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# The European Multiple Sclerosis Platform Work Plan 2009

JA2015 - GPSD [705038]

START DATE: 01/01/2009

END DATE: 01/01/2010

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-2008)

TOPIC: Exchange knowledge and best practice

EC CONTRIBUTION: 100000 EUR

KEYWORDS: Multiple sclerosis

PORTFOLIO: Major and chronic diseases

## Mission and vision of the operating grant holder

Multiple Sclerosis (MS) is an unpredictable and progressive disease of the central nervous system affecting the quality of life of more than 500.000 Persons with MS, their families and their carers across Europe. To date, no cure has been found for this complex, chronic and disabling condition.

The European Multiple Sclerosis Platform (EMSP) is the Pan European association working for and with more than 30 MS national member associations / organisations to achieve its goals. Being part of a worldwide community of Persons with MS (PwMS), we are committed to dialogue with, respect for and collaboration with other stakeholders in the field of MS, particularly the Multiple Sclerosis International Federation (MSIF).

### Our Vision

Throughout Europe, Persons with MS have equal access to the highest quality treatment and support they need to live their lives to the full.

### Our Mission

...is to ensure the development and implementation of high quality standards of treatment and support for PwMS, their families and their carers throughout Europe, to allow them to lead their life independently and to recognise them as equal members of society.

The 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
- to network with other European organizations in which the patient is central
- to provide MS member associations with information on relevant EU draft legislation and projects
- to develop and promote recommendations for improved medical treatment and rehabilitation to be implemented in the EU member states and other countries
- to encourage research of all kinds aiming at the benefit of PwMS
- to initiate and implement cross-border projects to improve the living conditions of PwMS, e.g. in the fields of therapies, employment, social security, infrastructure...
- to act as an information platform by exchanging information and best practices relevant to the work of the national MS member associations
- to enhance a general awareness on multiple sclerosis by informing and educating external audiences
- to support national MS societies both recent or long-established in Europe

## Strategic objectives and specific activities

### STRATEGIC GOAL I: EQUAL ACCESS TO THE BEST QUALITY HEALTHCARE AND SERVICES IN EUROPE FOR PwMS, THEIR FAMILIES AND THEIR CARERS

- to develop and promote recommendations for improved medical treatments and rehabilitation to be implemented in the EU member states and other countries
- to encourage research of all kinds aiming at the benefit of PwMS
- to enhance a general awareness on multiple sclerosis by informing and educating external audiences

### STRATEGIC GOAL II: STRENGTHENING THE LEGITIMACY AND EFFECTIVENESS OF EMSP AS THE EUROPEAN VOICE OF PwMS

- to initiate and implement transnational projects to improve the living conditions of PwMS, e.g. in the fields of therapies, employment, social security, health infrastructure...
- to act as an information platform by exchanging information and best practices relevant to the work of the national MS member associations
- to support national MS societies in accordance to their needs

### STRATEGIC GOAL III: EMPOWERMENT of PwMS

- to influence EU institutions and other decision-making bodies to improve the quality of life of PwMS
- To encourage patient- centred healthcare policy and delivery of direct benefit to PwMS
- to network with other European organizations promoting patient- centred healthcare

## Expected outcomes

At the end of 2009, we expect to have achieved internally:

- an increased awareness and understanding among our more than 30 national member organisations of the necessity to combine patient advocacy work on national and European level (and for some issues even on worldwide level)
- an increased level on skills and knowledge within EMSP and its membership on realistic and effective ways forward towards a better quality of life for the PwMS in

## Europe

- an increased understanding among ExCom and staff of EMSP on the needs, expectations and real problems of our member organisations and their members, the PwMS, care givers and families
- a sustainable financial framework guaranteeing the continuation of the work of EMSP in 2010 and beyond

### externally:

- an increased awareness and understanding among the national Ministries of Health, Ministries for Social Affairs, HTA bodies, health insurance systems and health care professionals on the needs of PwMS ensuring a better quality of their life, of the currently existing gaps and discrepancies in healthcare, but also of the existing tools and opportunities to improve this discriminatory situation of health care inequalities. Realistically, we can be satisfied if such increased awareness and understanding can be achieved in those countries, in which "High Level National Roundtables " will be organised in close cooperation between the national MS Society and EMSP.
- a few CONCRETE improvements in access to and/or quality of healthcare measures in a few countries in Europe
- another two examples of "Good Practice" in healthcare development on European level (update of the "European Guideline on Rehabilitation in MS" and development of a draft European Consensus Paper "Juvenile MS")

## COORDINATOR



European Multiple Sclerosis Platform (European Multiple Sclerosis Platform)

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## PARTNERS

No partners related to the current project

## D01-01 - Annual Report 2008 (EN)

European Multiple Sclerosis Platform

The European Multiple Sclerosis Platform Work Plan 2009 (EMSP Work Plan 2009)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372\\_d01-01\\_en\\_ps.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372_d01-01_en_ps.pdf)

## D01-02 - Pocket Guide (EN)

European Multiple Sclerosis Platform

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## D01-03 - Romania Roundtable on the EU Code of Practice on MS (EN)

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## D02-01 - EMSP Annual Congress

European Multiple Sclerosis Platform

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## D02-02 - MS-ID Consensus Meeting on May

## 14, 2009 (EN)

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## D02-03 - People with MS Do Not Have the Most Advanced Drugs Available (EN)

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## D02-04 - Topicalities of the Multiple Sclerosis (EN)

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## D02-05 - EMSP Seminar (EN)

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## D03-01 - EMSP Interim Report (EN)

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## D04 - Final technical and financial Report Operating Grant (EN)

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[http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372\\_d04-00\\_en\\_is.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372_d04-00_en_is.pdf)

## Final Report

European Multiple Sclerosis Platform

The European Multiple Sclerosis Platform Work Plan 2009 (EMSP Work Plan 2009)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372\\_ffr\\_en\\_is.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083372/20083372_ffr_en_is.pdf)