

## 2014 Joint ACTRIMS-ECTRIMS Meeting

### EMSP Highlights Report

For us at the European Multiple Sclerosis Platform (EMSP), medical congresses are one of the highlights of our calendar and this year's [joint ACTRIMS-ECTRIMS congress](#) held in Boston was no exception. Congresses enable healthcare professionals and researchers to share the latest clinical updates and scientific breakthroughs; however we know that not everyone is always able to attend to hear first-hand. In this special report we provide you with a snapshot of the latest research, news and social media activity from the congress.



International conferences are a good way to find out more about research going on around the world to help those with MS. Below are some brief highlights from announcements, with longer summaries of key sessions on the next page.

### Highlights In Brief

#### **The Progressive MS Research Alliance**

As part of a global push to find treatments for progressive MS, the *International Progressive MS Alliance* announced funding for 22 new research projects. The projects, which caused a lot of excitement at MSBoston2014, will bring MS Societies from all around the world together to help fund research and therapies for people with progressive MS. The global funding will speed up research into the condition, as scientists will be able to share knowledge and avoid duplicating work.

#### **Five-Nation Survey**

Biogen Idec announced the results of its international survey, developed in partnership with the Consortium of MS Centers, which showed differences in the perceptions of MS patients and neurologists when discussing symptoms. While overall the results suggest a positive assessment of current practice in MS, important gaps were identified that could potentially impact disease management and patient quality of life, with one in five patients saying they were uncomfortable talking about their symptoms with their doctor.

#### **Patients as partners in clinical research, does the internet help or not?**

Dr Paul Wicks, Vice President of Innovation at PatientsLikeMe, presented on how use of the internet by patients has evolved and enabled them to become more aware of their own condition on matters such as self-management and involvement in clinical trials. The widespread use of smartphones and apps may also provide new channels to assess the efficacy of treatments by increasing the possibility of recording patient reported outcomes. You can view a summary video of the session [here](#).

#### MSBOSTON 2014 in Numbers

**7,000 attendees**



**...from 90 countries around the world**



**183 talks**



**981 poster presentations**

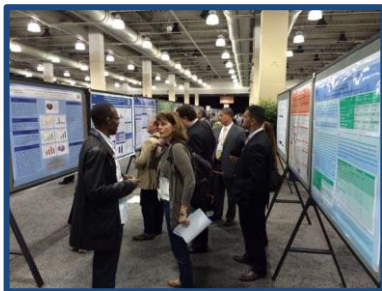


## Summary of Key Presentations

### ***Effects of Comorbid Disease and Health Behaviours on MS Susceptibility and Prognosis***

***Dr Ruth Ann Marrie - Associate Professor, Department of Internal Medicine (Neurology) and Community Health Science, University of Manitoba, Canada***

Dr. Ruth Ann Marrie is the lead on a MS comorbidities project launched by the *International Advisory Committee on Clinical Trials in Multiple Sclerosis*. The project aims to understand research priorities and needs for those with MS and how they relate to comorbidities (co-existing health conditions) and health behaviours. Dr Marrie presented on how many factors can affect a person's chance of developing MS; for example, those who smoke from a young age are three times more likely to develop MS and those who are overweight are 4 times more likely to develop the condition. High cholesterol, hypertension, diabetes are also risk factors for developing MS, and tend to cause faster progression of the disease. Mental health issues are common, with 50% of MS patients suffering from depression, and 35% from anxiety.



### ***Cognitive Impairment***

***Prof. Maria Pia Amato, Associate Professor of Neurology, University of Florence, Italy***

Prof. Maria Pia Amato presented on the importance of behavioural interventions for cognitive impairment and shared the insight that the more specific and targeted the interventions are, the better the response. Whilst cognitive impairment is common amongst people with MS (45%), medical therapies are limited, but cognitive re-training, using computer programmes such as Robo Com, have been found to help improve memory span and working memory. Other behavioural interventions using modified story techniques for multiple sessions over several weeks has also been shown to be helpful. Games, puzzles and word searches can all be used with people with MS to help keep their mind active, as well as computers and smart phones. These behaviour interventions can help to improve fatigue, depression, activities of daily living and attention.

