



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Annual
Report
2013

Advocacy
in action



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cover

EMSP President John Golding
and his wife and carer,
Elisabeth Golding

photo Fabrice Debatty

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Minsk, Belarus, 10/2011 • Lack of
elevators keeps most people with
MS trapped in their apartments.
But even if they could get out, they
would find it very hard to move
around the city. Almost no effort
is made to integrate people with
disabilities into society.

photo Walter Astrada

- The number of people living with MS worldwide has increased by 10 percent in the past five years, to 2,3 million
- In Europe there are at least 600,000 people with MS
- In many countries, MS is the leading cause of non-traumatic disability for young people
- The average age for diagnosis of MS is 29 years
- The cost of dealing with MS in Europe has been estimated at 15 billion euros per year
- There is a serious lack of centralised MS-data and a tremendous variation in access to optimal treatment and care
- The average unemployment rate among people with MS from Europe eligible for work is estimated at 55 percent
- Half of those living with MS lose their jobs on average three years after diagnosis
- Research into areas such as primary and secondary progressive MS has been largely overlooked so far

EMSP vision and mission: A world without MS

En route 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. We are engaged in **advocacy and awareness raising campaigns** to empower people with MS, we gather and provide **knowledge and expertise** among relevant stakeholders and we encourage **research** and the dissemination of information on MS.

EMSP brings together MS activists from across Europe, relying on 38 member organisations from 34 European countries. EMSP also accesses European funding sources, such as EU institutions and industry. We are the only MS-specific organisation that can influence the health and other policies of the EU. This capability reaps benefits at national level, where MS societies can use EMSP's lobbying achievements to influence national policies, as was the case with the successful Written Declaration on Multiple Sclerosis from September 2012.

Given that a single-condition approach is not always effective in relation to European institutions such as the European Parliament or the European Commission, EMSP also forges partnerships with other patient organisations or federations from a number of diseases areas – including the European Federation of Neurological Associations (EFNA) and the European Patients' Forum (EPF). EMSP can be persuasive on topics such as equity of access to treatment and care, drawing on its direct access to the European regulator for pharmaceutical products, the European Medicines Agency (EMA). EMSP's flagship projects aim to bring an improvement to the quality of life of over 600,000 people living with MS in Europe.

Flagship projects

- **European MS Barometer** – a comparative survey reflecting the situation of people living with MS in 38 European countries;
- **Under Pressure** – a multimedia project with high quality videos and pictures illustrating the healthcare inequalities captured by the MS Barometer;
- **EUREMS** – the first European MS data collection system designed to boost research and enable better outcomes for the broader MS community;
- **MS Nurse Pro** – an accredited online education programme for MS nurses which promotes the provision of care across Europe ;
- **Believe and Achieve** – an awareness-raising campaign to improve access to employment and training for young people with MS in Europe.
- **European Code of Good Practice** – guidelines for policy-makers and stakeholders in Europe promoting best practice and consensus papers in MS;

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 600,000 PEOPLE WITH MS ACROSS EUROPE

European MS data collection for research and better outcomes:

EUREMS

Comparative survey of the national situation in 38 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

EMSP 2013 – at a glance

- European **Month of the Brain** (May 2013) was marked by intense event and networking activities alongside key partners, with excellent results in outreach to high officials representing the European Commission and Parliament.
- European Register in Multiple Sclerosis (EUREMS) identified and started pooling MS-data from existing data providers in Europe; a major milestone on the road to a cross-border infrastructure for data collection, analysis, interpretation and dissemination in the MS field.
- MS Nurse training programme (**MS Nurse PROfessional**) was launched in four EU countries, a move forward in educating and popularising the concept of European accreditation of specialised MS nurses.
- The second phase of the multimedia project **Under Pressure** was marked by the launch of a dedicated website. Work on the third phase was started, involving the production of up to eight more country videos to be promoted primarily at national level.
- 23 national MS societies provided data for the 4th edition of the **MS Barometer** covering seven priority areas for people with multiple sclerosis. The Barometer is to be published in spring 2014.
- EMSP focused on employment by developing collaborative partnerships to raise awareness of the challenges faced by people with neurodegenerative diseases in the workplace. This helped to set the stage for the launch of a flagship EMSP project – **Believe and Achieve** – aiming to facilitate jobs for young people with MS.
- The **EMSP Secretariat was enlarged** to gain strength in key positions such as communications and event coordination.
- EMSP participated in the **First Scientific Conference of the Progressive Multiple Sclerosis Alliance**, an international effort aimed at enhancing research on progressive MS.

“ We believe multiple sclerosis doesn’t mean giving up your ambitions, just rethinking how to achieve them ”

[George Pepper, person with MS, UK, creator of online social network shift.ms]

Quellenhof Centre, Bad Wildbad, Germany, 12/2011 •
Barbara Klassing pictured. Rehabilitation programmes
help patients adapt to disease progression or regain
lost functions. *photo Carlos Spottorno.*



Introduction from the President and Chief Executive

Reviewing the year's activities in preparation for the annual report is the ideal time to test progress against our key objective of helping to ensure that people with MS have equitable access to high quality treatment and support leading to tangible improvements in their quality of life.

Where we have been able to make significant progress, success has been largely due to the exceptionally high degree of effective collaboration that exists between the staff team, the Executive Committee and our supporters and partners. The strength of these relations was put to the test during 2013, when EMSP, along with a number of other key NGOs, found out that it would not be in receipt of an EU operating grant in 2014, despite having made progress in every domain covered by the strategic and operating plans.

In the face of this set back, the team and the Executive Committee re-doubled their efforts to identify alternative sources of income to protect the essential activities upon which our members and people with MS in Europe rely. An urgent plan was successfully implemented to secure sufficient income for 2014, with the intention of increasing the prospects for sustainable income in the future by reapplying to the EU for an operating grant in 2015 and diversifying the fundraising portfolio.

“ 2013 has been a period of developments and has been successful for EMSP. This has included the continued refinement and strengthening of the organisations' Secretariat and the dedicated involvement of the ExCom in specific programmes, which has resulted in the empowerment and support of people with MS and in particular of young people with MS. Thanks to a committed team we have also strengthened our lobbying, fundraising, communication and operational capacities”

[John Golding, President]

In a European health policy landscape that is becoming increasingly focused on broad themes and alliances (such as health inequalities), rather than on single conditions, during 2014, EMSP worked closely with its partners to progress these themes whilst using MS as an exemplar of a long-term, disabling, neurological condition.

Most importantly, throughout 2013, EMSP has remained closely in touch with its beneficiaries, who have been extensively involved in a wide range of key consultations and activities shaping and influencing EMSP's direction and focus. There has been some notable progress in securing better access to high quality treatment and care as a result of EMSP's contribution to high level roundtables, particularly in some central and eastern European countries. EMSP's increased visibility at key international meetings and conferences as well as across a wide range of media has led to an enhancement of partnerships with other agencies that share a commitment to improving the situation for people with long-term neurological conditions.

A mark of long-term success will be the take up of the pan-European projects by member societies and their implementation in individual countries and this aim will be reflected in the 2014 Operating Plan and an emerging new vision and strategy for 2015-2020.



John C. Golding

President

A handwritten signature in black ink that reads "John C. Golding".



Maggie Alexander

Chief Executive

A handwritten signature in black ink that reads "Maggie Alexander".

