

How MS societies and EMSP can best work together to change the face of MS in Europe

Aligning the role of the MS Nurse across Europe: MS Nurse *PRO*fessional

What is MS Nurse PROfessional?

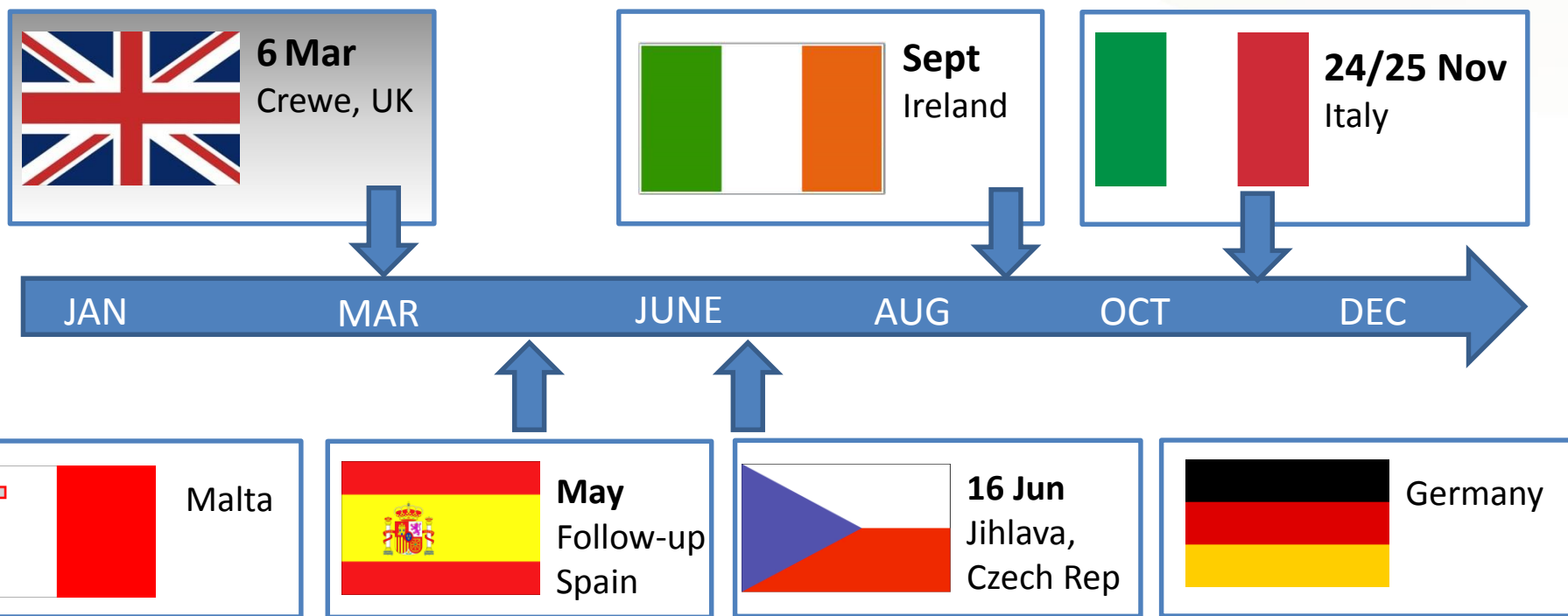
- MS NURSE PROfessional is a new, flexible e-learning training curriculum developed to meet the preliminary educational needs of nurses and other healthcare professionals providing MS care
- Targeted at nurses beginning their career in the field of MS
 - Developed to support nurses in acquiring the right knowledge and skill to be an MS Nurse
- Available in English, German, Italian, Spanish and Czech
- Accredited and endorsed by:



2013 Objectives

- Ensure successful roll-out of the programme based on launch country needs
- Drive uptake of the curriculum through ongoing promotion
- Ensure content of the curriculum is maintained, kept updated and relevant
- Continue to secure the endorsement of Consensus paper among stakeholders on a regional and country based level
- ***Ongoing Long-Term Objective: Engage and mobilise stakeholders to support collaborative steps for standardisation and certification of MS nurses across Europe***

