

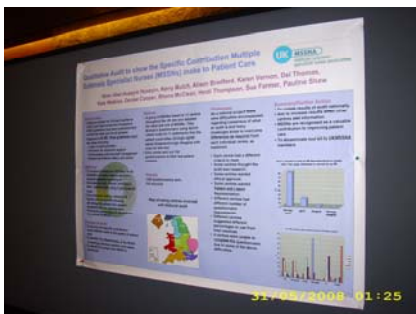
MS Professional

Issue No. 11 Summer 2008

www.ukmssna.org.uk

MS Nurse Audit Tool

Poster on Audit Tool at CMSC



The Audit Tool – now named **©criMSon** - has been finalised and a CD-ROM will be posted to all UKMSSNA members in the course of the next few weeks.

The aim of the audit tool is to identify the effectiveness of the Specialist MS Nurse's role in meeting individual patient care needs; specifically:

- To conduct a retrospective survey of service users who have regular contact with a MS Nursing Service
- Identify some of the key inputs which MS Specialist Nurses contribute to the outcomes and overall quality of patient care
- Illustrate some of the patient-expressed experiences of the MS Service
- Identify where improvements can be made.

Huge thanks to the team, especially Hüseyin who created the spreadsheet to analyse the results from the questionnaire. Thanks too, to Prof. Sir George Castledine for his initial input.

Nicki Ward-Abel
Del Thomas
Kate Watkiss

Denise Cooper
Kerry Mutch
Sue Farmer

Rhona MacLean
Huseyin Huseyin
Heidi Thompson

Pauline Shaw
Karen Vernon
Alison Bradford

©criMSon will also be available to non-members at a price of £40 including postage and packaging.

Adding Value and delivering NHS targets

Enclosed with **MS Professional** is a copy of this recent UKMSSNA publication written mainly for commissioners and managers.

Many of you will already have seen this booklet, but we feel that it is important that all members receive a copy. We intend sending copies to key people in Strategic Health Authorities and PCTs.

MS Pathway

Work continues on the Specialist Competencies and it is hoped that they will be completed very shortly. The MS Pathway consensus meeting took place on June 11th attended by Kerry Mutch, Del Thomas and Nikki Embrey. Following the meeting final amendments will be made prior to its launch.

MS Nursing International Certification Examination

All MS Specialist Nurses with at least two years experience are encouraged to take this examination which gives you international recognition of your expertise.

The exam consists of 150 multiple-choice questions based on clinical practice, advocacy, education and research. This year the UKMSSNA Committee have decided that your UKMSSNA subscription of £30 will cover your contribution to the exam fee. The rest of the \$250 can be met by a bursary from the IOMSN. Contact Mary Fielding for a Handbook for Candidates and an application form. **The closing date for applications is Friday 15th August.**

NB: I will be on annual leave from 22nd July to 5th August, so get your applications in early to avoid any possible difficulties.

Mary Fielding

Committee News

The Committee is now up to full strength of fifteen members with the co-option of **Del Thomas** and **Jennie Edis**.



Del, who works in Herefordshire, has been nominated as the representative for Wales and Jennie will take over from Sarah Olyett as the representative for Eastern England. Sarah has moved to the National Hospital for Neurology and Neurosurgery and so will join Janice MacDuff and Caroline D'Arcy as the representatives for London.

Support Alan Izat and the MS Trust

Alan Izat is one of two MS Specialist Nurse in Ayrshire and the representative for Scotland on the UKMSSNA Committee.

Ayrshire has the highest ever recorded prevalence of MS (260 per 100,000 people).

In July Alan is undertaking a 260 mile cycle for the Multiple Sclerosis Trust (as you see from the photo, he's training hard!!) The fundraising event is over 4 days and sets off from Greenwich, London to the Eiffel Tower in Paris. Alan says "The MS Trust have given a lot to me and thereby our service in Ayrshire and this is my way of trying to give them something back."



"If you feel you would like to support me and/or the MS Trust please do so by donating online at www.justgiving.com/alan_mstrustcycle. All the money will go directly to the Trust. Please pass this on to anyone else that may be interested in helping (especially someone with HUGE pockets...)."

MS Society Professional Network

Some people reading this will already be members of the MS Society Professional Network, but there may be members who are unaware of it, what it offers and who can join.

The Professional Network aims to enable people to learn, share information, promote good practice and exchange ideas and views. Currently, this is done via a magazine, *MS Network* that is issued three times a year; a quarterly e-newsletter and various study days and conferences around the country. Members can also access the MS Society's research, information & library updates. Any health & social care

professional can join – it's free and enables people to get regular updates on issues relating to MS.

