

European Multiple Sclerosis Platform
Annual Report 2012

Change for
the Better



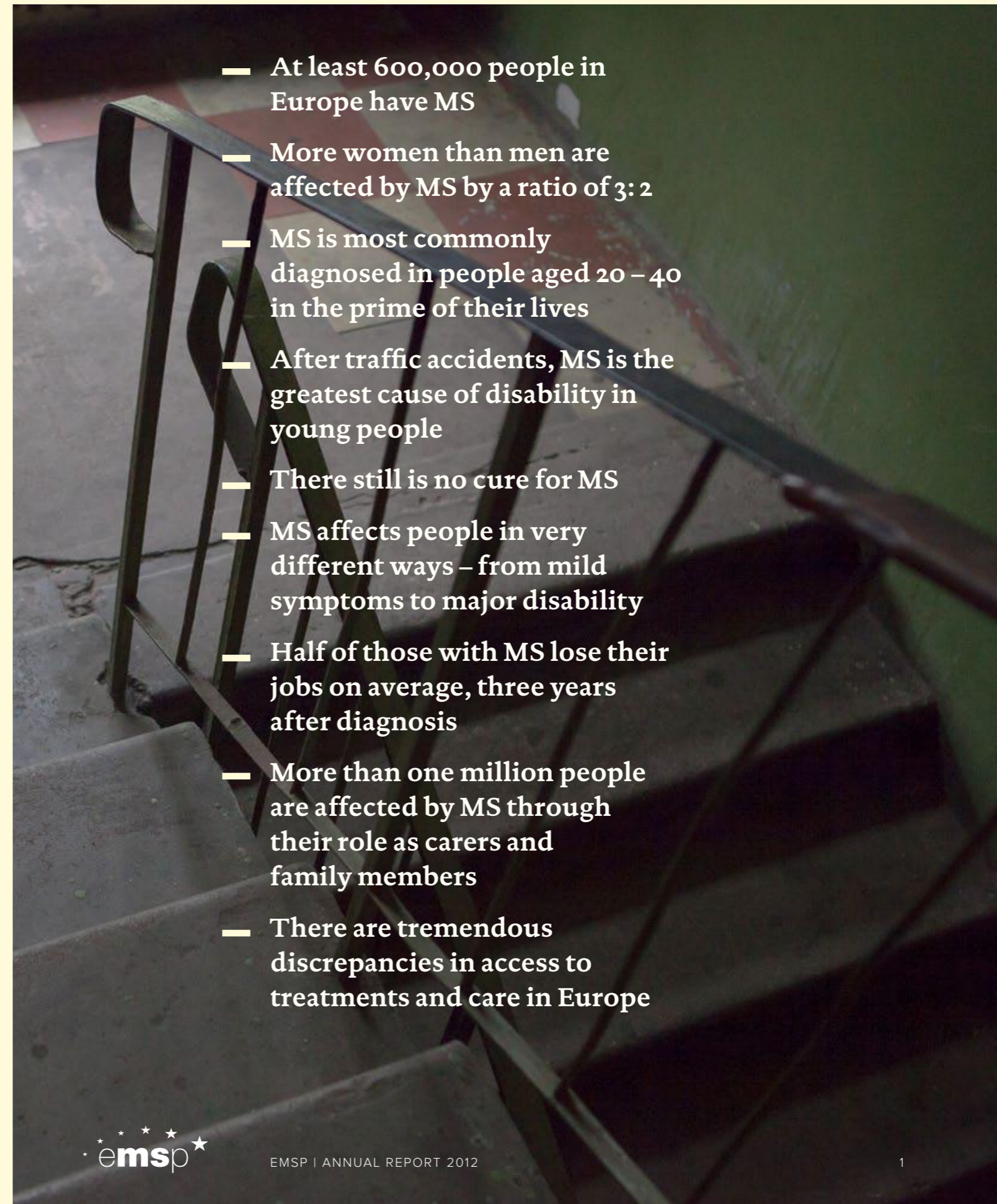
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cover
 Juri, Estonia • Reet Kiveste believes deeply in the power of science to find a cure for multiple sclerosis.
photo Lurdes R. Basolí

>
 Belarus • The MS Society of Belarus estimates that 430 people with MS are too disabled to leave their flats
photo Walter Astrada



- At least 600,000 people in Europe have MS
- More women than men are affected by MS by a ratio of 3:2
- MS is most commonly diagnosed in people aged 20 – 40 in the prime of their lives
- After traffic accidents, MS is the greatest cause of disability in young people
- There still is no cure for MS
- MS affects people in very different ways – from mild symptoms to major disability
- Half of those with MS lose their jobs on average, three years after diagnosis
- More than one million people are affected by MS through their role as carers and family members
- There are tremendous discrepancies in access to treatments and care in Europe

Access to medication and rehabilitation
can help to slow down the progression of
multiple sclerosis, sometimes by many years.
photo Maximilian Braun



PLEASE ALWAYS RING THE
DOORBELL BEFORE LETTING
YOURSELF IN. THANK YOU!!

EMSP represents the interests of people with multiple sclerosis (MS) in Europe. Working with 38 national MS societies, it aims to achieve high quality, equitable treatment and support for all people with MS, wherever in Europe they may live. EMSP is recognised as the voice of people with MS throughout Europe and its successful awareness-raising and advocacy work has been widely acknowledged at European and national levels.

Mission

- Exchange and disseminate information relating to MS through recognised medical and other organisations
- Promote the development of joint action programmes with the participation of national MS societies in Europe which are aimed at improving the quality of the activities and services of national MS societies
- Act as a focal point of liaison with the institutions of the European Union, the Council of Europe and other European organisations in order to propose new measures that will advance the rights of people with disabilities and to ensure their full and effective participation in society

Objectives

- Advocacy and awareness-raising
- Facilitating pan-European projects
- Providing key information on developments in MS
- Encouraging investment in high quality MS research

- Successful launch of two pilot projects for an **MS Nurse training programme** in Malta and Spain which marks a first step towards European accreditation of specialised MS nurses.
- New consensus study on **Recommendations on Rehabilitation Services** which provide up-to-date scientific knowledge on MS rehabilitation techniques and therapies.
- Multimedia project on **Under Pressure: Living with MS in Europe** presented for 'Awareness Day' in the European Parliament. The photo exhibition depicts people with MS in their daily lives and how they are affected – for better or worse – by the policies of the countries they live in.
- Written declaration on **Tackling Multiple Sclerosis in Europe** signed by 408 Members of the European Parliament gives new impetus to helping European citizens with MS.
- A **Youth Representative** was appointed to the Executive Committee for the first time in 2012 in order to better reflect and respond to the needs of young people, who are disproportionately represented amongst those newly diagnosed with MS.
- First interim evaluation of the 3-year project **European Register for Multiple Sclerosis**, which aims to provide comprehensive information on MS patients across Europe, showed important milestones were met in methodology and data analysis strategies.

