



European Multiple Sclerosis Platform Annual Report 2008



The European Multiple Sclerosis Platform (EMSP)

Since its inception in 1989, the European Multiple Sclerosis Platform has grown to become a pan-European body. Today, EMSP works in close collaboration with MS societies from 33 countries, providing a focal point for addressing issues that concern all persons with MS (PwMS).

EMSP members span the entire European Union from north (Iceland) to south (Greece), and east (Belarus) to west (Ireland).

The Platform's overriding goal is to ensure that each PwMS is equally empowered to exercise his/her rights in relation to factors that influence quality of life. To this end, EMSP has five main aims.

- Promote actively the interests of PwMS on a European level.
- Act as a focal point of liaison with relevant EU bodies.
- Facilitate joint programmes and sharing of skills amongst MS societies.
- Procure and disseminate information of interest to members.
- Encourage research related to MS in both medical and non-medical areas of relevance.

The following pages highlight EMSP's significant steps towards achieving these goals in 2008.

Multiple sclerosis (MS) is a complex, chronic and disabling disease. It affects twice as many women as men, and is usually diagnosed between the ages of 20 and 40 – a critical stage in young adult life, characterised by considerable family and professional responsibilities.

MS does not generally affect life expectancy; it does, however, profoundly affect an individual's quality of life. Its progressive and unpredictable nature make it particularly challenging for PwMS, as well as for their families and carers.

Table of Contents

Message from the President.....	4
EMSP Executive Committee.....	6
EMSP Key Achievements in 2008	7
MS Barometer	13
National High Level Roundtable Discussions	16
Slovenia	18
Bulgaria.....	20
Hungary	22
International Conferences and Networking.....	24
EMSP Annual Conference – Reykjavik, Iceland	29
Country Profile: The Russian struggle to improve the lives of PwMS.....	38
Financial Report 2008.....	40
Acknowledgements	43
Member Organisations.....	44
Annex 1. EMSP Vision, Mission and Values.....	48
Annex 2. MS Barometer Editorial in <i>The Lancet Neurology</i>	49
Annex 3. Audit Report 2008.....	51

Message from the President

For the European Multiple Sclerosis Platform (EMSP), 2008 marks the point at which numerous initiatives undertaken over the past three years came to fruition and began to intersect. The result is that the impact of each project is more powerful than it would have been on its own. Without question, we can look back on these last 12 months with a sense of accomplishment.

Having worked through the final stages of the MS Information Dividend (MS-ID) pilot project, we have established an effective model for a European-wide registry for persons with MS (PwMS). A comprehensive and centralised list of all diagnosed individuals will be vital to all of our future work. Through the MS Barometer project, we collected data needed to create a realistic picture of the health, social and economic conditions of persons with MS (PwMS) across 32 countries in the European Union (EU).

But more importantly, with this foundational work complete, we can look forward with

anticipation of achieving even greater things in the future. Collectively, these projects establish a framework and provide a set of tools that EMSP and its members can apply in their advocacy efforts at the EU level and within diverse national contexts.

As demonstrated in the body of this report, the first results of the MS Barometer show troubling disparities in the overall quality of life for PwMS in the EU. These findings contradict the principles of equal rights for all European citizens. The true value of the MS Barometer is that it provides a means of assessing how well each country is doing in relation to the standards established in the MS Code of Good Practice, which was endorsed by the European Commission in 2007.

Ultimately, the MS Barometer provides a structure through which each country can take steps toward implementing the Code. Annual reporting against these baseline results will allow us to measure progress on

a year-to-year basis, within individual countries and across the EU.

EMSP chose to highlight the value and usefulness of the MS Barometer by unveiling the first results through a new initiative designed to promote high level dialogue at the national level. EMSP partnered with Zdruzenje Multiple Sklerose Slovenija (ZMSS, the Slovenian MS Society) to host a Roundtable discussion (7 May 2008) on the current state of affairs for PwMS in Slovenia. As reported later in this document, the Roundtable led to commitments to action on the part of all players on the national level, and was important to raising both political and public awareness of MS. Additional Roundtables were subsequently held in Bulgaria and Hungary, and EMSP is currently working with several members to organise events in 2009.

In June 2008, the MS Barometer gained international attention through an editorial published in *The Lancet Neurology* (see

Annex 2). The editorial clearly states that “All people with MS, regardless of where they live, should have equitable access to treatment and services” and identified the need for a shared European research agenda for MS. In August, EMSP presented the MS Barometer to the European Parliament.

The need to act at every level, and to cooperate across all levels, was very much brought to light by EMSP during an excellent conference on the topic of “Living Independently with MS” (May 2008; Reykjavik, Iceland).

Over the past few years, EMSP has taken steps to provide solid evidence of our claims that European nations must do more to improve the quality of life of PwMS. We have developed tools to facilitate this process of improvement. Our next challenge is to engage with the external agencies that can instigate action. As this is a major shift in our focus, a main task of the Executive Committee in 2009 is to establish a clear strategic plan for the coming years.

Within our own community, we have already determined that we need to do more to support young people with MS, and have begun planning an annual conference for 2010 that will be directed partly toward this target group.

The challenges foreseen for the coming years require a sustainable and smooth-running EMSP office in Brussels. Considering the scope of the work ahead and the number of people needed to carry forward our aims in a cohesive manner, the Executive Committee felt the time was right to establish a more formal presence and operating structure for EMSP.

To this end, we applied for – and received – a funding grant from the EU Director-General for Health and Consumers (DG SANCO). To realise the full potential of these recent initiatives despite these difficult economic times, EMSP must leverage this endorsement to secure funding and support from other sources.

I also want to acknowledge specifically the support of the Belgian MS Society in

helping to provide office space within their facilities, where the entire EMSP team of four staff persons can work and interact on a daily basis.

I truly believe that as we forge ahead in 2009, EMSP is better positioned and better equipped than at any time in its history. We have stronger ties with a wider range of individuals and organisations that recognise the importance of our work and support our goals. At the same time, a well-balanced mixture of sponsors is the key for our financial sustainability and serves as an indicator of our independence. This ability to act politically at the European level is the core of the service and the value we can provide for PwMS.



Dorothea Pitschnau-Michel,
EMSP President

EMSP Executive Committee



The EMSP Executive Committee comprises eight posts. The current Committee includes:

The principle roles of the Committee include:

- Strategic and financial long-term planning.
- Lobbying and networking.
- Procuring and dissemination of information.
- Facilitation of Pan-European projects.
- Fundraising and relations to Industry.
- Research and treatment.
- Support and development of emerging MS Societies.
- Workshops and skill sharing

President
Vice- President
Treasurer

Dorothea Pitschnau-Michel (Germany)
John C. Golding (Norway)
Christiane Tihon (Belgium)

Eva Havrdova, MD, PhD (Czech Republic)
Robert Schlathau (Austria)
Anssi Kemppi (Finland)
Michael O'Donovan (United Kingdom)
Mateja de Reya (Slovenia)

Secretary General

Christoph Thalheim (Belgium)

EMSP Key Achievements in 2008

As highlighted throughout this report, several of EMSP's key achievements in 2008 are related to the MS Information Dividend (MS-ID) project. Indeed, this project will continue to drive our activities in the coming years.

MS-ID Pilot Project

In 2008, EMSP finalised the bulk of the work for the MS-ID pilot project, which aims to create a model for a European registry of all PwMS. The main task of the past year involved collecting the previously agreed minimum data set with data from MS centres in five European countries (Germany, Spain, Poland, Iceland and Romania). The information collected included clinical data, the social-economic situation of PwMS, and aspects of quality of life.

Due to its very limited scope, the assessment of the data collected to date will not provide any statistically relevant

information. However, it serves as a valid test for the feasibility of our future European MS Register project.

EMSP will present the main results of the MS-ID project at its next conference (May 2009) and will finalise the project shortly thereafter (September 2009).

MS Code of Good Practice & Consensus Papers

In late 2008 and early 2009, EMSP undertook to work with European Committee on Treatment and Research in MS (ECTRIMS) and Rehabilitation in MS (RIMS) to update the Code of Good Practice, taking into account important new research and consensus papers on palliative care and juvenile MS. Plans are also underway to update the European Guidelines on Rehabilitation for MS.

The European Commission has shown its support for the Code and Consensus

Papers by making both available on DG SANCO website, through the EU Health Portal:

http://ec.europa.eu/health/ph_information/dissemination/diseases/neuro_en.htm#monitoring

EMSP continues to offer financial support to members wishing to translate the Code into their national official language; to date 14 such translations have been undertaken. EMSP intends to translate the Consensus Papers into four or five major European languages. In addition, plans are underway to create a "pocket guide" for both documents.

EMSP contributes to EUGLOREH

In March 2009, the EU Public Health Programme launched its publication *Report on the Status of Health in the European Union*. More than 170 health experts have contributed to this vital report. EMSP took a lead role in

developing content on the topic of MS, including proposals for policy reform. To date, no decision has been taken as to whether the report will be updated on an annual basis. A synthesis of the report's main findings is available at:

www.eugloreh.it/ActionPagina_988.do

MS Interest Group / MS Champion in the European Parliament

EMSP wishes to express its sincere gratitude to Scottish MEP Catherine Stihler, who for several years acted as the MS Champion within the European Parliament and led the MS interest group, a set of MEPs who actively supported our efforts.

This group was vital to obtaining major acknowledgement and support for the Code of Good Practice and Consensus Papers by the European Parliament in 2007. We are pleased to announce that a new MS Champion has been identified, pending re-election in the coming months, who will help to establish new priorities for the MS interest group.

Having numerous allies within both the political and administrative sections of the European Parliament is vital to our ongoing work.

EMSP Welcomes New Member

In May 2008, the All-Russian MS Society submitted its application for membership in EMSP. In unanimously accepting the application, the Executive Committee and EMSP members acknowledged that bringing such a large entity (the All-Russian MS Society represents approx. 150,000 PwMS) into membership would be challenging given the limited resources available through EMSP. Yet all members agreed that formalising the relationship offers a unique chance to extend the reach of EMSP and also provides the All-Russian MS Society with important opportunities to network and strengthen its own advocacy efforts. (See page 38 for full profile.)

DG-SANCO Grant Supports Core Funding

In 2008, EMSP applied for – and received approval of – a funding grant of €100 000 from the European Commission's Director-General for Health and Consumers (DG-SANCO). The grant will be forthcoming in 2009 and will support EMSP operations.

For many years, EMSP has been one of several patient groups lobbying for core funding from the EU. Out of 40 applicants, EMSP was one of 10 organisations selected to receive this grant. This is a clear recognition of the relevance of our work.

With this high-level acknowledgement, EMSP will be well positioned to attract additional support from other agencies.

EMSP funding derives from multiple sources including membership fees, European institutions, industry and foundations. To ensure a high degree of neutrality, EMSP's funding policy stipulates that all major industry sponsors

must provide an equal amount of core funding.

Over the past eight years, EMSP has been able to quadruple its base funding. Additional effort will be made in 2009 to diversify sources of funding to ensure stability during these difficult economic times.

Code of Conduct for Working with Pharma

In December 2008, EMSP posted on its website an updated version of the Code of Conduct that regulates its relationships with stakeholders, including the pharmaceutical industry.

At present, there are no laws at European level regulating relations between the voluntary health organisations (such as EMSP) and the pharma industry. However, the relationship between industry and the general public is strongly regulated at EU and national levels. The most directly relevant regulation is European Directive 92/28/EEC on the advertising of medicinal products.

Additional regulations and codes in different countries have implications for relations between MS Societies and industry. These are interpreted in different ways according to the national environment and traditions. EMSP is committed to working within the framework of whichever codes and regulations are most strict.