Missing from the group photo:
Torben Damsgaard,
Dorothea Pitschnau-Michel,
Dr Olivier Heinzlef,
Andre Van de Putte



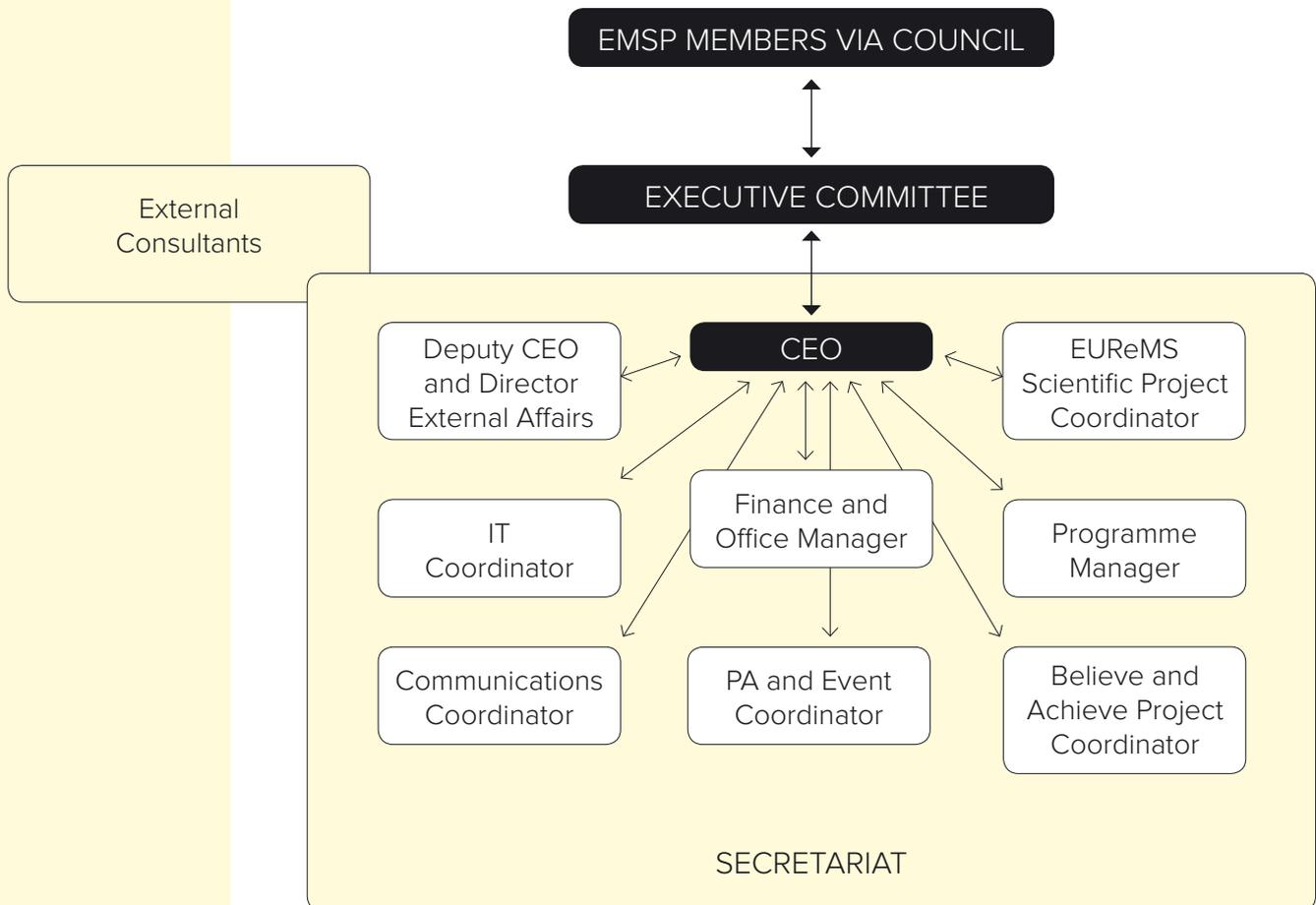
photo by Fabrice Debatty

EMSP's Executive Committee, Brussels, 11 March, 2014
From left to right: Pedro Carrascal, Emma Rogan, Antonella Moretti,
Anne Winslow, John Golding, Beatrika Koncan-Vracko, Peer Baneke,
Maggie Alexander



Strengthening capabilities

EMSP is headed by the Council of Members which delegates powers to the Executive Committee composed of active 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 Strategic Plan for guiding the activities of the Secretariat and its related committees and working groups.



Executive Committee

PRESIDENT	John Golding	MS Society of Norway
VICE-PRESIDENT	Anne Winslow	MS Society of Ireland
TREASURER	Torben Damsgaard	MS Society of Denmark
PAST PRESIDENT	Dorothea Pitschnau-Michel	MS Society of Germany
	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
CO-OPTEE	Pedro Carrascal	MS Society of Spain (FELEM)
OBSERVER	Peer Baneke	MS International Federation (MSIF)
YOUTH REPRESENTATIVE	Emma Rogan	MS Society of Ireland

EMPS Secretariat

In order to fully deliver on the objectives set out in the Strategic Plan 2012-2014, EMSP decided to bolster its capabilities by employing a Communications Officer and an Event Coordinator. With the two positions occupied by April 2013, EMSP gained strength in both internal and external relations, becoming more flexible and effective in relation to members and partners.

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

At peak periods, EMSP was also able to bring in voluntary support in the form of two interns occupying the position of Assistant during two separate periods. This helped in structuring and prioritising the workflow and in enabling us to progress with several of our key initiatives. This report therefore allows us to acknowledge with gratitude the valuable assistance received from Anna Zaghi and Sarah Monkcom, as well as Maria del Amor Gomez.

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.

Not present for the group photo
Tsveta Schyns-Liharska



EMPS 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



photo by Fabrice Debatty

Top achievements in 2013

2013 was a very active year for EMSP, when we achieved notable progress in a number of essential areas for our organisation and constituency: enhancing our capabilities; advancing our flagship projects and gaining increased visibility through strategic partnerships; and promoting our messages via a number of landmark events.

- Under Pressure moved into a third phase where EMSP encouraged and supported its members societies to extensively use and promote this project at national level.
- EUREMS embarked on the road to produce the first MS studies based on data pooled by numerous MS registries from across Europe. This will mark a successful conclusion of the first stage of this project (2011-2014)
- Expanding MS Nurse PROfessional and the concept of specialised MS nurse training in Europe by adding the United Kingdom, the Czech Republic, Italy and Ireland to the list of countries which have implemented this project
- Acting as a recognised voice of people with MS by successfully targeting our main audiences – member societies, the broader MS community, specialists and researchers, partners and policy-makers

“ Of the many highlights of 2013 three things stand out: the incredible enthusiasm and commitment of all those who contributed to the Spring Conference and their invaluable ideas for the future; working with member societies across Europe to lever the power of Under Pressure and the MS Barometer to change the minds of decision-makers; and the addition of two outstanding new members to the already strong EMSP team.”

[Maggie Alexander, Chief Executive EMSP]

12/2011, Trim, Ireland • Looking back, Grace O'Sullivan points to a case of vertigo as her first symptom of MS, but her doctor thought it was a viral infection. *photo Walter Astrada*



Under Pressure – national ownership of the fight against health inequalities

The multimedia project Under Pressure covered important ground in 2013 and is now entering its fourth year boasting significant accomplishments and ambitious plans for the road ahead. The ultimate aim of this project is to raise awareness of the impact of multiple sclerosis on the lives of individuals and to drive improvement in the quality of life for patients and carers.