**2012 was a year of intense activity,
and a year of change.**

Madrid, Spain • As Antonio Bellot Molinero's world becomes more confined, his wife feels her role is changing from partner to nurse.
photo Lurdes R. Basolí

Multiple sclerosis means something different for each person whether they are affected directly or indirectly.



Introduction from the President and Chief Executive

2012 was a time of much activity and change at EMSP. In November we welcomed Maggie Alexander as the new Chief Executive. This provided the occasion to review and assess with a fresh perspective the entire scope of EMSP activities undertaken during 2012 and our future needs. The team was further strengthened by Christoph Thalheim taking up the new role of Deputy Chief Executive and Director of External Affairs.

The 2012 Annual Work Plan was appropriately ambitious for an organisation committed to making a significant difference to the more than 600,000 people in Europe who are living with multiple sclerosis, a condition whose variability and unpredictability as a cause of disability is mirrored by the variability in access to essential treatment, care and employment across Europe.

It is notable that despite a very modestly-sized secretariat of only six permanent members of staff together with a number of external consultants and a very active Executive Committee, the key elements of all the deliverables were met and progress was made against each of the main activities set out in the 2012 Annual Work Plan.

There are necessarily a myriad of alternative ways and means to tackle the problems of health inequalities in relation to MS. The art for a membership-based, pan-European NGO such as EMSP with relatively modest resources is to identify the most effective, impactful activities that genuinely reflect the needs and circumstances of people affected by MS, wherever in Europe they live.

It is therefore particularly crucial to establish the right balance between long-term, strategic programmes that have potential to significantly advance the situation for people with MS and direct engagement and networking with individuals and member societies aimed at building skills, sharing best practice and supporting effective advocacy activities.

It is apparent that EMSP has made tangible progress in achieving this balance. Demonstrable highlights in support of this contention include the four high-level roundtable events in Poland, Estonia, Czech Republic and Lithuania, each of which were influential in securing political support and commitment for improvements in MS services in the respective countries. Building on the initiative, started in 2010, to better reflect and respond to the needs of young people affected by MS, a Youth Representative has been appointed for the first time to EMSP's Executive Committee and a Youth Advisory Committee has been established. This helps to put young people, who are disproportionately reflected in the figures for those newly diagnosed with MS, at the heart of EMSP's strategic decision-making and represents a real step forward in this area.

Investment in the long-term programmes is also starting to pay off. The consistent theme running through each of EMSP's major programmes is raising awareness of the needs of people affected by MS, reducing health inequalities and improving access to essential treatment, care and employment. The MS Barometer has proved to be a valuable tool in highlighting variations in access and as a potent lever and advocacy tool to encourage countries low on the scale to raise their standards. The MS Barometer has confirmed the need for and value of comparable data and it is widely recognised that major gaps exist in accurate epidemiological and outcome data for MS in Europe. EMSP's European Register for Multiple Sclerosis (EUREMS) programme is aimed at addressing this issue and during 2012 many milestones were reached in establishing the methodology, core data and potential uses of the material as well as overcoming some of the considerable barriers to sharing data across national borders.

MS specialist nurses are known to play a crucial role in the delivery of coordinated, patient-centred care and yet there is currently no pan-European, accredited training for this group of nurses. EMSP's MS Nurse Professional (MS Nurse Pro) programme is aimed at bridging this gap. During 2012, the programme was successfully piloted in Malta and Spain. Plans for making the curriculum available in multiple languages are well underway.

Collaborative partnerships, as evidenced by the EUREMS and MS Nurse Pro programmes, are a vital tool for fostering the participation of clinical specialists, patient organisation representatives and professional organisations. It is equally important to raise awareness of the impact of MS with the public and their political representatives if progress is to be made on all fronts. The multimedia project, Under Pressure, has shown that innovative reportage can be a potent means of gaining attention and encouraging engagement and support for the cause from European policy-makers and the public. Early exhibitions held in 2012 generated widespread enthusiasm and the strong desire, from member organisations, for access to the materials representing their particular country's circumstances.

EMSP's Annual Spring Congress, focused on scientific developments, provided an excellent opportunity for participants to exchange ideas and allowed a forum for Young People with MS to discuss issues of particular importance to them. Our Winter Conference, held jointly with Rehabilitation in Multiple Sclerosis (RIMS), was an opportunity for participants to focus on social media and other tools used in improving access to specialised rehabilitation programmes.

Much has been achieved during 2012 and details of progress in each of the areas included in the 2012 plan are provided in the report that follows. The challenge for EMSP and its constituents will be to ensure that the advances made in capacity-building to support this ambitious programme are maintained and that we continue to invest strategically in the infrastructure, resources and staff that will be essential to underpin progress in the future. The challenges of the world-wide economic crisis and the strain on health budgets mean that we will need to maintain the pressure in the coming year. It is with great expectation that we move forward in 2013 and beyond.



John C. Golding
President



Maggie Alexander
Chief Executive

“ Multiple sclerosis respects no boundaries. People with MS need access to the best available treatment, care and services. They also need the opportunity to work and fully participate in their communities.”

