



“When the Watering Hole Shrinks, the Animals Look at Each Other Differently”

Diane Lowden MSc(A), MSCN and President, IOMSN

It is with great pleasure that I write to you as the President of the International Organization of MS Nurses (IOMSN) and a recent honorary member of the UKMSSNA. I was thrilled with this latter nomination as I have tremendous respect for the UK MS Specialist Nurses and your level of scholarly inquiry, work on establishing standards of MS nursing care, research into health outcomes and commitment to the care of individuals and their families.

At IOMSN we have followed with interest, concern and some dismay the discussions about threats to the MS Nurse posts, when clearly nursing care leads to improvements in quality, safety and cost-effectiveness of patient care. This situation reminds of one in my own province in Canada in which there was a movement to replace nurses who immunize children, with technicians – after all, anyone can do an injection, right? Nurses argued that immunizations were about more than just providing injections to babies. The time spent with mother and child was one in which nurses assessed the normal growth and development of the child, observed for developmental delays, assessed mother-infant bonding, educated about health related child care and observed for signs of abuse. It was also an opportunity to commend the parent on their parenting skills and help them learn to be competent in caring for their family. Nurses are indeed value-added and short-term cost-saving strategies have the potential to threaten longer-term health outcomes.

I applaud the eloquent description of nurse’s work in the UKMSSNA newsletter, “Supporting the Case for MS Specialist Nurses”, and the research done on highlighting and articulating nursing outcomes. In today’s changing health care environment, it has become increasingly important to employ evidence-based approaches to practice and to measure the outcomes of various health care interventions. Newer paradigms dictate that rules of evidence are needed to guide clinical practice, while not ignoring the richness of “expert evidence” and clinical experience. A patient met me in my office recently and emailed me in the days following. She reported that she had found our meeting very helpful, that it was the first time she had had the opportunity to express her concerns about the disease, and she felt “much lighter” after she left. She also said she felt more at ease about starting her treatment knowing that such a knowledgeable and supportive team surrounded her. How do you capture such rich descriptions in a way that is meaningful to those who make decisions about health care spending? This is our ongoing challenge.

In a 2005 publication, “Advanced Practice Nursing in Multiple Sclerosis: Advancing Skills, Advancing Responsibilities”, a team of MS nurse experts developed a comprehensive list of outcomes attributable to advanced practice nurses in MS care. While the roles of nurses

around the globe may look somewhat different, there are some key threads of learning, coping and self-efficacy that are universal outcomes of nursing practice. There is still much to be done in testing out some of these models of nursing care and the benefit to patients and families, in terms that are measurable and understood.

I invite you all to have a look at our website at www.IOMSN.org (or go to Links on the UKMSSNA website) for inspiration and support as you continue your quest to protect your valuable MS Specialist Nurse posts. At IOMSN we have funding available for research projects that may help to demonstrate the effectiveness of the nursing care that you do. Our thoughts will be with you on the 3rd March, your Day of Action.

Warm Regards,
Diane Lowden

IOMSN Membership Directory

Full Members will find enclosed with this Newsletter the 2006-2007 IOMSN Membership Directory. June Halper, Executive Director of the IOMSN, reports that 2006 has been a banner year for the IOMSN. It now has MS nurses in 19 countries.



2007 marks the 10th anniversary of the IOMSN. Achievements have included numerous MS nursing publications, multi-media educational projects, many MS nursing update meetings, an interactive and educational website, the International Journal of MS Care and the MS Exchange, mentorships and training programmes, a large presence at national and international meetings and several landmark research projects. The organisation has spawned the MS nursing certification programme and many members will be re-certifying as MS nurse specialists this coming year. The IOMSN has worked with non-profit partners, the pharmaceutical industry and other nursing organisations to sustain growth and development.

June Halper says “you are blessed with an active and productive Board of Directors with numerous volunteers for our many projects. We have provided our members and nurses worldwide with scholarships, fellowships and traineeships to sustain the growth of our speciality. You should be proud of your organisation know for caring, commitment and excellence. We have many projects for 2007 and welcome your input and suggestions for additional ideas.”