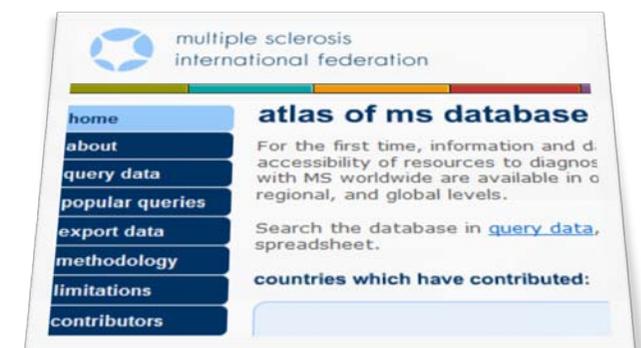
The Code of Conduct is available at: www.ms-in-europe.com/networking/index.php?kategorie=pharmaindustry&cnr=31&anr=271

European Map of MS

Several years ago, EMSP undertook to create a **European Map of MS** as a means of charting a broad spectrum of relevant data and information from across all countries in the EU. The project was expanded to a global **Atlas of MS** by the Multiple Sclerosis International Federation (MSIF). An updated version of the Atlas was launched in 2008, and is now available both online and as a print publication. The Atlas covers 10 topics:

- Epidemiology – prevalence, incidence and total numbers
- Epidemiology – average age of onset and male/female ratio
- MS organisations
- Diagnosis
- Information
- Support and services
- Drugs and treatment
- Human resources
- Disability entitlements, legislation and social insurance
- Major issues

Atlas of MS (www.atlasofms.org)



European Map of MS
(www.europeanmapofms.org)



EMSP Travel Tips

In response to recurring enquiries and, indeed, legitimate complaints about airline services, EMSP prepared a list of tips to help PwMS plan and undertake airplane travel with the minimum inconvenience.

The tips cover aspects of booking flights as well as being fully prepared for the day of travel. The tips stress the importance of balancing the rights and responsibilities of travellers with disabilities. A key aspect is open communication about needs at the

earliest possible date. At the same time, the tips emphasize that it is in the best interests of travellers to ensure they receive written confirmation of all details discussed.

Achievements and Activities at the EU Level

MS in Europe

Available data suggest there are about 500,000 PwMS in Europe. It is the most common disability of young adults, and is progressively debilitating. About 10% to 15% of PwMS eventually require wheelchairs or become bed-ridden.

The total cost of MS in Europe is estimated at €8.8 billion, including healthcare costs and loss of productivity – making it one of the most costly diseases.

The following paragraphs provide an overview of important initiatives at the EU level.

Written Declaration in the European Parliament

The issue of discriminatory practices in MS across the EU continues to attract attention. MEP Dariusz Grabowski has launched a petition that calls on governments of the new Member States to follow in the footsteps of those who adopted the MS Code of Good Practice in 2007.

The Declaration acknowledges the following discriminations:

- Restricted access to immunomodulating drugs to small portions of the patient population (Lithuania – 15%; Slovakia – 5% and Poland – 2% in comparison to 35% in Germany and Belgium), rehabilitation and essential specialist treatment.
- Owing to poor quality care, the average life expectancy of PwMS in new Member States is 10 to 20 years lower than the healthy population whereas no such disparity is evident in other Member States.

The European Parliament

1. Calls on the Commission and the Council to address this issue of discrimination at the earliest possible opportunity and improve the quality of life for PwMS.
2. Instructs the President to forward this declaration to the Commission and Council and to the parliaments of the new Member States since the 2004 enlargement agreement.

EMSP is grateful to Mr. Grabowski for his ongoing efforts. At the same time, we are strongly concerned about the ongoing debate on the EU Directives on Non-Discrimination. At present, various EU countries have differing positions, particularly in relation to how policies will influence daily constraints of PwMS. EMSP takes the stand that these Directives must integrate the principles of the UN Convention on the Rights of Persons with Disabilities. On this issue, EMSP is closely following related work being undertaken by the European

Disability Forum (EDF), the European Patients Forum (EPF) and the MS International Federation (MSIF).

EP Recognises the Right to Petition

In June 2008, the EP officially recognised that any citizen of the EU has the right to petition Parliament, individually or in association with others. Documents outlining the processes and procedures for such petitions make specific reference to the petition made by Louise McVay (2001) regarding the disparities in treatment of MS. This is clear evidence that all EU institutions recognise the important step Ms. McVay made for the MS community, and confirms that the door is now open for other individuals or groups to bring their issues to the attention of the EP.

EC Activities in MS Research

In response to a request by Marcin Libiki, Chairman of the Petitions Committee, the European Commission developed a summary statement of research activities undertaken since the 2003 Resolution.

The following highlights provide evidence of increased interest in and commitment to MS.

- In the 5th Framework Programme (FP) (1998-2002), €20 million were invested in research in neurodegenerative diseases.
- In the 6th FP (2002-2006), funding in this area increased to €40 million, with a focus on potential mechanisms common to several diseases, as well as potential new therapies.
- The project “NeuroproMiSe – Neuroprotective Strategies for MS” (€12 million) is specific to MS, and is investigating inflammation-induced neuro-degeneration and developing novel drugs for effective neuroprotection.
- In January 2008, the EP published the first call for proposals for NEURON, an initiative for the European Research Area Network that aims to reduce fragmentation of

activities across the EU by promoting and supporting joint research.

- The 7th FP (2007-2013) offers an opportunity to direct funding toward MS research within the context of an activity on “Research on the brain and related diseases, human development and ageing.” The total budget for health research in this period is €6.1 billion. It is anticipated that 9 projects on neurodegenerative diseases will be funded (€36 million), including one on MS.
- The Commission is also undertaking research related to the social aspects of persons with physical and intellectual disabilities, specifically investigating care and support options for integrated living and assessing various service delivery models and care practices.
- Additional work is looking at strategies to integrate people with disabilities in the workforce. Directive 2000/78 prohibits discrimination based on disability.
- In support of the MS Code of Good Practice, the EC is developing a Community Framework for safe, high quality and efficient services across all Member States, partly through sharing of knowledge and best practices.
- The Commission intends to host (in 2009 or 2010) a major European Consensus Conference on neurodegenerative diseases, the objective of which is to propose a Communication or other relevant policy initiative including specific actions in the fields of disease prevention, research and management of this group of diseases.

MS Barometer: A new means of measuring the atmosphere and applying pressure

In 2008 EMSP was able to provide, for the first time, much-needed data to verify general knowledge that has affected the lives of PwMS and underpinned the lobby efforts of EMSP and its members for many years.

It is already well known that the care and treatment of PwMS within the European Union, as well as their socio-economic conditions and quality of life, varies dramatically from one country to another. In fact, it could be said that the local environment creates a certain “pressure”. In countries with strong programmes to support PwMS, the pressure on the individual is lower and quality of life is higher. Where policies and programmes are lacking, the burden of the disease is much more intense.

Eliminating such disparities is a key aim of the **MS Code of Good Practice**. However, to date, it has been difficult to

quantify many of the contributing factors. The **MS Barometer** addresses this challenge by measuring specific aspects of how individual countries manage MS (see “*A Sensitive Probe...*” in the green box), and how policy decisions affect the pressure experienced by individual PwMS.

The MS Barometer also functions as a bench-marking tool that facilitates comparison across all participating countries. As such, it will help national administrations identify areas in which they excel on a pan-European scale, as well as those in which they are weak.

Each EMSP member is expected to report annually as a means of marking progress from one year to the next, a requirement that provides incentive for continuous improvement.

A sensitive probe of seven pressure points

The MS Barometer is a bench-marking tool that covers seven¹ areas pertaining to the MS environment at the national level.

- Access to treatment and therapies
- Research agenda on MS
- Employment and job retention
- Empowerment of PwMS
- Reimbursement of costs related to MS
- Accurate data collection on MS at national level
- Medication coming on the market.

A high score in any category indicates that the atmosphere for PwMS is fair – the quality of policies and programmes effectively reduces the pressure in their daily lives. The scoring system highlights the strong points of national policy, while also identifying gaps in service provision that place undue pressure on PwMS (whether it be related to medical, socio-economic or quality of life issues).

1- The first four areas of the MS Barometer are directly aligned with the headings of the Code of Good Practice.

How can the MS Barometer be applied?

The MS Barometer will raise awareness in the political arena about what resources need to be mobilised in order to institute the necessary policy changes. It will also help to identify policies and practical solutions that have been effective in one country and could be adopted by others. EMSP believes it could also serve as a means of enabling MS societies to apply “peer pressure” in their efforts to advocate for more equitable implementation of the Code.

Ultimately, the information derived from the MS Barometer will equip MS societies and advocacy groups to *exert* pressure on national authorities and relevant actors. In fact, EMSP believes it will be most effective for lobbying for change in areas in which it is difficult to provide hard data. The MS Barometer will offer “best estimates” – averaged across 32 countries – of many of the intangible aspects that define the quality of national programmes.

MS Barometer: Key Findings

The aim of the MS Barometer is not to name and shame, but rather to encourage peer review and benchmarking.

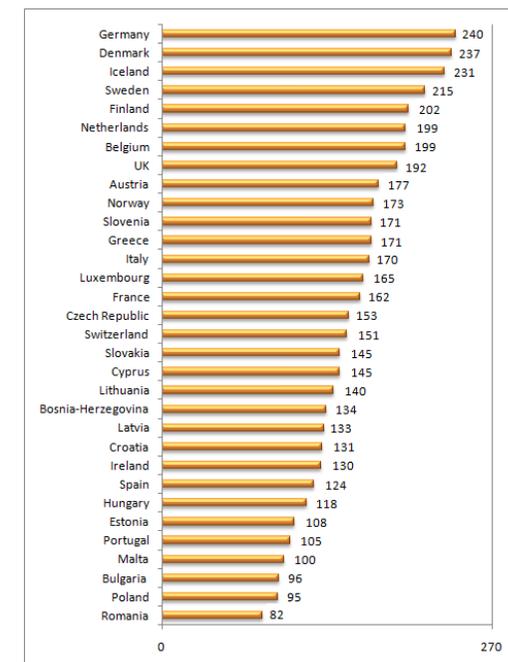
Presentation to the European Parliament

On 13 November 2008, EMSP presented to the European Parliament the findings of the first round of MS Barometer reporting. The event raised awareness of conditions for PwMS amongst high-level representatives from the European Commission and national governments, as well as leading neurologists and PwMS.

EMSP President Dorothea Pitschnau-Michel reiterated that “too many Europeans with MS are being denied access to the treatment and supports they need, when they need them.” She also emphasized the opportunity to use the MS Barometer as a tool for persuading national governments to

adopt more effective policies, in part by raising awareness of reforms that are working well in other countries.

The MS Barometer has been endorsed at the EU level and there is broad support for the efforts to reduce these inequalities. National governments are strongly encouraged to take steps to improve the situation for their own citizens.



The maximum score attainable is 270 points; the average score in 2008 was 155 points.

Key Findings

- In Germany, 70% of PwMS receive disease-modifying drugs (DMDs); in the United Kingdom, similar drugs are available to only 14% of the MS population. Overall, only five of 32 countries show more than 50% of PwMS receiving DMDs.
- Figures for out-patient rehabilitation show an alarming gap. In Spain, 98% of PwMS receive out-patient rehabilitation services; in Italy, only 5% to 10% of PwMS have access to similar services. Ireland has no rehabilitation clinics specialising in MS on an out-patient basis.
- In Latvia, PwMS receive 100% reimbursement for the costs of rehabilitation; in Bosnia-Herzegovina, only 25% of such costs are reimbursed.
- The Czech Republic reports having one neurologist for every 100 PwMS. By contrast, Poland has one neurologist for every 500 PwMS.

- Only eight of the 32 countries reporting have adequate pensions or benefit systems for PwMS. In Finland, more than 50% of PwMS are obliged to take early retirement, whereas support in Austria is such that 80% of PwMS are able to remain in the workforce.
- In Slovakia, there is no opportunity for health professionals (doctors, nurses, therapists, etc.) to receive specific training in treatment and therapy for MS.
- Once a drug has been approved by the European Medicines Agency (EMA), the Slovakian national drug regulatory can adopt it in less than three months. In Denmark, the adoption process typically takes 12 to 15 months.

See Annex 2 for full text of an editorial on the MS Barometer, published in *The Lancet Neurology* (Vol 7, June 2008).

National High Level Roundtable Discussions

As the MS Barometer demonstrates, MS remains under-diagnosed and sub-optimally treated in many European countries. In light of the need to raise awareness of these inequalities at the level at which action can and must be initiated, EMSP launched in 2008 a series of National Roundtables.

These events aim to engage key stakeholders in candid and committed dialogue about national issues. But they also provide an opportunity to inform stakeholders about EU level support for EMSP initiatives, including:

- The European Parliament resolution related to MS.
- Endorsement of the European Code of Good Practice in MS and its relevant Consensus Papers.
- Recognition of the MS Barometer and its purpose as a “healthcare and service performance indicator”.

The Roundtables encourage endorsement of the Code and the Consensus Papers by national level stakeholders and decision-makers, and provide opportunity to discuss the application of the Code as a tool to measure and improve quality of life for PwMS.

Support from the European Commission

“We are not dealing with patients, but with citizens who have fundamental rights.”

Johan ten Geuzendam, Head, Unit for Integration of People with Disabilities, DG Employment, Social Affairs & Equal Opportunities, European Commission.

