

## Setting new standards in multiple sclerosis care and research

In the run up to the 2012 European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) meeting in Lyon, France, two important new multiple sclerosis (MS) initiatives are making progress. The International Collaborative on Progressive MS published its agenda of research priorities in late August, while the European MS Platform (EMSP) is due to roll out the next stage of MS Nurse Professional (MS Nurse PRO), a programme to standardise training for MS nurses across Europe, in Barcelona, Spain, at the end of September. Despite taking very different approaches, these initiatives have the potential to benefit many of the estimated 2.5 million people worldwide who have MS.

About 10–15% of people with MS present with primary progressive disease and 80% of the rest develop secondary progressive MS within 20 years. But, despite relative success in the development of treatments for relapsing-remitting MS, the options for people with progressive MS remain limited and a breakthrough is desperately needed. The International Collaborative on Progressive MS, a group of researchers and representatives of MS patient societies from Europe and North America, has the ultimate goal of expediting the development of disease-modifying and symptomatic treatments. In its research agenda, the Collaborative outlines five priority areas for research: experimental models, identification and validation of therapeutic targets, strategies for proof-of-concept clinical trials, clinical outcome measures, and symptom management and rehabilitation. Working groups are now looking at how to overcome the barriers to progress in these areas, and a call to the wider MS research community to collaborate on ongoing and new projects to address these challenges is planned for 2013.

Meanwhile, MS Nurse PRO is being developed to improve care for people in Europe with MS of all types. Specialist MS nurses can be an important point of contact for patients from diagnosis onwards, and they can enable neurologists to devote more time to the patients who need it most and to research. However, in 2010, the MS-Nurse Empowering Education (MS-NEED) survey led by the EMSP identified substantial variability across Europe in the roles and training of MS nurses and in the quality and availability of nursing care. To address these disparities and provide formal recognition for MS nurses, the EMSP has developed MS Nurse PRO with input from

the European Rehabilitation in MS (RIMS) network and the International Organization of Multiple Sclerosis Nurses (IOMSN), which already provides international training for MS nurses. MS Nurse PRO will be based on five core modules: epidemiology and pathophysiology, clinical presentation, diagnosis and assessment, management of MS, and patient care and support. Despite the desire for standardisation, the training will accommodate national differences in the availability of drugs and the needs of employers of MS nurses, which can include charities, health-care providers, and pharmaceutical companies. The scheme has already run a pilot in Malta, and the Spanish launch will be the first test in a language other than English; MS Nurse PRO should also be available in German, Italian, and Czech by the end of 2012 and rolled out to other European countries from 2013 onwards.

Collaboration between organisations in different countries will be crucial for both projects. Large multicentre studies will be needed to overcome at least some of the barriers identified by the International Collaborative on Progressive MS, and any eventual recommendations, such as for outcome measures and trial design, will need to be recognised and implemented internationally if they are to lead to further progress. The MS Nurse PRO curriculum is accredited by the UK Royal College of Nursing, but similar endorsement in other countries will be needed if the programme is to become a standard qualification across Europe. The results from Malta and Spain, a planned consensus paper, and a written declaration in the European Parliament calling for recognition in member states should raise awareness. Funding will also be needed to sustain MS Nurse PRO beyond the development phase, which is being supported by a pharmaceutical company. For the International Collaborative on Progressive MS, member societies and government, corporate, and private organisations have been identified as potential sources of financial support.

More information should be available on both initiatives at ECTRIMS: from the Multiple Sclerosis International Federation, one of the societies behind the International Collaborative on Progressive MS, and from the EMSP. With enough funding and collaborative will, these initiatives could be important opportunities to improve the lives of thousands of people, and we look forward to following their progress. ■ *The Lancet Neurology*

For more on **ECTRIMS** see <http://www.congrex.ch/ectrims2012.html>

For the **progressive MS research agenda** see *Mult Scler* 2012; published online Aug 23. DOI: 10.1177/1352458512458169

For more on the **EMSP** see <http://www.emsp.org/>

For more on **MS Nurse PRO** see [http://www.mstrust.org.uk/professionals/information/wayahead/articles/16032012\\_06.jsp](http://www.mstrust.org.uk/professionals/information/wayahead/articles/16032012_06.jsp)

For more on **neurological specialist nurses** see *InContext Lancet Neurol* 2012; **11**: 210–11

For the **MS-NEED results** see *Eur Neurol Rev* 2011; **6**: 106–09

For more on the **IOMSN** see <http://www.iomsn.org/>