Full Members of the UKMSSNA are entitled to free membership of the IOMSN. If you are not currently listed as a member, this is probably because you have not given our Administrator permission (under Data Protection regulations) to pass your name and contact details to the IOMSN. Check with Mary Fielding if you wish to join the IOMSN.

IOMSN Board of Directors

The Executive Committee of the IOMSN invites nominations from its members to join the Board of Directors (BOD). Five BOD positions are available. To be eligible you must be an active member of the IOMSN, be a licensed nursing professional, have an interest in developing and promoting programmes and activities for the IOMSN and be available by 'phone, fax or email.

For more information and a nomination form visit the UKMSSNA website and go to the Members' Section.

Diagnosis of Multiple Sclerosis DVD

The IOMSN have also supplied the enclosed DVD, developed by Colleen Harris and Dr Michael Yeung on the Diagnosis of Multiple Sclerosis.

Elections and New Committee

Several new members joined the committee following their election/co-option at the AGM in November. **Welcome to:**

Huseyin Huseyin **Thames Valley**
Luton & Dunstable (*Beds, Bucks, Berks,*
NHS Trust *Herts, Oxon*)

Caroline D'Arcy **South London**
Charing Cross Hosp.

Janice MacDuff **North London**
Royal Free Hospital

Maureen Speed **South East**
East Kent Hospitals
NHS Trust

Nikki Embrey **West Midlands**
Univ. Hosp N. Staffs

Jane Ware has been nominated as the representative for the **Southern** region (Hants, IOW, Dorset, Surrey, parts of Wilts) and attended the January meeting at the invitation of the Committee. Jane is based at Southampton Univ Hosp NHS Trust.

Alan Izat, at Ayrshire Central Hospital has been nominated for **Scotland**.

East Anglia is still without a representative.

Contact information for the committee and election forms for Jane and Alan are available on the UKMSSNA website on the Members' Section/Committee page.

Kerry Mutch will take over as Chairperson in March when **Nicki Ward** and **Sylvie Hurst** stand down as Co-Chairs, although Nicki will remain on the committee until October.



Gutteridge for their valuable contribution as committee members

Many thanks to Sylvie and Nicki for their tireless work as Co-Chairs of the UKMSSNA and to Pauline Shaw, Nicola MacLeod and Vicki

Website

Username and Password

The password to the Members' Section will shortly be changed. This time the **username** will be **your own name**, (e.g. mfielding – i.e. the initial of your first name followed immediately by your surname) **plus** a **password** which I will circulate by email where I have an email address and letter to those who don't. As well as being easier for you to remember (I hope!), it will also ensure that **only** paid up members have access to the information. If you can't remember the password, it is printed on the UKMSSNA membership card.

Website visitors

Since October 2006, when I first signed up to an analysis of visits to the website, 661 people have visited 2956 pages. Not counting the Home page, the most popular section is the Slide Library followed by the Members' Section generally and then the News section.

Please pass on news, information, education and events that I can put on the website – and also remember to visit it on a regular basis to keep up-to-date, in particular, check out the Members' Enquiries in the Members' Section *Mary Fielding*

Slide Library

The new presentations will be on the website by early March. The Working Group are making some final adjustments before making them public.

International Certification Exam

You are encouraged to take the MS Exam in November to validate your knowledge and expertise as an MS specialist. If you want to know what it's about, why not contact one of the nurses who has already passed the exam. Names are on the website.

Please let Mary Fielding know if you want your name added to the list to receive a Handbook and application form when they are available later this year.

Making a Difference 2006

This Award is made to the MS Specialist Nurse who, in the judgment of his or her peers, has “made a difference” to MS Nursing in the last twelve months. If you wish to nominate someone for the Award, to be presented at the York meeting in March, download the nomination form from the Members’ Section of the website and return it to “Making a Difference” UKMSSNA, PO Box 63, Little Marcle, Ledbury HR8 9AA. Alternatively you can email the form to Nicki at nicki.ward@uce.ac.uk. The closing date for nominations is Thursday 15th February.

Young Carers and the Expert Patient Programme

Jo Ridley, Carers Lead at the MS Society, has been working with the Expert Patient Programme to develop a course aimed at young carers. You may have heard of ‘Looking After Me!’, which is their course aimed at carers in general.

