MOVING TOWARDS THE PAN-EUROPEAN UNIFICATION & RECOGNITION OF MS NURSES

Anne Winslow
Vice President, EMSP
The development and increased education of MS Nurses will have a strong direct impact on patient outcomes, along with innovative new treatment options. This may mean the expansion of the MS Nurse role with the MDT.
The Need For MS-Nurses

1. MS Nurses play a **central role** in long-term treatment of MS and provide significant support to persons with MS

2. Positive effect on **coping and compliance**

3. Relieves doctors from excessive workload

4. Relevant for **enhanced treatment adherence**
MS Nursing: Greater Adherence to Medication

Patient Adherence Rates

- MS Nurse: 88% (n=4000)
- Historical: 63% (n=6292)
“The link between **professionalism** and **high standard treatments** impact the QoL of people with MS (PwMS) and their capacity to continue to contribute to society as workers and as citizens is well known.”

“Yet there is **huge disparity** in the way in which people affected by MS are treated across the EU, causing **unacceptable and unnecessary lack of QoL** of MS patients, more in some member States and less in others.”
First and Largest Survey of MS Nurses Across Europe - *Multiple Sclerosis Nurse Empowering EDucation (MS-NEED)*: European Survey
The MS-NEED European Survey

Objectives:

• Understand and raise awareness of the roles of nurses in MS care
• Understand the existing provision of care across Europe
• Identify areas for improvement and best practice and
• Assess the need for comprehensive nurse services across Europe

Published in the *European Neurological Review: Disparities in Nursing of Multiple Sclerosis Patients – Results of a European Nurse Survey*
A Collaborative Effort

- Founded in 1989, EMSP is the umbrella organisation for 38 MS societies from 34 European countries

- RIMS, a network of MS Centres in Europe, was created in 1991, in Milan, Italy. Today RIMS has 40 member Centres throughout Europe

- Founded in 1997, IOMSN is the first and only international organisation focusing solely on the needs and goals of professional nurses, anywhere in the world who care for people with MS

Collaborative effort over the last three and half years
# MS-NEED Steering Committee Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Country</th>
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<tbody>
<tr>
<td>Anne Winslow</td>
<td>Vice President, European MS Platform</td>
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<tr>
<td>Amy Perrin Ross</td>
<td>Past President, International Organization of MS Nurses</td>
<td>USA</td>
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<tr>
<td>Christoph Thalheim</td>
<td>Secretary General, European MS Platform</td>
<td>Belgium</td>
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<td>Director of Projects and Services, Multiple Sclerosis Society</td>
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<td>Nicki Ward-Abel</td>
<td>Board Member, International Organization of MS Nurses</td>
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<td>Lenka Pyciaková</td>
<td>Head Nurse, Charles University</td>
<td>Czech Republic</td>
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<td>MS Nurse</td>
<td>France</td>
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<td>Jörg Kraus</td>
<td>Neurologist, Austria</td>
<td>Austria</td>
</tr>
<tr>
<td>Samuel Sanchez</td>
<td>Rehribition Specialist, FEM Foundation</td>
<td>Spain</td>
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</table>
MS-NEED: Methodological Summary

- MS Specialist Nurses / nurses seeing patients with MS
- CATI (Computer Assisted Telephone Interviewing)
- 35 minutes per interview
- Screener
- Clinical Practice
- Advocacy
- Training and Education
- Research and Publication
- General Questions

280 MS Nurses were polled in total for the survey
Sample and Recruitment Criteria

<table>
<thead>
<tr>
<th>Country</th>
<th>Sample Achieved</th>
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<tbody>
<tr>
<td>UK</td>
<td>50</td>
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<tr>
<td>Germany</td>
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<tr>
<td>Italy</td>
<td>50</td>
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<tr>
<td>Poland</td>
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<tr>
<td>Finland</td>
<td>50</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>30</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>280</strong></td>
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Recruitment Criteria

- No involvement in any market research regarding MS in the last 3 months
- UK and Czech Republic: Specialist MS nurse
- Germany, Italy, Poland: Nurse >30% of time spent with MS patients
- Finland: Nurse >25% of time spent with MS patients
- Germany, Italy, Poland, Finland: working with MS patients as a nurse for >1 year
MS–NEED: Key Recommendations

- Role of MS Nurses is evolving and expanding
  - Recognise MS Nursing as a specialty across Europe

- Best practice sharing can exacerbate MS Nurses role within the MDT
  - Need for shared MS nursing educational events/opportunities/resources across Europe in range of settings that include web technology & social media
  - Ensure there is a structured, formalised and improved partnership working within current European forums and international organisations

- Tools and education are needed
  - Need for a stepwise professional development structure against an agreed European definition for MS Nursing
The pan-European unification of MS Nurses will increase quality of care for people with MS and their families and will also directly address the European Commission’s Green Paper – Modernising the Professional Qualifications Directive (2005/36/EC) – focused on preparing for mutual recognition of a national degree (such as an MS Nurse exam) across all member states.
Given the inconsistencies in MS Nursing across Europe, and the many advantages of MS Nurses, there is an urgent need for pan-European unification of MS Nursing supported by a modular educational programme to increase quality of care for people with MS and their families.
MS-NEED – Key Accomplishment