### ***Parents' Experience of Paediatric Multiple Sclerosis***

***Dr David Rintell – Psychologist, Partners MS Center, Brigham & Women's Hospital in Boston, USA***

A study to describe the experience of parents of children with MS under 18 years found that, understandably, parents have a strong reaction to their child's diagnosis of MS and are deeply affected by living with MS over time. However, they can also have very different views and experiences compared with that of their child. For example, parents were more concerned about long term planning and future, whilst the children were more concerned with the day-to-day activities. It was concluded that parents need support to manage family issues while negotiating treatment and care with their child. Management should focus not only on the patient, but on supporting the family unit.

## #MSBoston2014: Social Media and the Congress

facebook

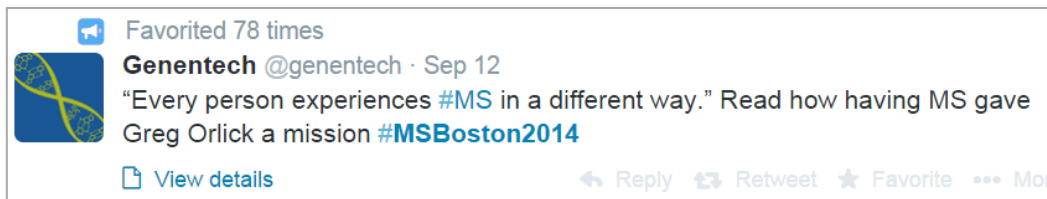


The advent of social media allows delegates to share live updates and continue conversation beyond the confines of the congress hall. We at the EMSP have been early adopters of social media and firmly believe in its power as a medium of communication and are excited to see social media use amongst the medical community growing so rapidly. This year engagement during ACTRIMS-ECTRIMS 2014 surpassed previous years and the official #MSBoston2014 hashtag registered some impressive statistics:<sup>1</sup>

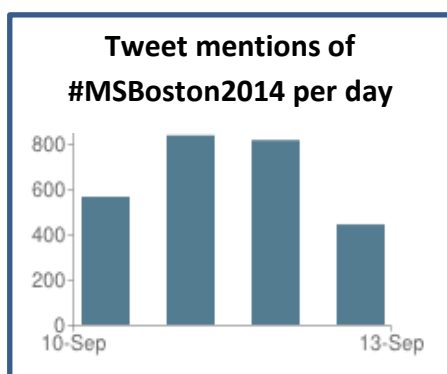
### Twitter:

- **7 million** estimated impressions
- **2,792** mentions of #MSBoston2014 on Twitter by **653** users during the event
- **698** Tweets on average per day
- **29** Tweets on average per hour
- The most tweets were from users in the USA, followed by the Netherlands, Spain, the UK, Canada and then Switzerland

### Most Popular #MSBoston2014 Tweet:



Click [here](#) to read Greg Orlick's Story, along with those who were following #MSBoston2014



Social Media was also used in other forms to convey information to key stakeholders at MSBoston 2014, such as the Q&A session between EMSP and Novartis on twitter using the hash tag #4patients, and the [MS Trust Blog](#) which provided live updates each day. The blog was an innovative way to keep followers up to date on the latest news, even if they were unable to attend.

<sup>1</sup> Source: Sysomos (English Language) Search terms: #MSBoston201. Analytics run from 10 – 13 September 2014

## EMSP at MSBOSTON 2014

The Joint ACTRIMS-ECTRIMS Meeting was an important opportunity for us to share information with the medical community and it was great to see that MS patients and advocates had an increased presence at the meeting.

The main highlights for us were a dissemination event on the 11<sup>th</sup> and 12<sup>th</sup> September and two poster presentations for the [EMSP's European Register for Multiple Sclerosis \(EUREMS\)](#), which were presented by scientists involved with the project from the start.



EUREMS, launched in 2011 and run by a consortium of academic institutions and NGOs, addresses the lack of data at EU and national level on treatment and care for people with MS. When concluded, at the end of 2014, EUREMS will help all relevant stakeholders in Europe better understand the nature and impact of MS, and shape research and policy action towards improving the quality of life of those affected.

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## MS Nurse PROfessional

Coinciding with the Joint ACTRIMS-ECTRIMS Meeting, we took the opportunity to announce that 1,500 multiple sclerosis nurses have now enrolled for the ground-breaking online tool, MS Nurse PROfessional, since its launch in 2012.



The first CME-accredited educational programme is designed to standardise care for people with multiple sclerosis across Europe and is currently available in four languages (English, Spanish, Czech and Italian).

To find out more or register for the course, visit: <http://www.msnursepro.org/>

*This activity is supported by educational grants from founding and lead support Novartis and co-supporters Biogen Idec, Genzyme, Teva and Bayer HealthCare*