*[Prof. Alan Thompson,
Dean of the UCL Faculty of Brain Sciences, London]*

Restructuring for strength

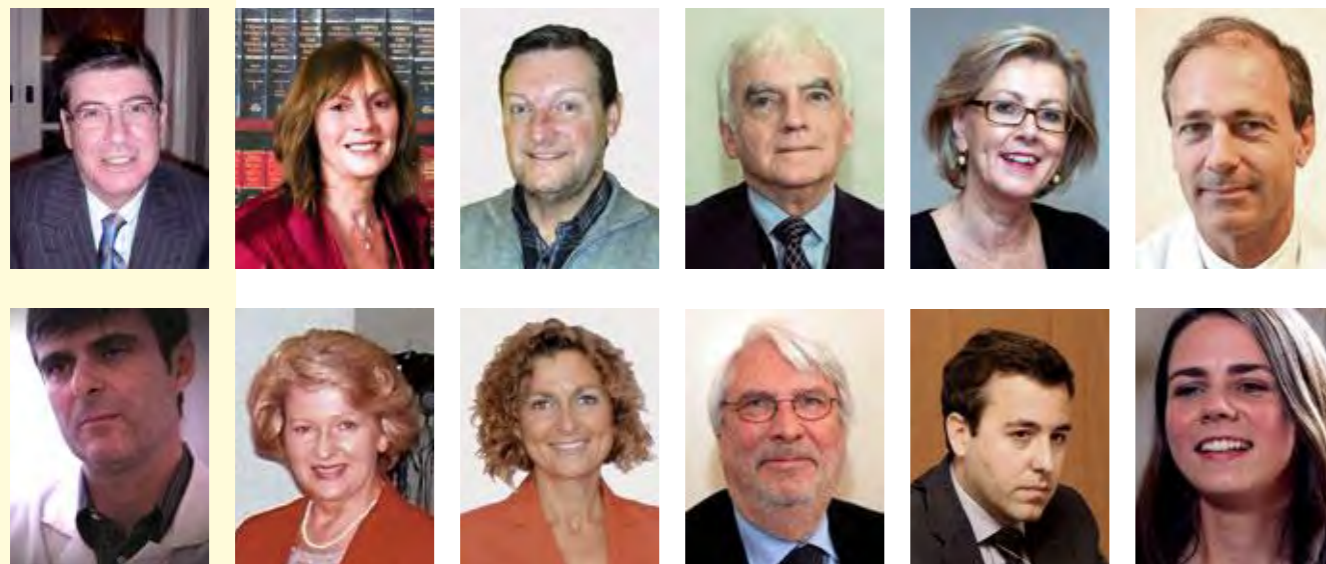
EMSP is headed by the Council of Members which delegates powers to the Executive Committee composed of high-ranking members from national MS societies. Under the Presidency of Mr John Golding, the Executive Committee oversees the vision, mission and values of EMSP. It also establishes the annual strategic plan for guiding the activities of the Secretariat and its related committees and work groups. For the first time a Youth Representative was appointed to the Executive Committee in 2012 in order to better reflect and respond to the needs of young people.

Executive Committee

John Golding	MS Society of Norway
Anne Winslow	MS Society of Ireland
Torben Damsgaard	MS Society of Denmark
Mike O'Donovan	MS Society of UK and Northern Ireland
Dorothea Pitschnau-Michel	MS Society of Germany
Prof. Pierre Clavelou	MS Society of France
Dr Olivier Heinzlef	MS Society of France
Dr Beatrika Koncan-Vracko	MS Society of Slovenia
Antonella Moretti	MS Society of Italy
Andre Van de Putte	MS Society of Belgium
Pedro Carrascal	MS Society of Spain (FELEM)
Emma Rogan	MS Society of Ireland

PRESIDENT
VICE-PRESIDENT
TREASURER *since XI 2012*
TREASURER *until XI 2012*
PAST PRESIDENT
until XI 2012
co-opted XI 2012

YOUTH REPRESENTATIVE



top left to right • John Golding • Anne Winslow • Torben Damsgaard • Mike O'Donovan • Dorothea Pitschnau-Michel • Prof. Pierre Clavelou
bottom left to right • Dr Olivier Heinzlef • Dr Beatrika Koncan-Vracko • Antonella Moretti • Andre Van de Putte • Pedro Carrascal • Emma Rogan

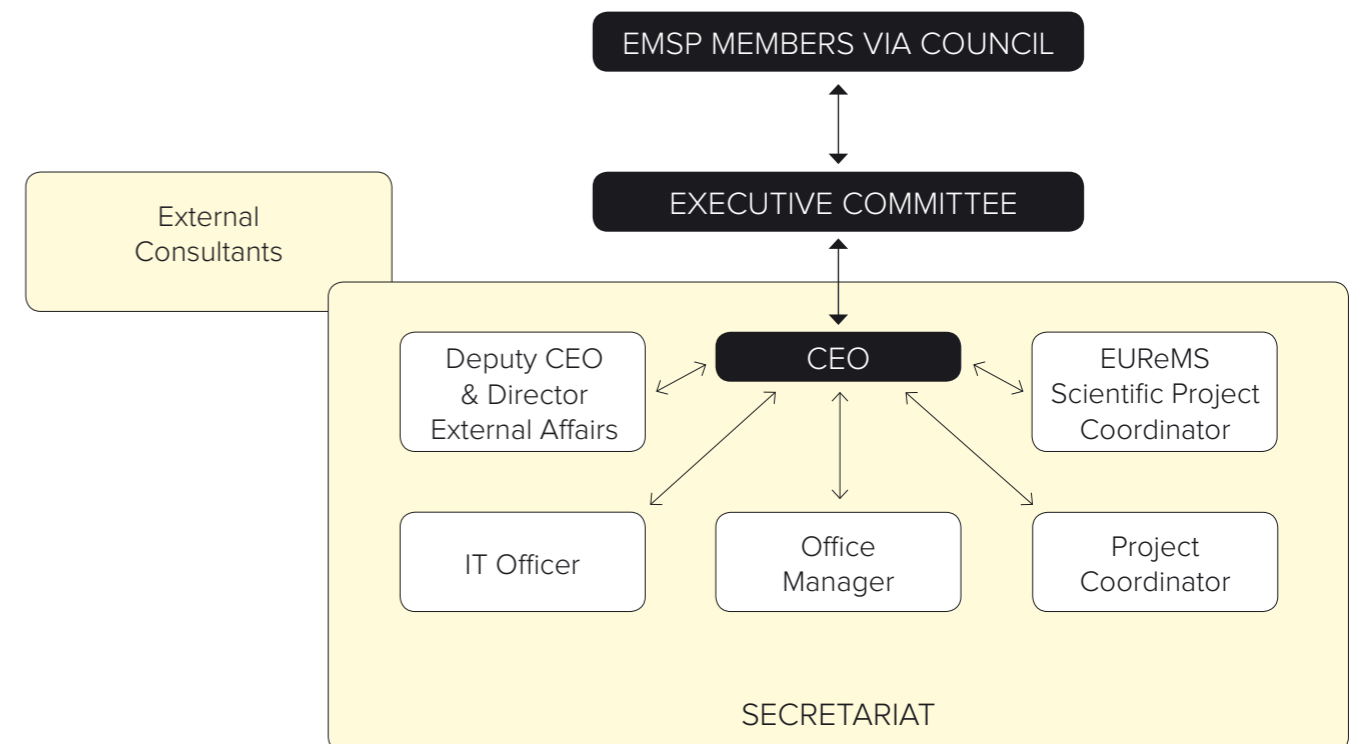
In 2012, the EMSP secretariat was reorganised to make the necessary adaptation to changing economic and political conditions in Europe and to ensure that its resources are used most effectively for improving the circumstances of all people affected by MS across Europe. Maggie Alexander was appointed as the new CEO in November and Christoph Thalheim moved to the position of Deputy CEO and Director of External Affairs.