The first Roundtable (see below) in Slovenia was attended by high-level representatives from the European Commission, who demonstrated their support for EMSP initiatives and conveyed important messages that will apply across all EU countries. The EC specifically acknowledged the importance of the MS Barometer, and stated that it will integrate EMSP findings into its own data.

Mr. ten Geuzendam discussed actions being taken to address the labour market impact of MS, particularly the difficulties PwMS face in remaining active within the labour force. The sensitivity of the issue must not be overlooked: many PwMS prefer to avoid being labelled negatively, yet recognising the disease as a disability provides better opportunity to protect the fundamental rights of individuals affected. Equal opportunity in the labour force is a key priority under the Lisbon Strategy, which aims to make the EU the most competitive economy in the world by 2010. The EC will present its action plan for disability in 2008/2009.

Ms. Isabelle de la Mata, Principal Advisor, DG Health and Consumer Affairs, acknowledged the need for further action at the EU level, and promised continued support for MS-related projects as a complement to the implementation of the EU Health Strategy, which also aims to reduce health inequalities overall.

Planning for Success

To assure these Roundtable events translate into positive change for PwMS, EMSP undertakes to support member countries in their planning and preparations, including the development of a strategy that reflects each national context.

- Invitees should include high-level individuals with the power make decisions or to influence decision-makers.
- Each event should have sufficient representation of stakeholder groups, but remain small enough to ensure frank discussion and encourage relationship-building and commitments to action.
- The agenda should be country-specific and target the most pressing issues identified in through the MS Barometer.
- The objective should be to collectively establish concrete short- and long-term goals.
- Organisers should carefully map stakeholders and stakeholder issues.

- The Roundtables should seek to create a sense of urgency.

In 2008, EMSP co-hosted Roundtables in three member countries: Slovenia, Bulgaria and Hungary. The following pages summarise each event, including Outcomes and Commitments. The list of participants demonstrates the high level of attention the Roundtables have been able to attract.

Overall Results

The 2008 Roundtables achieved the aim of raising awareness about MS issues amongst stakeholders in attendance. Additional awareness amongst the general public (and possibly other stakeholders) was achieved through media coverage of the events.

Next on the Agenda

Several EMSP members have already expressed interest in hosting Roundtables including Croatia, Romania and France. Members from the Balkan states are organising a joint event for spring 2009.

Tools for Organising Roundtable Events

EMSP has developed a set of tools to assist members who wish to organise Roundtables.

Guidelines provide advice on establishing the agenda (including which issues to address based on the MS Barometer and the Code of Good Practice), selecting invitees, and raising awareness of national issues.

A Cooperation Agreement sets out the roles and responsibilities of the host country and EMSP.

A Checklist helps to ensure that all aspects of event planning are covered.

Press release templates assist host countries in crafting of key messages to attract media attention before and after the event.

EMSP can also supply speakers and speaking materials, and offer financial support when need is demonstrated.

Ljubljana, Slovenia, 7 May 2008 – Hosted by EMSP and Združenje Multiple Sklerose Slovenija (ZMSS, the Slovenian MS Society)

Moderated by:

- Alojz Ješelnik, President, ZMSS¹

Participants:

- Isabelle de la Mata, DG Health & Consumer Affairs, European Commission
- Johan ten Geuzendam, DG, Employment, Social Affairs & Equal Opportunities, European Commission
- Jadwiga Hajevska Kosi, Terme Topolšica Rehabilitation Centre
- Silvester Krelj, Zdravilišče Laško Rehabilitation Centre
- Saša Šega Jazbec, University Medical Centre Ljubljana
- Alenka Horvat Ledinek, Head of MS Centre, University Medical Centre Ljubljana
- Marta Petelin-Suhadolnik, Dept. for MS, Institute for Rehabilitation, Rep. of Slovenia
- Beatrika Koncan Vracko, University Medical Centre Ljubljana/President Medical Advisory Board, ZMSS
- Mateja de Reya, Secretary General, ZMSS
- Cveto Uršic, DG, Ministry of Labour, Family and Social Affairs, Directorate for Disabled, Slovenian Government

- Metka Teržan, Ministry of Health
- Darja Kušar, Health Insurance Institute of Slovenia

The Roundtable also included members of the MS community and the media.

MS Barometer Context

The ZMSS reported to the MS Barometer that PwMS in the country have access to disease-modifying drugs (DMDs) with no limit on the duration of treatment, but that only 30% of individuals currently receive such treatment. On a more positive note, 70% of PwMS in the country have unlimited access to symptomatic treatments, in line with the EMSP Consensus Paper. Rehabilitation therapy is available at clinics specialising in MS. At present, there is one clinic for approximately 1500 PwMS, with the greatest distance a patient must travel being between 100 km and 150 km.

Key Focus: Access to Therapy and Treatment

The MS Barometer helped to identify access to therapies and treatment as a main area of concern in Slovenia. For example, while 8% of PwMS receive rehabilitation therapy on an in-patient basis, only 2% receive such therapy on an out-patient basis. In-patient therapy is available more than once per year, but access to out-patient therapy is limited by health insurance rules.

In recent years, Slovenia has acquired better equipment and is now able to provide earlier diagnosis of MS. The initial result of this is high growth in the number of patients diagnosed at younger ages. Neurological clinics need to be adapted to this fact.

¹ The ZMSS celebrated its 35th anniversary in 2008

Additional Areas of Concern

At the Roundtable, the ZMSS highlighted the challenge that Slovenia currently lacks the right policy framework to provide holistic treatment and therapy. This can be attributed to several factors:

- Shortage of properly equipped hospital beds.
- Shortage of properly trained health staff and carers.
- Poor integration of physio- and psycho-therapeutic treatments.
- Cost of certain drugs (e.g., Tysabria) is prohibitive to availability.
- Discrimination against PwMS over the age of 50 who are not eligible for treatment with interferons, irrespective of disease progression and outlook.

The most critical rationale for addressing these issues is that PwMS who receive effective treatment have a life-expectancy that is in line with the general population. This means that the cost of care is high, but also that steps must be taken to help

PwMS remain socially and economically active.

A major concern is the lack of appropriate facilities for younger PwMS who are not able to remain independent. At present, the only option is to house them in retirement facilities, which is inappropriate. Another area of concern is that Slovenia currently has no programme to support palliative care for individuals in the late stages of MS.

Outcomes and Commitments

The Slovenia Roundtable led to several important decisions. The social affairs ministry agreed to commence dialogue with ZMSS on establishing homes for young people with MS. The national health insurance institute agreed to take measures to make health insurance more accessible for PwMS.

Finally, the groundwork was established to request official endorsement of the Code by the new Slovenian health minister, following elections that took place in late 2008.

Frank discussion in the wrap-up session led to general agreement on four points, including the need to:

- Continue raising awareness of MS at every possible opportunity.
- Accelerate dialogue between insurance companies and the government to reach consensus on the availability of new treatments/drugs.
- Advance discussion on employment access and retention, a point which the EC is specifically committed to supporting.
- Address the housing situation for younger PwMS.

At the close of the Roundtable, representatives from the Slovenian Health Ministry, health insurance agency and other relevant bodies welcomed the Code and Consensus Papers as being helpful to their work.

Sofia, Bulgaria, 20 November 2008, hosted by EMSP and the MS Society Bulgaria Foundation

Moderated by:

- Dr. Plamen Dimitrov, Chairman, Bulgarian Psychological Society.

Participants:

- Dr. Bagryana Markova, National Health Insurance Fund (NHIF)
- Dr. Sashka Rousseva, NHIF
- Dr. Daniela Hristova, NHIF
- Dr. Galya Vassileva, NHIF
- Dr. Romyana Lazarova, NHIF
- Dr. Elena Toteva, NHIF
- Dr. Krassimir Guenov, Military Medical Academy
- Dr. Valentin Ignatov, National Cardiology Hospital, Sofia –Neurology
- Dr. Kssenya Kmetska, Saint Naum University Hospital, Sofia
- Prof. Ivan Milanov, Saint Naum University Hospital, Sofia
- Prof. Dr. Paraskeva Stamenova, Queen Giovanna University Hospital, Sofia
- Dr. Marko Klisursky, Queen Giovanna University Hospital, Sofia
- Dr. Vladimir Atanassov, Bayer Bulgarian
- Maria Dimitrova, Actavis Company
- Elena Koleva, Office of MEP Biliana Raeva
- Dessislava Raianova, Council of Ministers

The Roundtable also included members of the MS community and the media.

MS Barometer Context

With a score of 96 points (out of a possible 270), Bulgaria ranked amongst the lowest countries in the first reporting of the MS Barometer. In terms of “access to treatment and therapies”, Bulgaria scored only 21 – the lowest of all 32 countries (the average was 51, with the Netherlands being highest at 72). A similarly low ranking (second last) was received for “percentage of people receiving symptomatic treatment”. Bulgaria does not appear in the “rehabilitation” section of the survey because there were no precise data on how many Bulgarians with MS have access to or avail themselves of rehabilitation services. In regard to “Healthcare expenditure as a percentage of GDP”, Bulgaria again slipped to the bottom of the league with only 4% (compared to highest scores of 11.3% in Switzerland and 11.1% in France).

The NHIF MS Treatment Programme shows 1,632 registered PwMS for the period 2003-08, with an average of 239 new cases per year.

Key Focus: Treatment and Rehabilitation

Mr. Andrey Avramov presented the results of a recent survey conducted by the MS Society Bulgaria Foundation. Amongst key findings was that more than half of PwMS had received information from their neurologists about opportunities for symptomatic treatment, and more than 90% had obtained such information from other sources (such as the MS Society itself). Yet, more than 65% of respondents said they were not aware of the NHIF’s reimbursement schemes.

This is believed to play a role in the finding that very few PwMS resort to symptomatic medication, despite its obvious benefits. Even of those who are aware of the reimbursement plan, only half had used it. Fully 80% of respondents indicated they were not familiar with the NHIF’s main

package “Physical and Rehabilitation Medicine” and only 50% knew about the “Prevention and Rehabilitation Program” offered by the National Social Security Institute.

Clearly, more work is needed to raise awareness of the programmes and services available to PwMS.

The NHIF offers a variety of treatment programmes, including in-patient care, access to DMDs and other medical products, and rehabilitation. It also includes annual testing (using MRI, evoked potentials, and sodium and potassium levels), the costs of which are covered by the NHIF. This final point raises a question regarding appropriate use of limited health resources. Some critics would argue that once a person has been diagnosed with MS, there is little value in repeating the MRI tests on an annual basis.

When standard treatments are insufficient, Bulgarian legislation provides for access to medical products not yet approved by the Medical Products in Human Medicine Act. As set forth in an Ordinance, such products

can be ordered on special request by the hospital for use in treating a specific patient. The approval is granted by the Minister of Health; the head of the medical facility is responsible for overseeing proper use of the new medication.

Additional Areas of Concern

During the Roundtable discussion, participants expressed concern about the following issues:

- Insufficient quantity and variety of functional drugs for symptomatic treatment.
- Neurologists sometimes prescribe drugs that are not reimbursable for MS (only for other diseases), which means patients must pay the cost. In some cases, part of the issue is that manufacturers do not specifically list MS amongst the diseases for which it is effective.

Outcomes and Commitments

Participants agreed to work together on the following initiatives:

- Implement the register of symptomatic drugs listed in the EMSP Consensus Papers as the basis for selecting drugs.

- Amend legislation that requires explicit mention of MS in the leaflets of medicines.
- The MS Society Bulgaria Foundation indicated it would circulate the MS Code of Good Practice and Consensus Papers with the aim of having them recognised and implemented by all stakeholders.

Although no specific agreement was reached on how to address the issue, participants recognised the need to improve training in MS for neurologists, particularly in rural areas. At present, lack of knowledge leads to poor patient-physician communication, poor management of symptoms through medication, and poor access to available rehabilitation services.

All parties agreed on the need to establish specialised facilities for MS treatment and rehabilitation in various regions of the country. A general shortage of beds in neurological wards means hospitals are rarely able to accommodate PwMS needing long-term rehabilitation or those in the terminal stage of the disease.

