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# The European Multiple Sclerosis Platform

JA2015 - GPSD [705038]

START DATE: 01/01/2012

END DATE: 01/01/2013

DURATION: 12 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: Second Programme of Community action in the Field of Health 2008-2013

PROGRAMME PRIORITY: -

CALL: Generate And Disseminate Health Information And Knowledge (Hi-2010)

TOPIC: PROMOTE HEALTH (HP-2011)

EC CONTRIBUTION: 294588 EUR

KEYWORDS: Chronic Diseases, Collection of Best Practices, Health education, Healthcare, Rare diseases and disorders

PORTFOLIO: Interest groups, Rare diseases

## Mission and vision of the operating grant holder

Founded in 1989, EMSP is the umbrella organisation representing 38 national MS societies from 34 European countries. EMSP represents their interests at European level and works collectively with its members to achieve our goals of high quality equitable treatment and support for all people with Multiple Sclerosis (PwMS) throughout Europe.

EMSP vision is to move from high quality treatment and support for all PwMS in Europe to a world without MS.

EMSP`s mission is to ensure the development and the implementation of high quality standards of treatment and support for PwMS, their families and their carers in all EU member states, to allow them to lead their life independently and to recognise them as equal members of the society.

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 which share of vision of truly patient centred approach;
- provide MS member organisations with information on relevant EU draft legislation and how we can influence it, and evidence - based projects that will contribute to their work;
- develop and promote recommendations for improved medical treatment and rehabilitation to be implemented in the EU member states and other countries;
- encourage coordinated research aiming to benefit of PwMS;
- initiate and implement cross-border projects to improve the living conditions of PwMS (e.g. in the field of therapies, employment, social security, infrastructure, etc.);
- act as information platform by exchanging knowledge and best practices relevant to the work of the national MS member organisations;
- enhance a general awareness on MS by informing and educating external audiences;
- and to support national MS Societies both recent and long-established in Europe.

## Strategic objectives and specific activities

In October 2011, EMSP established five main goals for its activities for 2012 -2014.

**STRATEGIC GOAL I:**

**TO PROMOTE EQUITY OF ACCESS TO HIGH QUALITY HEALTH AND SOCIAL CARE AND SUPPORT FOR PwMS, THEIR FAMILIES AND THEIR CARERS, REGARDLESS OF WHERE THEY LIVE, OR THEIR ECONOMIC STATUS**

**STRATEGIC GOAL II**

TO STRENGTHEN EMSP AS THE REPRESENTATIVE EUROPEAN VOICE OF PwMS, WORKING IN GENUINE PARTNERSHIP WITH OTHER STAKEHOLDERS AND EMPOWERING MEMBER ORGANISATIONS TO CONTRIBUTE TO AND BENEFIT FROM EMSP AS THEIR PLATFORM

#### STRATEGIC GOAL III

TO PROMOTE THE EMPOWERMENT OF PwMS AT INDIVIDUAL, ORGANISATIONAL AND POLICY LEVEL TO REPRESENT AND ADVANCE THEIR COLLECTIVE INTERESTS , ACKNOWLEDGING THEIR UNIQUE EXPERIENCE AND EXPERTISE AS PwMS AND CO-DECIDERS IN THEIR CARE

#### STRATEGIC GOAL IV

TO ENCOURAGE THE MS RESEARCH AGENDA AT EUROPEAN LEVEL AND PROMOTE EUROPEAN DATA COLLECTION AND COMPARISON THAT PUTS PATIENTS AT THE CENTRE AND PROVIDES THE EVIDENCE BASE FOR ADVANCING MS POLICY AND PRACTICE ACROSS EUROPE.

#### STRATEGIC GOAL V

TO PURSUE EXCELLENCE IN EMSP`S PERFORMANCE AND DELIVERY THROUGH EFFECTIVE MANAGEMENT, ORGANISATIONAL DEVELOPMENT AND EVALUATION OF ITS HUMAN RESOURCES

## Expected outcomes

EMSP`S approach to plan and to evaluate its work is to start with the overall work priorities as outlined under specific objectives for the year as outlined in the Operations Plan:

- FINALIZE THE RESTRUCTURING OF THE SECRETARIAT TO RESPOND TO NEW EMSP PRIORITIES AND GOALS / Key Operational Activity contributing to this objective is the Recruitment of a CEO and negotiation with all other staff members on the new distribution of tasks, following good practice in HR. External recruitment service will find the right CEO, based on a needs assessment and job description done by the ExCom. Expected results are new contracts, a better balance of tasks and capacities and ultimately a well structured, sufficiently staffed and smooth running Secretariat.

- STRENGTHENING VISIBILITY OF EMSP THROUGH INCREASED PARTNERSHIPS, EFFECTIVE ADVOCACY AND PROACTIVE POLICY SETTING /Key Operational Activities contributing to this objective are

1) A Sponsor Networking Dinner in which all corporate sponsors are coming together for an update on EMSP operations plan, actions and initiatives. Expected result is a better mutual understanding of working priorities and overlapping or diverging interests, resulting also in better and wider funded projects.

2) A Pre-launch of our UNDER PRESSURE photo exhibition at the key awareness event of our UK member organisation in Manchester. Method are the translation of known inequalities (indicated repeatedly by our MS BAROMETER) into photo-journalistic messages, main target group is the general public and expected result is a higher

media interest in Multiple Sclerosis issues.

3) A MS Awareness Day in the European Parliament on the issue of inequalities in access to treatments, care and other services for MS patients in Europe. Method: UNDER PRESSURE-poster exhibition, short expert speeches and testimonies by MS patients. Expected result is a number of highly newsworthy findings for the participating European and national media on increased rather than decreased discrepancies in health care in Europe.