A new initiative is Special Interest Groups which will have their own password-protected discussion boards later this year. The first of these is the Mental Health in MS group. This will be followed by Palliative care in MS and Paediatric MS interest groups. If you wish to join any of them, watch out on the web-site, or in the e-newsletters.

To join, go to the MS Society website www.mssociety.org.uk. Click on the "for professionals" link and then the Professional Network Login/Register button.

Please pass on this information to all health & social care professionals so that they can join!

If you have any queries or comments about the Professional Network, please contact me at rmaclean@mssociety.org.uk or 'phone 01845 578196.

*Rhona MacLean
Professional Network Manager*



MS Trust Conference

UKMSSNA members should have received a personal invitation to the MS Trust conference due to

take place in Leeds from November 2nd to 4th. Leeds proved to be an excellent venue last year and the Trust is planning what promises to be another inspiring programme. For instance, Prof. Deborah Miller from the USA will discuss the use of IT to improve the patient experience, Prof. Clare Fowler will launch new MS Bladder Guidelines and Prof. Neil Scolding will update conference on stem cells.

Bursary to attend the MS Trust Conference

A bursary to attend this year's MS Trust Conference in November is available from the UKMSSNA for a nurse who is not

currently specialising in MS, but who is interested in doing so.

The bursary will cover the conference fee, registration and hotel accommodation, so all the nurse will have to find is his/her travel costs. If you wish to nominate someone you can download a nomination form from the website. **The closing date for nominations is 15th July.** The successful nominee will be notified by the end of July.

New staff at the MS Trust

Two new members of staff have joined the education team at the MS Trust. Marielle Brouwer joins from Disability Essex, and Juliette Wilson Bond, an OT by training, joins from Age Concern. They will bring their expertise from different areas to help develop new education programmes for the MS Trust. It will also mean that there are more people to support any requests you may have.

New Look MS Trust Logo and Website: www.mstrust.org.uk

Have you looked at the MS Trust website recently? If you haven't, have a look at their new look and their new logo. As part of the re-design they have completely changed the health professional section to provide more information of specific relevance to MS specialist nurses and easy online booking for educational events. Have a look too at the web-based Stay Active section which is now a great recommendation for your patients. This is a complete rewrite of the CD the Trust produced some years ago providing many useful links and helpful advice to people with MS about a variety of activities. The fact that it is now web based provides people with a myriad of additional links and a very safe first port of call when considering exercise and leisure pursuits.



The Trust is now using Google map technology to build a log of services which will be useful to people with MS and Health Professionals; do please look and send the

Trust information for your area and keep them updated with any further services on offer.

Long Term Neurological Conditions

A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse

“MS nurses are a vital component of the MS service.No other healthcare professional can provide such a range and depth of patient centred services. MS nurses are essential to ensure the standards outlined in the NICE MS guidelines and NSF for LTnC are met. Indeed it is impossible to conceive how an MS service could function without MS nurses.”

Consultant neurologist, Manchester (extract from document; p.16)

This document has been published by the Department of Health working in partnership with the RCN and various neurological support charities including the MS Society. There is a link on the UKMSSNA website News page to the NHS National Workforce Projects website to download the document.

Update to Slide Library

The Slide Library Working Group is updating the presentations in the Slide Library and adding a few new ones. You can download the Powerpoint presentations on the UKMSSNA website – available only to UKMSSNA members.

New presentations are **The Role of the MS Specialist Nurse** and **Tysabri**. Symptom management presentations on **Pain** and **Sexual Dysfunction** have been updated.

Thanks to Nicki Abel, Karen Vernon, Kate Watkiss, Helen Parry and Denise Cooper.

Reviewing the Care Manual

Each member of the Committee has agreed to review a Chapter of the Care Manual within their Region. Hopefully there won't be too many revisions and we hope that we can introduce them gradually and circulate

them electronically rather than have the huge task of sending complete new copies of the Manual to every member.

COPAXONE® and Live Vaccines

Carol Turner received the following information from Teva, which we thought was worth passing on.

Vaccinations are not contraindicated in patients receiving treatment with Copaxone.

During the double blind placebo controlled studies involving 269 Copaxone treated patients, 26 patients received vaccinations against the following diseases; influenza, tetanus, hepatitis A, hepatitis B, rabies, typhoid, pneumococcus and polomyelitis. No adverse reactions were reported in these individuals and no evidence of interference was observed.

Once a patient has received a vaccination we would recommend that Copaxone is not administered into the same injection site area until any local skin reaction to the vaccine has subsided.