Budapest, Hungary, 12 September 2008, Hosted by EMSP and Magyar SM Társaság (The Hungarian MS Society)

Moderated by:

- Gábor Jakab, MD, PhD, Head, Dept. of Neurology, Budapest, Member of the Hungarian College of Neurology

Participants:

- Mr. Robert Schlathau, EMSP Executive Committee
- Dr. Lajos Hegedűs, President, Hungarian Disabled Peoples Organisation
- Dr. Ferenc Juhász, Director-General, Institute for National Rehabilitation and Social Advisors
- Dr. János Zámboi, National Health Insurance, Dept. of Pharmaceuticals
- Dr. Miklós Gresz, National Health Insurance, Chief Counsellor
- Dr. Miklós Fehér, Past President, Hungarian College of Rehabilitation
- Mrs Imréné Egyed, President, Fejér Chapter, Hungarian Chamber of Nurses
- Dr. András Guseo, President, Hungarian MS Society
- Mrs. Ágnes Ván, President, Hungarian National MS Organisation
- Mrs. Adréu Juhász, National Organisation of Young People with MS

MS Barometer Context

The MS Barometer identified Hungary as a country in which the quality of services provided to PwMS is unquestionably high. However, the extent of services is lacking. Of a possible 270 points, Hungary scored 118, placing it 25th amongst 32 countries. Thus, the aim of this Roundtable was to determine how to stimulate meaningful change to improve the overall quality of life for PwMS.

A positive step forward in 2008 was the introduction, by the Ministry of Health, of unlimited DMD treatment to all PwMS for whom it is deemed necessary.

The Roundtable event had strong political support; unfortunately, due to unforeseen political circumstances the Hungarian MS Society received last minute regrets from the Minister of Health, Dr. Tamás Székely and Hungarian MEP Dr. László Surján (former Minister for Social Welfare in

Hungary). Both gentlemen sent addresses, which were read to participants.

Key Focus: Evaluate the Status of Policies, Service Provision and Care Management

The main topic of discussion was the need to modify the existing system in key areas, including the importance of a team-based, holistic approach that is customised to the particular patient yet offers standardised levels of care across the country. As the actual prevalence of MS is unknown (estimated to be 15,000), there is an urgent need to improve data collection.

As reported to the MS Barometer, access to formal rehabilitation treatment is very limited in Hungary. However, an innovative community-based programme provides opportunity for PwMS to meet for cardio and muscular work-outs in a facility with appropriate equipment. The

impact of the “club” has been positive, with participants experiencing increased mobility, enhanced overall well-being and reduced feelings of social isolation.

More effort is also required to enable PwMS to participate in the workforce, and to provide suitable facilities for people who are not able to live independently and are currently “housed” in retirement homes.

Additional Areas of Concern

During the course of general discussion, participants raised the following concerns:

- Lack of professional training and staff shortages. It was noted, for example, that the number of rehabilitation beds has doubled in recent years, but staffing levels have not kept pace. Similarly, although a resolution (43) allows for unlimited home visits where needed, budget constraints and lack of staff create structural gaps in service provision.
- Need to increase cooperation amongst health, medical and social care services to improve cohesion across in-patient and home care.
- Need to increase access to rehabilitation (the current criteria effectively limits PwMS to one intervention per week).
- Preparation amongst professionals and the MS community for an expanded definition of home care services, to be implemented in 2009.
- Expand the parameters of home-based rehabilitation as a cost-effective form of service delivery; also develop a plan for home-based symptomatic treatment.
- Establish accredited and progressive training for professional physiotherapists. Note: Magyar SM Társaság has developed a 40-lesson course for domestic support services (including therapeutic massage and physiotherapy), which is ready for implementation upon accreditation.
- Undertake a review of the disability support payments system, particularly in regards to wage, bureaucracy, eligibility criteria and reimbursements for pharmaceuticals.
- The Chamber of Nurses offered to collaborate with Magyar SM Társaság to develop a needs inventory for PwMS, with the aim of submitting to the Ministry of Health an accurate assessment of resources required to improve access to treatment and therapy.

Outcomes and Commitments

Participants agreed on several initiatives, the most critical being to:

- Improve access to DMDs, particularly in support of newly diagnosed PwMS.
- Establish specialised MS rehabilitation centres to provide in-patient services (including the completion of a centre that was abandoned during construction).

International Conferences and Networking

EMSP both hosts and participates in a range of international activities as a means of raising awareness of and support for MS amongst a broader network of stakeholders. These activities also allow EMSP to learn from the experience of others and to derive mutual benefit by working closely with agencies that share our mission, vision and values (see Annex 1).

24th ECTRIMS Congress Montreal, Canada 17-20 September 2008

The 24th Congress of the European Committee on Treatment and Research in Multiple Sclerosis (ECTRIMS) provided an opportunity for EMSP to strengthen its long-standing ties with European health professionals who specialise in MS while also establishing new contacts in the Americas through the ACRTIMS (American) and LACTRIMS (Latin American) committees.

As the Congress focused on recent advances in the treatment and research, EMSP had hoped to highlight the MS-ID project as a framework for sharing best practices. The abstract was not selected due to stiff competition, but EMSP made use of a booth in the exhibit area to display a poster, provide take-away materials and

engage in one-on-one discussion with interested parties. www.ectrims.eu

EMSP Information Day in the European Parliament Brussels 13 November 2008

Five years following the 2003 Resolution by the European Parliament to support the concept of a Code of Good Practice for MS, EMSP planned this information day as a chance to take stock of progress and strategise for the future.

EMSP President Dorothea Pitschnau-Michel opened the event with the MS Information Hour and a presentation entitled "From the European Parliament Resolution to where the Code of Good Practice in MS is Today". In response, MEP Michael Cashman (Vice Chair of the Petition Committee) expressed satisfaction of progress to date and confirmed the Committee's continued support. Mr.

Cashman also indicated the time was right to undertake an assessment of the Aaltonen Report/MS Resolution, particularly in regard to the following questions:

- Which of the proposals/demands of the EP have been put into practice, by whom and with what impact for PwMS?
- Which problems being identified by the EP remain ignored?
- What can be done to further improve the situation of PwMS in Europe?

Subsequent presentations shifted the focus to recent advances in treatment and therapy. Oral treatments for MS are increasingly popular, and several are now in clinical trials: BG12, Fingolimod, Cladribine, and Teriflunomide are in or approaching Phase III trials, and could be available as early as 2011. The potential benefits of a diagnostic blood test that detects a biomarker (IgM GAGA4 ELISA) in certain

sub-groups of PwMS were discussed. Early results show that the blood test facilitates early diagnosis of MS – that is, before patients exhibit the two conditions (at least two relapses and having more than one lesion on the brain or spinal cord) currently required for traditional diagnosis.

Dr. Karl Gross, a US neurologist and a PwMS, concluded the day with a discussion of the importance of early treatment and appropriate care, highlighting the recently published book *Together We'll Make It*, which describes the turbulent journey PwMS face after diagnoses.

EMSP wishes to acknowledge the generous grant provided by the Medtronic Foundation to support this event.

Continuous Networking with EPF

EMSP is actively involved in policy interventions led by the European Patients' Forum (EPF), particularly in the areas of cross-border health care, patient safety, information to patients, the Pharmaceutical Forum, transparency in the funding mechanisms of patient organisations, health literacy and e-health. EMSP anticipates

contributing to the EPF's Value+ initiative in 2008 and 2009, largely through the MS-ID project. The objective of the Value+ project is to exchange information, experiences and good practices among key stakeholders in relation to the meaningful involvement of patients' organisations in the EU, supported by health projects at EU and national levels.

In April 2008, EMSP Board Member Aiki Vrienniou made a presentation at the EPF Health Literacy Conference (Brussels), which focused on how access to health information empowers patients to better manage their disease/condition. Increased health literacy is crucial to the transition from "monologue" to "dialogue" between patients, healthcare providers and other relevant stakeholders. The conference called on governments to support patient empowerment by implementing health literacy policies and establishing a European Health Literacy Network.

In October, EMSP showed its support for the EPF initiative to launch a Patients' Manifesto in the EP. This important document highlights, from the patients'

perspective, three fundamental areas to improve the quality of healthcare delivered across the EU and outlines new measures. It specifically calls for:

- Equal and timely access to safe, effective diagnosis, therapies and support.
- Better information and resources for patients to be partners in determining their care.
- A patient's voice to be heard in Brussels and throughout the European Union.

www.eu-patient.eu

The EPF is an umbrella organisation for 39 pan-European disease-specific patient organizations and patients' platforms. A recent membership survey indicates that EPF represents more than 150 million patients throughout the 27 EU Member States.

European Medicines Agency (EMA)

After several years of representation through the EMSP Secretary General, in 2008 EMSP became an official member of the EMA's Patients and Consumers Working Party (PCWP). This Working Party was established to provide

recommendations to the EMEA and its human scientific committees on all matters of interest to patients in relation to medicinal products.

EMSP Executive Committee member Michael Donovan is representing EPF and EMSP in PCWP, and is also one of two patient representatives in the Management Board of the EMEA. .

www.emea.europa.eu/htms/general/contacts/CHMP/CHMP_PCWP.html

High Level Pharmaceutical Forum

In 2005, European Commission Vice-President Günter Verheugen and Health Commissioner Markos Kyprianou jointly established the Pharmaceutical Forum. The aim of the Forum is to find relevant solutions to public health considerations regarding pharmaceuticals, while ensuring the competitiveness of the industry and the sustainability of national healthcare systems. The initiative is now led by Health Commissioner Androulla Vassiliou, who took office in spring 2008.

The Pharmaceutical Forum comprises representatives from the EC, the 27 Member States, the European Parliament, and the European Free Trade Association (EFTA), as well as key stakeholders from the public and private sectors including:

- European Patients Forum (EPF)
- Standing Committee of European Doctors (CPME)
- Pharmaceutical Group of the European Union (PGEU)
- Association Internationale de la Mutualité (AIM)
- European Social Insurance Platform (ESIP)
- European Federation of Pharmaceutical Industries & Associations (EFPIA)
- European Generic Medicines Association (EGA)
- European Self-Medication Industry (AEGSP)
- European Association for Bioindustries (EuropaBio)
- European Association of Full-Line Wholesalers (GIRP)

In 2008, the Pharmaceutical Forum reaffirmed its initial mandate, acknowledged the value of its consensus-building activities, and welcomed the political momentum gained. It also put forth recommendations in each of its three main areas:

Information to Patients

1. Enhance quality of information
2. Increase accessibility and dissemination of information
3. Generation of information by making the best use of all actors
4. Continued momentum on information to patients

Relative Effectiveness

5. Implement agreed good practice principles for Relative Effectiveness assessments
6. Promote the exchange of information on Relative Effectiveness assessments in order to improve the data availability and transferability

Pricing and Reimbursement

7. Access to medicines for EU citizens
8. Expect, identify and reward valuable innovation
9. Optimal use of resources
10. Continued momentum on Pricing and Reimbursement

Christoph Thalheim, EMSP Secretary General represented the membership of EPF at the Pricing and Reimbursement Group. His main concerns included:

- Lack of involvement and participation of patient representatives in national decision-making processes that address patient needs.
- Lack of recognition of “patient experts” as the end-users of drugs under discussion.
- Lack of “holistic” thinking in relation to the establishing national budgets.

MS in Poland: Press Conference

Warsaw, Poland • 20 March 2008

As demonstrated by the MS Barometer, Poland remains one of the weakest EU Member States in relation to providing

support to PwMS and those with other chronic conditions.

At a press conference in Warsaw, Christoph Thalheim presented the findings of the MS Barometer to interested parties and the press, expressing EMSP’s disappointment that the situation for PwMS in Poland had changed very little over the past three years. Thalheim encouraged the government and other stakeholders to take more active roles in addressing this matter in a holistic way.

Rehabilitation in MS (RIMS) Conference

Leuven, Belgium • 9 May

To strengthen the excellent relationship with Rehabilitation in MS (RIMS), Christoph Thalheim presented EMSP’s recent work on the European Code of Good Practice in MS and the Consensus Papers.

European Federation of Pharmaceutical Industry Associations Think Tanks

EFPIA Think Tanks are organized four to five times per year, in order to provide an opportunity to exchange knowledge and information on recent activities in relation to

health policy issues in Europe. In 2008, Think Tank topics included issues such as patient safety, pharmaceutical packaging, and EU actions on rare diseases. In addition, EMSP had opportunity to present the objectives and initial findings of the MS Barometer.

Health Policy Decision Makers Forum

Paris, France • 4-5 December

Upon special invitation as patient representative in the 2nd European Health Policy Decision Makers Forum, Christoph Thalheim presented the patient perspective on the role of innovative medicines and the need to ensure the best value for society.

MS Life UK

Manchester, UK • 29-30 March

In 2008, this highly successful national MS awareness and information event attracted more than 2000 visitors. EMSP was represented by Secretary General Christoph Thalheim.

