



## MISSED THE LATEST ECTRIMS CONGRESS?

For us at the European Multiple Sclerosis Platform (EMSP), ECTRIMS 2015 is one of our calendar highlights. Congresses enable the most up-to-date clinical updates and scientific breakthroughs to be shared as soon as they happen.

However we know that not everyone is always able to attend to hear firsthand. In this special report we provide you with a snapshot of the latest news and social media activity from the congress, as well as an update on our online training tool MS Nurse PRO*fessional*.

Read on and please feel free to share this newsletter more widely!

# ECTRIMS CONGRESS 2015

EMSP Highlights Report



### **SESSION HIGHLIGHTS**

Our roving reporters at EMSP attended as many of the sessions as they could at ECTRIMS. Please find below a summary of those we found of most interest for nurses. Full abstracts and information can all be found online.

## Nurses' Session 1 – Living with MS: Challenges for patients (and nurses)

#### Management of psychosocial adjustment among people with MS - S.Guerra (Barcelona)

As we are all aware, accepting a diagnosis of multiple sclerosis and adapting to the unpredictability of the disease can be overwhelming. As such Sevilla Guerra wanted to look at the psychological interventions that could be carried out by nurses to have a positive impact. Amongst others, the interventions that had the largest benefit for people with MS with low mood included cognitive behavioural and expressive group therapy and should be explored further. The researcher made special note that nurses are key to supporting the management of emotions in patients.

#### Sexuality in patients with Multiple Sclerosis – M.C. Petersen (Copenhagen)

The aims for this study were twofold. Firstly to review the information that is currently provided to people with MS about sexuality for suitability and secondly to understand what information patients would like to receive to support existing relationships and their sexuality. Each of these aims were explored using different methodologies – the first through a socio-demographic questionnaire and the second through focus group interviews. Full results are being shared at a later date, but preliminary findings include that more training is needed to provide optimum information on sexuality. Furthermore any information should be adapted to the person's age and treatment pathway.

#### MS compliance, how to motivate patients – R. Haugstad (Bergen)

Randi Haugstad and researchers presented the results from a Norweigen study looking at motivational factors that impact on people with MS using disease modifying treatment (DMT). Especially the use of techniques such as shared decision making and motivational interviews. The study found that amongst people with MS, support for using DMT is determined by health-related quality of life. Those with high scores on physical health and low on mental health were less motivated to use DMTs. Although more research is needed the study concluded that an understanding of disease-related stress, age at diagnosis and education level should be considered when developing motivational adherence strategies for people with MS.







### Nurses' Session 1 – Patient involvement

#### Understanding patient activation – H. Gilburt (London)

The focus of Helen Gilburt's research was to understand how you can use a patient activation measure – in this case a self-completed questionnaire measuring how much people know about MS and how skilled they feel – to improve MS outcomes. Like all researchers, they wanted people to take an active role in their health and make informed decisions. Once they had taken the questionnaire people with MS were classified within four levels: starting to take a role, building knowledge and skills, taking action, maintaining behaviours.

Interestingly the results revealed that people with relapsing and remitting MS in current employment are much more activated than others, however many more people don't understand the role they can play in managing their own health. Also some clinical approaches may be ineffective or overwhelm some patients – so a one size fits all approach to healthcare delivery may be limited in effectiveness and cost-effectiveness.

Importantly the role of healthcare professionals in supporting patients to make changes is as important as diagnosis and delivering the treatment itself. And the interventions must be tailored to benefit those with different levels of activation to maximise outcome and cost.

#### How technology can help improve MS care - B. Porter (London)

This short session provided a top line review of the importance of technology and asked the question 'as a community are we on the right track'. Although a further review is ongoing, the conclusion was that although of care via digital communication platforms is of great interest across the globe, currently there are no tailor-made solutions for MS and new models are needed.







## #ECTRIMS2015 – Social media and the congress

Like yourselves, we at the EMSP are big fans of social media and fully believe it is a great way to stay in touch and communicate with our wider network. However over recent years social media channels, particular Twitter, have been used more and more for communicating key clinical updates as well, especially at congresses. Like other large-scale congresses, ECTRIMS was no exception with a staggering **6,873 Tweets** sent out using the special congress hashtag #ECTRIMS 2015.

Twitter use over congresses is becoming a valuable tool for healthcare professionals, nurses and the general public to keep up to date with the latest announcements without attending in person. We provide a snapshot of the activity below, and for next year we strongly recommend you go online and check it out yourself!

If you have more time also check out some other blogs about ECTRIMS from around the globe:

- Canada http://drkarenlee.ca/encouraging-results-presented-at-ectrims-late-breaking-news-session/
- Italy <u>http://www.aism.it/index.aspx?codpage=2015\_10\_ricerca\_fism\_ectrims</u>
- UK <u>https://www.mssociety.org.uk/ms-news/2015/10/first-phase-three-trial-show-positive-results-primary-progressive-ms</u>



#### Top 10 by Mentions Top 10 by Tweets @mssociety 6 @congrex 5 CTRIMS @ectrims 4 @jennarraway 3 MŞ @mstrust 3 @mswebnl 2 @jeroenjggeurts 3 @suzannemrobins 2 @dr\_karenlee 3 @dr\_karenlee 2 @suzannemrobins 2 @curemsutahidaho 1 @ms saudi org 2 @bikemsutah 1 @uib 1 @segovma1 1 @drbarrysinger 1 @florencedolivo 1 @marmendibe 1 @nancydekens 1

## 6,873 tweets ral - Up from 2,792 last year

# Generating 15.3 million impressions

TWITTER

8-10 OCTOBER

## 1,704 tweets per day

That's 71 tweets an hour

# Top countries tweeting include:

- Spain
- USA
- Switzerland
- UK
- Canada
- Netherlands

## The influencers of #ECTRIMS2015



## MS Nurse PROfessional at ECTRIMS 2015

As ECTRIMS is such a big milestone in the MS calendar, we always like to use the opportunity to raise the profile of our online nurse educational tool MS Nurse PROfessional and engage with MS nurses to provide more information. We are delighted to share two of the activities we undertook this year with you.

To find out more on the course please visit: http://www.msnursepro.org/

### THUNDERCLAP A CROWD SPEAKING PLATFORM

We used the online tool 'Thunderclap' to develop the following pledge for nurses, physicians and people with MS to share on the last day of ECTRIMS, including a link to MS Nurse PRO*fessional*:

"Let's support nurses caring for people with MS through greater access to education. Are you in? #MSNursePRO"

If we received a target of 100 people signing up then our message would be sent out on one date, at the same time, to amplify the reach across social media

Thank you to all those that took part – we had a total of 111 supporters which meant we reached over 148,000 people with our message and drove interest to the site!



## Support for MS Nurses "Let's support nurses caring for people with MS through greater access to education. Are you in? #MSNursePRO http://thndr.it/1Jm367S'

111 of 100 SOCIAL REACH 148,340 TIME LEFT Complete

## **REDESIGN OF PROGRAMME FLYERS**

To introduce nurses to MS Nurse PROfessional, we redesigned our programme flyers to appear as engaging as possible.

Now available as four separate flyers or one large poster, each flyer tells one part of the story, from the history of the programme to how it works and how nurses can access it.

The poster was displayed at our EMSP booth at ECTRIMS and we will be showcasing it at future meetings

We have more flyers available in English, Dutch, French, German and Polish. Please email GlobalAdvocacyMS@ogilvy.com if you would like a copy!



