



## Multiple Sclerosis – Information Dividend (MS-ID) Project to be Co-funded by the European Commission

Fourteen months of intensive preparation work by the European Multiple Sclerosis Platform and its six project partners finally lead to approval of the project.

DOI:10.17925/ENR.2007.00.01.21

As the title of the project suggests, Multiple Sclerosis – Information Dividend (MS-ID) concerns information about multiple sclerosis (MS) and the benefits to be gained from such information. In Europe, very limited data are gathered about MS, its incidence, who is affected by it, who is taking which drugs as treatment, how MS impacts on the lives of people who are diagnosed, the implication for their participation in the labour market and what additional supports the state provides and needs to provide. However, in order to better understand the impact of MS, we have to know the effects it has on society in general.

### What Is the Multiple Sclerosis – Information Dividend Project?

In essence, the MS-ID project consists of two priorities:

1. The development and piloting of a European register on MS. This register will gather data on people with MS from organisations participating in the project. The advantage of developing this tool on a European level means that the information will be comparative across borders. For example, one can assert that a treatment accessed by 40% of those with MS in one country may only be accessed by 5% of the MS population in another country. Without this information, no light can be shed on the situation of people with MS in Europe.
2. Activation of the European Code of Good Practice in MS across the participating organisations, with eventual roll-out to all European MS Platform (EMSP) members.

### Who Is Involved?

The EMSP is leading the MS-ID project, with active participation from six national societies in Germany, Iceland, Poland, Romania, Spain and the UK. The remainder of the EMSP membership base also contributes to the promotion and distribution of the project's results.

### What Are We Seeking to Achieve?

The MS-ID project is seeking to:

- raise awareness across the EU about MS, enabling stakeholders both at European level and in the Member States to better understand the condition and share information on the positive impact of early diagnosis coupled with high-quality treatments, choice of therapies, sufficient social support and the benefits of good MS management;
- identify and address the major inequalities in MS treatment and care across the EU and within Member States through the development of new and effective strategies and indicators to measure performance; this will enhance the quality, comparability,

applicability and transfer of statistical and factual data and qualitative information on MS across EU Member States; and

- use high-quality comparable data at EU and trans-national levels to positively impact on EU/national MS policy and programmes; ultimately, this will empower those EU citizens directly and indirectly affected by MS.

In short, the MS-ID project is aiming for an improved, better managed and more equitable approach to the treatment of MS in Europe, enabling people with MS to contribute to and participate rightfully as full and equal citizens in society. ■

### Conference Review

**EMSP Conference**  
29–30 May 2007  
Brussels, Belgium

Arising from the MS-ID project, this conference addressed a range of salient subjects, including the cost of illness, the role of national MS associations in implementing the Code of Good Practice and the promotion of the principles of quality of life. The following key messages emerged from discussions:

1. The cost of diagnosis and treatment of MS at the earliest possible stage (but definitely within the window of the first five years of the disease) can be offset by the reduction of societal costs in the long term, with considerable gains in quality of life for the MS sufferer at the same time.
2. An MS-specific economic model needs to be developed, which should be fed with data from all European countries in order to gather hard evidence and back-up what existing studies are suggesting. The MS-ID project will be a critical vehicle for advancing in the right direction.
3. The immediate implementation and use of the Code of Good Practice in MS on a national level – as specified by the European Parliament and as recommended and explicitly endorsed by Ulla Schmidt, Health Minister of the Federal Republic of Germany and Chairwoman of the EU Health Council – will help to overcome the current inequalities in access to therapies, care and services for people with MS.

For further information visit [www.ms-in-europe.org](http://www.ms-in-europe.org)