European Citizen Action Service (ECAS)

Although the mandate of the European Citizen Action Service is not directly and exclusively related to patient concerns, EMSP derives several benefits from its membership in this network. One key advantage is that ECAS provides both information and service to assist NGOs (such as EMSP) in relation to fund-raising.

Slovakian Rehabilitation Centre Project Sabinov, Slovakia • November 2008

The number of PwMS in Slovakia is estimated to be 8,400; until recently, they had no facilities dedicated specifically to rehabilitation of MS. The Slovakian Rehabilitation Centre project is an outstanding example of how one person's dream – in this case, one man with MS – can capture the imagination of many others and eventually become reality.

Christoph Thalheim was invited to visit the centre and to learn its extraordinary history. Despite significant obstacles such as limited financial resource, the project leaders used creative approaches to generate broad support. They were able to obtain a piece of land at no cost, including a building which is old but stable enough to use temporarily. A local architectural firm is providing pro bono services to design new facilities, taking into account the special needs of PwMS.

In 2009, the mayor of Sabinov will present the project to the Slovakian National Agency with the aim of acquiring financial support through the EU Structural Funds.

The masterminds behind this project will present their experiences at EMSP's annual conference in May 2009.

EMSP Expands Its Networks

Over the past 12 months, EMSP has made a concerted effort to build relationships with agencies that share its vision to empower individuals whose lives are affected by disease, including: the Think Tank for Patient Organisations and Industry; the European Disability Forum; the Disability Intergroup of the European Parliament; and the European Citizens Action Service

We have also pursued joint actions with other organisations specialising in neurology and brain diseases, such as Alzheimer Europe, Parkinson's Europe and the European Brain Council (EBC).

Taking into account the growing importance of home care and information technologies, EMSP anticipates forging new relationships with relevant agencies such as EUCOMED (an agency representing 4500 designers, manufacturers and suppliers of medical devices) and individual producers of medical devices. As a first activity to this end, Christoph Thalheim attended the EUCOMED Homecare Dinner on 14 October 2008.

Living Independently with Multiple Sclerosis¹ • 24-25 May 2008, Reykjavik, Iceland

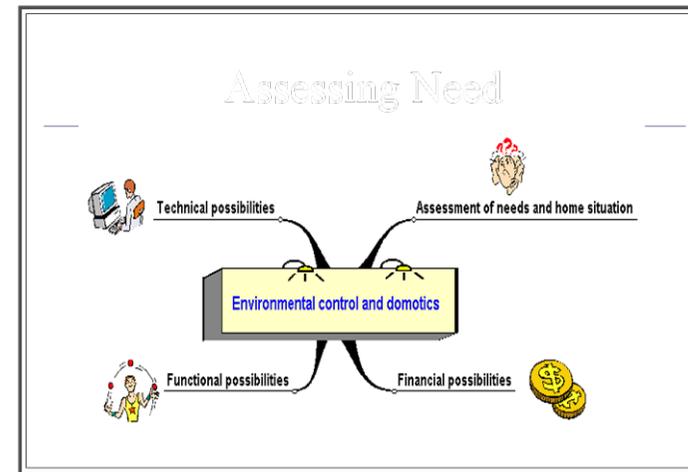
The theme of this conference reflected the fact that “living independently” means many different things for PwMS. At home, it may mean ensuring that living spaces are properly equipped for disabled persons. In the broader world, it means having opportunities to travel, to move around in public places, and to be useful to society. It also means having unrestricted access to available medicines and treatment.

The conference also emphasized that PwMS have the right to shape their lives independently. Despite the illness and possible disability, they have the right to ensure that the disease is treated through state-of-the-art medicine, that they can maintain gainful employment, and that the public accepts, recognises and esteems PwMS as fully adequate members of society.

Part I: Independent Living with a Chronic Illness – A Non-MS-specific Approach

Intelligent Homes for the Chronically Ill

Marijke Duportail, Head Occupational Therapist, National MS Centre Melsbroek, Belgium



1- In-depth summaries of the conference presentations are available at: <http://www.ms-in-europe.org/ourevents/index.php?kategorie=events2008&cnr=59&anr=252>

For PwMS, an intelligent home can be a key factor in the overall level of independence. The concept of an intelligent home comprises two areas: the technical aspects (environmental

controls and domotics²) and the actual design. Intelligent design implies housing that is adaptable and developed with a long-term view. On the technical side, the ideal situation is to have a single computerised device (e.g., remote control) that controls all environmental aspects. Such systems may be mobile (moveable within the home) or integrated with the wheelchair; either option can be operated by switches/controls or by voice.

In creating an intelligent home, it is vitally important to put the person first: to assess what the patient needs and his/her capacities (including financial means), and then adapt the house accordingly. Intervention should involve exploration and experimentation with all available options, keeping in mind that compromise is sometimes needed to create a workable solution for the PwMS and others who live in the home. It is important to remember that intervention often requires a large amount of administration (paperwork), as well as training for the PwMS and his/her caregivers.

One of the most critical things to remember when addressing the issue of independent living is that every house is a home. PwMS should be able to live safely and independently in the place of their choosing, and have access to the devices that make this possible.

² Domotics is generally defined as the use of information and communication technologies for more comfort and convenience in and around the home.

Independent Living Philosophy: Implications for the Individual, Organisations and Society

Dr. Peter Anderberg³, Doctor in Rehabilitation Engineering, Lund University, Sweden / Research Analyst, Independent Living Institute

The Independent Living philosophy

EMPOWERMENT implies being able to:

- **Customise individual solutions** according to our individual needs, which may change over time.
- **Access several different solutions** at the same time.
- **Take individual control** over funds for paying wages and administrative costs.
- **Organise personal assistance users** into a pressure group that negotiates with governmental bodies (together we have political power, individually we have none).
- **Help and teach each other**, through peer counseling, the skills it takes to run one's own personal assistance scheme and get the most use out of it.
- **Devise ways to allow all of us**, regardless of physical or mental disability, to take more responsibility over our lives

In the late 1960s at the University of California at Berkeley, a group of disability advocates led by Ed Roberts began what has become known as the Independent Living (IL) movement. The IL movement has four cornerstones:

³ Dr. Anderberg kindly agreed to step in for Dr Adolf Ratzka, who was unable to attend the conference.

- **Anti-discrimination** – IL argues that not letting individuals with disabilities participate in ALL aspects of life (education, work, income, transport, family, social, economic and political life) is discrimination. The movement aims to introduce legislation against such discrimination in all countries.
- **De-medicalisation** – IL raises awareness that “disabled” is not the same as “sick”. Persons with disabilities also have a broad range of abilities and can fulfil various roles in society: they are entitled to the same rights and lifestyles as everyone else.
- **De-institutionalisation** – IL supports the individual’s need to live “in” mainstream society, not be sequestered in hospitals or institutions where they are under “care”.
- **De-professionalisation** – The IL philosophy argues that disabled persons are the best experts regarding their own situations, and as such must maintain control of their own lives as. They need to interact with specialists who can offer advice and assistance, but they must not be expected to abdicate control to this team. They must retain the right to decide, including the decision to find different advisors if they receive poor advice.

Empowerment is the most important concept in the IL philosophy. The slide provided highlights some areas of daily living and collective activity in which persons with disabilities need to be able to exercise their authority to achieve independence.

Personal Assistance: The Key to Independent Living

The Swedish example of personal assistance policy

Dr. Peter Anderberg, Doctor in Rehabilitation Engineering, Lund University, Sweden / Research Analyst, Independent Living Institute

Sweden offers the most comprehensive application of law in support of independent living (IL). This legislation, first introduced in the mid-1980s, can be traced back to the efforts of Adolf Ratzka, who was involved in the early days of the IL movement and the founding of the Stockholm Cooperative for Independent Living (STIL). In 1987, STIL overcame massive opposition from political parties, labour unions, traditional service providers and established disability organisations to start a cooperative IL pilot project.

In 1994, STIL achieved a major political breakthrough when it became the model for a new legal reform (The Special Support and Services Act; Lagen om särskilt stöd och service or LSS). The new law guaranteed funds from the national social insurance programme to persons under 65 years of age who need more than 20 hours of assistance per week. A direct payment scheme (based on needs assessment) allows eligible persons to use the money to “purchase” whatever type of assistance is required

At present, about 15,000 people in Sweden receive payments under the LSS Act. Statistics show that, on average, men require slightly more hours per week of assistance than women. The number of hours varies greatly: some people may require the

minimum 20 hours per week; others may need more than 100 hours.

The LSS Act allows persons with disabilities to lead the life they want to lead, to pursue the careers they want to pursue. All evaluations show it has increased independence and overall quality of life. The plan is more expensive than the government anticipated: the total cost is EUR 1.5 billion per year (EUR 100 000 per person). However, many disabled persons have been able to re-enter the workforce and a significant portion of the money paid out for assistance goes back to the government through taxes. Together the STIL movement and the LSS Act have made persons with disabilities full citizens in society: Can you put a price on that?

Encounters with Health and Social Services: Co-operative, Obedient or Excluded Citizens

Dr. Heli Valokivi, University of Tampere, Finland

Using a phenomenographical⁴ approach, Dr. Valokivi studied the concept of “citizenship” amongst two groups that use health and social service systems: elderly people and offenders. Her findings in relation to aspects “status” and “process” in these interactions

⁴ Phenomenography is a [qualitative research methodology](#), within the [interpretivist paradigm](#), that investigates the qualitatively different ways in which people experience something or think about something. Marton, F. (1986), “Phenomenography - A research approach investigating different understandings of reality,” *Journal of Thought*, 21(2): 28-49

between client and service provider may be applicable to the situation of PwMS.

This study examined two key aspects of citizen interaction with the system: the level of participation or non-participation; and the perception of citizen’s responsibilities and rights. The study identified three “voices” and suggested strategies to improve interactions with each type of citizen.

- The **strong and demanding voice** is aware of rights and demands access to them; it does not hesitate to go to the highest level of authority to ensure needs are met.
- The **co-operating or negotiating voice** is aware of rights, but is less assertive. It is likely to attribute lack of service to some “mix-up” rather than a failure of the system or the individual service provider. This voice is more likely to rely on negotiation, collaboration and communication, and to build alliances.
- The **weak voice** is reflected by low access to services; the individual may not be aware of service s/he is entitled to, or does not have energy to pursue them. This voice goes unheard, and eventually the user withdraws from or falls outside the system.

In Dr. Valokivi’s research, the weak voice was dominant in the two study groups, reflecting a lack of the sense of “citizenship” within social and health systems. As a result, most users do not gain access to services to which they are entitled.

What can be done to address this situation? Dr. Valokivi argues that all voices are valid, and should arise at different times during interactions. If adequately trained to recognise the voices, the social worker can guide the interaction to allow the client to adopt the voice needed for the situation at hand. Overall, it is the citizen's right to choose services and the authority's responsibility to offer services. In particular, the weak voice should serve as a sign to social workers that there is a need for care-taking of the client.

Part II: Latest Developments in MS Research, Medicines and Rehabilitation: What they Can Do for Independent Living

Latest Treatments for Spasticity, Neuropathic Pain, Bladder Dysfunction and Other Symptoms

Dr. Thomas Henze⁵, Nittenau, Germany

As it is impossible to adequately cover the three main areas of Dr. Henze's presentation in this brief summary, the following focuses on aspects that apply to treatment in general.

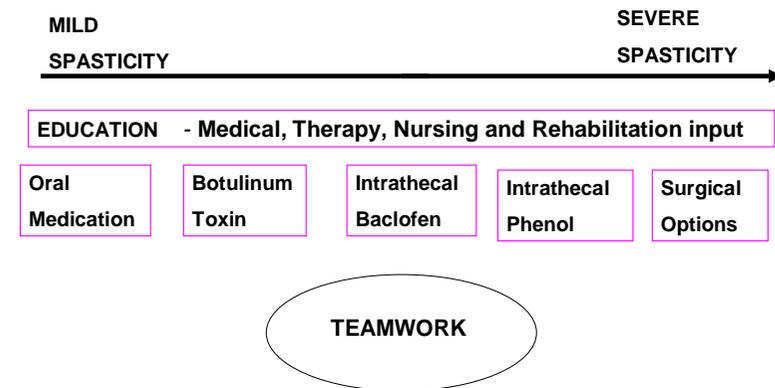
Symptomatic treatment is vital to PwMS. To ensure it is done effectively, neurologists must engage with patients to carry out an

⁵ Dr. Henze was unable to attend the conference for personal reasons; this presentation was delivered by Dr. Alan Thompson

exact enquiry about existing symptoms, keeping in mind that patients may not "link" a specific symptom with the condition of MS, or may not spontaneously offer information about symptoms that cause embarrassment or are very intimate (e.g., depression or



Options for Spasticity Management



T Henze, Germany, Reha-Zentrum Nittenau

sexual dysfunction). The physician should take the lead in asking questions to draw necessary information from the patient.

