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EMSP Policy Report 2014

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EMSP's policy priorities in 2014 were centred on a dual approach: on the one hand – creating the link between European health policy and the deliverables of our flagship projects, and on the other – supporting the work of the European Patients' Forum (EPF), in our capacity as founding members.

Acting on the recognition fact that healthcare decisions need data support, EMSP has concluded its EUREMS project which created a model of efficient cross-border MS data pooling. We have also tackled the demand for improved care standards through our MS Nurse Pro project which offers a harmonised, evidence-based training programme for MS nurses. We have continued our work on the topic of tackling health inequalities from the patients' perspective, and this is where the MS Barometer and Under Pressure projects provide examples of good practice, and an original approach to telling the stories of people living with MS in Europe. In addition, we have recognised the urgent need to create better employment opportunities for people with disabilities, which is what our Believe and Achieve project is doing for young people with MS.

EMSP realised many years ago that only a powerful European patient voice can stimulate tangible change in health policies. Consequently, we have used our status within EPF to promote joint activities and regular contributions to policy discussions. In this regard, we stand by the view shared recently by another EPF founding member, the European Men's Health Forum:

“EPF has not subsumed the role of other voluntary organisations but rather augmented and facilitated their work. The net result is a strong, independent, influential overarching voice combined with an enhanced input at the National and local level. It is impossible to overstate the effect this has had on policy makers and thus potentially on the lives of people we represent.”

[Ian Banks, European Men's Health Forum]

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“EMSP realised many years ago that only a powerful European patient voice can stimulate tangible change in health policies.”

[Christoph Thalheim, European Multiple Sclerosis Platform]

EMSP has worked together with EPF on complex dossiers such as clinical trials (European Medicines Agency), medical devices (medical technology industry – EUCOMED) and data protection (European Parliament).

Inspired by a request for help from a French person with MS living in Germany but compelled to travel to France regularly to obtain treatment, we encouraged our members to participate in one of the four regional conferences of EPF on the Cross-Border Healthcare Directive of the EC. The European Commission will assess the implementation of the Directive in Member States in 2015 and we will ensure that it integrates the “grassroots” patients’ experience across the EU.

In a separate initiative, EMSP continued to play an important part in creating an effective and sustainable network for health technology assessment (HTA) across Europe – the EUnetHTA Project. After its successful completion, a new collaboration emerged in the form of a Joint Action to implement the findings. EMSP is part of the Stakeholder Forum representing patients among the four stakeholder groups