EMPS Secretariat

Maggie Alexander	Chief Executive
Christoph Thalheim	Deputy CEO and Director of External Affairs
Ralph Lehmborg	Office Manager
Elisabeth Kasilingam	Assistent Project Manager
Zilvinas Gavenas	IT and Webmaster
Tsveta Schyngs-Liharska	Scientific Project Coordinator

External Consultants

EMSP also benefited from expert advice in policy from Nicola Bedlington of the European Patients' Forum and communications from Bettina Hausmann, Director of bhconsult.



Akureyri, Iceland • Haukur Dur no longer needs to use a wheelchair, but continues to live with uncertainty about what the future holds.
photo Fernando Molerés

Multiple sclerosis is a complex condition. No two people are affected the same way.



Building on its recent achievements and consolidating its past successes, EMSP continued in 2012 to strengthen its efforts to improve the lives of people with multiple sclerosis wherever they live in Europe. In accordance with the Strategic plan of 2012-2014 developed by the Executive Committee, EMSP achieved tangible results on a number of its core projects.

Following years of preparation, the **Multiple Sclerosis – Nurse Empowering EDucation** (MS – NEED) project was translated into reality through the successful launch of the first two pilot programmes in Malta and Spain.

A new scientific report on **Recommendations on Rehabilitation Services for Persons with MS**, which were first produced by EMSP in 2004, was updated to provide the latest scientific advances for rehabilitation, in collaboration with Rehabilitation in Multiple Sclerosis (RIMS) the European Network for Best Practice and Research.

EMSP organised an awareness day in the European Parliament presenting a multimedia project **Under Pressure: Living with MS in Europe**, followed by an 'MS Information Hour' with Members of the European Parliament. The event resulted in a written declaration by 360 EU Parliamentarians which calls on European institutions to improve conditions for the lives of people with MS.

A three year research project (2011-2014) for the development of a **European Register for MS** (EUReMS), which is co-funded by the European Commission, reached a number of important milestones and established consensus on core elements of the programme during its first year of work.

People with multiple sclerosis were at the forefront of our work in 2012 and will continue to be so in the future. We would like to express our heartfelt thanks to all those who so generously contributed their stories.

There is a clear need for recognition of the MS nurse profession as a specialisation in its own right.

EMSP successfully launched two pilot projects for the training of specialised MS nurses in 2012, which marks a major milestone on the road to unified European accreditation of the profession. The first pilot took place in Malta with twenty nurses from across Europe, followed by a similar programme for Spanish MS nurses that was launched in Barcelona, in September.

The programme has been accredited by the Royal College of Nursing in the United Kingdom and endorsed by the European Association for Neuroscience Nurses. It was further endorsed by the prestigious academic journal, *Lancet Neurology*, in its editorial article entitled *Setting new Standards in Multiple Sclerosis care and research*, in October 2012.

EMSP plans for making the training programme curriculum available in multiple languages are now well under way in preparation for launching the programme in several different European countries during 2013.

The EMSP consensus paper: *Moving Towards the Pan-European Unification of MS Nurses. What are the most important points?*, published in 2012, provides the foundation for the new training programme. The Consensus paper defines the MS nurse as an integral member of an inter-disciplinary team caring for people with MS, capable of responding to the changing needs of people with MS, while promoting successful self-care throughout the disease pathway.

It also provides an analytical job description of the key functions of the MS nurse. The consensus paper therefore provides for agreement on a curriculum and alignment of tasks, roles and competencies, all of which will facilitate the achievement of European accreditation and mutual recognition across all member states. It marks the first step therefore towards the unification and recognition of the MS nurse profession throughout Europe.

There is a clear need for recognition of the MS nurse profession as a specialisation in its own right. At present, many general nurses are carrying out this function without any formal acknowledgement. Although MS specialist nurses play a crucial role in the delivery of co-ordinated, patient-centred care of people with MS, there is no pan-European accredited training course for this group of nurses.

There is also a need for MS nurses across Europe to collaborate and share best practice, to ultimately improve the safety and consistency of the standards of care provided to those affected by multiple sclerosis. The MS Nurse programme will bridge this gap.

Rehabilitation recommendations

EMSP published a new edition of *Recommendations on Rehabilitation Services for Persons with MS*, which provides up-to date scientific knowledge on MS rehabilitation techniques that will be useful for all MS stakeholders. By significantly expanding the original Recommendations of 2004, the new edition will help MS patients to get the right rehabilitation tailored to the individual needs of each patient.

The Recommendations, which are the fruit of collaboration between EMSP and Rehabilitation in Multiple Sclerosis (RIMS), highlight advances in three key areas. First, the traditional, narrow definition of rehabilitation has been expanded to a broader concept of treating the full range of disabilities and handicaps resulting from MS. Second, new developments in neurological science are outlined, especially in the area of neuroplasticity which recognises the brain's ability to react when functions are damaged or lost due to deterioration of neuronal networks. And third, the importance of moving towards rehabilitation programmes designed to help patients address quality of life issues and help them participate in making decisions to determine which treatment is best for them.

The Recommendations emphasise that the rehabilitation team should gather health care professionals from an interdisciplinary team including neurology, rehabilitation medicine, nursing, physiotherapy and sports, clinical psychology, social counseling, occupational therapy and speech therapy. Rehabilitation services must also be integrated with other existing health services relevant for MS such as hospital departments, outpatient clinics, and community services. This helps to ensure that rehabilitation services are continuously adapted to the needs of the person with MS.

The Recommendations are only a first step in the improvement of rehabilitation techniques for people with MS. For EMSP, the real test is to ensure they are now implemented at the local, national and European level. Towards achieving this goal, the Recommendations have been recognised by the *Code of Good Practice in MS*, which has been endorsed by the European Parliament and is now available at national level in a number of different European languages. The European Commission supports the Code and the Recommendations by making them available on the website of Health Directorate-General of the European Commission through the EU Health Portal.

It is intended that implementation of the recommendations will trigger new research work in the field of rehabilitation, which will also benefit people with MS.

Under Pressure: Living with MS in Europe

“The exhibition illustrates what’s possible when policy is right and when support networks are in place. It also shows that there is still much room for improvement.” [John Golding, EMSP President]

The multimedia project *Under Pressure: Living with MS in Europe*, which EMSP presented to the European Parliament in April 2012, highlights growing disparities in MS care across Europe. The project explores how national health and social policies influence – for better or for worse – the experience of living with MS in Europe.

The pictures and interviews show how people with MS in some countries risk becoming disabled more rapidly due to a lack of access to adequate support and insufficient reimbursement for essential treatments.

The photo exhibition graphically depicts the results of the MS Barometer published by EMSP in 2011, which shows important discrepancies in access to quality care and treatments across EU countries. As President Golding said, “the exhibition shows what’s possible when policy is right and when support networks are in place. It also shows that there is still much room for improvement”.