The physician must also help the patient understand the complexity and diversity of therapeutic recommendations, which can be overwhelming. Several recent efforts have tried to structure this information through consensus papers and guidelines, usually by rating the evidence of each treatment option and providing

information on how to escalate treatment in case of insufficient efficacy.

The evolution of symptoms and of treatments highlights the need for frequent examinations so that the neurologist can assess the patient's response to treatment, as well as any adverse effects, that might warrant changing to another course of treatment. These factors also reflect the need for a holistic approach and teamwork between the PwMS and a variety of health professionals. As regards the symptoms mentioned in the title, recent developments in treatment options warrant an update of the consensus paper on symptomatic treatment published by the Advisory Board of the German MS Society (DMSG) approximately three years ago.

Both neurologists and patients should note that numerous studies of individual MS symptoms have NOT been performed with PwMS, but rather with patients suffering other neurological diseases. For example, antispastic drugs have been evaluated on patients after spinal cord injury or spastic paraplegia. Anticholinergic drugs to reduce urge incontinence and frequency have mainly been tested on patients suffering other bladder disorders. Thus, the results of scientific studies should be interpreted with caution.

Overall, treatment of some MS symptoms is becoming more and more effective. However, we must never lose sight of the fact that access to the treatments available is far from equal within European countries. EMSP and the MS societies continue to play

an important role in propagating the MS Code of Good Practice, developing consensus papers, and advocating on behalf of PwMS.

Rehabilitation in MS: A Sustainable Method to More Physical and Cognitive Independence?

Prof. Alan Thompson, Institute of Neurology, The National Hospital, UK

The title of this presentation raises some interesting questions. First, we must ask: What does "sustainable" mean? Second, to which term is one applying the adjective: Are we talking about sustainable results from rehabilitation? Or are we talking about sustainability of the rehabilitation itself? Perhaps the real question incorporates both: Are the effects sustainable and is delivery sustainable?

Evaluating interventions

- Comparable groups
- Unbiased selection
- Randomisation
- Placebo – controlled
- Blinding
- Adequate duration of study
- Limited drop-outs
- Well-defined intervention
- Scientifically sound outcomes



Evaluation

- **Components of rehabilitation process**
 - expert selection, goal setting, outcomes
- **Specific therapies**
 - physiotherapy/occupational therapy
- **Different settings**
 - post relapse, in-patient / out-patient
- **Different functions**
 - physical, cognitive

In fact, there is a pressing need to demonstrate the efficacy of rehabilitation interventions for PwMS – not least because many therapists must justify the provision of rehabilitation treatment to health agencies or insurers. However, it is difficult to

define exactly “what” one would evaluate, how to measure efficacy, and how to evaluate outcomes in a rigorous manner. The two slides below suggest aspects of rehabilitation that might be evaluated. Several studies have begun to attempt this type of evaluation, including those by the Cochrane Collaboration (www.cochrane.org).

Jenny Freeman (United Kingdom) assessed the continuity of benefit (are the effects sustainable?) following rehabilitation, looking at aspects of both health and quality of life sustained over a 12-month period. The benefits in relation to disability and handicap were maintained over six months; benefits to coping and management were sustained over a longer period.

However, it is increasingly evident that delivery of rehabilitation is not sustainable – even in the United Kingdom. Studies show that, as recently as 1998/99, access to services remained largely a matter of chance. Freeman et al. (1999) found that more than 80%

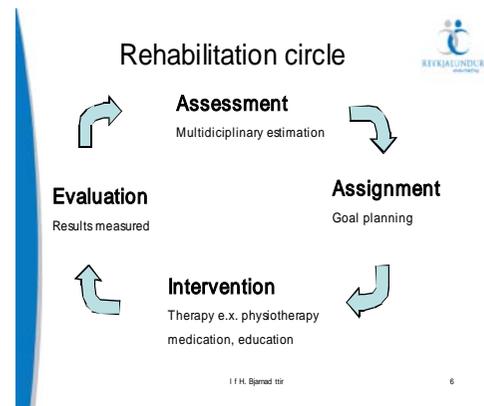
of individuals with mild disability received no rehabilitation services. More troublesome is that 50% of people with severe disability did not have access to proper services. Carton (1999) found that 89% of care received by people with disabilities can be classified as “informal care” delivered by partners, carers, family and friends.

To date, the desired model – a rehabilitation strategy with the PwMS at the centre – does not exist. The MS Barometer shows that 40% of European nations lack a specialist rehabilitation centre for PwMS. In order to advocate for improving access to rehabilitation services, we must be able to demonstrate that rehabilitation is appropriate to and effective in MS, in part by providing some evidence of sustained efficacy. We need to acknowledge that more research (and more rigorous research) is required in all three areas of rehabilitation (physical, cognitive and vocational). We also need to seek funding to carry out such research.

Rehabilitation of PwMS in Iceland: What is new?

Dr. Ólöf H. Bjarnadóttir, Reykjalundur Rehabilitation Centre, Iceland

The first goal of the Reykjalundur Rehabilitation Centre is to help patients identify problems and to determine what is most disturbing to them. Experience shows that patients share common concerns and questions: Will mobility impairment restrict my daily activities? Will my independence decline? Will my plans for the future hold? For how long will I be able to work? Must I change my hobbies or find new ones?



The Centre uses a four-stage model (see slide) that involves assessment, assignment, intervention and evaluation. All stages are carried out by a multi-disciplinary team comprising some or all of the following specialists: doctor, nurse, physiotherapist, occupational therapist, psychologist, neuropsychologist, social worker, speech therapist, and dietician.

The intervention stage covers medication, therapy and education and is goal-oriented in terms of the following areas:

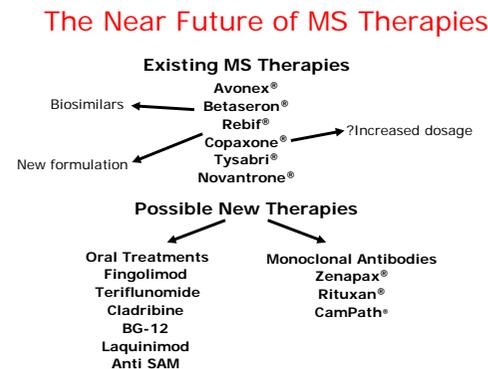
- **Physical** – *Goal: Identify limitations while improving endurance.* Use muscle training to build endurance, improve coordination and prevent contractures.
- **Psychological** – *Goal: Improve mental well-being.* Encourage patient to reflect on goals and progress, and to re-define problems and goals if necessary.
- **Increase participation and activity** – *Goal: Encourage individual to do and create things.* Using activities to focus on abilities and skills provides positive experiences that help to reduce minor anxiety symptoms and improves self-confidence.

- **Technical instruments and environment** – *Goal: Identify devices that can increase independence.* Devices are selected according to needs, symptoms and environment.

Wade⁶ shows that a goal-oriented approach is more likely to lead to behavioural changes (both short and long term) on the part of the patient. In addition, the benefits of rehabilitation are higher if the goals are: a) defined with the patient; b) relate to ability and participation; and c) written down and accompanied by measurable targets. Knowing one's abilities and limitations makes it possible to gain more control over daily life, ultimately supporting greater independence when living with MS.

The future of disease-modifying therapies

*Dr. David Bates,
University of
Newcastle on
Thyme, UK*

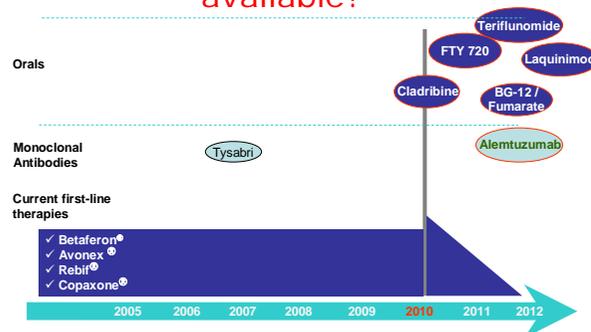


Twenty year ago, most scientists would have said there was no future for disease-modifying drugs (DMDs); even ten years ago, the

⁶ Wade, DT (1999), "Goal Planning in Stroke Rehabilitation: How?" *Topic of Stroke Rehabilitation*, Vol. 6(2):16-36.

treatment was only moderately effective. Yet today, pharmaceutical research has delivered four DMds of particular interest to PwMS:

When will new treatment be available?



intramuscular interferon beta-1a (Avonex); subcutaneous interferon beta-1a (Rebif); interferon beta-1b (Betaferon); and glatiramer acetate (Copaxone). All four tend to be used in the initial management of MS and are available in some (but not all) European countries.

More recently, we have seen the launch of a monoclonal antibody (Tysabri) that interferes with certain functions of the immune system. A sixth agent, mitoxantrone (Novantrone), is sometimes used to treat worsening forms of relapsing-remitting MS (RRMS) and secondary progressive MS (SPMS).

Looking to the future, there is reason to be cautiously optimistic on some fronts. Although the next DMds will likely not be available until 2010-12, some 300 MS clinical trials are currently ongoing, involving ~100,000 people worldwide. Overall, more than 50 therapies for MS are under development, including several promising oral products. However, most are anti-inflammatory: there is a dearth of therapies

designed to prevent damage to neurons or to reduce damage that has already occurred. At present, there are no promising agents to counter this progressive disease and it will be some time before the next generation of therapies becomes widely available.

In the interim, there is a need to make better use of existing therapies. We need more collaborative efforts to develop predictive and response markers to allow better choice of therapy for the individual. We need more evidence about what makes an individual respond to a certain therapy. EMSP and its members can play an important role in supporting this type of research and information gathering.

Sunday, 25 May 2008 - Parallel Workshops: Aspects of Independent Living

The conferences more informal workshop sessions provided an opportunity for small groups to discuss the following topics.

- | | |
|--------------|--|
| Workshop I | Training and Certification of MS Nurses: What MS Societies Can Do
<i>Margarita Corry, Lecturer in Nursing, Trinity College, Ireland;</i>
<i>Dr. Gabriele Seestaedt, DMSG, Bundesverband e.V., Germany and</i>
<i>Victoria Matthews, MS Trust, UK</i> |
| Workshop II | Support of Carers and Family Members of PwMS: What MS Societies Can Do
<i>Jean Marie Eral, CEO, MS Society France and Dr. Kristin Stuke, MS Forschungs-und Projektentwicklungs-gGmbH, Germany</i> |
| Workshop III | Barrier-free Travel, Sports and Other Aspects of Mobility of PwMS
<i>Emrys Harries, BDFA, UK; Robert Schlathau, ExCom EMSP, Austria And Renate Dimbeck, Austrian Airlines Group, Austria</i> |
| Workshop IV | Creating an Inclusive Society: Mainstreaming Disability based on the Social Economy Example
<i>Ana Mohedano, CEP-CMAF Disability Group</i> |

Country Profile: The Russian struggle to improve the lives of PwMS



Just a young child in comparison with other European MS societies, the All-Russian Public Organisation of Disabled People with MS (PwMS RPO or “the Russian MS Society”) was officially established in 2001.

The Russian MS Society encompasses 48 regional MS societies, covering approximately 75% of the vast country. Its main objective is to advocate for the constitutional rights of persons with MS (PwMS). Today the organisation has more than 35 500 members, but this is barely half of the 70 000 people in Russia who are known to have MS. Moreover, some estimates set the number of PwMS as high as 200 000. The country’s sheer size and rural landscape with many remote towns has made it difficult to establish a formal registry of PwMS. The Russian MS Society began undertaking this task in 2007.

One of the most critical challenges for the Russian MS Society is to ensure that MS patients throughout the Russian Federation (RF) receive adequate treatment and medication. As recently as 2000, only 1% of people with chronic disabling diseases were assessed to receive proper therapy. Similarly, from 2000 to 2004, only 3% of patients in need received high-priced pharmaceuticals (HPPs). The Russian MS Society applied pressure on the government and, in 2004, the results finally came: the government passed a new law that guaranteed patients free medication, including HPPs. Over the next two years, the number of PwMS receiving adequate medication increased from approximately 1 200 to 5 387.

