

## Brussels, 15 December 2009

## Dear EMSP friends and supporters,

Thanks to Your extraordinary support and commitment towards our work as "European Voice of 500.000 Persons with MS", the *European Multiple Sclerosis Platform* today has good reason to be content when looking at the results and achievements obtained in 2009:

Our membership covers **all EU Member States plus 7** countries around the EU, in total 34 countries.

MS ID, our major EU project has been terminated very successfully with the EMSP Information Hour 2009 in the European Parliament. The two hour event summarized the outcome of the MS-ID project and outlined the path for a new challenge for the coming years, the European MS Register – the Online Patient & Research Database.

Two expert working groups —one on OBJECTIVES, one on METHODOLOGY — have been created to prepare an application for EU funding and are waiting for the call for proposals by the European Commission.

Our **spring conference 2009**, divided into one day devoted to MS-ID and one day on EU resources and support to PwMS, has attracted a lot of interest and caused very positive feedback to the speakers and to EMSP.

The update of the "European Code of Good Practice in MS" and of some of its related European Consensus Papers is done or has started. These vital documents were (informally) acknowledged by EU Parliament, Commission and some national Health Ministers in 2007 and can be found at the EU Health Portal of the European Commission: <a href="http://ec.europa.eu/health-eu/news">http://ec.europa.eu/health-eu/news</a> 2007 en.htm and on the USB card being attached to:

The **Pocket Guide to the Code**, a small booklet explaining history, background and structure of the CODE.

The transposition of these key documents from European to national level has continued with **four High Level National Roundtables** bringing together national health policy decision makers and administration, medical experts and patient representatives

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The revision and second survey of the **MS Barometer as innovative benchmarking tool** was done – results will be shown in early 2010.

EMSP together with IOMNS (the global umbrella organisation of MS nurses) and RIMS (the European umbrella organisation of MS Centres) prepared and run a **Survey on the Role of MS Nurses** in six European countries, showing another important, sometimes underestimated contribution in the work for more quality of life of PwMS. Results and proposals for action will be shown in early 2010.

Last, but not least: The very first "Membership Satisfaction Survey" showed strong agreement with our work and services by our members, outlining at the same time areas in which room for improvement is seen. We will provide a summary of results and proposed actions in early 2010.

On behalf of the Executive Committee together with your secretariat in Brussels, we would like to extend a sincere thank you for supporting the association in its initiatives and in the ongoing fight for a better quality of life of persons with MS over the (almost) passed year.

We take this opportunity to wish you a merry Christmas and an excellent year 2010

Best regards,

Dorothea Pitschnau-Michel President EMSP

European Multiple Sclerosis Platform (EMSP)

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