The first half of 2013 saw Under Pressure gain widespread recognition among MS societies, specialists and decision-makers. The launch of the inspiring Italian video – telling the story of Martina, a young woman living with MS – was one of the highlights of EMSP’s Spring Conference. It brought a fresh incentive to our members to campaign around the message that the stark variations in treatment and care for people with MS across Europe are unacceptable and have to be addressed by all stakeholders. Another landmark for Under Pressure was the launch of the project’s website – a powerful advocacy tool hosting 600 evocative photos and a collection of videos featuring people with MS from 12 European countries.

These two milestones spurred renewed interest in Under Pressure exhibitions and photos. The Italian MS society organised dynamic outdoor exhibitions in Milano and Rome during the Month of the Brain (May 2013), while members from Hungary, Poland and Estonia used the persuasive force of the Under Pressure pictures in several awareness-raising events around the World MS Day (29 May).

Following on from the completion of the second phase of the project, EMSP decided to hold a consultation process mainly with the member societies already involved in Under Pressure in order to assess the interest and direction for a third phase. The results were encouraging and a framework for the next phase was agreed, with the focus on dissemination and promotion at national level. The team of photographers produced two more country videos by the end of 2013, for Poland and Greece. The two respective national MS societies took full advantage of the new Under Pressure products, organising a special launch of the short film to mark their annual meeting (in Greece) and arranging for screenings in cinemas around the country (in Poland).

Up to six more country videos will be produced in 2014, with the Irish video already scheduled for its first official viewing on the occasion of EMSP’s 25th Anniversary Conference, held in Dublin, in May 2014.

“Truly excellent campaign. The quality of the individual photos is stunning.”

[Tonio Borg, European Commissioner for Health and Consumer Policy]

European Health Commissioner Tonio Borg (right) browsing through the Under Pressure Brochure. Also in the picture: Audrey Craven (EFNA).



Better outcomes from better data

Co-funded by the European Commission's Executive Agency for Health and Consumers, the European Register for Multiple Sclerosis (EUREMS) is addressing the lack of robust, comparable data at EU and national level on treatment and care for people with MS. In 2013, EUREMS made substantial steps towards its goal of providing a European infrastructure for data collection, analysis, interpretation and dissemination of data in the MS field.

The consortium of academic institutions and NGOs involved in EUREMS announced two major achievements in 2013: the identification of existing MS registers and the start of cross-border data pooling with a view to publishing landmark studies. In parallel, EMSP revamped the project's website and refreshed the EUREMS brochure.

Identifying the MS registries and gathering detailed knowledge of their content and structure was an essential first step for EUREMS. A standardised questionnaire was then sent to a list of 20 MS registries from across Europe. The survey dealt with aspects such as background and purpose of the registry, inclusion criteria for centres and patients and quality control mechanisms. The findings were summarised in a poster-study signed by Karoline Buckow, Peter Flachenecker and Maura Pugliatti. The poster-study was presented at the 29th annual congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in October 2013, in Copenhagen. On this occasion, EUREMS' Scientific Advisory Board, joined by external experts from the European Medicines Agency, EUnetHTA and the PARENT project, also discussed the overall progress of the project.

Based on these positive outcomes, the EUREMS consortium started pooling the data from the selected MS registries. This is the first time that such an endeavour has been successful. The shared information will be utilised in a series of four studies which will mark the conclusion of the first stage of the project, 2011-2014. The studies focus on key topics such as the prevalence and incidence of MS in Europe and the effectiveness of disease-modifying treatments. Since its inception in July 2011, EUREMS has already delivered on several short-term outcomes that include the implementation of an IT platform for collaboration and dissemination of knowledge on MS. In the long term, EUREMS aims to promote increased knowledge and understanding of MS among clinicians and the general public and to shape research and policy action towards improving the quality of life of those affected.

“ Comparing data from different countries will be of great benefit to MS patients.”

[Karoline Buckow, IT Professional, Department of Information Technology, Medical University Centre in Göttingen, Germany]

Multiple sclerosis registries in Europe – results of a systematic survey

Peter Flachenecker¹, Karoline Buckow² and Maura Pugliatti³, for the EUREMS Consortium

¹Neurological Rehabilitation Centre, Bad Wildbad, Germany

²University Medical Center, Georg-August-Universität Göttingen, Germany

³Department of Clinical and Experimental Medicine, University of Sassari, Italy

Background

The EUREMS (European Register for Multiple Sclerosis) project was designed as a platform aimed to facilitate harmonized merging and collection of existing data from MS registries and databases, as well as comprehensive analyses and comparisons across European populations¹. For this purpose, identification of MS registries and databases that are currently in use in Europe as well as a detailed knowledge of their content and structure is important. In this study, we report the results of a survey on MS registries in Europe that was performed between January and April 2012 as part of the EUREMS project.

Identification of MS registries and databases

The existing registries and databases in Europe were identified by recent reviews², records from the EMSP (MS Barometer)³, PubMed search, checking of publications and abstracts, and contacting 33 national MS societies in Europe. With this approach

- 20 registries were identified
- 13 registries responded to the standardized questionnaire
- 7 registries took part in the interviews:



Development and content of the standardized questionnaire

The standardized questionnaire was developed and circulated between members of the steering committee. After reaching consensus, it was sent to the registry leaders. The following information was obtained:

- Organizational structure
- Background/purposes of the registry
- Inclusion criteria for centers and patients
- Documentation process
- Data that are collected
- Quality control
- Governance
- Current state of the registry (updated to December 31th, 2011)

The original pdf can be downloaded from www.eurems.eu News&Events

Results of the standardized questionnaire

The main purposes of the 13 registries were epidemiological research (n=10), health care research (n=9), long-term therapy research (n=8), and support/basis for clinical trials (n=8). One registry (Spain/Catalunya) was specifically designed for patients with clinically isolated syndromes (CIS). There is large heterogeneity in organizations running the registries, duration of data collection, number of centers and patients included and follow-up:

Country	Institution	Start	# of pts	# of ctrs	follow-up
Croatia	MS society	2007	2,477	10/21	annually
Denmark	Danish MS registry	1948/1996	12,500	16	no
France	EDMUS Coord. Center	1976	~ 40,000		yes
Germany	MS society	2001	~ 30,000	~ 150	no
Greece	MS society	2011	3,500		yes
Italy	Network of MS centers	2001	~ 20,000	40	bi-annually
Norway	University of Bergen	1998	5,100	20	yes
Russia	Healthcare ministry	2006	21,500		unknown
Serbia	MS society	2000	3,500		no
Spain	Vall d'Hebron university	2008	616	~ 20	CISpts only
Sweden	Swedish MS registry	1997	12,900		yes
Switzerland	University of Basel	2012	270	8	bi-annually
UK	University of Swansea	2009	8,300	5 (pilot)	yes

All registries indicated that they collect personal data (date of birth and gender) and basic disease data (i.e. disease course, time of disease onset and diagnosis, symptoms at onset and diagnostic accuracy). Data on disease-modifying treatment are documented by 11 registries, whereas symptomatic treatment is recorded in 7 registries, mainly as optional. Socioeconomic data (employment, care/support due to MS) are collected in 9 and 7 registries, respectively. Only 6 registries included patient-reported outcomes:

Country	HRQoL	Depression	Fatigue	Disability
Croatia	-	not specified	-	-
Denmark	-	-	-	-
France	not specified	not specified	not specified	-
Germany	-	-	-	-
Greece	-	-	-	-
Italy	FAMS/MSQoL-54	BDI/Hamilton	FSS	-
Norway	MSIS-29/EQ5d	-	FSS	-
Russia	-	-	-	PPDS
Serbia	-	-	-	-
Spain	-	-	-	-
Sweden	MSIS-29/EQ5d	-	-	-
Switzerland	-	-	-	-
UK	MSIS-29/EQ5d	HADS	-	-

Conclusions

The present survey on MS registries in Europe shows that (1) national MS registries exist in many European countries, (2) these registries differ widely from country to country, and (3) despite this heterogeneity, a considerable number of registries share common objectives. Patient-reported outcomes are underrepresented in the existing registries but need to be considered in future basic sets.