In 2007, the Russia MS Society experienced a significant setback. The federal government withdrew the 2004 law and introduced the division of PwMS into two categories, “federal” and “regional”. Federal patients included those who had been formally diagnosed, while regional patients included those still waiting for such confirmation. Under this plan, federal patients received treatment on the state budget whilst regional patients were covered by regional budgets, which differed from region to region. The situation was – to say the least – one of “unequal opportunities”, says Dr. Vlasov, President of the Russian MS Society.

The Russian MS Society responded promptly and, together with other patients organisations, managed to secure the revision of several laws, ensuring once again equal access to necessary treatment for all MS patients. In addition, government structures were reformed to some extent and granted the Russian MS Society representation in several key bodies: the Public Chamber of the RF; the Public Council at the RF Ministry of Healthcare and Social Development; and the Federal Service on Surveillance in Healthcare and Social Development in the RF. The Russian MS Society also entered into an agreement with federal authorities that led to the establishment of the Institute of Plenipotentiary Public Expert within the Public Control. The Institute’s main purpose is to ensure that the quality of medical and social services is upheld across all regions of Russia.

These steps were a great victory for the Russian MS Society. The importance of its work was further emphasised by the 2007 implementation of the “Programme of Seven Nosologies”, which placed PwMS under a separate clause of the federal budget. As a result of the

programme, which has been approved for a three-year period, today it is estimated that 40% of people in need of HPPs receive them.

The Russian MS Society has good reason to take pride in these achievements but recognises that much work remains. The Society's other current priorities include the development of MS centres and other neurological facilities, and the social integration of people with MS. The Russian MS Society works with the regional societies to arrange a variety of social events such as sporting events, quiz nights and concerts. This enables Russian PwMS to get out of their homes and meet other people who share the same destiny, and to meet new friends and potential partners. As handicap accessibility is still problematic in many areas of Russia, these events are particularly important for people in wheelchairs who live in the large apartment complexes found in Russia's biggest cities. Unless such individuals have someone to assist them, a simple trip to the park or the supermarket might in fact be impossible for wheelchair users. Social events are an important means of preventing more or less complete isolation. The Russian MS Society also keeps a focus on the continuous development of social support for MS patients.

Highlights of 2008

The Russian MS Society has been active since its establishment and 2008 was no exception, as demonstrated by the following highlights:

- **The All-Russian Public Organisation of Disabled People with MS joins the EMSP**

On 23 May 2008, the European Multiple Sclerosis Platform (EMSP) welcomed the Russian MS Society as its 33rd member. This marked European recognition of the Society's work and progress in improving life for PwMS in Russia.

- **New faces in the Russian MS Society**

The Russian MS Society has established 28 MS consulting offices and 14 new branches joined the organisation. In addition, the Society trained 72 Plenipotentiary Public Experts on PR-technologies, non-profit activities and legal basics to advocate for patient rights.

- **Samara regional MS society in the All-Russian Book of Honour.**

The All-Russian Book of Honour acknowledges the contribution of organisations, enterprises and companies to social and economic development. On the suggestion of the Samara Municipal District Government, the regional MS society in Samara was entered in the book in November 2008.

- **MS awareness in the media**

The Society conducted eight Roundtables with media (in Moscow, Saint Petersburg, Samara, Ulyanovsk, Khabarovsk) on 12 TV-channels, three of which are transmitted throughout Russia. The Society also gave interviews to the BBC Russian Service, Radio Europe Plus, Radio Megapolis and Radio 'Silver Rain' (Serebryany Dozhd).

Despite the many positive results in recent years, the Russian MS Society does not rest on its laurels. The organisation continues to fight for the improvement of life quality for PwMS and for the recognition of their constitutional rights. The Society is keen to use its membership in the EMSP as a means of exchanging knowledge and experiences with fellow organisations in Europe. Hopefully, the connection will lead to good and lasting mutual relations, and help to establish the Russian MS Society as one that ranks amongst Europe's best.

www.ms2002.ru

Written by Kristina Vinci, The Danish MS Society

Financial Report 2008

	2006		2007		2008	
ASSETS						
Fixed Assets		2835,56		5432,14		3064,98
Plant machinery and equipment	2835,56		5296,60		2929,44	
Guarantee			135,54		135,54	
Current Assets		370000,99		295752,72		384183,90
Trade debtors	94877,69		159510,44		37634,37	
Other amounts receivable	10380,21		8561,00		13434,33	
Cash at bank and in hand	224638,24		119412,13		327275,41	
Deferred charges and accrued income	40104,85		8269,15		5839,79	
TOTAL ASSETS		372836,55		301184,86		387248,88
LIABILITIES						
Capital and Reserves		225070,45		186328,00		305191,95
Capital (Issued Capital)	13584,97		13584,97		13584,97	
Special reserve	129753,98		147102,66		265966,61	
Provisions for liabilities and charges	61731,50		5640,37		5640,37	
Development fund emerging countries	20000,00		20000,00		20000,00	
Creditors		147766,10		114856,86		82056,93
Amounts payable within 1 year (trade debts/other)	72266,10		93068,86		72648,30	
Accrued charges and deferred income	75500,00		21788,00		9408,63	
TOTAL LIABILITIES		372836,55		301184,86		387248,88

Financial Report 2008 (continued)

	2006		2007		2008	
INCOME & EXPENDITURE STATEMENT						
OPERATING INCOME						
Turnover		436408,00		664520,15		763691,64
Membership fees	49475,00		74900,00		75900,00	
Corporate Core Funding	213300,00		216121,21		242342,98	
Project Funding	173633,00		221767,52		339446,44	
EU Funding			151731,42		101154,28	
Extraordinary income			-			
Financial Income		4285,65		3418,88		10017,93
Interest current/term account	3535,93		3401,92		3714,30	
Other financial income	749,93		16,96		6303,63	
Other Operating Income		398,94			4847,94	
Reinvoicing	398,84					
TOTAL INCOME		441092,80		667939,03		773709,57

Financial Report 2008 (continued)

	2006		2007		2008	
OPERATING CHARGES						
Services and other goods		370179,23		633731,62		576566,24
Administrative costs	3075,59		2816,99		2640,70	
Fees (Consultants, Audit, Legal)	164182,17		165920,84		168569,40	
Distribution of EU subsidy			102069,60		68046,40	
Project Expenses	126439,51		356183,56		320735,20	
Other Costs Travel/Newsletter	1099,14		4557,37		15859,25	
Affiliation Fees	75382,82		2183,26		715,29	
Salaries				63089,57		71049,23
Salaries employees & related costs			63089,57		71049,23	
Depreciation & Write-offs		2796,96		3364,70		3156,76
Write-off Office Equipment	2796,96		3364,70		3156,76	
Other Operating Charges		6185,88		1416,24		1010,78
VAT	6185,88		1416,24		1010,78	
Financial Charges		5839,60		5079,35		1933,08
Payment differences			107,81		178,53	
Exchange Rate differences	5038,90		4327,84		1217,50	
Bank costs	800,70		643,70		537,05	
Extraordinary Charges						1129,53
Extraordinary charges					1129,53	
Profit/Loss for the Period		56091,13		- 38742,45		118863,95
Transfer to/from special reserves	56091,13		- 38742,45		118863,95	
TOTAL CHARGES		441092,80		667939,03		773709,57

For the Audit Report 2008 please see Annex 3 on page 51

The EMSP is grateful to all Sponsors for their financial and professional support



European Commission

EMSP Member Organisations



Multiple Sklerose Gesellschaft Oesterreich
Neurolog Univ Klinik
Währinger Gürtel 18-20
A-1090 Wien,
AUSTRIA
Tel: + 43 1-40400 3123
Fax: + 43 1-40400 3141
Email: msgoe@gmx.net
Web: www.msgoe.at



Ligue Nationale Belge
de la Sclérose en Plaques
144/8 Rue Auguste Lambiotte
B-1030 Bruxelles,
BELGIUM
Tel: + 32 2736 1638
Fax: +32 2732 3959
Email: ms.sep@ms-sep.be
Web: www.ms-sep.be



MS Society Belarus
Ul. Kalinina 7
220012 Minsk
REPUBLIC OF BELARUS
Tel.: +375 172 884194
Fax: +375 172 2284194
Email: msbelarus@inbox.ru



Savez Udruzenja Gradana Oboljelih
od Multiple Skleroze BiH Sarajevo
Antuna Branka Simica 13
71000 Sarajevo
BOSNIA AND HERCEGOVINA
Tel.: +387 33 659671
Fax: +387 33 659671
Email: msk-sa@bih.net.ba



Savez drustava multiple skleroze Hrvatske
Trnsko 34
10000 Zagreb
CROATIA
Tel.: +385 1 655 4757
Fax: +385 1 655 4757
Email: sdms_hrvatske@sdmsh.org
Web: www.sdmsh.org



Unie Roska / Czech MS Society
P.O. Box 38
120 00 Praha 2
CZECH REPUBLIC
Tel.: +420 2 66712511
Fax: +420 2 66712511
Email: roska@roska.eu
Web: www.roska.eu



Scleroseforeningen
Mosedalvej 15
D-2500 Valby, Copenhagen
DENMARK
Tel: + 45 36 46 36 46
Fax: + 45 36 46 36 77
Email: pka@scleroseforeningen.dk
Web: www.scleroseforeningen.dk



Estonian Multiple Sclerosis Society
Paldiski mnt 68
10617 Tallinn
ESTONIA
Tel.: +372 5011841
Email: info@smk.ee; vladislavav@hotmail.ee
Web: www.smk.ee



The Finnish MS Society
Seppälantie 90, PL 15
SF-21521 Masku
FINLAND
Tel: + 358 2439 2111
Fax: + 358 2439 2133
Email: tiedotus@ms-liitto.fi
Web: www.ms-liitto.fi

EMSP Member Organisations (continued)



Ligue Francaise Contre la
Sclérose en Plaques
40 rue Duranton
75015 Paris
FRANCE
Tel: +33 153 98 98 80
Email: info@lfsep.asso.fr
Web: www.lfsep.asso.fr



Deutsche Multiple Sklerose Gesellschaft
Küsterstr. 8
30519 Hannover
GERMANY
Tel: + 49 511 96 8340
Fax: + 49 511 96 83450
Email: dmsg@dmsg.de
Web: www.dmsg.de



Greek MS Society
3, P. Haralambaki str
Thessaloniki – P.O. 55132
GREECE
Tel: + 30 2310 949 672
Fax: + 30 2310 949 909
Email: info@gmss.gr
Web: www.gmss.gr



Hungarian Multiple Sclerosis Society
Jancsar u. 9
H-8000 Szekesfehervar
HUNGARY
Tel: + 36 22 535 691
Fax: + 36 22 535 691
Email: drguseoa@mail.datatrans.hu



MS Felag Islands
Slettuvegur 5
103 Reykjavik
ICELAND
Tel: + 354 568 8620
Fax: +354 568 8621
Email: msfelag@msfelag.is



MS Society of Ireland
MS Resource Centre
80 Northumberland Road
Dublin 4
IRELAND
Tel: + 353 1 678 1600
Fax: + 353 1 678 1601
Email: info@ms-society.ie
Web: www.ms-society.ie



Associazione Italiana Sclerosi Multipla
Via Operai 40
16149 Genoa
ITALY
Tel: + 39 010 2713225
Fax: + 39 010 2713205
Email: relest@aism.it
Web: www.aism.it



Latvijas Multiplas Sklerozes Asociacija
Melidas Str. 10
Riga, LV - 1015
LATVIA
Tel.: +371 7 351 792
Fax: +371 7 351 792
Email: lmsa@lmsa.lv
Web: www.lmsa.lv



Lithuanian Multiple Sclerosis Union
A.Jaksto 9-126
LT-01105 Vilnius
LITHUANIA
Tel. & Fax: +370 5 260 9068
Mobile: +370 656 35599
Email: info@liss.lt
Web: www.liss.lt

EMSP Member Organisations (continued)



Ligue Luxembourgeoise de la
Sclérose en Plaques
An der Bongeschgewan
48 rue du Verger
L-2665, LUXEMBOURG
Tel: + 352 400 844
Fax: + 352 402 804
Email: msslux@pt.lu
Web: www.msweb.lu



Multiple Sclerosis Society of Malta
PO Box 63
B'KARA - BKR 1000
MALTA
Tel.: +356 2 141 32 06
Fax: +356 2 141 32 06
Email: mssmalta@gmail.com
Web: www.mssmalta.org.mt



