European Patients' Forum (EPF), the European Federation for Neurological Associations (EFNA) and the European Brain Council (EBC). We are also in a position to leverage our direct access to the European regulator for pharmaceutical products, the European Medicines Agency (EMA).

Our deliverables for MS communities in Europe make us a credible and transparent partner for important stakeholders in the pharmaceutical industry. Their support is significant in helping to improve the continuation of our flagship projects aiming to enhance the quality of life of over 700,000 people living with MS in Europe.

## A WORLD WITHOUT MS

### ADVOCACY

- Ensure the voice and influence of people with MS is recognised
- Campaign for equitable access to high quality treatment, services and employment across Europe

### KNOWLEDGE AND EXPERTISE

- Share and promote evidence-based best practice
- Foster effective cooperation between people affected by MS, health professionals, policy decision-makers and researchers

### RESEARCH

- Encourage and support high quality MS research and international MS research collaboration
- Support the collection, pooling and interrogation of essential MS data across Europe

## IMPROVING THE QUALITY OF LIFE OF MORE THAN 700,000 PEOPLE WITH MS ACROSS EUROPE

European MS data collection for research and better outcomes:

**EUREMS**

Comparative survey of the national situation in up to 34 European countries:

**MS Barometer**

Online education supporting the crucial role of European MS nurses:

**MS Nurse PRO**

European Code of Good Practice in MS:

**Defeating MS Together**

Multi-media campaign to raise awareness of the impact of MS:

**Under Pressure**

Improving access to employment for young people with MS:

**Believe&Achieve**

Producing and promoting a European Employment Pact for MS and other neurodegenerative diseases:

**Paving the Path to Participation**

# Introduction from the EMSP President and Chief Executive

2014 was an exceptionally eventful year for EMSP. The organisation's 25th anniversary year as the voice of people with MS in Europe was marked at a number of key events and throughout our refreshed publications and online communications.

2014 was also a landmark year for several of our flagship projects. Important milestones were attained in completion of the first three years of the EU co-funded EUREMS project which will ultimately enable better outcomes for people with MS via comprehensive MS data collection and analysis. More countries were added to the growing list of those for which translations into the national language and accreditation for the MS Nurse Pro online training are available.

Of the many positive developments, EMSP continued to benefit from its enhanced visibility at European level – which has enabled us to foster productive relations with parliamentarians; pan-European clinical, professional and academic groups and key decision-making institutions, such as the European Medicines Agency.

EMSP's 25th Anniversary Spring Conference in Dublin provided the ideal setting for us to share and exchange knowledge and best practice with our members and partners. These two key groups of stakeholders have shown a sustained interest in our projects and initiatives throughout the year as exemplified by the enthusiastic take up of Under Pressure (UP) materials at national level in support of a wide range of awareness-raising and advocacy events.

Disappointingly, despite a successful track record in securing funding from both the EU and from corporate supporters, EMSP's application for an EU operating grant in 2014 was declined. Despite this set-back, we were able to attract additional project funding and in particular, we initiated two exciting new projects aimed at boosting employment opportunities for people with MS: Believe and Achieve (B&A), and Paving the Path to Participation (PPP).

The overwhelmingly positive reactions we received after organising the first PPP workshop, and upon announcing the maiden B&A paid internships helped us to maintain momentum in a challenging financial environment.

**“ People with MS need to be listened to. From that grows the work of national societies and that of EMSP. ”**

*[Anne Winslow, EMSP President]*

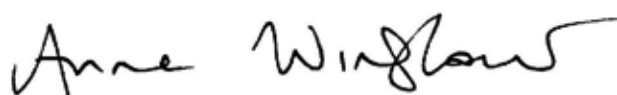
We also took the opportunity to renew our Fundraising Strategy with an even greater emphasis on finding ways to diversify our income generating activities and sources of sustainable funding.

Despite these potential obstacles, the Secretariat team rose to the challenge with their customary high degree of expertise, resilience and commitment. This was greatly helped by the enthusiastic contribution of members of the Executive Committee (ExCom) – both those who served up until the election of new members at the AGM in May, and those who joined the committee after the elections. Although, after his outstanding presidency of EMSP, it was sad to see John Golding step down at the end of his term of office, we are pleased that he will continue to contribute to the ExCom in the role of Past President and to provide his expertise and wisdom in support of the new presidency under Anne Winslow who had previously served as EMSP's Vice President.

Throughout the latter half of 2014, we focused attention on developing a new strategic plan for 2015-2020. Based on consultations with members and other key stakeholders the plan will emphasise the vital importance of working even more closely with member organisations and our new ExCom to ensure continuity and development of our programmes and infrastructure, while also striving to improve our effectiveness as the voice of people with MS in Europe. At the core of the strategic plan will be a framework for implementing the calls included in the revised Code of Good Practice in MS: *Defeating MS Together*.

2014 was a year in which EMSP forged closer alliances with a number of key organisations including Rehabilitation in Medicine (RIMS); European Federation of Neurological Associations (EFNA) and European Committee for Treatment and Research in MS (ECTRIMS) and we intend to build on these as it has been clearly demonstrated that collaboration is key to making the progress that is urgently needed for all those affected by MS in Europe and beyond.