MS-NEED SC Meetings (ECTRIMS, Dublin & Milan)

Needs Assessment / Audit
(n=15-20 stakeholders including review of courses in the UK, Germany, Italy & US)

Development of EU Consensus Paper

Detailed Content Developed
(5 modules - key references / data sources / Preliminary design agreed)

Refinement of EU Consensus Paper
(based on Needs Assessment)

Validation of Consensus Paper by local markets

Malta Pilot (May)
(24 nurses from across 10 countries / Press event with Minister of Health & key Maltese Media)

Endorsement from the organisations represented by the Steering Committee under the guidance of EMSP

Completed

In progress: Consensus paper

In progress: MS Nurse Professional

• Prototype testing (Spain – September)
• Translation of MS Nurse PRO into multiple languages
• Anticipated Launch ECTRIMS / followed by country specific launches

In cooperation with:
Setting the Standard –
MS Nurse Consensus Paper
Consensus Paper – Overarching Objectives

• Provide a clear definition of an MS Nurse which will act as a benchmark to enhance/align the delivery of MS care throughout Europe

• Articulate the benefits of the MS Nurse role to others to conserve and protect the MS Nurse post by acting as a resource for key stakeholders

• Drive awareness and understanding of the MS Nurse role in Europe to improve patients’ access to care and treatment in order to optimise their quality of life

• Unify MS Nurses at a European level and provide an opportunity to share and learn from one another
Consensus Paper Content

• MS Care in Europe
  – Overview of current care practices based on findings from MS-NEED Survey

• Making a Difference – The MS Nurse
  – Articulate the MS Nurse key roles/ responsibilities and competencies

• The Case for MS Nurses
  – Benefits of the MS Nurse to key stakeholders including patients and healthcare professionals

• A Call to Action – Where Next?
  – Recommendations for moving forward

To be available in: German, Italian, Russian, Spanish, Czech and French
Where Next? Validation Process

- Identify key nurse champion in each country to facilitate reviews
- Engage professional medical bodies/organisations to secure their buy-in & validation (i.e. ECTRIMS, EANN, EFN, RIMS, IOMSN, EMSP)
- Engage key stakeholders at a national level (local patient, nurse and medical organisations)
- Present the paper to the European Commission in alignment with Green Paper, “Modernising the Professional Qualifications Directive” (2005/36/EC)
- Demand for national level acknowledgement of MS Nursing as a specialist profession
First and only European CME Accredited MS Nurse Training Curriculum – MS Nurse PROfessional
Mission and Target Audience

• To provide a modular, online training curriculum to support the evolving role of European MS Nurses (in line with Consensus Paper on roles and competencies of MS Nurses)

• To increase their competency in patient / family advocacy and brokerage, health education, symptom and treatment management
  – Additionally, to develop leadership skills for the advancement of patient care

• Targeted to all MS Nurses – but with an initial focus on those starting their career in MS Nursing and may not have access to vocational training
  – The scope can then be widened to embrace the needs of experienced MS Nurses
<table>
<thead>
<tr>
<th>Committee</th>
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<tbody>
<tr>
<td>Vicki Matthews (Chair)</td>
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<td>Wolfgang Köhler</td>
<td>DMSG</td>
<td>Germany</td>
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<td>Eija Luoto</td>
<td>RIMS</td>
<td>Finland</td>
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<tr>
<td>Roberta Motta</td>
<td>IMSS &amp; IOMSN</td>
<td>Italy</td>
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<tr>
<td>Amy Perrin Ross</td>
<td>IOMSN</td>
<td>USA</td>
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## Results from Needs Assessment

<table>
<thead>
<tr>
<th>Key issue</th>
<th>Current status</th>
<th>Desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease background</strong></td>
<td>Variable knowledge</td>
<td>Discuss disease trajectory with patient. Foundation in immunology to inform drug MOA, outcomes and safety</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>Nurses mainly involved after initial diagnosis</td>
<td>Need working knowledge of primary diagnostic techniques in order to explain to patients post diagnosis. Relapse is key</td>
</tr>
<tr>
<td><strong>Patient support</strong></td>
<td>Critical component in all countries</td>
<td>Be fully conversant with psychological, psychosocial, family / carer issues and be able to provide self-help guidance</td>
</tr>
<tr>
<td><strong>Symptom management</strong></td>
<td>Key competency in most countries</td>
<td>Know about non-pharmacological, practical support in all areas: fatigue, rehab, pain, spasticity, incontinence, cognition workplace issues, etc</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>Knowledge depends on nurses’ role</td>
<td>Focus on therapy for symptoms. Understand biologics – particularly administration and possible ADE Benefit: risk</td>
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*Needs Assessment conducted to inform the direction, structure, content and format of the MS Nurse PROfessional programme*
## Results from Needs Assessment (cont’d)