Multiple Sclerose Vereniging Nederland
Postbus 30470
2500 GL Den Haag
NETHERLANDS
Tel: + 31 70 374 7777
Fax: + 31 70 374 7770
Email: info@msvn.nl
Web: www.msvereniging.nl



Multipel Sklerose Forbundet I Norge
Tollbugata 35
0157 Oslo
NORWAY
Tel: + 47 22 47 79 90
Fax: + 47 22 47 79 91
Email: epost@ms.no
Web: www.ms.no



Polskie Towarzystwo Stwardnienia Rozsianego
ul. Bagatela 13 m 43
00-585 Warsaw
POLAND
Tel.: +48 22 856 7666
Fax: +48 22 849 1065
Email: m.filipowicz@ptrs.org.pl
Web: www.ptrs.org.pl



Sociedade Portuguesa de Esclerose Multipla
Rua Zofimo Pedroso 66
1950-291 Lisboa
PORTUGAL
Tel: + 351 218 650480
Fax: + 351 218 650489
Email: spem@spem.org
Web: www.spem.org



Romanian MS Society
Str Buzaului 2B OP3 CP11
410241 Oradea
ROMANIA
Tel.: +40 259 476 557
Fax: +40 259 417 136
Email: ssmr@smromania.ro
Web: www.smromania.ro



All Russian Public Organization (RPO) of Disabled
PwMS
Yuria Pavlova Street 8 – office 4
443090 Samara
RUSSIA
Tel / Fax : +7 846 951 36 45
Email : sams99@inbox.ru
Web: www.ms2002.ru



Drustvo Multiple Skleroze Srbije
Dr. Subotica 6
11000 Beograd
SERBIA
Tel.: +381 11 3610 520
Fax: +381 11 3610 520
Email: mssserb@eunet.yu

EMSP Member Organisations (continued)



Slovenský zväz Sclerosis Multiplex
Culenova 12
91701 Trnava
SLOVAKIA
Tel.: +421 57 44 93 113
Fax: +421 918 636 623
Email: szsm@szm.sk
Web: www.szsm.szm.sk



Združenje MS Slovenije
Maroltova ul. 14
SI - 1000 Ljubljana
SLOVENIA
Tel: + 386 1 568 7299
Fax: + 386 1 568 7297
Email: info@zdruzenje-ms.si



Asociación Española de EM (AEDEM)
C/ Sengenjo, 36
28034 - MADRID
SPAIN
Tel: +34 90 215 18 22
Fax: +34 91 448 12 61
Email: aedem@aedem.org
Web: www.aedem.org



NHR-Neurologiskt Handikappades Riksförbund
Box 49084
S-100 28 Stockholm
SWEDEN
Tel: + 46 8 6777010
Fax: + 46 8 24 13 15
Email: annica.bernehjalt@nhr.se; nhr@nhr.se
Web: www.nhr.se



Schweizerische MS Gesellschaft
Jozefstrasse 129 - casa postale
CH-8031 Zurich
SWITZERLAND
Tel: + 41 43 444 43 43
Fax: + 41 43 444 43 44
Email: info@multiplesklerose.ch
Web: www.multiplesklerose.ch



MS Society of Great Britain & Northern Ireland
372 Edgware Road - Crickelwood
LONDON, NW2 6ND
UNITED KINGDOM
Tel: + 44 20 8438 0700
Fax: + 44 20 8438 0701
Email: info@mssociety.org.uk
Web: www.mssociety.org.uk

Annex 1: EMSP's Vision, Mission and Values

As part of a worldwide community of PwMS, EMSP is committed to dialogue with, demonstrate respect for, and collaborate with all stakeholders in the field of MS, particularly the Multiple Sclerosis International Federation (MSIF).

Our Vision

Throughout Europe, Persons with MS have equal access to the highest quality of treatment and support they need to live their lives to the full.

Our Mission...

...is to ensure the development and implementation of high quality standards of treatment and support for PwMS, their families and their carers throughout Europe, to allow them to lead their lives independently and to recognise them as equal members of society.

The EMSP work priorities to achieve this mission are to:

- Influence EU institutions and other decision-making bodies to improve the quality of life of PwMS.
- Network with other European organisations in which the patient is central.
- Provide MS member associations with information on relevant EU draft legislation and projects.
- Develop and promote recommendations for improved medical treatment and rehabilitation to be implemented in the EU member states and other countries.
- Encourage research of all kinds aiming at the benefit of PwMS.
- Initiate and implement cross-border projects to improve the living conditions of PwMS, e.g. in the fields of therapies, employment, social security, infrastructure.
- Act as an information platform by exchanging information and best practices relevant to the work of the national MS member associations
- Enhance a general awareness on multiple sclerosis by informing and educating external audiences
- Support national MS societies both recent or long-established in Europe

Our Values

Independence - In our working relation with external partners, we only represent the interests of Persons with MS.

Impartiality - work for all our member associations and those they represent, regardless of nationality, race, religion, gender, sexual orientation, or political conviction.

Democracy - We involve our MS member associations in determining our plans and in the work we do. We consult them on all key issues and accept the decisions they make.

Dialogue - We are part of the global MS community where the PwMS is central. We collaborate with our member associations, other organisations and supporters in order to achieve our goals for the benefit of PwMS.

Transparency - Everything we do is open and honest. We welcome scrutiny by others.

Annex 2: MS Barometer Editorial in *The Lancet Neurology* (Vol 7, June 2008)

League table puts pressure on nations to improve MS care

As *The Lancet Neurology* went to press, neurologists, policy makers, and patients' groups were preparing to come together for a roundtable discussion of pan-European inequalities in access to treatments for people with multiple sclerosis (MS). The meeting, in Ljubljana, Slovenia, on May 7, marked the release of the findings of the MS Barometer—a benchmarking initiative undertaken by the European Multiple Sclerosis Platform, an umbrella organisation of national MS societies—which revealed the enormous differences in the standards of care for patients with MS in different European nations. All people with MS, regardless of where they live, should have equitable access to treatments and services. Thus, strategies that aim to raise the awareness of treatment inequalities and improve the situation for patients with MS are welcome.

There are about 500 000 people with MS in Europe. MS is the most common cause of disability in young adults, and about 10–15% of patients eventually require a wheelchair or become bedridden. With a total cost in Europe estimated at €8.8 billion, including health-care costs and loss of productivity, MS is one of the most costly diseases. Disease progression is associated with increasing costs, and the hope is that early initiation of disease-modifying drugs might reduce disability, which in turn would reduce costs. However, there are no long-term, controlled studies to support this claim.

The MS Barometer, a survey completed by the national MS societies of 22 European countries, assessed several aspects of MS management, including access to treatments and services; reimbursement of costs; and national data collection on MS. Scores in each category are summed to produce a league table of the best and worst countries. The results reveal widespread differences in the management of MS across Europe. In Germany, for example, about 70% of patients with MS—including relapsing-remitting and progressive disease—receive treatment with disease-modifying drugs, such as interferon beta, glatiramer acetate, and natalizumab. However, in some countries, particularly in eastern Europe, less than a fifth of patients receive disease-modifying drugs. The situation in Poland and Bosnia-Herzegovina is especially dire, with only 2–3% of patients with MS receiving diseasemodifying therapies.

Geographic variations in the treatment of MS not only reflect differences in individual health-care systems and local guidelines, but also doctors' and patients' beliefs. Currently available treatments for MS are only modestly effective: no treatments can slow the progressive course of MS and, depending on the drug used, only about one to two thirds of patients with relapsing-remitting MS respond well to disease-modifying therapies; the relatively low levels of use of these drugs in some countries might reflect the scepticism of some neurologists about their long-term efficacy, which remains unproven. For other countries, such as Poland, it is a question of priorities; glatiramer acetate and natalizumab are not reimbursed by the government, and treatment with interferon beta is only funded for 2 years. It is easy to blame poverty for

the lack of reimbursement of expensive MS treatments. But with a GDP of US\$420 billion, Poland is not a poor nation. Neighbouring countries such as the Czech Republic (\$175 billion) and Lithuania (\$38 billion) fare much better, with about 20% of patients receiving disease-modifying drugs.

Service provision also varies widely from country to country. 40% of European nations lack a specialist rehabilitation centre and the number of neurologists in some countries is exceptionally low. The UK and Ireland lag behind the rest of western Europe with less than 1 neurologist per 100 000 people compared with about 4 to 8 per 100 000 in most other European countries.

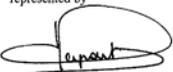
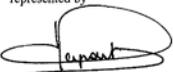
Less than a quarter of European countries have a national register of patients with MS. Thus, for some countries the survey results represent little more than educated guesses about the standards of care for

people with MS. But regardless of these limitations, the widespread variations in access to treatments and rehabilitation cannot be ignored. By naming and shaming the countries that perform poorly, the hope is that nations at the bottom of the league table will be inspired to make a commitment to improving the care of patients with MS.

Health authorities that deny access to MS treatments should be more receptive to current knowledge provided by experts. Physicians and patients in these countries need the support of the EU and other European bodies in their fight to overcome political barriers to effective treatment. A shared European research agenda for MS and closer collaboration across EU countries would fit well with this aim. Only then will geographic inequalities in the management of MS be eliminated.

■ The Lancet Neurology

Annex 3: Audit Report 2008

 <p>KPMG and Partners Delfoorgen 23 bus 13 9002 Gent Belgium</p> <p>Tel: +32 (0)9 241 88 00 Fax: +32 (0)9 241 88 99 www.kpmg.be</p> <p style="text-align: center;">Statutory auditor's report to the general meeting of the members of the association EUROPEAN MULTIPLE SCLEROSIS PLATFORM AISBL on the financial statements for the year ended 31 December 2008</p> <p>In accordance with legal and statutory requirements, we report to you on the performance of our audit mandate. This report includes our opinion on the financial statements together with the required additional comment.</p> <p>Unqualified audit opinion on the financial statements</p> <p>We have audited the financial statements of EUROPEAN MULTIPLE SCLEROSIS PLATFORM AISBL for the year ended 31 December 2008, prepared in accordance with the financial reporting framework applicable in Belgium, which show a balance sheet total of € 387.249 and a profit for the year of € 118.864.</p> <p>The board of directors of the association is responsible for the preparation of the 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.</p> <p>Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with legal requirements and auditing standards applicable in Belgium, as issued by the "Institut des Réviseurs d'Entreprises/Institut 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.</p> <p>In accordance with these standards, we have performed procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on our judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, we have considered internal control relevant to the association's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances but not for the purpose of expressing an opinion on the effectiveness of the association's internal control. We have also evaluated the appropriateness of the accounting policies used, the reasonableness of accounting estimates made by the association and the presentation of the financial statements, taken as a whole. Finally, we have obtained from management and responsible officers of the association the explanations and information necessary for our audit. We believe that the audit evidence we have obtained provides a reasonable basis for our opinion.</p> <div style="text-align: right; margin-top: 20px;">  W </div>	 <p style="text-align: center;"><i>Statutory auditor's report to the general meeting of the members of the association EUROPEAN MULTIPLE SCLEROSIS PLATFORM AISBL on the financial statements for the year ended 31 December 2008</i></p> <p>In our opinion, the financial statements as of 31 December 2008 give a true and fair view of the association's net worth, financial position and results in accordance with the financial reporting framework applicable in Belgium.</p> <p>Additional comments</p> <p>The Association's compliance with the Law of June 27 1921 on the non profit associations, non for profit international associations and foundations and with the Association's bylaws is the responsibility of the board of directors.</p> <p>Our responsibility is to supplement our report with the following additional statements, which do not modify our audit opinion on the financial statements:</p> <ul style="list-style-type: none"> • 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 association's bylaws or the Law of June 27, 1921 on the non profit associations, non for profit international associations and foundations that we have to report to you. <p>Ghent, 15 May 2009</p> <p>KPMG & Partners Statutory auditor represented by</p> <div style="text-align: center; margin-top: 10px;">  Wim Heyndrickx Réviseur d'Entreprises / Bedrijfsrevisor </div>
<p>KPMG and Partners, a Belgian civil (BVBA/SRL) and a member firm of the KPMG network of independent member firms affiliated with KPMG International, a Swiss entity.</p>	<p>KPMG and Partners (BE)AS/PS, Belgium and member firm of the KPMG network of independent member firms affiliated with KPMG International (Belgium) - Réseau juridique mondial.</p>



European Multiple Sclerosis Platform aisbl

rue Auguste Lambiotte 144/8

B-1030 Brussels - Belgium

Tel. +32 (0) 2 305 80 12

Fax. +32 (0) 2 305 80 11

Email: secretariat@emsp.org

www.ms-in-europe.org