The detailed information obtained in this study is a prerequisite to evaluate comparability of existing registry data. These results will serve as a basis for several studies conducted within the framework of EUREMS.



Popularising MS nurse education

MS Nurse PROfessional, EMSP's ground-breaking educational tool for MS nurses, expanded to four new countries and saw its first scientific sessions organised in a busy 2013. The significant interest from stakeholders once again proves that there is a serious demand throughout Europe for health professionals specialised in MS – which was the first argument behind this project.

Two country launches of the programme in the first part of the year, UK (March) and Czech Republic (June) were followed by the scientific sessions organised during the 29th annual congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in October, in Copenhagen. Vicki Matthews, MS Specialist Nurse Advisor and member of the MS Nurse PROfessional Steering Committee, was one of the experts giving a presentation at ECTRIMS. Vicki Matthews reinforced the message that the role of MS nurses in ensuring comprehensive care should be properly recognised.

The third national launch of MS Nurse PROfessional in 2013 took place in November, at a specialist meeting held in Dublin. Representatives from leading professional and patient groups including MS Society Ireland and Health Service Executive (HSE) Ireland welcomed the programme and spoke of the importance of development and educational opportunities in supporting nurses and other staff who provide care for those living with MS. Italy also officially adopted the MS Nurse PROfessional project.

These latest launches come after Malta and Spain became officially linked with the project in 2012. The next country on the list is Germany. Answering to the growing demand on behalf of its members and partners, EMSP made the online training programme curriculum for MS Nurse PROfessional available in Italian, Spanish and Czech as well as English.

MS Nurse PROfessional was initiated by EMSP in collaboration with Rehabilitation in Multiple Sclerosis (RIMS) and the International Organisation of MS Nurses (IOMSN) in continuation of the 2009 MS-Need programme, which was the largest survey of MS nurses in Europe. The project aims to support MS nurses develop the right knowledge and skills and builds on an agreed core of set competencies that will promote consistency of practice and nursing care across the whole of Europe. It has been accredited by the Royal College of Nursing in the United Kingdom and by the European Association of Neuroscience Nurses and further endorsed by prestigious publications such as Lancet Neurology and the Multiple Sclerosis Journal.

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 the PwMS.

photo Carlos Spottorno



“ By defining the new, evolved role of MS nurses and equipping them with the skills and knowledge they need and the recognition they deserve, we hope to see a change in the effectiveness of MS care that extends across the entire multi-disciplinary team which will affect the most important beneficiaries of all – people with MS.”

[Anne Winslow, EMSP Vice-President]

Making our voice heard

EMSP has enjoyed a rewarding 2013 year in terms of reaching our key audiences and enhancing the visibility of our messages and flagship projects.

The comprehensive 48 page Conference Report following our Spring Conference is an example of EMSP's recent progress in external communication around key events: it combines inspired messaging (such as the theme of the conference: Better together – Sharing expertise and influence to improve access to treatment, care and employment) with high resolution pictures and a lean design. This provided a sound template for the Report on the panel discussion on Neurodegenerative Diseases in the Workplace, which EMSP produced in collaboration with event co-organisers Alzheimer's Europe (AE) and European Parkinson's Diseases Association (EPDA). Both reports were disseminated to member societies, academics and specialists, policy-makers and MS communities.

EMSP also created, published and promoted two new brochures: a presentation flyer on our mission and activities and a refreshed flyer for one of our flagship projects – the European Register for Multiple Sclerosis (EUREMS).

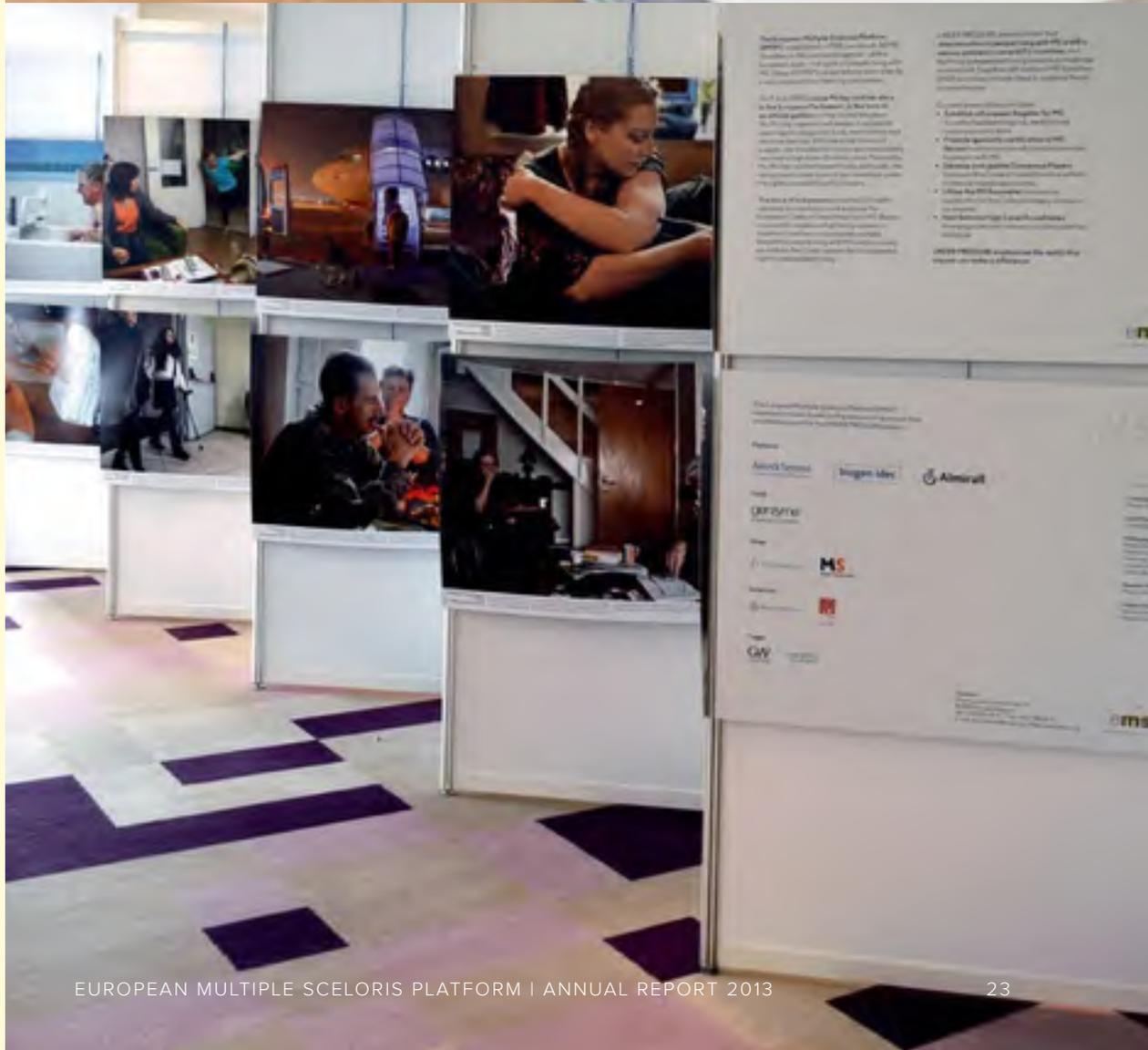
EMSP's intense activity during the European Month of the Brain attracted the recognition of two European Commissioners and a number of Members of the European Parliament and subsequently caught the attention of important policy-related media outlets. Two notable examples: EurActiv published an opinion piece signed by MS advocate Shana Pezaro and The Parliament Magazine hosted a feature article on the event related to neurodegenerative diseases.