Following the exhibition, an MS Information Hour was hosted by the honorable Member of the European Parliament, Petru Luhan from Romania, to inform Members of Parliament directly about the ongoing inequalities in Europe in access to therapy and care. Mr Luhan emphasised the need for closer international scientific collaboration in the context of the EU Horizon 2020 framework in order to find the causes of MS and accelerate the development of more effective treatment of the disease in all its forms.

This special event gave new impetus to the work of the Parliament in tackling MS in Europe. There is need for continued attention of MEPs, as eight years after the European Parliament’s first *Resolution on Multiple Sclerosis* there have been relatively modest improvements for people with MS in Europe. In response to EMSP’s advocacy, a Written Declaration was approved by the President of the Parliament.

Under Pressure: Stories from 12 countries

from left to right
top • Belarus • Estonia • Ireland • Italy
middle • France • Germany • Poland • Romania
bottom • Greece • Iceland • Spain • United Kingdom



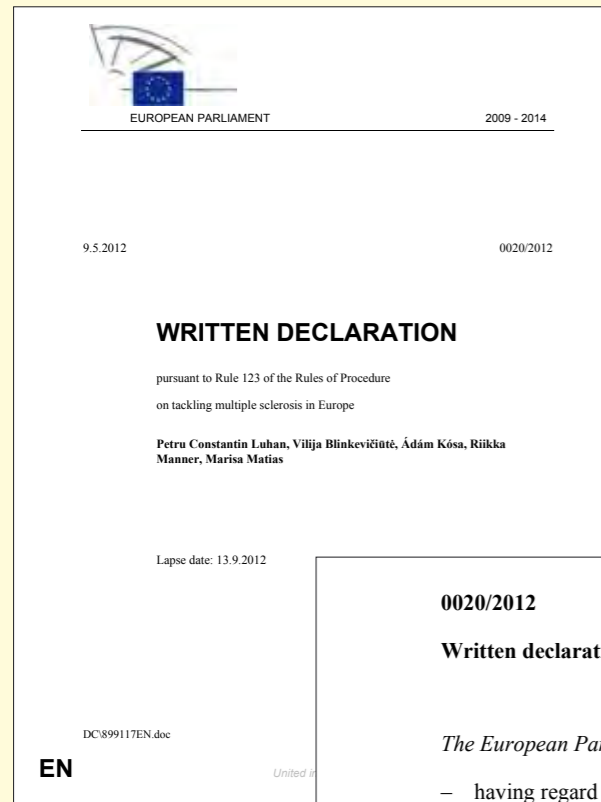
photographers
top left clockwise
• Walter Astrada
• Lurdes R. Basoli
• Carlos Spottorno
• Lurdes R. Basoli
• Max Braun
• Fernando Molerres

Under Pressure depicts how people's personal and professional opportunities are inextricably linked to the country in which they live.

photographers
top left clockwise
• Carlos Spottorno
• Fernando Molerres
• Max Braun
• Lurdes R. Basoli
• Carlos Spottorno

A full life makes people with MS no different from anyone else, and that needs to be the ultimate goal of our work.”

[Carlos Spottorno, lead photographer]



Tackling Multiple Sclerosis in Europe

written declaration signed by
360 Members of the European Parliament,
13 September 2012

0020/2012

Written declaration on tackling multiple sclerosis in Europe

The European Parliament,

- having regard to Rule 123 of its Rules of Procedure,
- A. whereas approximately 600 000 Europeans suffer from multiple sclerosis (MS), which is the most common neurodegenerative disorder and is a major cause of non-traumatic disability in young adults;
- B. whereas most people with MS are diagnosed in the prime of their working lives, and almost half leave the workforce within three years of diagnosis;
- C. whereas in Europe tremendous discrepancies in access to disease-modifying treatments and quality of care exist, and have worsened in recent months;
- 1. Calls on the Commission and Council to:
 - encourage, within the framework of Horizon 2020, closer scientific collaboration and comparative research on MS;
 - promote, in their Reflection Process on Chronic Disease, equal access to treatment and flexible employment policies for people with chronic neurological disorders such as MS;
- 2. Calls on the Member States to:
 - enhance equal access to quality care, for example by using certified educational training tools (such as ‘MS Nurse Professional’) to develop, standardise and benchmark specialist nursing staff training;
 - support the European Register for MS by encouraging patient data collection at national level;
- 3. Instructs its President to forward this declaration, together with the names of the signatories, to the Council, the Commission and the Parliaments of the Member States.

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EN

The European Register for Multiple Sclerosis (EUReMS) programme, which is a three year research project receiving co-funding from the EC Executive Agency for Health and Consumers, is one of EMSP’s main projects. Launched in 2011, it is aimed at addressing the issue of major gaps which exist in accurate epidemiological and outcome data for MS in Europe through the creation of a European register.

The European Register will develop a European set of epidemiological, clinical and socio-economic data on MS at the national level, which will allow for comparisons between countries and groups of population, and provide data for scientific research and MS health policies.

In 2012, the first interim report showed that many milestones were reached in establishing the methodology, core data and potential uses of the material as well as overcoming some of the considerable barriers to sharing data across borders.

Consensus was achieved on the basic purposes, mission and vision of the European Register. On more technical issues, the definition of MS needs, minimum core and clinical data sets, characteristics of identified MS registers/ data sets and European registry systems for other chronic diseases were also agreed by consensus. Progress has also been made on methodology and data analysis strategies.

The provision of European data will allow for comparisons of situations in different countries and help EU institutions to identify areas and topics worthy of future financial support. Comparing data will help to reveal best practices applied between different countries. It will therefore be of great assistance to all MS stakeholders including medical professionals, researchers, policy makers and the health industry.

Through this project, EMSP aims to enhance its role of liaison between specialised MS professionals and general health professionals, to increase patient participation and to enhance awareness. The ultimate aim of the project is to have at least one institution compiling and managing data in all EU member states by the third year.

EMSP, which is the leading coordinator of the project, works with a number of associated and collaborating partners representing a wide range of stakeholders in the field of MS.

Warsaw, Poland • For 13 years, Ania Szepaniak's father had asked the doctor to hide the diagnosis from his daughter – a gesture for which Ania is grateful.
photo Carlos Spottorno

Five renowned photographers went out to meet people with multiple sclerosis across Europe. They were impressed with the strength and resilience of so many of the people they met.



Annual Spring Congress in Barcelona 18-19 May

EMSP's Annual Congress of 2012 focused on the latest scientific developments with leading experts presenting updates on MS treatments in the pipeline. Held under the patronage of Catalanian Minister of Social Welfare and Family, Mr Josep Lluís Cleries Gonzales, the congress also provided an excellent opportunity for participants to exchange ideas and a forum for young people with MS to discuss issues of particular importance to them.