<table>
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<tr>
<th>Key issue</th>
<th>Current status</th>
<th>Desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical outcomes</strong></td>
<td>Very little emphasis at present</td>
<td>Be conversant with disease outcomes, assessment criteria. Validates role of nurses when improved. Health economics of care delivery</td>
</tr>
<tr>
<td><strong>Service development</strong></td>
<td>Variable awareness /implementation</td>
<td>Patient advocacy (psychosocial, workplace) Patient tuition (1 on 1; group) Teaching other staff</td>
</tr>
<tr>
<td><strong>Personal development</strong></td>
<td>Individually instigated</td>
<td>Communications, leadership / management; teaching. Role of MS Nurse</td>
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Framework for MS Nurse PROfessional

ACCREDITED CORE CURRICULUM

Understanding MS

- Definitions
- Demographics and risk factors
- Pathophysiology

Clinical presentation

- Types of MS and their features
- Typical signs / symptoms
- Prognosis

Diagnosing and Assessing MS

- Investigations
- Criteria / differential diagnosis
- Supporting patients at time of diagnosis
- Identification of relapse

Treating MS

- Acute episodes
- Disease modifying treatments
- Symptom management
- Treatment optimisation
- Outcome measures

Care and Support

- Optimising communications
- Patient education and empowerment
- Emotional and psychological support
- Lifestyle management
- Role of MS Nurse

Certification test

Reflective learning

Accreditation

What are the practical implications for MS Nurses

What are the practical implications for MS Nurses

What are the practical implications for MS Nurses

What are the practical implications for MS Nurses

Final test

In cooperation with:

European Multiple Sclerosis Platform (EMSP)

International Organization of MS Nurses (IOMSN)
To be available in multiple languages including French, Spanish, Italian, German and Czech.
Accreditation and Endorsement

• Curriculum to be accredited by the UK Royal College of Nursing (RCN)
  – RCN will proactively assist with submitting the programme to other European accrediting bodies for recognition and approval in target countries
  – RCN will facilitate discussions regarding higher level of education qualification (Diploma etc)

• European Association for Neurosciences Nurses (EANN) will officially endorse the activity

• Accreditation also being sought from the International Council of Nurses (ICN)
Malta Pilot Objectives

Created a forum to stimulate discussion and gather feedback on:

• MS Nurse Consensus Paper:
  – Evaluated the Consensus Paper to ensure clinical relevance / ‘real world’
    application at a basic level

• MS Nurse PROfessional:
  – Tested the core scientific content that will form the foundation level
    of the MS Nurse PROfessional curriculum
# Nurse Participants from Across the World

<table>
<thead>
<tr>
<th>Name</th>
<th>Country</th>
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<tbody>
<tr>
<td>Pierangela Riani</td>
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<td>Dr Hala Darwish</td>
<td>UAE</td>
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<td>Lenka Pyciakova</td>
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<td>Margaret Maguire</td>
<td>Ireland</td>
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<td>Jana Becvarova</td>
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<tr>
<td>Mary Blake</td>
<td>Ireland</td>
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<tr>
<td>Megan Burgess</td>
<td>UK</td>
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<td>Marisa Vella</td>
<td>Malta</td>
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<td>Wendy Hartland</td>
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<tr>
<td>Catherine Bugeja</td>
<td>Malta</td>
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<tr>
<td>Jane Fowler</td>
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<td>Silvana Mangion</td>
<td>Malta</td>
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<tr>
<td>Andrea Gertz</td>
<td>Germany</td>
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<td>Alexandra Apap</td>
<td>Malta</td>
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<td>Heidi Schilling</td>
<td>Germany</td>
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<td>Catherine Mouzawak</td>
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<td>Franziska Lipske</td>
<td>Germany</td>
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<td>Kitty Harrison</td>
<td>Netherlands</td>
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<td>Roseline Iqbal</td>
<td>Belgium</td>
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<td>Eija Luoto</td>
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<td>Jan Verlinden</td>
<td>Belgium</td>
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<tr>
<td>Chrysa Chrisovitsanou</td>
<td>Greece</td>
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*Participating remotely

22 nurses from 12 countries
Malta Pilot - Outcomes

Outcomes:

• Robust insights and feedback gathered on the MS Nurse PROfessional training programme and the European Consensus Paper on MS Nursing

• Empowered key nurses from across Europe that are willing to act as advocates to support collaborative steps towards the unification and recognition of the MS Nurse
  – Initiated steps towards the establishment of the first European MS Nurse network organisation
Close & Next Steps
Next Steps

• Spanish Pilot – September (Pending review/outcomes from Maltese pilot)
• Programme and Consensus Paper to be translated and validated nationally – May – June
• Anticipated launch – ECTRIMS 2012 / October
Thank You