In line with the priorities set in our Communications Strategy for 2013, EMSP boosted its presence on social media, with more regular updates and interaction with our partners and collaborators. There were encouraging results: the number of 'likes' for our Facebook page tripled (over 350 at the end of the year) and the number of followers on Twitter more than doubled (to over 200) in a few months. Such achievements put our organisation on the right track in our pursuit to be recognised as a leading authority in the MS field. And to "raise the voice of people with MS".

“ Communicating the abilities of young people with MS, we recognised opportunities to be a transformative force across Europe and to make a tangible difference to people's lives. There are no limits to what people with MS can achieve!”

[Emma Rogan, EMSP Young People's Representative]

top Under Pressure brochures
 in the EMSP stand at ECTRIMS, October 2013
 bottom Under Pressure exhibition at EMSP
 Spring Conference, Brussels, May 2013



Special Events: Annual Spring Conference in Brussels, 3-4 May

Taking place at the start of the European Month of the Brain, EMSP's Annual Conference provided members and partners with further insight and renewed motivation to campaign for better access to treatment, care and social support for people living with MS in Europe.

More than 100 participants were able to draw from the experience of key speakers and were involved in six thematic workshops in the areas of effective lobbying, cooperation with industry and employment for young people with MS. One of the highlights of a dynamic agenda was the Citizens' Jury on sustainable healthcare – Generics for the poor, new drugs for the rich, chaired by Sir Nick Partridge, CEO of Terrence Higgins Trust, a flagship AIDS/HIV NGO in the UK.

The contributions from all the panellists provided the audience with valuable insight into the complexities of this controversial topic.

Further topics addressed by speakers:

Championing the needs of people with MS in the Parliament

Mihaela Militaru, Policy Advisor for Member of the European Parliament Petru Luhan

Why rehabilitation matters for people with MS

Professor Peter Feys, President of Rehabilitation in Multiple Sclerosis (RIMS)

What are the real choices? Therapy options for people with MS

Doctor Jaume Sastre-Garriga, Deputy Director, Department of Neurology at the MS Centre for Catalonia, Hospital Vall d'Hebron

Progressive MS in focus – perspectives from the first progressive MS meeting in Milan

Antonella Moretti, CEO of Italian MS Society

Ceri Angood, Multiple Sclerosis International Federation (MSIF)

John Golding, President of EMSP

The two-day conference was concluded with a Gala Dinner, which provided everyone present with an excellent networking opportunity and an outstanding musical recital by twin classical singers Clara and Nina Kanter, accompanied by pianist Olga Bobrovnikova, herself a person with MS and an MS activist.

“ It was an excellent event – the programme, the speakers, the good ideas and the group spirit and the willingness to move towards something meaningful.”

[Quote from the Conference follow-up questionnaire]

top Conference room at EMSP's Spring Conference in May 2013

bottom Concert at the Gala Dinner included in the programme of the 2013 Spring Conference



Panel discussion on Neurodegenerative Diseases in the Workplace

The panel discussion on The Challenges of Neurodegenerative Diseases in the Workplace, chaired by Member of the European Parliament Angelika Werthmann on 9 July, can be regarded as an important landmark in the advocacy efforts aimed at improving the quality of life for people with neurodegenerative diseases (NDDs), such as Alzheimer's, Parkinson's and multiple sclerosis.

The event was co-organised by Alzheimer's Europe (AE), the European Parkinson's Disease Association (EPDA) and the European Multiple Sclerosis Platform (EMSP), organisations representing three different but intersecting diseases areas. EMSP's speaker at the panel discussion was inspiring MS advocate Shana Pezaro, who spoke about her own experience of coping with the symptoms of multiple sclerosis while in the workplace. Alzheimer Europe was represented at the event by EU Public Affairs Advisor Annette Dumas, who talked about the challenges faced by people with dementia. The European Parkinson's Disease Association's representative was EU Affairs Officer Heather Clarke. Her speech also tackled the difficulties which arise for people with Parkinson's who want to stay in work.

The European Commission acknowledged the great burden of neurodegenerative diseases through the voice of Philippe Cupers, Head of Neuroscience Sector, Directorate-General for Research and Innovation within the Health Directorate. His speech at the event gave an account of the EU-supported actions on neurodegenerative diseases.

One positive outcome of this event was the Written Declaration bid initiated by Angelika Werthmann and other 10 MEPs. The document asking for implementation of long awaited measures to support people with NDDs in employment and job retention was eventually signed by a total of 161 Members of the European Parliament. The event also offered the chance for some of those directly affected by NDDs to be heard by policy-makers in a dialogue-friendly environment.

“ Staying in the workplace means that people with neurodegenerative diseases can maintain self-esteem, a regular life and independence. . . I think the neurodegenerative community needs all the support of national and European policy-makers.”

[Angelika Werthmann, Member of the European Parliament]

12/2011, Trim, Ireland • Before being diagnosed with MS, Grace O’Sullivan taught a class of 30 active children. When she returned to work after being on leave, the school re-assigned her to a learning support role, which involves focused teaching for small groups of kids with learning difficulties. Despite her diagnosis, the school board made her position permanent. *photo Walter Astrada*



Landmark meetings for EUREMS and MS Nurse PROfessional at ECTRIMS

EMSP succeeded in driving forward two of its flagship projects – the European Register for Multiple Sclerosis (EUREMS) and MS Nurse PROfessional – by organising a number of events during the 29th annual congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in October 2013, in Copenhagen, Denmark.

The EUREMS consortium and partners gathered at ECTRIMS to mark the identification of existing MS data providers in Europe, a crucial achievement in the process of building a centralised system of MS data from across the continent. Another objective was to plan for the road ahead and in this sense EMSP arranged for three meetings to take place: the EUREMS Steering Committee, the Scientific Advisory Board and a Consultation with Industry.

The MS Nurse PROfessional saw its first scientific sessions organised at ECTRIMS, where qualified MS nurses gave specialised advice and counselling to those interested in following this career path. EMSP's Vice President Anne Winslow was present at the event and said that “these inaugural nurse-led sessions are testament to the catalysing effect of MS Nurse PROfessional. EMSP is proud to be a part of this process”.

