CHANGING THE LANDSCAPE OF MS IN EUROPE

Overview of the
EMSP 2015-2020 Strategic Plan

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

The Voice of People Living with MS in Europe

The European Multiple Sclerosis Platform (EMSP) exists to improve the quality of life for people with multiple sclerosis (MS) in Europe.

EMSP is the umbrella organisation of 39 national multiple sclerosis societies from 34 European countries, representing the voice of 700,000 people living with MS in Europe.

Together with our partners, we are working towards a world without MS. Our mission is to ensure that people with MS have a real voice in determining their own objectives and priorities.

We are engaged in advocacy and awareness-raising campaigns to influence European decision-makers and EU policy-makers; we gather and provide knowledge and expertise; and we encourage high quality research on MS as well as the dissemination of information that is based on new evidence.

MS is a complex neurological condition for which currently there is no cure. MS is:

- One of the most common long-term conditions affecting the central nervous system
- The main cause of non-traumatic disability in young adults.
- Symptoms range from fatigue to severe mobility problems and blindness in extreme cases.
- Twice as many women as men are affected.

MS is a challenge for people and society

- 70% of people with MS are diagnosed between 20 and 40 years of age.

- Early onset can severely limit a person's capacity to contribute to and play a part in society.
- 80% of people with MS stop working within 15 years of the onset of the disease*.
- 15 billion euros are spent every year in Europe to tackle MS**.

PHOTO: CARLOS SPOTTORNO / GERMANY 2011

The MS lottery

- Access to treatment, care and employment varies substantially throughout Europe.
- In many European countries, people with MS cannot access MS specialists and experience considerable difficulties in obtaining reimbursement for treatment.

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* *Work Foundation, Ready for Work?, 2011*

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

Many aspects of MS can be managed with appropriate, specialised support. Together with its member organisations, EMSP works to ensure that high quality support is available throughout Europe. EMSP teams up with many players in the field of MS, chronic diseases and human rights to ensure that the voice of people with MS is heard in Europe.

This brochure aims to provide our members and partners with an overview of the goals, objectives, priorities and programmes for the years to come. It is only through continued alliances and smart choices that we will be able to drive changes throughout Europe.

Our focus, work and value proposition

As the umbrella organisation for national MS organisations in Europe, EMSP is uniquely placed to:

- Identify and run programmes that make a real difference to people with MS
- Facilitate cooperation between European players in the fields of research and advocacy
- Influence European health, social and employment policies
- Support national MS societies in their advocacy projects, including outreach to policy-makers
- Build alliances between MS, chronic disease and disability advocates across Europe

25+ Years of Advocacy for People with MS – highlights

IMPROVED ACCESS TO TREATMENTS AND THERAPIES:

- European Parliament Resolution on discriminatory treatment of persons with MS within the EU (2003)
- Reversal of the rejection of fampridine as MS medication by the European Medicines Agency after intervention of EMSP and its members (2011).

INCREASED AWARENESS OF MS AT EUROPEAN AND NATIONAL POLICY LEVEL:

- European Code of Good Practice in MS, Therapy Guidelines and Consensus Papers, published on the European Commission's website (2003)
- Written Declaration on tackling multiple sclerosis in Europe adopted by the European Parliament (2012)
- National high level roundtables held across Europe addressing challenges faced by people with MS (since 2006)

TOOLS FOR BETTER UNDERSTANDING AND MANAGEMENT OF MS ACROSS EUROPE:

- MS Barometer, a benchmarking tool providing an overview of the disease management across Europe (since 2008)
- Multiple Sclerosis Information Dividend (MSID), a feasibility study on the Europe-wide pooling of data of MS patients and first EMSP project co-funded by the European Commission (2007-2009)

RAISING THE VOICE OF PATIENTS AT EU LEVEL:

- EMSP co-founds the European Patients' Forum, now representing 150 million patients with chronic diseases (2003)

PHOTO: CARLOS SPOTTORNO / POLAND 2011

A WORLD WITHOUT MS

European Code of Good Practice in MS
'Defeating MS Together'
Commit. Support. Advocate. Act.

ADVOCACY and AWARENESS RAISING

4 **Ensure the voice and influence of people with MS is recognised in every relevant arena (political, scientific, academic and general public)**

4 **Champion major issues which can escalate progress in the field of MS**

KNOWLEDGE and EXPERITSE

4 **Share and promote evidence-based best practice**

4 **Foster effective cooperation between people affected by MS, health professionals, policy decision-makers and researchers**

RESEARCH

4 **Encourage and support high quality MS research and international MS research collaboration**

4 **Support the collection, pooling and interrogation of essential MS data across Europe**

Improving the quality of life of more than 700,000 people with MS across Europe

Empowering people with MS

Individuals and organisations across the EU need to come together to channel their efforts in tackling MS. In close dialogue with our members and partners, EMSP has recently revamped its Code of Good Practice entitled Defeating MS Together. Its core objective is to help empower people with MS.