MS Nurse PROfessional 2013 Launch Sequence



Consensus Paper

- Consensus paper to be shared with all EMSP national chapters for endorsement
- Consensus paper to be submitted to Multiple Sclerosis journal for publication in advance of ECTRIMS
 - This will allow us to build momentum for activities at ECTRIMS
- Consensus paper to be submitted to the European Commission for publication for the relevant website

ECTRIMS 2013

- ECTRIMS has confirmed that MS PROfessional will be presented during a plenary session at ECTRIMS on Friday 4th Oct 2013
- The interest in MS PROfessional has generated several major developments and significant interest in MS nursing within the ECTRIMS Scientific committee
 - RIMS has been awarded a grant by ECTRIMS EC for an educational / training programme for all HCPs' (including nurses) on evidence based rehabilitation in MS.
 - MS Nursing will have 2 sessions at ECTRIMS for the first time ever. This is an historic event for MS Nursing in Europe
- These sessions will take place in a regular session room the congress centre. The only session that will run in parallel is the young investigators session

Written Declaration

WD No. 20 - More than a signature



Estimated 600,000 Europeans suffer from Multiple Sclerosis (MS) - as many as people living in cities like Frankfurt or Posnan. MS is the most frequent neurodegenerative disease in Europe and most people are diagnosed in the prime of their working lives. MS costs Europe 15 billion Euro per year - 36.000 Euro per patient.

It makes a huge difference whether people with MS live in Frankfurt or Posnan, in Paris or Prague. It influences whether they are entitled to disease-modifying treatments; the quality of care; and whether they can stay productive at work.

Written Declaration no. 20 on Multiple Sclerosis calls on the member states to enhance equal access to quality care, foresee specialised nursing training and elaborate national registers to better

document the impacts of MS. It calls on the Commission and Council to elaborate a research agenda for even more effective treatments.

Petru Luhan, MEP, initiator of WD no.20 on Multiple Sclerosis:
Main reasons why you should sign WD No.20:

1. Recent studies show that at least 30% of MS patients loose adherence to their recommended therapies¹ accepting the risk of new disease related disability. Specialised educated MS-nursing was able to improve the capacity for a shared decision making in people with MS, thus reducing therapy discontinuation rates significantly and increasing quality of life measures at the same time². Trained nurses help ensure effective treatment, and herewith also increase return on investment.
2. Half of the people with MS leave the workforce within only three years of diagnosis. Better care prolongs the chances for people to remain productive.
3. The declaration will help prepare the floor for a better acceptance of patient initiatives in countries in which no or little action would be taken otherwise.

63 signatures are still needed - PLEASE SIGN WD NO. 20 DURING THE STRASBOURG PLENARY SESSION BETWEEN 10-13 SEP. - Thank you!

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¹The Global Adherence Project (GAP), a multicenter observational study on adherence to disease-modifying therapies in patients with relapsing-remitting multiple sclerosis. [Eur J Neurol. 2011; Dec; 18(12):169-77.
²Effect of specialised MS-nursing on MS therapy adherence and quality of life parameter. Data from a German MS-Center, Wernsdorf, Saxonia. Dr. W. Köhler, personal communication.

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How can we work together?

- Facilitate discussions with key stakeholders (professional organisations, health attaches, nurse advocates)
- Road test / introduce MS Nurse PRO with a number of key advocates
- Role out of MS nurse online training on national level in 6 countries in 2013 / more to come in 2014
- Identify opportunities to extend the reach of the programme among other healthcare professionals with an interest in MS
- Explore how MS Nurse PROfessional fits with other educational programmes for MS practice
- Endorse consensus paper and translate if necessary

Better together – sharing expertise
and influence to improve access to treatment, care and
employment