“ People with disorders of the central nervous system want to be recognised for the contribution they can make to companies and to the wider culture of the EU.”

[Shana Pezaro, MS Advocate, UK]

San Quirico D'Orcia, Italy, 02/2012 • Martina Vagini has balance problems. In a country like Italy, disability and history create a difficult barrier: laws that encourage (or even mandate) public buildings to improve accessibility often collide with laws that protect artistic heritage. *photo Carlos Spottorno*



Roundtable influencing

Throughout 2013, EMSP was strongly focused on building relations with its members and contributing to their capacity-building efforts. The MS national societies were consulted at key moments: following EMSP's Spring Conference or prior to entering the third phase of Under Pressure. EMSP organised or participated in a number of high-level meetings which brought our EU-wide agenda closer to national stakeholders.

Membership Satisfaction Survey

The most comprehensive tool for member consultation came in the form of the Membership Satisfaction Survey. It collected data from 13 different member organisations on a range of parameters, such as their interaction with EMSP and their participation in our projects and events. The main purpose of this evaluation was to obtain feedback from our associations on their satisfaction level with EMSP's work and initiatives and to take up suggestions for future action.

This survey highlighted that the work of EMSP meets the expectations and is valued by members. For example, the EMSP Secretariat has scored well in terms of availability (almost 80% of respondents rated as good), quality of advice (over 50% of respondents rated as good), problem resolution (about 38% of respondents assessed as excellent) and understanding of the organisations' needs (more than 30% respondents assessed as good). There were also useful suggestions for ways in which EMSP's activities could be even better.

Firstly, EMSP could boost its networking activities so that member organisations can get in touch with each other and share experiences regarding MS-related projects. EMSP could promote a more efficient and immediate communication among the different European associations – for example, by arranging special debates and discussions during EMSP's events so that members can exchange opinions and express suggestions.

And secondly, EMSP should improve its outreach through a more efficient use of social media. Over a third of respondents rated the use of social media as good, suggesting that we could enhance the dissemination of key information via Facebook, Twitter or Youtube. These platforms may be an effective instrument especially when reaching out to younger audiences and involving them in EMSP's projects and events.

Madrid, Spain, 10/2011 • Many couples say living with MS is like having a third person in the marriage: one who often interferes with plans and creates physical, psychological and emotional strain. Almudena Movilla Morena takes advantage of a quiet moment to reassure her husband David that right now, they are just two. *photo Lurdes R. Basolí*



High-level meetings held in CEE countries

Poland

EMSP participated alongside the Polish MS Society (PTSR) at a debate organised in the Polish Parliament in September. The event was focused on the social costs of MS, highlighting patients' perspectives. EMSP's President John Golding was the guest of honour. He opened the debate with a presentation about the situation for people with MS in Europe. He was followed by health economist Gisela Kobelt's insightful lecture on the social costs of MS.

The President of the Polish Health Technology Assessment (HTA) Agency, Dr Wojciech Matuszewicz, was also present at the event. He explored the possibility of eliminating the 5-year time limit set by authorities in order to "equalise" access to the waiting lists for disease-modifying drugs (DMDs). Experts agree that stopping the DMD treatment increases the risk of progression of the disease. The neurology expert present at the event, Professor Krzysztof Selmaj, gave a lecture on new innovative treatments and the present trend of patient tailored therapies. The debate was organised by the "Neuropozytywni Foundation" and was boosted by the presence of Hungarian, Slovakian and Czech patient organisations.

Romania

The Romanian MS Society (SSMR) organised the National Multiple Sclerosis Seminar, in late September, in the city of Cluj-Napoca. This event was attended by 140 stakeholders: MS patients, their carers, neurologists, MS nurses, psychologists and local authorities. The city's mayor, ex-PM Emil Boc, expressed his admiration for the work of SSMR and pledged his support for the development of a centre where people living with MS would get information and counselling. EMSP was represented by Event Coordinator Andreea Antonovici. Previously, in August, SSMR together with one of its members and partners, SM Speromax Alba, founded the Youth Committee for Multiple Sclerosis Patients in Romania. Attending the event were over 20 people directly or indirectly affected by multiple sclerosis (MS), especially young people recently diagnosed with MS, some before the age of 20. Communications Officer Claudiu Berbece attended on behalf of EMSP.

Radom, Poland, 10/2011 • Monika Kladko receives electrotherapy every day for about 30 minutes. The treatment uses a mild electrical current to stimulate nerve fibres, thereby releasing endorphins (the body's natural pain-killing chemicals). This service is provided by the MS Society in cooperation with the Radom City council. *photo Carlos Spottorno*



Greece

The Greek MS Society organised the annual meeting titled “BmyLife – Improve the quality of your life”, in October, in the city of Thessaloniki.

EMSP was represented by President John Golding and Chief Executive Maggie Alexander.

An important milestone at the event was the launch of a new video from EMSP’s Under Pressure project. This short film contains a series of stories on living and coping with MS in Greece, a country severely hit by the economic crisis.

The event was attended by numerous stakeholders from the MS community in Greece, including specialists from fields such as nutrition, urology and physiotherapy.

It was also a good occasion to organise an Under Pressure photo exhibition.

Furthermore, EMSP intermediated a meeting between its member society in Thessaloniki (Greek MS Society) and its associate member in Athens (Hellenic Federation of Persons with MS), resulting in plans of working together towards a common roundtable in the Greek Parliament, in autumn 2014.

Belgium

At a packed roundtable discussion in Brussels, in early December, representatives of MS societies and organisations from more than 20 countries reinforced the need for up-to-date information on the experiences of people affected by MS in Europe – which could be met through a future Pan-European MS Patient Experience Survey.

Data from the MS Barometer and other surveys provides invaluable information about the national situation but this picture needs to be completed by testimonies on what living with MS means on a day-by-day basis for people with this condition and their carers.

Contributors recognised the considerable challenges in obtaining a representative overview and the importance of making contact with hard-to-reach groups as well as those who are members of established organisations (an example: certain MS patients confined to their apartments in Belarus vs MS patients receiving treatment and care in specialised facilities in Germany). A complete outreach is vital if we are to highlight unmet needs and to advocate effectively for the reduction of health inequalities known to be linked to MS and other neurodegenerative diseases.