The Expert Patient Programme is keen to involve young carers in the development and promotion of this course and have developed a questionnaire and a flyer which seeks their views on the course, whether they would attend, what they think of the approach so far. If you are in contact with any young carers (primarily teenagers) who might be interested in responding, Jo Ridley and Michelle Procopi at the MS Society can send supplies of the documents for your use.

Email: jridley@mssociety.org.uk; Tel: 01793 877575 or mprocopi@mssociety.org.uk

Care Manuals

The new Care Manuals are gradually being distributed. Many thanks to Joan, Phyllis and the reps at Serono (now Merck Serono) for their invaluable help with this. If you haven’t received your Manual by the end of February please let Mary Fielding know.

MS Trust Nurse Advisor

Vicki Gutteridge is now working for the MS Trust as nurse advisor, communicating their, and MS specialist nurses, interests, concerns and views within the arena of health and social care. Vicki will support the UKMSSNA and MS nurses in audit and service development within the current political arena and support the MS Trust information team on clinical issues, publications and chatrooms. She will also advise on the development of educational programmes, web-based learning and research projects.

Vicki says “never was it more important to ensure that MS nurses are able to feel confident about the delivery and security of their service. I feel passionately that we have long underestimated our value. Our role is to put the person with MS at the heart of all we do and we often neglect ourselves in the process. It is now a difficult arena where we are asked to put money before people. MS Nurses need to be well armed in the face of potential conflict between principles and politics. I hope that, together with the MS Trust and the UKMSSNA, I can encourage MS nurses to provide the evidence of their worth as an ongoing and dynamic process that secures their future and makes public their incredible value.”

MS Specialist Skills Workshops

(Coachwise) is a resource to support MS nurses. The workshops are being reviewed and re-launched within the context of AfC and Skills for Health (LTCNS). They can be regionally delivered, are free to MS nurses, link to the “Competencies for MS nurses”, are RCN accredited and will help meet the current challenges of the specialist role.

The day long workshops include:

- Leadership skills
- Influencing skills
- Coaching skills
- Team building skills
- Presentation skills

For further information about the workshops or any issue relating to resources for managing challenges to your service contact Vicki.gutteridge@mstrust.org.uk

Ayrshire & Arran MS Managed Clinical Network



The Ayrshire & Arran Managed Clinical Network (MCN) was formally launched in June 2006 to build on the high standard of the existing MS Service through greater involvement of professional colleagues and people with MS and their carers. The vision is one of a co-ordinated approach to the development of the MS service for the area. Such developments will include the creation of formal protocols in relation to assessment and management of patients and a system of audit to facilitate follow up and improve quality of care delivery to patients.

The MCN is supported by the Scottish Executive Health Department for two years as one of two pilot sites. Following approval by NHS Quality Improvement Scotland it is the intention that the model developed in Ayrshire and Arran will serve as a template for the establishment and guidance of further Networks throughout Scotland.

The MS Specialist Team consists of

- Consultant Physician in Rehabilitation Medicine
- two MS Specialist Nurses
- MS Specialist OT Service –part of a 3 year programme funded by SEHD, MSS and NHS Ayrshire & Arran.
- Extended Scope Practitioner Physiotherapist – Also a 3 year MSS/NHS A&A funded post.
- Speech and Language Therapy
- Psychology
- Dietetics

The team circulated a Patient Satisfaction Questionnaire, anonymous and

independently analysed, to give a baseline from which to improve existing services and develop new ones. Responses on the existing service were very positive; on new ideas, responses indicated that 51% want the introduction of patient-held records, 42% would like specific exercise classes like yoga or pilates, 29% would be happy for increased review appointments by a member of the specialist team other than the consultant and 22% would like more patient/carer education sessions.

The key areas of focus will include Service Development, Education, Research and Innovation.

Service Development – includes introduction of a Relapse Clinic, Rapid Access Diagnostic Clinic, multidisciplinary assessment of patients with severe disability within their own homes, involvement of Primary Care Physicians, domiciliary assessments with community-based nursing, AHP and social work staff, strengthening links with tertiary care.

Education – professional and patient education sessions throughout the area, the possible development of a post-graduate Diploma/MSc Course in MS care in collaboration with Glasgow Caledonian University.