To make a real difference for people with MS, coordinated improvements are urgently needed in the following areas:

1 / Equal access to MS treatment, therapies, rehabilitation and services in Europe

2 / Enabling employment, job retention and education

3 / Focusing MS research, e.g. in under-researched areas such as progressive MS

4 / Better understanding and treatment of paediatric MS

5 / Support and empowerment of MS carers

Defeating MS Together is more than a set of ideals. In the form of 12 Calls to Action, it provides guidance for the whole MS community, alongside policy makers, the media, clinicians and academics on how to join forces where it matters.

EMSP Priority Projects

ACCESS TO HIGH QUALITY CARE:

MS Nurse PRO – an online training tool to raise standards of MS nursing across Europe.

UNDER PRESSURE - a photo exhibition and video documentaries to communicate the experience and pressures of living with MS in Europe.

BETTER DATA FOR IMPROVED OUTCOMES:

European Register for MS (EUReMS) – a pioneering data collection system to boost MS research and enable better outcomes for the European MS community.

MS Barometer – a comparative survey reflecting the situation of people living with MS in 39 European countries.

Pan-European Patients Survey (PEP) – a survey capturing the challenges of people with MS in Europe in order to ensure their needs and concerns are met.

KEEPING PEOPLE IN WORK:

Believe & Achieve – meaningful work and training opportunities for young people with MS.

Paving the Path to Participation – EU co-funded public policy initiative to develop best practice and promote equal employment opportunities for people with MS.

2015-2020 Strategic Policy Aims

In a European social and health policy landscape that is becoming increasingly focused on broad themes and alliances, EMSP will work closely with its partners and allies to progress these themes, using MS as an exemplar of a long-term, disabling, neurological condition.

All our political advocacy projects have the aim of reducing inequalities in Europe.

Examples of activities that will be further pursued in the period 2015-2020 include:

- Promotion of the new European Code of Good practice in MS: Defeating MS Together – guidelines for policy makers and stakeholders in Europe promoting best practice and consensus papers in MS.
- Promotion of the European Pact for employment, a tool to raise awareness of the issues facing people with neurodegenerative diseases in the workplace and support for people who want to remain at work.
- Campaigning aimed at all employers and education providers on existing legislation and policies which require provision of support for people with long-term conditions, such as MS.
- Facilitation of cooperation and networking between patients, health professionals, policy decision-makers and other players to improve responses to long-term and neurodegenerative diseases.
- A human rights based approach to address the barriers that stand in the way of the inclusion and participation of people with MS in society on an equal basis.

Together we must–
Commit, Support
Advocate, Act!

SPREADING THE WORD: increasing visibility and impact through communications

Effective communications and acting as an engine for change is pivotal to achieving EMSP's goals and enabling our members to make the most of available resources.

By 2020, EMSP will make further significant progress in communications outreach and enhancing the impact of EMSP's mission and projects. We undertake to:

4 Address people with MS beyond the role of ambassadors and by broadening its partner base.

4 Continue to shift from a single to a multi-disease approach in European health and social policies.

4 Focus on young people with MS and the theme of access: to better treatment; improved healthcare and employment.

4 Encourage investment into under-researched MS areas.

Your Partner of Choice

PHOTO: LURDES R BASOLÍ / FRANCE 2012

EMSP's aim and ambition for the period 2015-2020 is to consolidate and build on its programme successes and organisational development as follows:

- **Form a stronger network of national MS societies**
  We aim to welcome new members and help national societies to strengthen their voice and advocacy capabilities. We will support them to implement the projects initiated by EMSP.

- **Become the "go-to" expert for EU organisations and other NGOs**
  We strive to be more widely recognised as a network of and for patients' advocates, experts and defenders of the rights of people with MS, other neurological conditions and disabilities.

- **Consolidate our role as facilitator of key networks and partnerships**
  We have built strong partnerships and projects. We intend to maintain the momentum and trail blaze so that others can take up and develop the most promising ideas.

- **A sustainable and independent organisation acting for the best interests of people with MS**
  We seek to further strengthen our Secretariat, Board and committees, ensuring that the quality of EMSP's overall activities is maintained and further improved.

Let's team up to change the landscape of MS in Europe!

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