In his keynote opening address, Professor Alan Thompson of University College London, spoke about **Emerging Therapies and Multiple Sclerosis**. Much progress has been made in providing effective medication for MS since the introduction of Interferon-B twenty years ago and the more recent release of oral therapies. Nevertheless, "the unmet needs remain massive", Prof. Thompson underlined. Major challenges still exist in the areas of disease modifying drugs, anti-inflammatory strategies, symptomatic therapies and measures for MS prevention.

Further topics addressed by medical experts included:

■ **The impact of female hormones, pregnancy and breast feeding on MS**

Dr. Mar Tintore, MD, PhD

■ **Progress being made in remyelination research**

Professor Catherin Lubetzki

■ **The use of cannabis for management of MS symptoms**

Professor Patrick Vermeersch

To meet its members' expectations and share their respective experiences, four workshops were organised on EMSP's main projects following the introductory speeches. The workshops allowed national members to focus on their field of interest, to facilitate exchange of good practice and to develop good working relations between national societies.

Day two of the congress was devoted to national political developments in health and social care and how MS groups could get their message across to their policy makers most effectively. It was agreed that messages to politicians are more powerful when they come from a union between medical professionals and patient organisations. This is all the more important to bear in mind given the cuts to health budgets in the present economic climate.



Role of the Youth Representative on the Executive Committee

Emma Rogan, who was appointed to the Executive Committee as representative of young people with MS in 2012, was selected for this role by the Youth Advisory Group. Emma was diagnosed with MS in 2007. The appointment of the first youth representative is the start of a new drive towards more active participation of young people in EMSP.

“The ability to share experiences between young people with MS in Europe through EMSP will provide for greater engagement, more discussion, and increased solidarity. All of this, together with greater communication will be beneficial for young people with MS and also inform EMSP about its future direction.” [Emma Rogan]

What young people with MS have to say

The Third Annual Youth Congress, which was held in parallel to the annual congress, has gained growing recognition as a forum for young people to discuss issues of particular importance to them.

The issues chosen for this year's discussion were sexuality and pregnancy. Young people with MS consider those issues very important for their lives now and in the future. "Discussing what are sometimes considered private, taboo topics in a clear and open hearted fashion is a way to open up the dialogue for MS societies across Europe", said Emma Rogan, about the Youth Congress.

The group intends to ensure that topics of sexuality and pregnancy are considered as important as other issues. Many women confronted with fears and uncertainty about having children have to face some difficult questions: how does MS treatment affect fertility? does pregnancy affect the progression of MS? does treatment have to stop during pregnancy? where does research stand on MS and heredity?

By using personal experiences and developing strategies and discussions about sexuality and pregnancy in an open way, resources can be developed for the benefit of all MS societies.

Winter Conference with Rehabilitation in MS (RIMS)

The annual winter congress, which was organised in collaboration with RIMS in Prague, 24-25 November, focused on the use of social media in MS.

People with multiple sclerosis and their physicians are increasingly using social media to educate themselves and to share information via the increasingly popular platforms of Facebook, Twitter and Youtube.

In contrast to the previous mode of one-way, physician-controlled health information sharing, social media allows an interactive exchange of information between patients and physicians. Social media has advantages, such as reaching a wider audience, low cost, instantaneous communication and easy updating. There are also risks involved in terms of misinformation and maintaining patient privacy. It is therefore important to emphasise that new technologies should not be used to replace interpersonal contact between patients and physicians but rather used as complementary mechanisms.

Subjects covered at the Prague conference included:

- **Social media and MS** – why it is important
- **Awareness campaigns** – how social media can help
- **Social media and the power of connecting like-minded people**
- **Internet-based training programme for MS nurses**

The conference brought together senior managers and communications professionals working with MS societies, with EMSP and RIMS members, for the purpose of learning and sharing experiences at the patient and professional level.

EMSP has started to use social media in order to widen its audience to a more general public and, more specifically, young people with MS. The use of social media also allows more frequent interactions with other stakeholders such as EMSP members and the MS International Federation. EMSP used social media during its awareness day in the European Parliament as an experiment for the use of social media during its events.

Access to rehabilitation is key for people living with MS. Yet, only a small number of European countries offer comprehensive rehabilitation.

Roundtable influencing

Through its involvement in high-level meetings organised by member societies in four Central and Eastern European (CEE) countries in 2012, EMSP strengthened its relationships with MS stakeholders in those countries and contributed to capacity-building for improved MS policies.

Utilising the MS Barometer

The MS Barometer provides for data on the quality of life of people affected by multiple sclerosis. It is proving to be an effective tool for EMSP to help CEE countries to improve overall treatment and quality of life for people with MS in their countries.

The 2011 MS Barometer provided indicators on six key areas of national policies: access to treatment and therapies; research agenda on MS; employment and job retention; reimbursement of costs for MS treatment, accurate data collection on MS at the national level and new medication coming onto the market. The results show that CEE countries tend to have relatively lower scores compared to other European countries.

The survey results, however, show variation in strong and weak points across the four Central and Eastern European countries – Poland, Estonia, the Czech Republic and Lithuania, each of which organised high-level debates on the issue with EMSP. While the Czech Republic tended towards relatively high scores on a number of indicators, it appears to invest few resources in developing an MS research agenda. By contrast, while Poland's ranking across the board was rather low, it ranks high in MS rehabilitation measures, employment and job retention. The general situation in the two Baltic states gets a low ranking, which has stimulated intensive discussion to raise awareness of this and to get the political establishment involved in improving the situation.

Through the high-level roundtable events, EMSP worked with the CEE countries to ensure they are fully informed about the MS Barometer results specific to their country and to discuss ways for improving the situation. Collecting this kind of data, which is a key aim of the *MS Code of Good Practice*, can be very helpful to those countries in achieving policy reforms. Moreover, by regularly updating the MS Barometer, EMSP will be able to monitor countries' progress over the coming years.

High-level meetings held in CEE countries

Poland The high level roundtable in February brought the Polish MS Society, a major opinion-shaping newspaper, prominent political personalities and health professionals together to assess the national situation regarding access to treatment and rehabilitation for people with MS. The results of the MS Barometer, presented by EMSP at the meeting, fill a gap in accurate information available to the Polish authorities. The meeting concluded that Poland now urgently needs improved pharmaceutical and economic data on the cost of the condition, as well as specific statistics on MS treatment as a basis for improved policy-making. The creation of a national database under the auspices of the EUREMS mechanism currently being created by EMSP holds out promising prospects for progress in this context.