References:

1. Copaxone, Summary of Product Characteristics
2. Bornstein M et al., A Pilot Trial of Cop 1 in Exacerbating Remitting Multiple Sclerosis, *The New England Journal of Medicine* 1987; 317 (7): 408-414
3. Johnson K et al., “Copolymer 1 Reduces Relapse Rate & Improves Disability in Relapsing-Remitting Multiple Sclerosis: Results of a Phase III Multicentre, Double-blind, Placebo-Controlled Trial”, *Neurology* 1995; 45: 1268-1276
4. Comi G et al., “European/Canadian Multicenter, Double-blind, Randomised, Placebo-Controlled Study of the Effects of Glatiramer Acetate on Magnetic Resonance Imaging-Measured Disease Activity & Burden in Patients with Relapsing Multiple Sclerosis”, *Annals of Neurology* 2001; 49 (3): 290-297

MS Society launches its Carers Emergency Card

Many carers say that they feel unable to spend time away from the home, due to worries about what might happen if they can't get back. Some give up work

because of the stress that this can cause, others give up socialising with friends or family, leading to feelings of isolation and loneliness.

The MS Society's Carers Emergency Card offers peace of mind, with 24-hour back up support if a carer is held up away from home. Carers can nominate friends and family locally who can be contacted in an emergency. If all else fails, the call centre will contact social services to alert them to the situation.

Please do promote this service to carers you meet. Further information, including an information leaflet and a registration form is available at: www.mssociety.org.uk/support_and_services/carers

Calendar of Events

As you will be well aware, there is a plethora of conferences, study days, seminars and courses available for MS professionals to attend. Although we already have a webpage to publicise events and activities, we would like to develop this further, so that it is as comprehensive as possible. If you know of any event that is coming up, please complete the form on the "Contact Us" page of the website, giving full details of the event.



New Publications

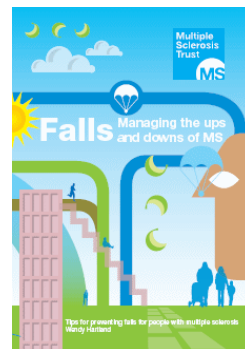
The MS Society has produced *Childhood MS: a guide for parents*. This is part of the Society's commitment to raising awareness of this issue more widely. A report of the workshop held in November 2007 is also available.

You can order a copy of the guide at www.mssociety.org.uk/publications or by writing to the MS Society information team, MS National Centre, 372 Edgware Road, London NW2 6ND.

To obtain your own supply contact infoteam@mssociety.org.uk or take

advantage of the online ordering facility on the MS Society's website.

The MS Trust has launched a new book around **falls prevention**, written in collaboration with Wendy Hartland. It provides information for people with MS on managing the risk of falling.



As ever copies can be provided free to people with MS. An MS Trust publications leaflet is now available giving details of all Trust publications. Remember that both patients and professionals can sign up to receive Open Door at no cost.

Report on RIMS Conference

Congratulations to Vicki Matthews on joining the RIMS Board!

The beautiful medieval university town of Leuven in Belgium was host to the 13th annual conference of RIMS (Rehabilitation in MS) from the 8th to 10th May. The weather was stunning and the 250 delegates from all over Europe, Israel and the States enjoyed a very full, varied conference and social programme titled 'Targeting Good Practice in MS Care and Rehabilitation'. Topics included recent advances in MS treatment, the use of clinical pathways in MS rehabilitation, employment and the cost of quality of life in MS.



For those not familiar with it, RIMS is a multi-professional, European network of MS centres, hosting a variety of special interest groups (SIGs), encouraging communication, the sharing of good practice and

research, especially among novice researchers. The executive board has 8 elected members and is currently chaired by Eija Luoto, Director of Nursing from Masku Neurological Rehabilitation Centre in Finland. This year we were all delighted to see the UK represented again on the board. Vicki Matthews from the MS Trust was elected for a 3 year term. It is great to see such a strong nursing presence. I'm sure Vicki will make a great contribution to RIMS over the next few years and enable more valuable communication between like-minded professionals in the UK and Europe. I hope she finds it as interesting and as enjoyable an experience as I did a few years ago.

Jane Johnson

Website

I've been on a short Web Design course recently and am trying to put what I have learned into practice, but it's taking time. I will be making changes to the website in due course, such as having separate pages on different aspects of MS, e.g. a "Symptom Management" page, a "Treatment" page and so on. When I've found suitable images I will also be creating

pages for each Region with location maps so that you can tell where members are based. Regions will then be able to put information about their meetings, anything special they are working on, study days, etc. All this will be for members only, not for public access.

Remember that members' landline numbers and emails are on the Register of Members page – no need to wait until I'm in the office to find out someone's contact details.

Mary Fielding

The photograph is of Kerry at the CMSC Conference with the poster on Concordance workshops which she, Nikki Embrey, Del Thomas, Alison Bradford and Gail Hayes have developed..



Photo: Huseyin Huseyin

UKMSSNA Committee 2008

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