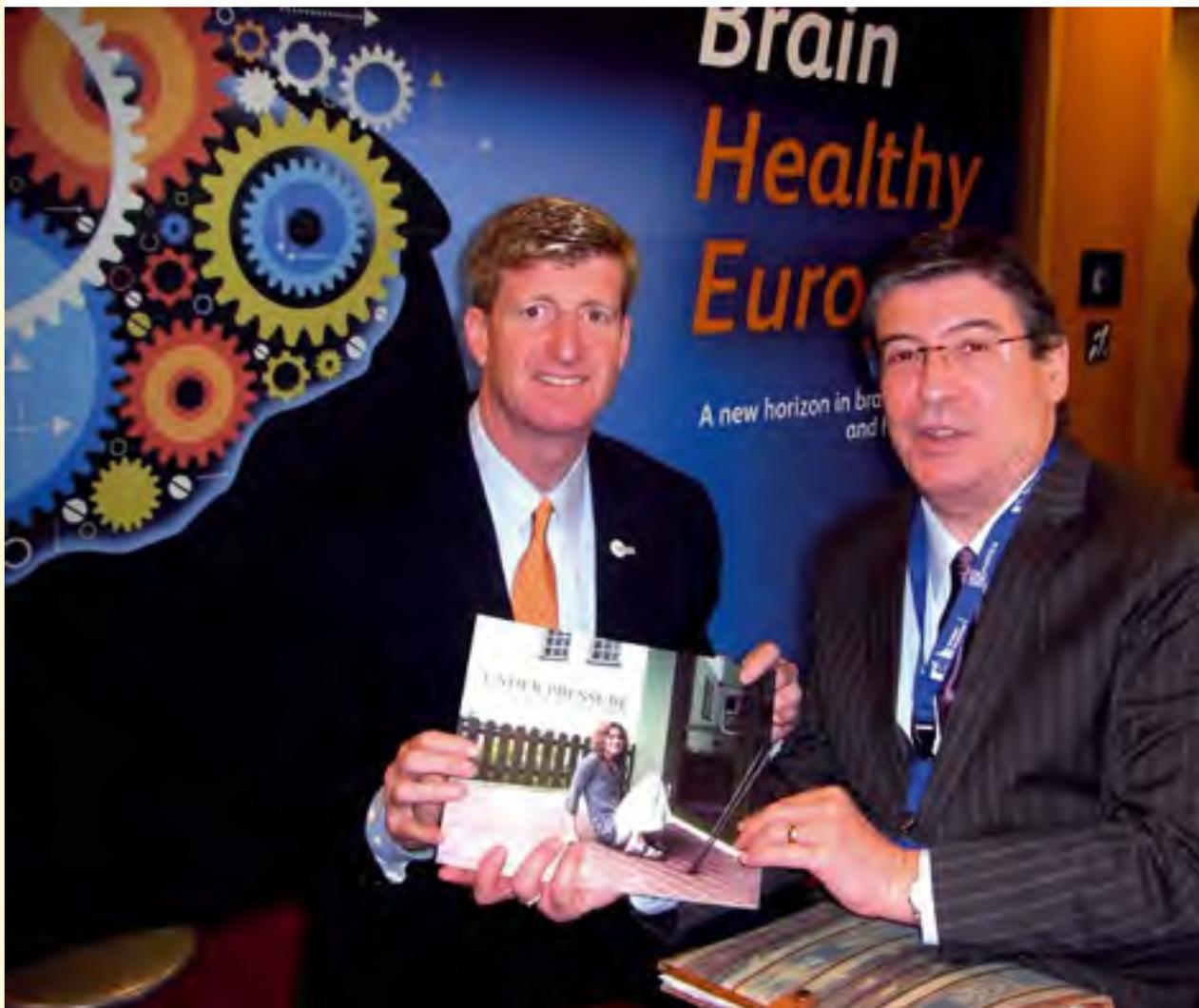
Warsaw, Poland, 10/2011 • Ania Szczepaniak dreamed of being a model and actress; a friend photographed her often to make a portfolio. As it becomes increasingly difficult to move around even inside her flat, Ania must re-evaluate how and where she can work. She finds it harder to go to students as she did in the past, but hopes to continue teaching Polish at home. *photo Carlos Spottorno*



Networking

EMSP gained enhanced visibility during the European Month of the Brain (May 2013) by promoting its key messages and elements of its corporate identity at several events organised by influential partners or European institutions.

The month started with EMSP joining its efforts with the European Federation of Neurological Associations (EFNA) and other partners on the occasion of the Pledge signing event in support of essential investment in neuroscience, organised in the European Parliament in Brussels. Towards the end of that month, EMSP participated in the 10th Anniversary Conference of the European Patients' Forum (EPF) and also at the European Commission conference "Healthy Brain: Healthy Europe" on brain research and healthcare, both events taking place in Dublin, Ireland. Yet again, the Under Pressure project served as a good ambassador for EMSP's advocacy work, with EMSP President John Golding presenting this initiative to the keynote speaker, former US Congressman Patrick Kennedy (as pictured below).



But perhaps the most notable praise received by EMSP came from Health Commissioner Tonio Borg, who spoke highly of our Under Pressure project. EMSP's leading figures also met with Research Commissioner for Research, Innovation and Science Maire Geoghegan-Quinn, and with a number of Members of the European Parliament who have a good track record of health-related initiatives.

Consolidating strategic partnerships

One of EMSP's priorities is to remain an important player in the field of neurology – especially in promoting more support for research – partly by strengthening ties with organisations such as the European Federation of Neurological Associations (EFNA).

EMSP's mission to be recognised as the representative voice of people with MS in Europe has brought a closer cooperation with Rehabilitation in Multiple Sclerosis (RIMS) – together we have and will continue to promote concepts such as the need for personalised treatment for MS patients.

EMSP also plans to be involved in a significant number of advocacy and awareness-raising activities marking Year of the Brain 2014 (YotB) and has established a fruitful dialogue with the Year of the Brain Advisory Board in this regard.

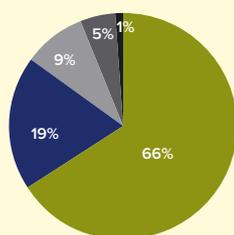
EMSP Networking Dinner

In February, EMSP organised its customary Gala Dinner for sponsors and supporters. Our prominent Industry partners attended and were greeted by CEO Maggie Alexander with an inspiring call to keep the ball rolling in the fight with multiple sclerosis: "So if our vision is a world where we can beat MS, how are we going to achieve that? I wouldn't be standing here tonight if I didn't believe in the possibility of progress – and not just incremental progress, but a significant escalation based on a much better understanding of the disease, better awareness, recognition, more accurate, specific and timely diagnosis and classification, systematic data collection and epidemiological research, tracking both clinical and quality of life outcomes and above all, in the absence of a primary prevention strategy, early intervention." The proof of the effectiveness of this call stands in the ongoing support EMSP is receiving from its sponsors and supporters with a common interest in ensuring a better quality of life for people with multiple sclerosis. EMSP's relations with the Industry are governed by a Code of Conduct which establishes clear roles and boundaries for the avoidance of doubt and for public interest.

Treasurer's Report

The accounts for 2013 show a surplus for the year of € 58,671 against a budget surplus of € 2,459, which is an excellent result for a year in which many organisations had to tighten their belts and cope with decreasing income and rising costs.

In accordance with the 2013 budget the total income of € 1,473,918, is less than EMSP raised in 2012, and expenditure is also considerably less with a total reduction of € 574,698. compared to 2012. The primary reason for this is that although the number of projects that we are working on remains the same, the expenditure required against MS Nurse Pro and EUReMS was considerably reduced as was the total project income, €862,918 against the 2012 total of € 1,346,370. Some saving has been achieved by being less reliant on outsourcing, and employing dedicated staff for specific tasks instead. Support from industry continued to be a significant contributor to EMSP's income, with a breakdown as shown left.



- Pharma support
- EU operating grant
- Events
- Membership fees
- Donations and other income

The proportion of industry income will increase in 2014 as, along with a number of other key pan European NGOs, we were not successful in our bid to the EU for an 2014 operating grant.

The total net assets of € 346,200 include the € 201,061 bank guarantee, so in real terms we operate on just over 5 week's expenditure each month. We are aiming to improve this ratio, with careful balancing of income before expenditure takes place, but this is not always possible when some projects only have funding released on completion. It is important that we are able to build our cash reserves to ensure future stability against any income fluctuations and this is incorporated in the Fundraising Strategy. The release of € 100,000 during 2013 from the bank guarantee for the EUReMS project has helped, and the final release of the guarantee in 2014 will help us to achieve this goal.