**Anne Winslow**  
President

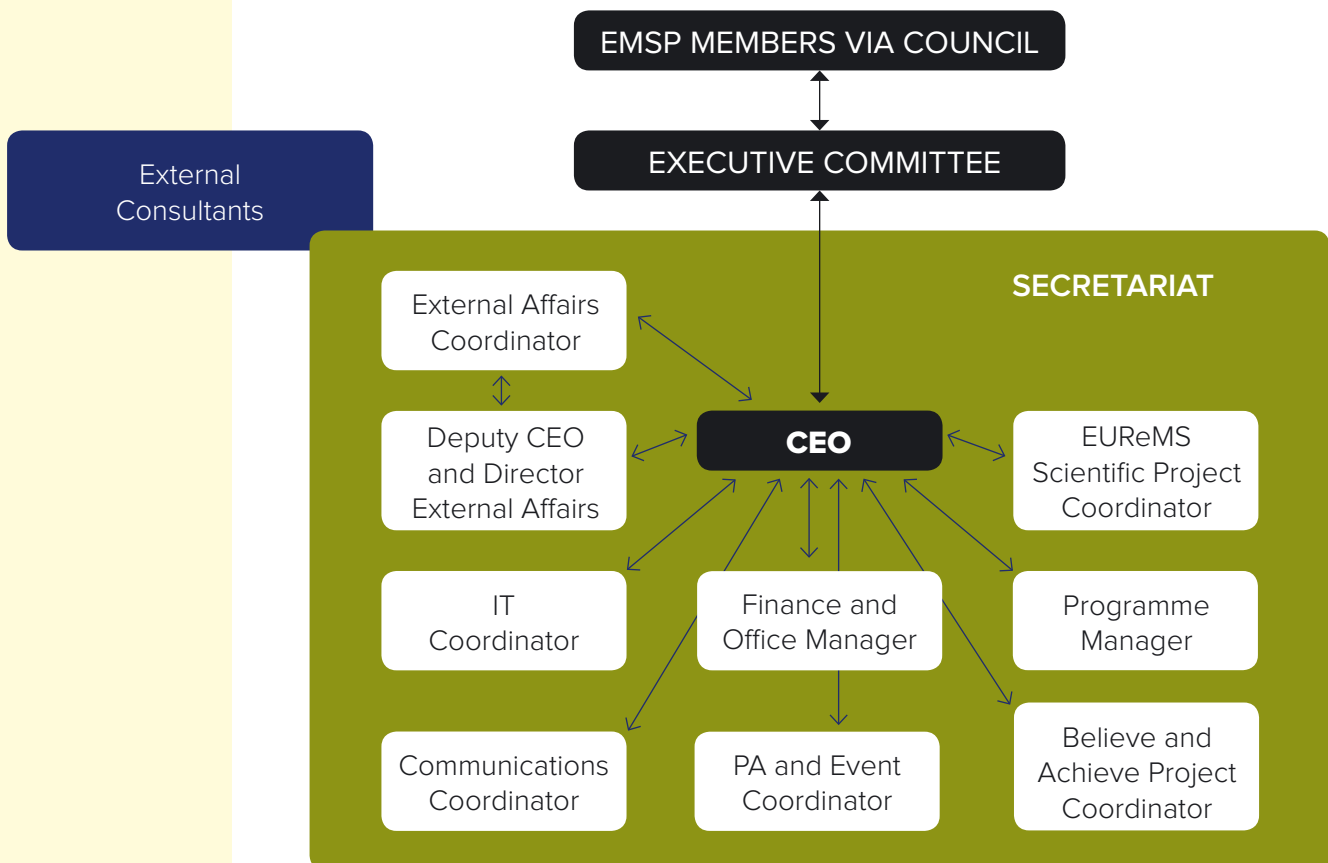


**Maggie Alexander**  
Chief Executive



# Reaching forward

EMSP is headed by the Council of Members which delegates powers to the Executive Committee composed of active members from national MS societies. The May 2014 AGM meeting hosted elections for a new EMSP President and Executive Committee. John Golding was replaced by Anne Winslow as President while four members of the Executive Committee also ended their mandate and ushered in new members. The Executive Committee remains the body overseeing EMSP's vision, mission and values. It also establishes the Strategic Plan which guides all the activities of the Secretariat.



EMSP would like to convey our deepest regret for the passing of our friend and valued ExCom member Andre Van de Putte. Our thoughts are with his family and friends.



## Executive Committee

PRESIDENT	Anne Winslow	MS Society of Ireland
VICE-PRESIDENT	Antonella Moretti	MS Society of Italy
PAST PRESIDENT	John Golding	MS Society of Norway
TREASURER	Torben Damsgaard	MS Society of Denmark
MEMBERS	Dr Olivier Heinzlef	MS Society of France
	Ed Holloway	UK MS Society
	Christoph Lotter	Swiss MS Society
	Majja Pontaga	MS Society of Latvia
	Constantinos Michalakis	MS Society of Greece
CO-OPTEE	Klaus Knops	MS Society of Belgium
CO-OPTEE	Pedro Carrascal	MS Society of Spain (FELEM)
OBSERVER	Peer Baneke	MS International Federation (MSIF)
YOUNG PEOPLE'S REPRESENTATIVE	Shana Pezaro	UK MS Society

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## EMSP Secretariat

EMSP continued to strengthen its secretariat in 2014 by bringing in an External Affairs Coordinator. This new role supports the fundraising activities of the External Affairs Director and also acts as a point of liaison with member societies.

Maggie Alexander	Chief Executive
Christoph Thalheim	Deputy CEO and Director of External Affairs
Ralf Lehmborg	Finance and Office Manager
Elisabeth Kasilingam	Programme Manager
Yves Brand	External Affairs Coordinator
Claudiu Berbece	Communications Coordinator
Andreea Antonovici	PA and Event Coordinator
Tsveta Schyns-Liharska	Scientific Project Coordinator
Emma Rogan	Project Coordinator Believe & Achieve (mainly Ireland-based)
Žilvinas Gavėnas	IT Coordinator

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## External Consultants

EMSP also benefited from the expert guidance and support offered by External Communications Consultant Bettina Hausmann, Director of bhconsult, and Sue Tilley, External Financial Adviser. On a per-project basis, we were also able to draw on the expertise of Dr. Alexis Willett, Director of Punch Consulting and Dr. Sophie Petit-Zeman, Director of SPZ Associates Ltd.

## EMSP team



EMSP Secretariat, Brussels, 11 March, 2014  
From left to right: Ralf Lehmborg, Elisabeth Kasilingam,  
Zilvinas Gavenas, Maggie Alexander, Claudiu Berbece,  
Andreea Antonovici, Christoph Thalheim, Emma Rogan

*Not present for  
the group photo*  
Tsveta Schyns-Liharska  
Yves Brand



*photo by Fabrice Debatty*

# Top achievements in 2014

Our 25th anniversary year brought a number of essential deliverables for EMSP and our constituency and also set the stage for very promising projects dedicated to people with MS across Europe. We've chosen to feature the ones with a potential to positively influence thousands of people throughout the continent:

## **Pioneering cross-border data collection**

EMSP and its project partners have successfully concluded the first major phase of the European Register for MS, started in 2011. This project delivered the first functional European cross-border infrastructure for MS data collection, analysis and dissemination.

## **Supporting employment of people with MS**

EMSP launched two projects aiming to create better and more accessible work opportunities for those living with multiple sclerosis in Europe. The Believe and Achieve programme focuses on identifying meaningful jobs for young people with MS, while EU-funded project Paving the Path to Participation aims to attract broad support for the implementation of a European Employment Pact for people with MS and other neurodegenerative conditions.

## **Unlocking the potential of storytelling**

EMSP's multimedia Under Pressure project – using powerful stories of MS to highlight the health inequalities in Europe – continued its journey in a very busy and rewarding year which saw new country-profile videos launched and numerous photo exhibitions organised by members and partners.

## **Promoting good practice**

EMSP launched a revised version of its 2005 European Code of Good Practice in MS, *Defeating MS Together* as a way of renewing our commitment towards helping shape national and EU health policies according to the priorities of our constituency.

**“ Our primary concern is the quality of life of the 700,000 people affected by MS, and indeed their carers, in Europe.”**

*[ Maggie Alexander, EMSP Chief Executive ]*



Bucharest, Romania, 11/2011 • Cristian Bunda was diagnosed with MS years ago; his case is aggressive and his disability is advancing quickly. He waits in a special area at the Bucharest airport before leaving Romania to get proper MS treatment. Just the previous day, his neurologist had confirmed that his MRI scan showed many more lesions than expected.  
*photo Fernando Molerres | [www.underpressureproject.org](http://www.underpressureproject.org)*

# Making cross-border data collection work

The European Register for MS (EUREMS) was completed by EMSP and project partners at end of 2014, and its main deliverables were highlighted through a special report followed by a stakeholder meeting organised within the Joint Congress of the American and European Committees for Treatment and Research in Multiple Sclerosis, ACTRIMS-ECTRIMS 2014.

EUREMS developed a comprehensive register of multiple sclerosis-related data, with the participation of 23 European MS registries, and on the basis of this data launched four key studies with a potential to improve the understanding of MS.

Gaining a more detailed knowledge of the characteristics of patients and their MS could provide new insight into the causes and course of the condition. Long-term collection of clinical data could also be the source of more information about the safety and effectiveness of disease-modifying drugs (DMDs) in the real world situation.

What EMSP and the 11 project partners achieved through EUREMS could also be significant for other disease areas, and for policy-makers. The successful data gathering method used for this project lends itself to replication and has implications for those interested in identifying better strategies to manage public health.

With the first phase of EUREMS under the EU Health Programme now complete, EMSP will build on the experience and momentum achieved between 2011 and 2014 to encourage a growing number of MS registers across Europe to adopt EUREMS protocols of data pooling and analysis. The post-2014 aim is to create a pan-European data pool to better assess the situation of people with MS.

**“ EUREMS illustrates the feasibility and importance of finding ways to access information directly from patients about their experiences and has implications for those interested in identifying better strategies to manage public health.”**

*[ EUREMS Report ]*

MS registers in  
13 European countries  
provided feedback  
through the initial  
EUREMS survey



# Shaping employment policies

In 2014, EMSP took two major steps in answering calls from a number of members and partners to find ways of supporting people with MS to get and keep jobs.