Research – Pharmacological Studies, Physiotherapy, Occupational Therapy and Psychology Research Studies.

Innovation – Patient-held records, therapist-led clinics, Functional Electrical Stimulation, introduction of Novel Treatments.

Rapid Access Diagnostic Service - The MCN is currently working towards establishing a Rapid Access Diagnostic Clinic with the Radiology Department at the Ayr Hospital.

For more information about the MS MCN service or any of its component parts, please contact Elizabeth Gracie, the Team Secretary elizabeth.gracie@aaaht.scot.nhs.uk or Jacquie Downs - jacquie.downs@aaaht.scot.nhs.uk

'Trekking with Altitude!!'

Gail Hayes, MS Nurse.

I returned from Peru on Saturday, October 14th 2006 having had the most amazing time. The sights, sounds, smells and experiences will be with me for ever. I could not have gone without the support of my sponsors and encouragement from all of you, my family and walking friends. Thirty-one of us went to raise funds for the MS Trust and have raised over £100,000!!! So far, I have raised £6,500 and there is more to come in.



I was one of the 7 MS Nurses and here we are at Macchu Picchu, near the end of our 11 day trip (I have a hat on – bad hair day and the sun was out). Amongst the others who completed the Lares Trail were two women with MS, and husbands, a Dad and a son of people with MS, OTs, and a physio. The youngest was 17, the eldest 70!

We started in Cusco, acclimatising to the altitude at 3,200m. above sea level. Here we saw the amazing Inca building style that has survived 500 years and many earthquakes and on which so many modern buildings are built. We also realised how the altitude affected our breathing and walked slowly up the hill into the main square where the architecture was a mixture of colonial and traditional.

The ozone layer in Peru is particularly thin and we had to use sunscreen but we walked through rain, hail and fair weather. The many layers that we carried in our day

rucksack were alternately being put on and off.

The organisation in the UK and in Peru was excellent, with staff transporting tents, loos and personal belongings twixt camp-sites as well as providing 3 meals a day. We had 2 doctors - the medical kit being carried by a mule that usually stayed at the back of the long line of walkers. It got bored on the last day with us and ran up the mountain and overtook us all. A few minutes later, his local guy was seen running to catch him up! We met again at our lunch-time stop about 45 minutes later.

Our spirits were high and we encouraged each other although it was certainly not a stroll in the park and we had to 'dig deep' to walk for up to 11 hours a day for 3 days. I felt this trip to be my personal challenge in both mental application and physical ability. None of us had much sleep whilst away. My tent buddy (Lynda) sorted the tent out at end of the day and I did the morning clearing up stint. We had to be awake for 5am and after taking off the many layers in which we had rested, had a speedy wet wipe wash and dressed for the days trek. We had 'tea in tent', yes, coca leaf tea that gave us a lift. At 6am we had a wonderful breakfast of porridge, toast, pancakes, butter and jam as well as an array of teabags, coffee and hot chocolate.



We always did early morning stretching exercises as a group with great hilarity while the locals watched with amazement. We packed our rucksacks with snacks and 3 litres of water before setting off at 7am. The mornings were bright and chilly but we soon warmed up as we made slow progress with stops every couple of hours or so for a drink and a snack. It was uphill in the mornings with steep and arduous paths culminating in a high pass with a little downhill to get to lunch and still further down to our campsite.

The views of snow-capped mountains, the closely cropped grass and tiny, colourful flowers that clung to the soil were wonderful. The tufty, hardier, taller grasses are the ones used for the roofs of the native



housing. We also passed turquoise lakes which always took us by surprise as they were so high up and were privileged to see the enormous, graceful condors flying.

As the air became thinner so our slow and steady pace became the norm. I was really chuffed that I was fit and well enough to be up with the front 15% walkers most of the time. We had guides at front, middle and back who kept a concerned eye out for those who were struggling or having a hard hour or so. Most of the time the track was quite narrow so we walked single file, but it was a joy to be able to walk alongside someone and chat.