We continue to monitor expenditure very closely against our budget and in particular our cashflow. Fortunately with the surplus for the year 2013 of € 58,671 and excellent network and relationships that we have with industry, the ExCom was able to decide to use the surplus from 2013 together with additional funding to bridge the gap in the 2014 budget. The commitment for an EU Progress grant of € 86,000 for the Believe and Achieve project in 2014 has already been received. The successful efforts of the whole team, but in particular, Christoph Thalheim in bringing this about should be acknowledged.

Torben Damsgaard

Treasurer

April 2014

These figures and statistics may be subject to a later update pending feedback from the responsible bodies of the European Commission



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E-mail : revisor@dpo.be
www.dpo.be

STATUTORY AUDITOR'S REPORT
TO THE GENERAL MEETING OF THE MEMBERS OF THE FOUNDATION
EUROPEAN MULTIPLE SCLEROSIS PLATFORM
AUGUSTE LAMBIOTTETRAAT 144/8
1030 BRUSSELS
ON THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31/12/2013
RPM BRUSSELS nr. 0473.317.141
=====

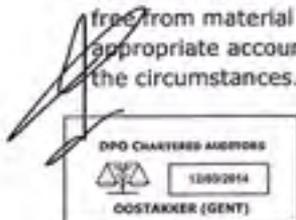
In accordance with the legal and statutory requirements, we report to you on the performance of the mandate of statutory auditor, which has been entrusted to us. This report contains our opinion on the true and fair view of the financial statements as well as the required additional statements (and information).

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 2013, prepared in accordance with the financial reporting framework applicable in Belgium, which shows a balance sheet total of 623.908,47 EUR and a profit for the year of 58.671,82 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.



RPM BRUSSELS nr. 0473.317.141

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. 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.

In accordance with the above-mentioned auditing standards, we considered the foundation's accounting system, as well as its internal control procedures. We have obtained from management and from the foundation'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 foundation 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 accounting period ended 31/12/2013 give a true and fair view of the foundation's assets and liabilities, its financial position and the results of its operations in accordance with the financial reporting framework applicable in Belgium.

Additional statements (and information)

The compliance by the foundation with the law of 27 June 1921 related to not-for-profit associations, international not-for-profit associations and foundations is the responsibility of management.



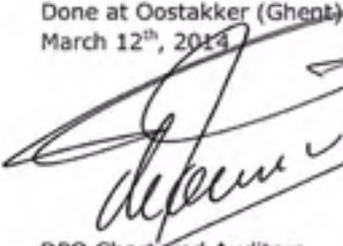
DPO CHARTERED AUDITORS
1200/2014
OOSTAKKER (GENT)

RPM BRUSSELS nr. 0473.317.141

Our responsibility is to supplement our report with the following additional statements (and information), which do not modify our audit opinion on the financial statements:

- Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- There are no transactions undertaken or decisions taken in violation of the foundation's by-laws or the law of 27 June 1921 related to not-for-profit associations, international not-for-profit associations and foundations that we have to report to you.

Done at Oostakker (Ghent)
March 12th, 2014




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

2013 Financial Statements

Income	2012 (restated)	2013
Membership fees	79,000	79,553
Corporate core funding	92,500	110,000
EU operating grant	277,340	278,417
Project funding	1,346,370	862,918
EUREMS	591,056	436,940
MS Nurse Pro	567,523	323,056
Under Pressure	169,791	73,500
Believe & Achieve	–	20,000
Other projects	18,000	9,422
Events	166,200	137,250
Other Income	13,758	5,780
Total income	1,975,168	1,473,918

Expenditure	2012	2013
Staff costs	216,886	498,741
External fees	166,227	77,743
Office and other costs	110,022	101,614
Events	224,453	122,376
Project expenditure	1,272,357	614,773
EUREMS	495,417	312,019
MS Nurse Pro	591,380	248,842
Under Pressure	179,594	52,687
Other projects	5,966	1,225
Total expenditure	1,989,945	1,415,247

Result	2012	2013
Profit/Loss for the period	– 14,777	58,671

all figures in euros

These figures and statistics may be subject to a later update pending feedback from the responsible bodies of the European Commission

2013 Balance sheet

Assets/Liabilities	2012	2013
Fixed assets	37,366	41,727
Current assets	869,832	582,183
Accounts receivable – Pharma	151,670	185,914
Accounts receivable – Members	2,500	4,550
Balance due EU operating grant	112,031	83,958
VAT	9,385	10,586
Prepayments & Other Debtors	23,576	34,652
<i>Total debtors</i>	<i>299,162</i>	<i>319,660</i>
Bank current accounts	272,442	61,462
Bank guarantee account	298,228	201,061
<i>Total bank and cash</i>	<i>570,670</i>	<i>262,523</i>
Current liabilities	577,942	235,983
Trade creditors	138,913	12,846
Accruals & other creditors	79,516	58,912
Deferred income	344,4261	111,078
Taxes & social security	15,087	53,147
<i>Net current Assets / (Liabilities)</i>	<i>291,890</i>	<i>346,200</i>
Total assets	329,256	387,927

Funds	2012	2013
Reserves	329,256	387,927
Capital	134,585	13,585
Reserves B'fwd 31 December 2012	310,448	295,671
Designated funds – developing countries	20,000	20,000
2013 surplus	– 14,777	58,671
Total Funds	329,256	387,927

all figures in euros

These figures and statistics may be subject to a later update pending feedback from the responsible bodies of the European Commission

“





photo by Fabrice Debatty

EMSP Member Organisations

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.sdms-h.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.ms-malta.org.mt

Multiple Sclerose
Vereniging Nederland
www.msvereniging.nl

Multipel Sklerose
Forbundet | 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

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
(9SMSGO)
www.multiplesklerose.ch

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

MS Foundation Bulgaria
www.msobshtestvo.org

Associate Members

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 Egysülete
(SMBOE)
www.smboe.hu

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

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

2013 has seen a consistent two-way flow of information, expertise and good practice from the majority of its 38 member societies. EMSP has supported members, particularly in Central and Eastern Europe, 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 600,000 people in Europe currently living with multiple sclerosis.

Corporate supporters

EMSP has continued to benefit from the unconditional support from ten corporate supporters who between them have provided part-funding for each of EMSP's key projects including the European Registry for MS (EURMS), MS Nurse Pro (a pan-European MS nurse education programme); MS Barometer; Under Pressure (a multi-media project on

the impact of living with MS in Europe) and Believe and Achieve (a new project aimed at helping young people with MS access work).

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 Medicine (RIMS); Multiple Sclerosis 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

LOYENS

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ERNST & YOUNG
Quality In Everything We Do


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genzyme


biogen idec


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Bioness
LiveOn


gsk
GlaxoSmithKline


Bionorica


GW
pharmaceuticals


Coloplast


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ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS


Medtronic
FOUNDATION

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

Credits



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

This report was compiled by
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Chief Executive Maggie Alexander

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www.studiovanson.com

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with reference to best practice
guidelines of visual accessibility.
We welcome your feedback on
the contents and design and
suggestions for ways of making
our publications more useful and
accessible.

Please email your comments to
claudiu.berbece@emsp.org



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EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

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

European Multiple Sclerosis Platform

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