The first step was starting a project which would enable young professionals with MS to access meaningful work. Two of EMSP's steadfast corporate partners, Novartis and Biogen, showed a great interest in this idea. And the potential employees we approached also gave clear signs that this is a right objective to pursue – a survey run by EMSP in the spring of 2014 among 1,300 young people with MS from all over Europe conveyed the strong message that those living with this condition who are able to work, want to work. This is how the Believe and Achieve project came to the fore. EMSP and project partners acted swiftly and, in the autumn of 2014, made a first round of 15 paid internships available in eight countries in Europe.

At the same time, EMSP's initiatives regarding employment received an important boost from the European Commission, which awarded our organisation a grant to help produce an Employment Pact that would encourage businesses to better integrate people with MS and other neurodegenerative diseases in the job market. This led to the second step: the birth of the Paving the Path to Participation programme. In the summer of 2014, EMSP organised a workshop with representatives from member organisations, national and EU authorities and industry partners which produced important ideas for the future Pact.

Both projects will feature high on EMSP's post-2014 agenda, with next steps including the start of the first Believe and Achieve internships and the launch of the Employment Pact.

**“ Believe and Achieve is a project which gives people with MS an opportunity to fulfil their ambitions. Keep thinking about what you want to achieve and you will achieve it!”**

*[Emma Rogan, EMSP Project Coordinator]*



# Believe & Achieve

This project aims to provide young people with MS with opportunities to work in supportive environments, through partnerships with businesses across Europe.

## Action

- Support young people with MS to gain professional experience.
- Promote healthier and more inclusive workplaces.



## Employees

- Have their abilities and resilience properly recognised and rewarded.
- Receive support to fulfil their potential while becoming full contributors to society.

## Employers

- Become better adapted to the changing needs of the workforce by supporting greater diversity and inclusion.
- Demonstrate good business practice while being able to tap into a new talent pool.

# Paving the Path to Participation

This project aims to promote policy change that will support maximum participation of people with MS in the labour market in Europe.

## Pact

PPP relies on a multi-stakeholder network in its efforts to promote a **European Employment Pact**. People with MS, employers, health-care providers and policy-makers are all taking part.

## Action

- **Implement Pact** in employment policy and best practice.
- **Support businesses** to create solutions for people to stay in or return to work.
- **Persuade policy-makers** and national authorities to adapt policies for flexible working.

# Advocating for real people

EMSP has long been aware of the fact that in representing hundreds of thousands of people with MS across Europe we cannot limit ourselves to disseminating statistics. We have chosen to show the lives of the real people behind the numbers. One way of achieving this is through the Under Pressure project – a multimedia campaign telling the stories of people living with MS in 12 countries in Europe, as different as Belarus and Iceland.

Entering its fourth year in 2014, the challenge for Under Pressure was to keep EMSP's members and partners engaged, following numerous national photo exhibitions, the launch of a project brochure, the creation of a dedicated website and the release of six short video documentaries focused on the countries involved.

The project's stories have remained in high demand. Under Pressure added two more video documentaries and a new exhibition set to its gallery and was present in a number of high profile member and partner events.

The photo panels featuring people with MS from across Europe were exhibited in Greece (January-March), Lithuania (February), Serbia (April) and Spain (May) by EMSP's members in the respective countries. Special highlights included the presence of Serbia's First Lady at the exhibition in Belgrade, and the meeting in Vilnius with then Health Minister Vytenis Andriukaitis, EU Health Commissioner from November 2014.

In the spring of 2014, EMSP launched the Under Pressure country videos for Ireland and Spain, presenting the former during our Spring Conference in Dublin, and the latter in a one-month exhibition in Ciudad Real.

The autumn of 2014 brought two more significant deliverables: the new Under Pressure exhibition set was displayed before a multi-stakeholder audience at the annual summit organised by the European Federation of Pharmaceutical Industries and Associations (EFPIA), and EMSP together with the MS Society of Estonia managed a successful grassroots fundraising campaign which secured the funds for the production of the ninth and last Under Pressure video. The Croatian MS Society translated the original project brochure in the national language and our partners from the MS International Federation used a number of Under Pressure pictures to showcase sections of their new website.

All these significant results prompted EMSP's new President Anne Winslow to describe the project as 'a reminder of what patient advocacy is all about'.

Madrid, Spain, 10/2011 • Almudena Movilla Morena spends a Saturday afternoon at the zoo with her son Jorge and husband David Fernández. For outings taking a long time or involving long distances, she uses a wheelchair. Saving her strenght enables her son to burn his own energy. *photo: Lurdes R. Basolí | www.underpressureproject.org*



“ People with MS actually feel an identity with those who have shared their stories. They feel less isolated and better understood. Also, national MS societies and their staff, as well as scientists and neurologists in the field have said that seeing the Under Pressure stories reminds them why we’re doing what we’re doing.”

*[ Anne Winslow, EMSP President ]*

# Defeating MS Together

EMSP chose 2014 to re-launch its European Code of Good Practice in MS. Started in 2005, it has led to some key deliverables for MS communities throughout Europe. These include the MS Barometer and the MS Information Dividend (MS-ID), which set the stage for the landmark European Register for MS (EUREMS).

In *Defeating MS Together*, the updated and refreshed version of the Code, we present the current issues facing people with MS, and those who care for them, and set out clear calls to action aimed at improving their lives and reducing inequalities.

*Defeating MS Together* has been developed as a vital tool in targeting attention on the issues that matter, highlighting the particular areas in which improvements are urgently needed. It is much more than a set of ideals. It stresses the need for the whole MS community, alongside policy makers, the media, clinicians and academics, to work together to address 12 specific Calls to Action centred around 5 Action Areas: Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services; Better Understanding and Treatment of Paediatric MS; Focusing MS Research; Enabling Employment, Job Retention and Education; and Supporting and Empowering MS Carers.

The revised Code was first presented before members and partners at the EMSP Anniversary Spring Conference in May 2014. There was a general agreement among those present that, despite the progress made since 2005, people with MS across EU continue to face unacceptably wide variation in access to treatment and support as well as barriers to employment and benefits. This is why...

**“Together we must: Commit. Support. Advocate. Act”.**

**“ Over 700,000 people in Europe are living with MS and yet the treatment and support they receive varies widely depending on where they live. Consequently, many people with MS are missing out on the vital care they need. This is unacceptable.”**

*[ Foreword, Code of Good Practice ]*

Madrid, Spain, 10/2011 • Heads turn at the zoo's amphitheatre as David carries his wife, Almudena, up to her seat. On the platform below, her wheelchair is equally eye-catching among many baby strollers.  
*photo Lurdes R. Basolí | www.underpressureproject.org*



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

**Together we must:  
Commit. Support.  
Advocate. Act.**



EUROPEAN MULTIPLE SCLEROSIS PLATFORM | THE EUROPEAN CODE OF GOOD PRACTICE IN MS

*Defeating MS Together*  
**The European Code of  
Good Practice in MS**

# Anniversary Spring Conference

## Dublin, 8-9 May

Our Annual Spring Conference was held on 8-9 May, in Dublin, Ireland. Close to 200 participants attended to mark a very special occasion: EMSP's 25th anniversary.

Together with event partners Multiple Sclerosis Ireland (MS Ireland) and Rehabilitation in Multiple Sclerosis (RIMS), EMSP offered those present at the Conference a dynamic mix of presentations, workshops, debates and entertainment.

In the subsequent Annual General Meeting, on 10 May, EMSP elected a new President, Vice President, Young People's Representative and Executive Committee members.

Outgoing President John Golding had a central role in the proceedings, and his openness and dedication were much appreciated by both colleagues and participants.