Estonia The major focus of discussion at the roundtable in April was the low score of the country in the MS Barometer. How can the quality and scope of MS treatment be improved is now the major policy question. The whole system of disabilities and rehabilitation is currently being reformed. The new system must focus on keeping people in work or getting them back to work. The roundtable, which was initiated by the Estonian Union of MS Societies and EMSP, was attended by politicians and medical professionals. All participants recognised the importance of the European Register for MS and they will start working towards the creation of their own national database as soon as a relevant European pilot project is completed.

Czech Republic The roundtable meeting in November addressed the topic of accessibility of health care for patients with MS in the Czech Republic, in particular, what had changed over the previous year. It looked into the progress made in terms of access to treatment for MS following on from the discussion held in October 2011 and the subsequent declaration made by the Ministry of Health in March 2012 on the subject. The meeting was held in the national parliament.

Baltic States An International conference was hosted in December by the Lithuanian Parliament, on the present situation of MS patients and their carers in the Baltic States – which is currently a cause of great concern. Those countries rank low in the MS Barometer results from 2011 and in order to improve the situation it is crucially important to get this issue on the political agenda. The conference was attended by 200 participants from different backgrounds including patient organisations, health professionals, government and non-governmental organisations from the three Baltic states.

EMSP has already developed strong working relationships with all major stakeholders in the MS community. Now, it is increasingly reaching out to significant new professional partners.

European Medicines Agency

EMSP participated in the activities of the European Medicines Agency (EMA) in 2012 through its work on the Patients and Consumers Working Party (PCWP). Issues for discussion included the role of patients in EMA scientific committees such as the Committee on Medicinal Products for Human Use (CHMP), their contribution to the evaluation of benefits and risks of medical products as well as the development of a plan for training and support.

Further issues included monitoring patient participation in EMA activities, reviewing information for the general public, participating in scientific advisory meetings as well as conferences and workshops. The outcome of those discussions has led to the establishment of a new framework for the involvement of patient and consumer organisations in EMA's future work.

Regular participation in the PCWP meetings helps EMSP to increase knowledge of the regulatory activities of EMA in relation to MS drugs and guidelines. Since the new EU pharmacovigilance legislation came into effect in 2012, PCWP has been directly involved in implementing its provisions for risk management, patient reporting and public hearings.

Developing new strategic partnerships

EMSP actively seeks to form new strategic partnerships with professional groups in the medical field that will be increasingly important in the coming years. For example, EMSP's relationship with the European Patients' Forum will take on additional significance in the future due to the increasing importance of patient participation as part of the evidence base for purposes of research and awareness-raising. EMSP will also give greater attention to developing a strategic partnership with the European Federation of Neurological Associations and the European Network for Rehabilitation as it explores how to increase patient participation and enhance its role as a liaison between MS and other health professionals.

Networking event with Funders

EMSP hosted its annual sponsor networking event in 2012 at the Royal Belgian Institute of Natural Sciences in Brussels. Through this event, which was attended by 35 participants from various companies and organisations, EMSP recognised the contribution of its funding partners and supporters to its key achievements in 2012.

Reykjavik, Iceland • Guðrún Sigríður Eiríksdóttir receives acupuncture to help manage pain at an MS centre run by the Icelandic MS-Society.
photo Fernando Molerés

There continue to be unacceptable disparities in access to treatment and care throughout Europe.

The accounts for 2012 show a significant rise in activity for EMSP, and this is reflected in the increase in income of 68% against the previous year.

We are pleased to report that funding for our core costs rose from 23% in 2011 to 32% in 2012, and our thanks are due to all those that have supported EMSP during the year.

Over 75% of our expenditure is directly related to our beneficiaries, with over € 1 million being spent on two projects alone – MS NEED and EUREMS. This is an excellent achievement for a small organisation and reflects the pressing need for more collaborative work within the MS community.

The final result for the year shows a small deficit of € 14,000, again very much in line with the previous year.

During the year we made changes to the staffing structure, to enable us to grow and service the ever increasing demands of the organisation. This will also enable us to further increase our fundraising capacity.

The Trustees also reviewed the risk associated with each level of activity, and systems have been established to mitigate those risks. In line with good practise, the Trustees have also reviewed a policy for the level of reserves held by the charity, to ensure that we have measures in place to enable the various projects to continue.


Torben Damsgaard
Treasurer

Income	2011	2012
Membership fees	79,025.00	79,000.00
Corporate core funding	165,000.00	92,500.00
EU operating grant	12,834.58	277,340.43
Project funding	653,607.38	1,328,370.49
EUREMS	101,542.82	591,056.18
MS NEED	438,356.07	567,522.80
Under Pressure	113,708.49	169,791.51
Other projects		274.48
Events	135,578.13	184,199.80
Extraordinary Income	125,000.00	6,548.04
Total income	1,171,045.09	1,968,233.24

Expenditure	2011	2012
Administrative costs	45,728.63	54,966.53
External fees	211,056.41	155,339.35
Project expenditure	596,760.42	1,286,554.78
EUREMS	49,997.00	495,417.40
MS NEED	423,775.25	591,379.91
Under Pressure	117,312.81	179,593.62
Other projects	5,675.36	20,163.85
Events	122,866.25	210,254.63
<i>Other costs</i>		
Salaries	190,236.97	257,225.39
Depreciation	6,149.96	6,455.58
Operating charges	1,841.03	9,682.60
VAT	4,646.52	2,531.47
Total expenditure	1,179,286.19	1,983,010.33

Result	2011	2012
Profit/Loss for the period	- 8,241.10	- 14,777.09

all figures in euros


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**EUROPEAN MULTIPLE SCLEROSIS PLATFORM
 AISBL**
**2012 financial year accounts
 Confidential audit report**

1. The administrative organization and the internal control were considered sufficient for the activities of the association in 2012.

The presentation of the financial situation and of the accounts as per 31/12/2012 is logical and correct in order to inform the board of directors and the general assembly. (i.e. total cost minus recharged costs)

You will receive our written audit report for the general assembly as soon as the board of directors adopt the presented accounts and after having received the annual accounts in its form as they have to be deposited at the Commercial Court.

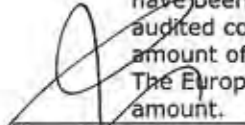

2. The financial position of EMSP is positive at the end of 2012

Current balance of assets and liabilities :


Debtors and bank (incl. transition accounts)	869.831,66 EUR
Current liabilities (incl. transition accounts & provisions)	<u>-577.941,50 EUR</u>
Balance	291.890,16 EUR

We like to point your attention to the following points:

- For operating grants (grant per year) the final claim is to be accounted as an amount receivable at the end of the respective year, even if the claim was only introduced in the following year and will be received only in the next year. This is a consequence of the fact that all cost relating to that grant agreement have been incurred before year end, that the final claim is based on eligible and audited costs -in accordance with the grant agreement- so that the calculated amount of the claim is pretty sure to be received. The European Commission has no discretionary possibility to reduce the claimed amount.