Afternoon walks were enjoyed as they were downhill but we still had to be careful of our footing. About 10–15 people suffered altitude sickness; for some, a mule ride was enough to help them for the rest of the day, but for others it meant that they were unable to tackle the high passes. At the end of our

longest day, I ran out of energy with another 30 mins to walk, so I gratefully accepted a mule ride for 10 minutes and apologised to it when I dismounted near camp.

The feeling of elation as we reached the peaks and the tears of emotion were shared by all as were the feelings as we walked into camp at about 5.30 at the end of the day, having achieved so much. There was a cuppa and a biscuit waiting, as well as popcorn, before we 'washed and dressed for dinner'. Well for lots of us that meant getting ready for bed, as it was dark at 6 pm, supper at 6.45 ish – another 3 course meal and bed at 8.30 ish. We were 'all in'.

We saw many friendly locals, hardy people who farm. Even the young children herd llama and alpaca as well as pigs in the high mountains. They grow enormous amounts of a great variety of vegetables, particularly in the fertile valleys through which we drove. Their clothes are dyed with natural bright colours and they have large families. We were graciously invited into their homes which, even up in the mountains, may have an electric light bulb, and an outside tap. There are no chimneys or windows, so the



wood smoke finds its way out round the door. They domesticate guinea-pigs for special meals and sleep on the floor wrapped in llama skins. They sold us their handmade gloves and hats and woven articles, setting up shop as they saw us coming into camp. The children attend school which may mean a 2 hour walk!

Our journey to Machu Picchu was by bus to the railway station in Ollantaytambo, train along the riverside to Aguas Calientes and bus to the sacred ruins. The views all around us were breathtaking and it was

really busy with people but quite quiet which suited us all.



It was a fitting end to an amazing trip. There were lots of highs in altitude, mood, fun and achievement - physical and raising so much money, meeting so many wonderful people with like minds and purpose. The only lows were altitude in Lima, an unscheduled stop on the way home and the heavy, painful hail storm through which we walked on the way to our highest peak of 4,500m.

Was I offered guinea-pig to eat? Yes and I refused because the thigh piece had the tiny claws still attached!! It must have looked as cute as the many we saw running around the living area of a few homes. I have the tea-shirt, the map of very close contours of our 25 mile trek and so many amazing memories.

The MS Trust is running another Trail next September. Might you be 'up for it'? Tel. 01462-476700 or look at the fundraising section of the Trust website. The MS Society also runs one but on the Inca Trail.

Many thanks to Gail for this and apologies for having to edit her original 5 page article due to lack of space.

Name for this Newsletter?

How about a snappy title for this newsletter? At the moment it is nameless. Can you suggest something appropriate? A gift voucher to the person who comes up with a winner! The next newsletter is due in May/June. Suggestions to Mary Fielding; admin@ukmssna.org.uk

National Forum Development for Intrathecal Baclofen Services

Friday 23 March 2007

Crowne Plaza Hotel, NEC, Birmingham

This will be a great opportunity for networking with many different specialities experienced in the management of severe spasticity with intrathecal baclofen therapy.

Provisional Programme

Update ITB national document and summary of the document from the Steering Committee – Dr Imad Soryal

Speakers on evidence base for:

- 1) Clinical effectiveness – Prof Mike Barnes
- 2) Quality of life and outcome measures (including stroke) – Dr Tony Ward
- 3) Up to date information on areas of future research – Prof Ian Whittle

Breakout Sessions

- a) Paediatric – Mr Guirish Solanki/Dr Martin Smith
- b) Spinal – Dr Martin McClelland/Mr Aheed Osman
- c) Neurorehabilitation – Dr Margaret Phillips/ Miss Louise Chadwick

Other topics include:

Acute withdrawal: Dr Richard Morton
System sepsis/meningitis: Dr Paul Eunson
Management of overdose Dr Jean Pierre Lin
Management of patient during MRI: Dr Angus Graham
Management of patients presenting with failure of therapy/seroma: Mr Martin McClelland
Problems associated with pump placement/movement/skin breakdown: Mr Michael Vloeburghs
Management of patients with pregnancy whilst receiving ITB: Louise Jarrett

It is free-of-charge to attend. CPD accredited. Registration is via email confirmation to clive.woodard@medtronic.com (note spelling of surname NOT woodward)