Day 1 of the Conference was endorsed by RIMS and focused on rehabilitation, while Day 2 was organised with the support of MS Ireland and centered on therapies and recent developments in the field of MS. Among the highlights of the two days:

- **Launch** of *Defeating MS Together*, a comprehensively updated version of EMSP's European Code of Good Practice
- **Launch** of EMSP's Believe and Achieve project
- **Launch** of the Under Pressure Irish country-profile video documentary
- **Special message** from then European Health Commissioner Tonio Borg
- **Special message** from past EMSP President Michael Willis
- **Presentations and addresses** from Irish Minister of State for Health, Justice, Equality and Defence, **Kathleen Lynch** and European Medicines Agency Head of Department for Patients and Healthcare Professionals, **Isabelle Moulon**
- Presentations from specialists including **Prof Peter Feys**, **Dr Olivier Heinzlef** and **Prof Gavin Giovannoni**
- **A 'well-being market place'** coordinated by **Prof Peter Flachenecker** and introducing a brilliantly energising sit-Zumba session coordinated by physiotherapist **Paul van Asch**.

The enthusiastic participation of all delegates was rewarded by a memorable evening of dance and music from traditional band The Irish House Party and London-based vocal jazz group Take Twenty.



“ The people and the atmosphere. This doesn’t just happen, it was brilliantly created by EMSP.”

[EMSP Conference Report]



# EUReMS at ECTRIMS

## Presentation of studies

EMSP made use of its participation at the Joint Congress of the American and European Committees for Treatment and Research in Multiple Sclerosis (ACTRIMS-ECTRIMS 2014), held in Boston, USA, on 10-12 September, to present the key outcomes from the European Register for MS (EUReMS).

Project partners presented preliminary results of the four studies conducted with the MS data collected and EMSP leaders outlined further achievements.

The studies were generally perceived by those present to be an important step forward towards better understanding MS, with participating Prof Jan Hillert declaring himself both “relieved” and “very satisfied”.

- **The EPI-1-d study** – data collected from 12 national MS registries. Data gathered from 17,000 patients over a total population of 18 million. The upcoming results are likely to ensure the ‘best estimate’ of MS burden in Europe available to date.

- **The EPI-1-s study** – again, 12 data providers participated. “We were able to find peaks in the month of birth of MS patients. April-May seem to be the peak”, reported Dr Pugliatti from the preliminary results. The experience of this study shows that data integration of many registers with different data architectures can be mastered.

- **The DMD-1 study** – three national registers participated, from Germany, Italy and Sweden, and were able to provide data referring to a total of almost 25,000 relevant cases, more than half related to German patients. “People on DMDs appear to be doing a bit better than those who were never treated. The difference is small”, conveyed Prof Hillert.

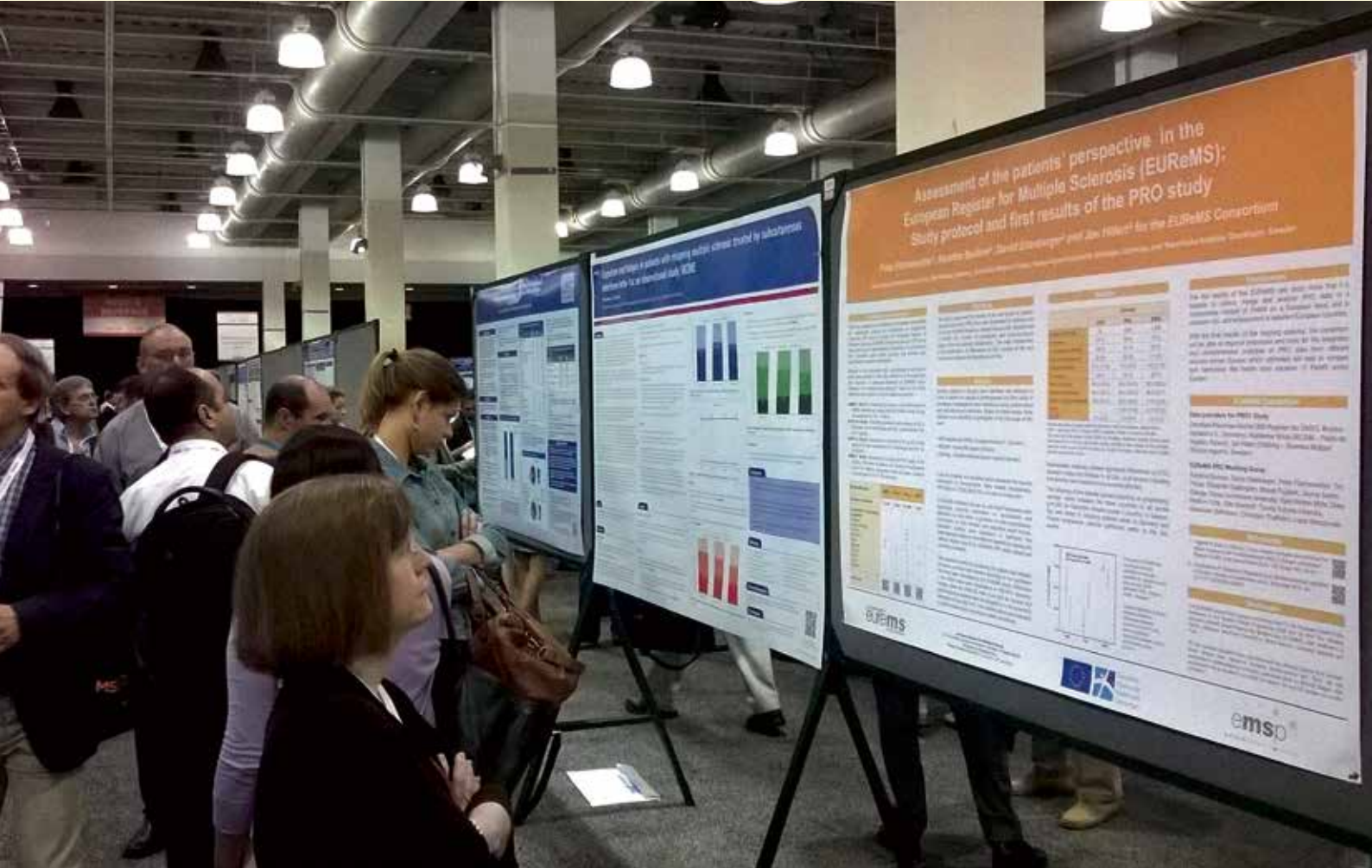
- **The PRO-1 study** – data on quality of life from 4,500 patients was provided by three MS registries, from Germany, Poland and Sweden. One ‘very preliminary’ result shows that MS patients who are unemployed tend to have a worse quality of life.

“ Sharing MS data with partners from across Europe has not been done so far.”

*[ Susana Otero, Epidemiologist,  
Hospital Vall d'Hebron in Barcelona, Spain ]*



The EUReMS project had two of its four studies exhibited as poster presentations at ACTRIMS-ECTRIMS, held in Boston, USA, in September 2014



european register  
**eurems**  
 project of european multiple sclerosis platform

**A collaborative initiative to improve MS research and policy across Europe**

**Better Outcomes with Better Data**  
[www.eurems.eu](http://www.eurems.eu)

emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Addressing a major public health challenge through better data

Multiple sclerosis (MS) is a major inflammatory disease of the central nervous system, affecting young people between the age of 20 and 40. It is widely known as being expensive to treat. In Europe, more than 700,000 people live with MS. Severity of the condition varies from person to person, from mild symptoms to major disability. Half of those with MS lose their jobs, on average, three years after diagnosis. More than 85% spend their lives of up to 15 billion euros per year in Europe. There is no cure for MS yet, but access to diagnostics and treatment have improved through the creation of EUReMS, a widely recognized hub of data and people.

