



Brussels, 22 December 2010

Dear Members of the European Multiple Sclerosis Platform,

Thanks to your extraordinary support and commitment to our work as the "European voice of more than 600,000 Persons with MS", 2010 was a very successful year for EMSP:

- Our membership increased to reach **37 members** (33 Full Members and 4 Associate Members) from 34 countries across Europe.
- The **Health-EU Newsletter** monthly published by the European Commission, Directorate General Health and Consumer Affairs (DG SANCO) was mainly dedicated to MS and the World MS Day in May. This newsletter is still available on the EU Health Portal (http://ec.europa.eu/health-eu/newsletter/50/newsletter_en.htm), it is a valuable tool to raise awareness on MS through Europe.
- EMSP Annual Congress took place in Stuttgart (26-28 May) on the "Current Challenges and Opportunities in Europe in the work for People with Multiple Sclerosis". In a parallel session to the EMSP Annual Congress, the first EMSP Youth Congress was organised. Both events attracted a lot of interest from all over Europe and were the most largely attended events in EMSP history. On the second day of the Congress, the new EMSP Board Members were elected during EMSP Council meeting.
- EMSP Lithuanian Member (LMSU) followed its initiative of organising **High Level National Roundtable** at the Seimas (Lithuanian Parliament) during which, results on the situation of people with MS were reviewed and good practice shared among participants (patients, politicians, doctors and representatives of the institutions that form the health policy of Lithuania). One of the positive outcomes is the future setting up of an **analytical center** to examine current and future situation of MS, and will take into considerations the LMSU proposals.
- For the first time, EMSP arranged a **Dinner for its Friends and Supporters from Industry** in Brussels at the end of August. It gave to its funding partners the opportunity to meet the newly elected EMSP Board members and also to hear more about EMSP's key achievements in 2009 and their impact and EMSP's goals for the coming years.
- In cooperation with ECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis), EMSP convened a **workshop on MS-NEED** (Multiple Sclerosis-Nurse Empowering Education) in Gothenburg (Sweden) in October 2010. The recently published MS-NEED survey findings were the starting point of the debate and gave material for the call for recognition of MS nursing as speciality. A first **National Roundtable** on this subject was held in Poland; other member organisations indicated their interest to follow the Polish example in 2011. As a major next step, EMSP will facilitate the development of a **European Consensus Paper on MS Nursing**.





- This new Consensus Paper will extend a series of European Consensus Papers and Guidelines on Disease Modifying Therapies, Symptomatic Treatment, Rehabilitation, Palliative Care and others which were facilitated by EMSP through its membership network. Another Consensus Paper in development will focus on Paediatric MS.
- MS Barometer 2009 results updated early 2010 were published confirming the huge disparities between European Countries in the management of the disease. The best overall performers in this year's edition are Austria, Germany and Iceland. 29 countries took part in 2009 Barometer survey against 32 in 2008. EMSP will keep encouraging its members to actively participate to the survey so that the evolution in each country could be monitored on a regular basis. Next survey: Spring 2011!
- The EMSP winter conference on "Better access to MS therapies & care in Central and Eastern countries - strategies for tangible improvement", held in Prague in November, was attended by 40 persons mainly from South Eastern European Countries.

The event was split into two parts: firstly, the audience (MS Societies & Industry partners) was updated on recent and current EMSP projects and activities; and then, an interactive training on sustainable "donors - receivers" relationships, best practices in fundraising, and optimal use of Board Members and volunteering was provided.

Last but not least: we are extremely pleased to announce the selection by the European Commission of EMSP's application for the European Register for MS (EUReMS). The EUReMS will address current lack of information and enable comparisons across EU countries, by both merging data from existing MS national register and collecting reliable and validated information. More details on the project will be sent to you soon. It is a real challenge for the coming years!

On behalf of the Executive Committee together with the Secretariat in Brussels and our events manager in Germany, we would like to thank you for continuous support to EMSP in its activities and projects.

We take the opportunity to send you our warmest greetings for a very happy holiday season and peaceful New Year 2011.

Best regards,

John Golding President

European Multiple Sclerosis Platform

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