4) Facilitation of a meeting between neurologists (members of national medical advisory boards) and EMSP ExCom as European body being responsible for patient advocacy on European level with more or less strong impact and participation of national level. Method: short PPPs to EMSP activities, followed by discussion. Expected results are better mutual understanding on overlapping and diverging interests and closer cooperation between national and European level.

5) Dissemination of Annual Report 2011 will improve visibility of EMSP, Multiple Sclerosis and national MS Societies together with a better understanding of their needs.

- INCREASED INVOLVEMENT OF PATIENTS` AS EVIDENCE BASE /Key Operational Activities contributing to this objective are

1) the pilot run of a European MS Nurse training course, being the start of an hopefully sustainable approach for more harmonisation in the training and continued education of MS Nurses as key partner for MS patients and their families. The pilot training in Malta and in Spain will be the provisional climax of a project developing such core training module for several months, based on a needs assessment though a survey in 2009 among more than 200 MS Nurses in six EU countries. Expected results: Better services for PwMS, better adherence to the prescribed therapies by PwMS, better knowledge on the unmet needs of PwMS for the development of therapies and services being of greater relevance for PwMS.

2) Launch of the MS Nursing Consensus Paper at RIMS Annual Conference in Hamburg: In relation to the earlier description of the training course for MS Nurse in development a parallel activity is the creation of an EUROPEAN CONSENSUS PAPER ON MS NURSING through a group of experts with wide consultation and (hopefully) approval in all EMSP member countries. Expected result is the same as in point 1: European MS Nurse training course.

3) regular involvement of MS patients and patient advocates in EMA activities through the Working Party for Patients and Consumer Organisations as well as through testimonials in Scientific Advisory Groups. Expected result: EMA services and decisions reflecting the needs of the patients as end -users of drugs being approved / not approved by EMA.

- MEMBERSHIP CONSOLIDATION AND DEVELOPMENT/Key Operational Activities contributing to this objective are

1) Mediation for two member organisations in Greece though visit and discussion with ExCom members. Expected result: closer cooperation or ultimately merge of the two MS organisations in Greece.

2) COUNCIL MEETING (General Assembly) with update on all current projects and activities and the discussion of the relevance for the individual member organisation and/or PwMS.

3) Capacity Building for CEE member organisations and exchange of good practice within and outside of EMSP membership - a two days event probably in Serbia as part of a series of similar gatherings of ca. 50 representatives and multipliers from member organisations. Expected results better sustainability of member finances as

base for their successful patient support work and improved practical know how on running such work.

- IMPROVED COMMUNICATIONS STRATEGY/Key Operational Activities contributing to this objective are

1) the more regular and more detailed newsletters to members and supporter plus interested stakeholders, the ongoing improvements on the websites (one general website, several ones for projects) and the increased use of Social Media to spread information and obtain feed back especially to/from YPwMS.

2) the booth at ECTRIMS, the biggest conference and exhibition event of MS medical experts and industry in Europe, with EMSP material and EMSP staff answering questions.

- ENSURE FINANCIAL SUSTAINABILITY OF THE ASSOCIATION/Key Operational Activities contributing to this objective are

1) the installation of a better collaboration by persons in charge for accounting, bookkeeping, VAT advice and auditing of EMSP finances (both external and internal): Expected results will be better correlation between quarterly finance reports and ExCom meetings as forum for discussion of those reports as well as better timed interventions in case of cash flow problems or even the threat of under-funding of projects.

2) ongoing networking with donors, potential donors and other stakeholders: Expected results are higher credibility of EMSP as serious project partner and better understanding of expectations, needs and opportunities.

## COORDINATOR



The European Multiple Sclerosis Platform Aisbl - EMSP (The European Multiple Sclerosis Platform Aisbl - EMSP)

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## PARTNERS

No partners related to the current project

## D01 - EMSP Website

The European Multiple Sclerosis Platform Aisbl - EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)  
Published on: 01/01/2012

## D02 - EMSP publications

The European Multiple Sclerosis Platform Aisbl - EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)  
Published on: 01/01/2012

## D03 - Follow up on EP Resolution on Persons with Multiple Sclerosis (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)  
Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d03-00\\_en\\_ps.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d03-00_en_ps.pdf)

## D04 - EMSP Annual Report 2011 (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)  
Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d04-00\\_en\\_ps.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d04-00_en_ps.pdf)

## D05 - European Consensus Paper on MS Nursing (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)  
Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d05-00\\_en\\_ps.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d05-00_en_ps.pdf)



## D06 - Report on Capacity building event for CEE countries/members (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP

The European Multiple Sclerosis Platform (EMSP\_FY2012)

Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d06-00\\_en\\_ps.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d06-00_en_ps.pdf)

## D07-01 - Final technical and financial report for EAHC (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP

The European Multiple Sclerosis Platform (EMSP\_FY2012)

Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d07-01\\_en\\_is\\_final\\_technical\\_report.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d07-01_en_is_final_technical_report.pdf)

## D07-02 - Final technical and financial report for EAHC (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP

The European Multiple Sclerosis Platform (EMSP\_FY2012)

Published on: 01/01/2012

[http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304\\_d07-02\\_en\\_is\\_final\\_financial\\_report.pdf](http://azorina.cc.cec.eu.int:8082/publications/20113304/20113304_d07-02_en_is_final_financial_report.pdf)

## D08 - EMSP Web Alert (EN)

The European Multiple Sclerosis Platform Aisbl - EMSP

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