**Better data brings better outcomes on the road to ultimately beat MS!**

The EUReMS project (2010-2018) involves an extensive, long-term study to assess the health and quality of life of people with multiple sclerosis. The EUReMS project is coordinated by the European Commission under the Horizon Programme.

**Improving Multiple Sclerosis Management in Europe:**  
**Better Outcomes with Better Data**  
[www.eurems.eu](http://www.eurems.eu)

**Why EUReMS?**

**Filling the data gap**  
 To better understand and ultimately beat MS we need better evidence. MS is a complex and chronic disease that has been difficult to study. The European Commission is offering a unique opportunity to collect and analyze data on MS across Europe - data that cannot be collected in any one country. This data will be used to improve our understanding of MS and to develop new treatments.

**Data management**  
 The information gathered through EUReMS is being managed by the National Centre for the University of Cologne, Germany. The information is organized in a secure and reliable database. The data will be used to improve our understanding of MS and to develop new treatments.

**Looking ahead**  
 EUReMS will be a key to the knowledge generation of the early stages of MS, a challenge in understanding the early stages of MS. EUReMS will be a key to the knowledge generation of the early stages of MS, a challenge in understanding the early stages of MS.

**Protecting patient data**  
 EUReMS studies exclusively work with anonymized data.

**Main deliverables**  
 EUReMS identified 20 MS registries across Europe. 17 of them started passing their data to EUReMS in 2014.

The EUReMS project is a major initiative to improve the health and quality of life of people with multiple sclerosis. The EUReMS project is coordinated by the European Commission under the Horizon Programme.

# Run for MS

## Raising fun and funds

On 5 October, EMSP's 'Run for MS' team completed the 21 km race of the Brussels Marathon, for a second consecutive year, building on our 2013 performance.

The crisp weather – 12 degrees Celsius at the start of the race – and brief drizzle did not stop our team from enjoying a good run and spreading the core message of this initiative: “Run for MS...not from MS”.

Ten runners joined our cause for this event but perhaps even more noticeable is the fact that, in the build-up for this race, we managed to raise over 1,500 euros for the production of an awareness raising video which will be included in our Under Pressure project – highlighting the sharp inequalities of MS management throughout Europe.

The 'Run for MS' campaign aims to encourage people with multiple sclerosis to take up running, or any other sport which best suits them. And to share their stories.

### Run for MS team

**Emma Rogan** MS advocate and  
EMSP Project Coordinator [emma.rogan@emsp.org](mailto:emma.rogan@emsp.org)  
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**Conor Devine** MS athlete and activist  
**Ramon Arroyo** MS athlete  
and all our partners and supporters

picture:  
Run for MS team,  
Brussels Half-Marathon,  
October 2013



[www.runforms.org](http://www.runforms.org)

# Run for MS

*not from MS*



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

“ Being part of the EMSP ‘Run for MS’ team is a powerful reminder that I am part of a bigger movement, a team to inspire.”

[Emma Rogan, EMSP Project Coordinator]



Emma Rogan,  
MS advocate and  
person living with  
MS in Ireland



'Run for MS' team  
before the October  
2014 Brussels  
Half-Marathon

# Members' Outreach

One of the reasons behind our fast growing membership, which post-2014 is likely to grow beyond 40 member societies, is our sustained outreach at national level. We send regular updates - one newsletter every two months – and pay close attention to any proposal coming from our national MS societies.

We also collaborate with members within our flagship projects. The national ownership concept has been effective in 2013 and 2014 within the framework of our Under Pressure project. But it has also reaped benefits for our MS Barometer and MS Nurse Professional initiatives.

The MS Barometer - a collection of comparative MS data gathered by national MS societies and centralised by EMSP - has reached its fourth edition in 2014. The document was launched around World MS Day. Benefiting from the active participation and involvement of 25 of our member societies, we put together an updated overview of the current situation of MS management in Europe.

EMSP's membership outreach also generated progress for MS Nurse Professional - an accredited online training tool aiming to raise standards of MS nursing in Europe. By September 2014, 1,500 MS nurses from across Europe had already enrolled for MS Nurse Pro. And we were able to arrange post-2014 translation in other European languages than the current English, Spanish, Italian and Czech versions. German and French are likely to be the next languages available.

2014 was also very important for EMSP in terms of networking and representation at national level. We have highlighted a number of events and meetings with a potential to make a positive change for people living with MS in the respective countries:

**“ My message to the MS community is let's pull together beyond 2014 and find the solutions that are needed by each and all of us. I believe this is possible and achievable.”**

*[John Golding]*

## Poland

On 20 February, the Polish MS Society met with representatives of the Polish Ministry of Health in a bid to convince the health authorities to solve the problem of multiple sclerosis patients losing their entitlement to state-funded treatment with disease-modifying drugs (DMDs). The meeting produced a temporary solution involving the pharmaceutical industry. Through Deputy CEO Christoph Thalheim, EMSP supported the cause of the 1,000 Polish MS patients at risk of having their access to subsidised DMDs cut.

## Spain

On 14 March, Her Royal Highness the Princess of Asturias Letizia Ortiz received a delegation from the Spanish MS Society (EME) at the La Zarzuela Palace in Madrid.

During this official reception, the Princess of Asturias showed a great interest in the area of MS research. She expressed her support especially for research into progressive MS, for which very little in the way of effective treatment exists.

## Russia

Over the last two months of 2014, EMSP added its voice to the efforts of its Russian MS Society to persuade Moscow authorities not to close down a very important MS centre, as part of the process of merging two hospitals.

EMSP's President Anne Winslow and Chief Executive Maggie Alexander addressed an official letter to the relevant authorities, drawing attention to the risks of limiting access to treatment. As a result of sustained lobbying, Moscow authorities gave up the plans to close the MS centre and also promised to "improve MS services".

## Hungary

On 2-4 December, the Hungarian MS Society organised a two-day workshop with the participation of the national MS societies of five Central and Eastern European countries. The event took place on 2-4 December, in Budapest, Hungary.

The title of the event was "Make your Voice Heard – How to Communicate with Impact".

The main topic referred to the challenges MS organisations have to face in this region of Europe. EMSP was represented by External Affairs Coordinator Yves Brand.

# Partners' Outreach

Building on positive experiences from 2013 – such as the initiative on neurodegenerative diseases in the workplace – EMSP continued to place great emphasis on the relation with our steadfast partners.

We can single out the important contribution of the MS International Federation (MSIF) to the activity of our Executive Committee, through Chief Executive Peer Baneke. In turn, we had similar arrangements through our Chief Executive Maggie Alexander as EMSP representative with the European Federation of Neurological Associations (EFNA) and European Brain Council (EBC). As in the previous years, EMSP's presence at partner events was considered significant. A few examples:

## **EPF**

The European Patients' Forum (EPF) campaigned for a "vote for a Healthier Europe" around the European elections, from March until May.

A special exhibition was organised in the European Parliament, between 17 and 20 March. EMSP's Communications Coordinator Claudiu Berbece participated in the event and supported the raising of signatures from Members of the European Parliament (MEPs).

Around 30 MEPs signed the Manifesto, rallying to the calls for clear strategies and initiatives on essential topics such as patient involvement, empowerment and equitable access to healthcare.

## **EFNA**

EMSP took part in the Joint Congress of European Neurology 2014 organised between 31 May and 3 June, in Istanbul, by the European Federation of Neurological Societies (EFNS) and the European Neurological Society (ENS).

EMSP was one of ten member organisations of the European Federation of Neurological Associations (EFNA) to participate in a special Patient Corner – an opportunity to raise awareness of individual disease areas. EMSP promoted the newly revised Code of Good Practice in MS, *Defeating MS Together*.

