EMSP 2014 Spring Conference

EMSP Celebration of 25 Years as the Voice of People with Multiple Sclerosis in Europe

John Golding
President EMSP

emsp 25
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PLATFORM

Founding members of EMSP

- Princess de Mérode (Belgium)
- Manuel Creyns (Spain)
- Udo Kruse (Portugal)
- Monique Crenesse (France)
- Professor René Marteau (France)
- Hans Arne Melbye (Norway)
- William Lonergan (Ireland)

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EMSP History I
1989–2000

- It all started when the creation of MS platforms on each continent (Europe, Asia/Pacific, America) was proposed at an MSIF meeting but was immediately rejected
- Europe went ahead and in 1989 EMSP was founded as an umbrella organisation of 21 MS Societies in Europe
- Between 1989 - 1999 EMSP was run by a volunteer Executive Committee and a part time Secretary
- In 1990 Mr. Alberto Saenz (Spain) became the first President of EMSP
- Between 1994-1997 Miriam Genesset was the President of EMSP

EMSP History II 1989–2000

- In 1997 Professor Mario Battaglia (Italy) was elected President of EMSP
- In April 2000, Michael Willis (UK), the new President of EMSP, appointed Christoph Thalheim as Secretary, later Secretary General of EMSP
- The organisation had at that stage a starting capital of EUR 30,000. No office, no other staff, no projects and only 1 sponsor (Schering).

EMSP History
Looking back at 2002

- In 2002 Peter Kauffeldt (Denmark) was elected as the new President of EMSP

- New priority: ”***Equal access to high quality therapy and care for all people affected by MS in Europe***”

- In June 2002 EMSP organised its first European MS Awareness Day in the European Parliament in Brussels.

- In September 2002 the first EU funded project: **Breaking the isolation - Cybercafés for People with MS**’ was launched

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EMSP History
Milestones from the past I

The first European event for Young People with MS was held at the EMSP 2005 Spring Conference in Bucharest.

In 2004 EMSP and MSIF started work on the "European Map of MS", later to become the global "**Atlas of MS**" developed by MSIF together with WHO.

EMSP History
Milestones from the past II

Looking back at 2006:

- EMSP presented patients’ views on the shortcomings of current pricing and reimbursement to representatives of EU Member States, EC, EP, health insurers, pharmacists and industry in the Commission’s “**High Level Pharmaceutical Forum**”
- Dorothea Pitschnau’-Michel from Germany was elected as the new President of EMSP
- The largest EU co-funded project: Multiple Sclerosis Information Dividend, the feasibility study for a European MS Register, was launched

EMSP History
Milestones from the past III

- January 2007 saw the start of the very successful multi-sponsor EMSP scheme for capacity building in the Polish MS Society
- In 2008 the first MS Barometer survey took place, followed by the first “High Level National Roundtable”, achieving agreement of the first “pure” MS Rehabilitation Centre in Slovenia

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EMSP Recent years

- In 2010 John Golding from Norway is elected as the new EMSP President. He is the first President of EMSP to have MS.
- John chooses continuous improvement (Kaizen) of the well-proven organisation as a main theme resulting in a change process for EMSP. This represented the beginning of a new era for EMSP.
- In 2011-2012 Maggie Alexander was appointed CEO of EMSP and Christoph Thalheim became Director of External Affairs.

EMSP Recent years II
Under Pressure Exhibition

- MS information Days were held in the European Parliament in 2011/2012/2013

- In 2012 the Under Pressure Exhibition was launched in the European Parliament

UNDER PRESSURE

Living with MS in Europe

24/04/2012 • 18h30

The Honourable Petru Luhan, Member of the European Parliament for Romania, and the European Multiple Sclerosis Platform (EMSP) invite you to the European launch of a photo exhibition featuring the work of WALTER ASTRADA, MAXIMILIANO BRAUN, FERNANDO MOLERES, LURDES R. BASOLÍ and CARLOS SPOTTORNO.

EMSP Recent years III
Written Declaration on MS

In 2012 the European Parliament has officially adopted the Written Declaration on tackling MS in Europe

WD No. 20 - More than a signature

Estimated 600, 000 Europeans suffer from Multiple Sclerosis (MS) - as many as people living in cities like Frankfurt or Posnan. MS is the most frequent neurodegenerative disease in Europe and most people are diagnosed in the prime of their working lives. MS costs Europe 15 billion Euro per year - 36.000 Euro per patient.

It makes a huge difference whether people with MS live in Frankfurt or Posnan, in Paris or Prague. It influences whether they are entitled to disease-modifying treatments; the quality of care; and whether they can stay productive at work.

Written Declaration no. 20 on Multiple Sclerosis calls on the member states to enhance equal access to quality care, foresee specialised nursing training and elaborate national registers to better document the impacts of MS. It calls on the Commission and Council to elaborate a research agenda for even more effective treatments.

Petru Luhan, MEP, initiator of WD no.20 on Multiple Sclerosis:
Main reasons why you should sign WD No.20:

1. Recent studies show that at least 30% of MS patients loose adherence to their recommended therapies[1] accepting the risk of new disease related disability. Specialised educated MS-nursing was able to improve the capacity for a shared decision making in people with MS, thus reducing therapy discontinuation rates significantly and increasing quality of life measures at the same time[2]. Trained nurses help ensure effective treatment, and herewith also increase return on investment.
2. Half of the people with MS leave the workforce within only three years of diagnosis. Better care prolongs the chances for people to remain productive.
3. The declaration will help prepare the floor for a better acceptance of patient initiatives in countries in which no or little action would be taken otherwise.

63 signatures are still needed - PLEASE SIGN WD NO. 20 DURING THE STRASBOURG PLENARY SESSION BETWEEN 10-13 SEP. – Thank you!

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EMSP in 2014

- Has 16 industry partners, 6 flagship projects, is member of the European Medicines Agency's Patient and Consumer Working Party, founding member of the European Patients' Forum, member of the European Disability Forum and member of the European Citizen Action Service and has 38 member organisations in 34 European countries.
- Acts as "interface" between its national members and European bodies such as the European Parliament, the European Commission, including the European Medicines Agency (EMA), the European Federation of Neurological Associations) and many other European Stakeholders.
- We can safely say that EMSP is an "initiator and leader" of innovative MS related projects at European level.

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www.emsp.org

Thank you!

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