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- For specific grant agreements should always be taken into account that no profit can be realised and reported on these projects. In case that other income relating to the project would be higher, the amount granted by the European Commission will automatically be reduced. This means that at each year end closing for each project had to be calculated how many cost are already incurred and how many revenue is already recognized. In case that there is more recognized income than incurred cost, the exceedent of recognized income will result in a debt (i.e. reimbursement of a part of the grant of the European Commission). In case that incurred cost of the year end are higher than already recognized income, the amount of exceedent costs will probably lead to a higher claim at the closing of the project. If this is so, at year end the exceedent amount can be accounted as "work in progress". However, when the exceedent costs are due to substantial overspending which would not lead to a higher final claim at the closing of the project, the exceedent amount of costs has to be reported as cost and not an asset.

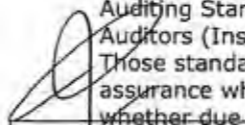
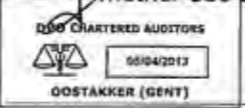
3. The responsible directors did confirm that they are not aware of any major issue which could influence the financial position of EMSP substantively in the negative way for the year 2013, and which should have been recorded as an expense or a liability in the accounts of 2012.

4. Unqualified audit opinion on the financial statements.
 (= Audit opinion where no remarks have to be made about the prepared and audited financial statements)


We have audited the financial statements for the year ended 31 December 2012, prepared in accordance with the financial reporting framework applicable in Belgium, which shows a balance sheet total of 907.197,45 EUR and a loss for the year of 14.777,09 EUR.

Management is responsible for the preparation and the fair presentation of these financial statements. This responsibility includes: designing, implementing and maintaining internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with the legal requirements and the Auditing Standards applicable in Belgium, as issued by the Institute of Registered Auditors (Institut des Réviseurs d'Entreprises / Instituut der Bedrijfsrevisoren). Those standards require that we plan and perform the audit to obtain reasonable assurance whether the financial statements are free from material misstatement, whether due to fraud or error.

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Nuttelijke Wervingschap onder vorm van een NVWA

In accordance with the above-mentioned auditing standards, we considered the association's accounting system, as well as its internal control procedures. We have obtained from management and from the association's officials the explanations and information necessary for executing our audit procedures. We have examined, on a test basis, the evidence supporting the amounts included in the financial statements. We have assessed the appropriateness of accounting policies and the reasonableness of the significant accounting estimates made by the association as well as the overall financial statement presentation. We believe that these procedures provide a reasonable basis for our opinion.

In our opinion, the financial statements for the year (accounting period) ended 31 December 2012 give a true and fair view of the association's assets and liabilities, its financial position and the results of its operations in accordance with the financial reporting framework applicable in Belgium.

Oostakker, April 5th, 2013

DPO Chartered Auditors
Statutory Auditor
Represented by Ulrich De Poortere
Chartered Auditor - Director

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“We are delighted to be able to report a significant increase in activity in 2012, thanks to the dedication of our staff, our project partners and the ongoing generosity of our supporters.”

[Torben Damsgaard, EMSP Treasurer]

Reykjavik, Iceland • When loss of balance threatened Guðrún Sigríður Eiríksdóttir's golf game, she and her husband Steinn Ólafsson devised a 'duck and grab' manoeuvre that keeps Steinn from taking a hit during the downswing and Guðrún from landing face-down on the fairway.
photo Fernando Molerés

“2013 will be another important year for EMSP. At a time of economic constraint, we need to provide persuasive arguments in favour of effective engagement with the research and political communities. We must demonstrate that now is the time to act to improve the situation for people with MS in Europe.”

[Maggie Alexander, EMSP Chief Executive]



Full Members

Multiple Sklerose Gesellschaft
Österreich
www.msgoe.at

MS Society Belarus
www.msbelarus.com

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

Savez Udruzenja Gradana Oboljelih
od Multiple Skleroze Bih Sarajevo
www.suomsbih.ba

Savez drustava multiple skleroze
Hrvatske
www.sdmsih.org

Unie Roska
www.roska.eu

Scleroseforeningen
www.scleroseforeningen.dk

Estonian Multiple Sclerosis Society
www.smk.ee

The Finnish MS Society
www.ms-liitto.fi

Ligue Francaise contre la
Sclérose en Plaques
www.lfsep.fr

Deutsche Multiple Sklerose
Gesellschaft
www.dmsg.de

Greek MS Society
www.gmss.gr

Hungarian Multiple Sclerosis Society
www.smtarsasag.hu

MS Felag Islands
www.msfelag.is

MS Society of Ireland
www.ms-society.ie

Associazione Italiana
Sclerosi Multipla
www.aism.it

Latvijas Multiplas Sklerozes
Asociacija
www.lmsa.lv

Lithuanian Multiple Sclerosis Union
www.liss.lt

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

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

Multiple Sclerose Vereniging
Nederland
www.msvereniging.nl

Multipel Sklerose Forbundet I Norge
www.ms.no

Polskie Towarzystwo Stwardnienia
Rozsianego
www.ptsr.org.pl

Sociedade Portuguesa de
Esclerose Multipla
www.spem.org

Romanian MS Society
www.smromania.ro

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

Associate Members

Drustvo Multiple Skleroze Srbije
e-mail msserb@sbb.rs

Slovensky Zvaz Sclerosis Multiplex
www.szsm.szm.sk

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

Neurologiskt Handikappades
Riksförbundet (NHR)
www.nhr.se

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

Schweizerische Multiple Sklerose
Gesellschaft (9SMSG0)
www.multiplesklerose.ch

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

MS Foundation Bulgaria
www.msobshtestvo.org

The Hellenic Federation of Persons
with Multiple Sclerosis (HfoPwMS)
www.msassociationhellas.org

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

Sclerosis Multiplexes Betegek
Országos Egyesülete (SMBOE)
www.smboe.hu

Federación Española para la Lucha
contra la Esclerosis Multiple (FELEM)
www.esclerismultiple.com

National MS societies have been instrumental in raising awareness of MS and representing the voice of people with MS in Europe.

EMSP acknowledges with gratitude the generous support in the form of unconditional grants from contributors from research and industry without which its work would not be possible.

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



This report was compiled by Maggie Alexander CBiol MSB, the EMSP Secretariat and Bettina Hausmann

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digital printing EAD
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This report has been designed with reference to best practice guidelines on 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 office.manager@emsp.org



This report arises from the work programme EMSP_FY2013 which has received funding from the European Union in the framework of the Health Programme. Sole responsibility of the information contained herein lies with the author and the Executive Agency is not responsible for any use that may be made of this information.

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