On 24-25 September, EFNA held its Advocate for Brain, Mind and Pain workshop to allow representatives of national neurology and pain patient organisations from across Europe to have their say on the issues that need to be on the European health agenda. EMSP again supported the event.

This was a good opportunity to identify potential case-studies, speakers and content for an MEP Interest Group on Brain, Mind and Pain to be formed by EFNA together with Pain Alliance Europe in 2015.

## EDF

EMSP was represented at the European Day of Persons with Disability – a European Disability Forum (EDF) event hosted by the European Commission on 2-3 December, in Brussels – by our Project Coordinator and MS advocate Emma Rogan.

In a very personal speech she delivered on 3 December, Emma shared her own experience of living with multiple sclerosis while stressing the importance of access to employment: “Paid work opens up opportunities and provides sense of purpose, security and dignity.”

Emma Rogan told an audience of more than 100 stakeholders that after being diagnosed with multiple sclerosis and going through a “heart-breaking” experience – which included losing career opportunities – she was finally able to re-discover “the joy of working”.

Emma Rogan at European Day for Persons with Disability, December 2014



EFNA's Audrey Craven (left) joined by EPF's Laurene Souchet (middle) and Camille Bullot



“Paid work opens up opportunities and provides sense of purpose, security and dignity.”

[Emma Rogan]

# Sponsors' Outreach

Faced with fundraising challenges due to the limited financial backing from EU sources, EMSP was able to rely on its corporate partners who recognised the value of our projects and initiatives for MS communities in Europe. We responded by officially acknowledging their role at our annual Networking Dinner and through lending our expertise to a number of key industry events:

## **BRAI.NS**

EMSP was a prominent participant in a two-day conference focusing on brain-related issues - BRAI.NS 2014 - organised on 14-15 February, in Barcelona, Spain. The event advocated for a “brain-political road map” under the motto “Understanding the brain: Where are we in 2014?”

EMSP's outgoing President John Golding and Deputy CEO Christoph Thalheim gave keynote speeches in front of a specialised attendance of more than 500 stakeholders from the fields of neurology, brain disorders and research: university professors, neurologists, EU decision-makers and industry partners among them.

John Golding and his wife Elisabeth delivered an inspiring presentation from a patient/carer perspective, telling the story of how they managed and are coping with multiple sclerosis. Christoph Thalheim spoke about the unmet needs and societal challenges of MS. BRAI.NS 2014 was organised by pharmaceutical company Novartis.

## **Networking Dinner**

EMSP's leading figures joined by representatives of our partners and sponsors gathered together on 11 March, at the Dominican Hotel in Brussels, for the annual Networking Dinner.

2014 was a very special year for EMSP, marking our 25th anniversary. This landmark provided the occasion to look back on some of the highlights of EMSP's organisational history. Under the motto “25 years as the voice of people with multiple sclerosis in Europe”, outgoing President John Golding's introductory speech briefly underlined EMSP's main achievements throughout the years.





top EMSP's Christoph Thalheim (left) at BRAI.NS, February 2014  
 bottom EMSP's Networking Dinner, March 2014

### **Oceans of Hope**

EMSP joined the worldwide campaign for a unique industry-funded initiative aimed at changing the perception of multiple sclerosis: Oceans of Hope – an international crew of healthcare specialists and people with MS embarked on a mission to sail across the world.

Our September 2014 newsletter featured the profile of one of Oceans of Hope's crew members – Luisa Matias, person with MS and representative of the Portuguese MS Society. We caught up with Luisa at ACTRIMS-ECTRIMS 2014, after she had sailed across the ocean to Boston, USA.

"It was a dream come true for me. Being at sea for one month, I could leave my MS behind and enjoy the experience", said Luisa.

#### **Oceans of Hope in 2014:**

- Tour of European ports, then crossed the Atlantic;
- In October, a multi-port schedule along the East Coast of the US, then the Panama Canal, New Zealand and Australia;
- 6-9 people with MS on board for each leg of the voyage;
- In each port, taking 30-40 local people with MS sailing for a few hours;
- Funded by biotech company Biogen.

### **EFPIA**

EMSP's Deputy Chief Executive Christoph Thalheim attended the Collaboration Summit organised by the European Federation of Pharmaceutical Industries and Associations (EFPIA), in Brussels, on 16-17 October.

Speaking in front of around 150 stakeholders from European institutions, patient organisations and businesses, Christoph Thalheim said that EMSP's European Register for MS (EUREMS) can be employed as a solid pattern for building more patient registries across Europe:

"A European initiative is needed for the establishment of patient registries. EUREMS can be used as an example of good practice in this sense."

The main topics debated during EFPIA's two-day summit included access to medicines, data transparency, unmet needs, patient involvement in health technology assessment (HTA) processes and the use of new technologies for patient advocacy.



## UNDER PRESSURE

### LIVING WITH MS IN EUROPE

The Under Pressure project focuses on the sharp discrepancies in the treatment, employment and empowerment of people with multiple sclerosis (MS) across Europe. It was carried out by a team of five renowned photographers under the coordination of the European Multiple Sclerosis Platform (EMSP) and with the support of MS societies from 12 countries in Europe. The dedicated website hosts up to 600 evocative pictures and a selection of powerful video testimonies emphasising the challenges faced by people with MS and their carers. Under Pressure is also providing MS communities with a photo exhibition and a brochure with facts and figures.

**About EMSP**  
The European Multiple Sclerosis Platform (EMSP) represents more than 600,000 people living with MS in Europe. 2014 marks our 25th anniversary – over the years we have gained the support of 38 member societies from 34 European countries.

Among our other flagship projects: the MS Barometer – a collection of comparative MS data provided by national MS societies; MS Nurse Pro – an accredited online education programme, promoting the role of MS nurses and the provision of care across Europe; and Believe and Achieve – an awareness raising campaign to improve access to employment for young people with MS in Europe.

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*25 years, and more to come, as the voice of people with MS in Europe*

**UNDER PRESSURE**  
LIVING WITH MS IN EUROPE  
Cristina, Romania, 02/2015

A group of people in a room, some standing and some sitting, engaged in a physical activity or exercise. They appear to be holding hands or objects, possibly a team-building exercise.

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**UNDER PRESSURE**  
LIVING WITH MS IN EUROPE  
Frankfurt, Germany, 03/2015

A close-up photograph of a person wearing a blue respiratory mask or device over their mouth and nose. They are wearing a dark cap and a light-colored sweater.

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**UNDER PRESSURE**  
LIVING WITH MS IN EUROPE  
Paris, France, 03/2015

A photograph of a person in a red shirt and dark pants, kneeling on a wooden floor and aiming a bow. They are in a room with a target board in the background.

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# Sharing knowledge and expertise

As part of its efforts to collect and share knowledge and expertise on multiple sclerosis, EMSP has consistently relied on its network of specialists and its excellent working relations with regulators. This was once again visible throughout 2014, when two relevant occasions stood out: the successful finalisation of our EUREMS project – owed in great proportion to specialists such as Peter Flachenecker, Maura Pugliatti and Jan Hillert; and our Anniversary Spring Conference – with a number of recognised professionals present as speakers as well as members of the audience.

The Spring Conference was a special example of disseminating knowledge for the benefit of all MS stakeholders.

For this purpose, EMSP organised a special parallel session on sharing good practice. The session was jointly conducted by specialists representing the the National MS Center in Melsbroek, Belgium and the 'John Paul II' Rehabilitation Center in Borne Sulinowo, Poland.

Renowned neurologist Gavin Giovannoni was also present at the conference, and he encouraged EMSP to continue to tackle the wide variation of access to treatment for people living with MS across Europe.

**“I would really like to encourage you to start an education programme not only for nurses, but for neurologists as well. It is essential that we also train the neurologists.”** *[Gavin Giovannoni]*



**Gavin Giovannoni**  
Neurologist



**Isabelle Moulon**  
European Medicines Agency

EMSP is a member of the European Medicines Agency's (EMA) Patients' and Consumers' Working Party. We acknowledged this special status by inviting EMA's Head of Patients and Healthcare Professionals Department, Isabelle Moulon, as a key speaker at our Anniversary Spring Conference.

With its main role of evaluating the marketing authorisation application for human and veterinary medicine, EMA is always looking at the quality, efficacy and safety of the proposed medicines.

Isabelle Moulon mentioned that the constant interaction between regulators on the one side and patients and healthcare professionals on the other is essential in the drug development process. Furthermore, she stressed that EMA is looking at ways to improve this interaction.

**“ This is a complex area that may require innovative methodology and this is what we want to look at, to capture all the different needs along the patient journey. We all need to collaborate in order to have high-quality medicine on the market.”**

*[ Isabelle Moulon ]*

**EMSP's policy priorities in 2014 were centred on a dual approach: on the one hand – creating the link between European health policy and the deliverables of our flagship projects, and on the other – supporting the work of the European Patients' Forum (EPF), in our capacity as founding members.**

Acting on the recognition fact that healthcare decisions need data support, EMSP has concluded its EUREMS project which created a model of efficient cross-border MS data pooling. We have also tackled the demand for improved care standards through our MS Nurse Pro project which offers a harmonised, evidence-based training programme for MS nurses. We have continued our work on the topic of tackling health inequalities from the patients' perspective, and this is where the MS Barometer and Under Pressure projects provide examples of good practice, and an original approach to telling the stories of people living with MS in Europe. In addition, we have recognised the urgent need to create better employment opportunities for people with disabilities, which is what our Believe and Achieve project is doing for young people with MS.

EMSP realised many years ago that only a powerful European patient voice can stimulate tangible change in health policies. Consequently, we have used our status within EPF to promote joint activities and regular contributions to policy discussions. In this regard, we stand by the view shared recently by another EPF founding member, the European Men's Health Forum:

**“ EPF has not subsumed the role of other voluntary organisations but rather augmented and facilitated their work. The net result is a strong, independent, influential overarching voice combined with an enhanced input at the National and local level. It is impossible to overstate the effect this has had on policy makers and thus potentially on the lives of people we represent.”**

*[Ian Banks, European Men's Health Forum]*

**“ EMSP realised many years ago that only a powerful European patient voice can stimulate tangible change in health policies.”**

EMSP has worked together with EPF on complex dossiers such as clinical trials (European Medicines Agency), medical devices (medical technology industry – EUCOMED) and data protection (European Parliament).

Inspired by a request for help from a French person with MS living in Germany but compelled to travel to France regularly to obtain treatment, we encouraged our members to participate in one of the four regional conferences of EPF on the Cross-Border Healthcare Directive of the EC. The European Commission will assess the implementation of the Directive in Member States in 2015 and we will ensure that it integrates the “grassroots” patients’ experience across the EU.

In a separate initiative, EMSP continued to play an important part in creating an effective and sustainable network for health technology assessment (HTA) across Europe – the EUnetHTA Project. After its successful completion, a new collaboration emerged in the form of a Joint Action to implement the findings. EMSP is part of the Stakeholder Forum representing patients among the four stakeholder groups.

# EMSP in the Media

2014 was a very prolific year in terms of the media and social media coverage around EMSP's projects and initiatives. Our increased focus on in-house communications tools combined with media outreach support from our corporate partners resulted in a selection of extremely useful press articles and advocacy videos with the potential to attract both specialised and general audiences. Examples include:



- Special Report 'Brain and Multiple Sclerosis' was published on EurActiv between 17 and 21 February
- The Report was translated in several EU languages
- EurActiv has an outreach of 100,000 EU stakeholders in Brussels and 500,000 in the European capitals





- MS advocate Shana Pezaro spoke at EMSP's Anniversary Spring Conference about the three main priorities for young people with MS
- The video was posted on our Facebook account on 30 June
- Shana's message reached over 13,000 people in a few days and totalled 47 shares and 25 likes



- EMSP's European Register for MS (EUREMS) received a half-page feature in The Parliament Magazine's issue published on 22 September 2014, dedicated to the Gaston Health Forum
- TPM is the magazine of the European Parliament
- TPM has a monthly online audience of more than 50,000 EU stakeholders
- 2,500 hard copies are also distributed in the European Parliament, Commission and Council every month

# Treasurer's Report

The accounts for 2014 show a planned deficit of € 52,829 against a budget deficit of € 50,150. The Council approved the deficit budget as we had made a surplus of € 58,671 in 2013, and it was agreed that € 55,000 of the surplus from the previous year be used to bridge the gap in income as for the first time in two years we did not receive an Operating Grant from the EU.

The total income raised fell below that which we had in our budget by € 219,380 but a large proportion of that was due to income expected against our EUREMS project which was not required. As a result, our expenditure on EUREMS was also below budget by € 216,701.

Compared to 2013 we managed to increase project funding by € 116,000 which partly made up for the lack of an EU Grant of € 278,000 received in 2013. We have managed to contain costs within the budget parameters that were set, which has been a notable achievement, particularly with new projects coming on stream during the year.

Total costs fell by € 52,000 from 2013 to 2014. Staff costs 2013-14 rose by € 94,230 due to the move from some consultancy arrangements to in-house staffing and inclusion of the new (project-funded) Believe & Achieve Coordinator post and the External Affairs Coordinator which was developed as part of the Fundraising Strategy. We also implemented a long-standing commitment to introduce a group pension scheme for EMSP staff.

The total change in results from 2013 to 2014 is € 111,000 (€ 58,671 + € 52,829) and our total reserves at the end of 2014 have been reduced by € 52,829 to € 335,099. It is recognised that a continued imbalance between our income and expenditure at that level in the years to come is not sustainable.

Looking forward to 2015 we have had to consider very carefully how we maximise income generation and make best use of our resources. We foresee that EMSP will not be in a position to obtain EU core funding for up to three years from now, which will necessitate a change in our funding structure. EMSP's Secretariat and the ExCom have developed a new fundraising strategy, which will be implemented starting in 2015. EMSP continues to be reliant both on the excellent relationships that we have within industry and identifying new income sources to help us achieve our goals.

The total cash held represents approximately three month's expenditure, so the emphasis on monitoring cashflow remains as strong as ever.

However, we are confident that we have the plans and expertise in place to ensure that EMSP remains on track and is in a position to pursue important opportunities as they arise.

**Torben Damsgaard** – *Treasurer*  
April 2015

# Auditor's Report



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STATUTORY AUDITOR'S REPORT  
TO THE GENERAL MEETING OF THE ASSOCIATION  
**EUROPEAN MULTIPLE SCLEROSIS PLATFORM**  
**AUGUSTE LAMBIOTTETRAAT 144/8**  
**1030 BRUXELLES**  
FOR THE YEAR ENDED 31/12/2014  
RPM BRUSSELS nr. 0473.317.141  
=====

As required by law and the association's by-laws, we report to you in the context of our appointment as the association's statutory auditor. This report includes our opinion on the annual accounts, as well as the required additional statements. The annual accounts include the balance sheet as at 31/12/2014, the income statement for the year then ended, and the disclosures.

### Report on the annual accounts - Unqualified opinion

We have audited the annual accounts of the association "European Multiple Sclerosis Platform" for the year ended 31/12/2014, which show a balance sheet total of 784.272,39 EUR and a loss for the year of 52.829,57 EUR.

#### *Responsibility of the board of Directors for the preparation of the annual accounts*

The board of Directors is responsible for the preparation of annual accounts that give a true and fair view in accordance with the financial-reporting framework applicable in Belgium, and for such internal control as the board of Directors determines is necessary to enable the preparation of annual accounts that are free from material misstatement, whether due to fraud or error.



RPR Gent 0475.558.633 • BTW BE 0475.558.633 • KBC OOSTAKKER 446-6623901-08 • BIC KREDBEBB • IBAN BESB 4466 6239 0108



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RPM Brussels 0473.317.141

### *Responsibility of the statutory auditor*

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing (ISA). Those standards require that we comply with the ethical requirements and plan and perform the control to obtain reasonable assurance about whether the annual accounts are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the statutory auditor's judgment, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the statutory auditor considers the association's internal control relevant to the preparation of annual accounts that give a true and fair view, in order to design control procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of valuation rules used and the reasonableness of accounting estimates made by board of Directors, as well as evaluating the overall presentation of the annual accounts.

We have obtained from board of Directors and association officials the explanations and information necessary for our audit.

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

### *Unqualified opinion*

In our opinion, the annual accounts of the association "European Multiple Sclerosis Platform" give a true and fair view of the association's equity and financial position as at 31/12/2014, and of the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.



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### Report on other legal and regulatory requirements

The board of Directors is responsible for the compliance with the Law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations, with the by-laws and with the legal and regulatory requirements regarding bookkeeping.

In the context of our mandate and in accordance with the Belgian standard which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, our responsibility is to verify, in all material respects, compliance with certain legal and regulatory requirements. On this basis, we make the following additional statements, which do not modify the scope of our opinion on the annual accounts:

- Without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- There are no transactions undertaken or decisions taken in breach of the by-laws or of the Law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations that we have to report to you.

Done at Oostakker (Ghent)  
April 28<sup>th</sup>, 2015



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



# 2014 Financial Statements

<b>Income</b>	2013	2014
Membership fees	79,553	79,278
Corporate core funding	110,000	90,000
EU operating grant	278,417	–
<b>Project funding</b>	<b>862,918</b>	<b>948,474</b>
EUREMS	436,940	302,229
MS Nurse Pro	323,056	386,540
Under Pressure	73,500	36,000
Believe & Achieve	20,000	110,900
Paving the Path	–	29,305
MS Barometer & Beyond	–	13,500
Other projects	9,422	70,000
<b>Events</b>	<b>137,250</b>	<b>175,381</b>
<b>Other Income</b>	<b>5,780</b>	<b>17,896</b>
<b>Total income</b>	<b>1,473,918</b>	<b>1,311,029</b>

<b>Expenditure</b>	2013	2014
Staff costs	498,741	592,971
External fees	77,743	34,914
Office and other costs	101,614	132,662
<b>Events</b>	<b>122,376</b>	<b>158,695</b>
<b>Project expenditure</b>	<b>614,773</b>	<b>444,616</b>
EUREMS	312,019	95,789
MS Nurse Pro	248,842	300,232
Under Pressure	52,687	31,575
Believe & Achieve	–	2,029
Paving the Path	–	12,727
MS Barometer & Beyond	–	628
Other projects	1,225	1,636
<b>Total expenditure</b>	<b>1,415,247</b>	<b>1,363,858</b>

<b>Result</b>	2013	2014
<b>Profit/Loss for the period</b>	<b>58,671</b>	<b>– 52,829</b>

*all figures in euros*

# 2014 Balance sheet

<b>Assets/Liabilities</b>	<b>2013</b>	<b>2014</b>
<b>Fixed assets</b>	<b>41,727</b>	<b>40,482</b>
<b>Current assets</b>	<b>582,183</b>	<b>743,790</b>
Accounts receivable – Pharma	185,914	220,096
Accounts receivable – Members	4,550	5,025
Balance due from EU	83,958	138,000
VAT	10,586	976
Prepayments & Other Debtors	34,652	9,536
<i>Total debtors</i>	<i>319,660</i>	<i>373,633</i>
Bank current accounts	61,462	168,604
Bank guarantee account	201,061	201,553
<i>Total bank and cash</i>	<i>262,523</i>	<i>370,157</i>
<b>Current liabilities</b>	<b>235,983</b>	<b>449,173</b>
Trade creditors	12,846	121,552
Deferred income	111,078	147,500
Accruals & other creditors	58,912	93,174
Taxes & social security	53,147	86,977
<i>Net current Assets / (Liabilities)</i>	<i>346,200</i>	<i>294,617</i>
<b>Total assets</b>	<b>387,927</b>	<b>335,099</b>

<b>Funds</b>	<b>2013</b>	<b>2014</b>
<b>Reserves</b>	<b>387,927</b>	<b>335,099</b>
Capital	13,585	13,585
Reserves b'fwd 31 December 2013	295,671	354,343
Designated funds – developing countries	20,000	20,000
2014 deficit	58,671	– 52,829
<b>Total Funds</b>	<b>387,927</b>	<b>335,099</b>

*all figures in euros*

# EMSP Member Organisations

## Full Members

Multiple Sklerose  
Gesellschaft Österreich  
[www.msgoe.at](http://www.msgoe.at)

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

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

Savez Udruzenja Gradana  
Oboljelih od Multiple  
Skleroze BiH Sarajevo  
[www.suomsbih.ba](http://www.suomsbih.ba)

Savez drustava multiple  
skleroze Hrvatske  
[www.sdms.org](http://www.sdms.org)

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

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

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

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

Ligue Francaise contre la  
Sclérose en Plaques  
[www.lfsep.fr](http://www.lfsep.fr)

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

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

Hungarian Multiple  
Sclerosis Society  
[www.smtarsasag.hu](http://www.smtarsasag.hu)

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

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

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

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

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

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

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

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

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

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

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

Romanian MS Society  
[www.smromania.ro](http://www.smromania.ro)

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

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

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

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

Neurologiskt  
Handikappades  
Riksförbundet (NHR)  
[www.nhr.se](http://www.nhr.se)

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

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

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

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

## Associate Members

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

Union de lutte contre la  
Sclérose en Plaques  
(UNISEP)  
[www.unisep.org](http://www.unisep.org)

Sclerosis Multiplexes  
Betegek  
Országos Egyesülete  
(SMBOE)  
[www.smboe.hu](http://www.smboe.hu)

Federación Española  
para la Lucha contra la  
Esclerosis Multiple (FELEM)  
[www.esclerosismultiple.com](http://www.esclerosismultiple.com)

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



# EMSP Acknowledgements

The success and impact of EMSP's work is built on the effective partnerships, cooperative working and close collaborations with a very wide range of stakeholders whose contributions are gratefully acknowledged.

In particular, we would like to recognise and note our appreciation for the support we have received from the following groups:

## EMSP Member organisations

2014 has seen a consistent two-way flow of information, expertise and good practice from the majority of its 39 member societies. EMSP has supported members in a number of advocacy campaigns for access to optimal treatment and services, and via EMSP members have generously shared their learning and advocacy tools with others in similar positions.

EMSP members have also been enthusiastic contributors to the key surveys and consultations that are crucial to inform EMSP's plans and priorities and to ensure that our work continues to be closely aligned to the needs and aspirations of the 700,000 people in Europe currently living with multiple sclerosis.

## Corporate supporters

EMSP has continued to benefit from the unconditional support from corporate supporters who between them have provided part-funding for each of EMSP's key projects including the European Registry for MS (EUREMS), MS Nurse Pro, the MS Barometer, Under Pressure and Believe and Achieve.

## EMSP Executive Committee (ExCom)

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

## EMSP Team

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

## Collaborating organisations

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

# EMSP Sponsors and Supporters



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

# Credits



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*25 years, and  
more to come,  
as the voice of  
people with MS  
in Europe*