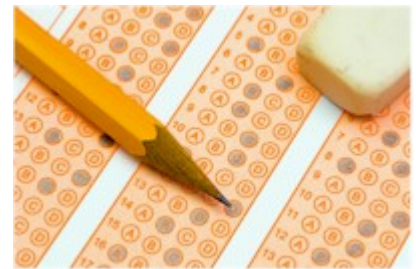


MS Professional

e-news 18 June 2010

www.ukmssna.org.uk

International MS Nurse Certification Examination & MS Specialists Examination



So far, there have been very few applications to sit this year's MS Nurse/MS Specialists exams in November. Please consider sitting the exam, which gives international recognition of your skills and knowledge as an MS Specialist Nurse. The committee is also in the process of getting NMC accreditation for the exam.

MS Nurses with two years experience or more are eligible to take the exam, which takes the form of 150 multiple choice questions covering concepts underlying clinical practice, assessment and intervention for clinical practice, advocacy, education and research. The exam is held on the Sunday morning before the opening session of the MS Trust Conference.

The examination fee is \$250 and can be covered by a fellowship from the IOMSN together with a contribution from the UKMSSNA to cover the balance of the fee. You can obtain an application form and handbook by contacting Mary Fielding (admin@ukmssna.org.uk) or phone 01531 670481 and leave a message.

Bursary to nurse to attend conference

Please consider nominating a non-MS nurse for a bursary to attend the MS Trust conference, 7th – 9th November 2010. The UKMSSNA will pay the conference fee, which includes accommodation. The bursary holder just has to find travel costs and provide a report after the conference. You can download an application form from the Members Section of the UKMSSNA website. The deadline to get applications back to Mary is 30th June.

Laminating membership cards

A member (who will remain nameless...) revealed that she had put her membership card through a laminating machine. I bet she's not the only one who's done this! Please note, these are self-laminating. Just sign your card, peel off the paper covering the sticky backing and carefully laminate your card between the plastic – *et voilà!*

Nurse Audit update

Work continues on the next version of the MS Nurse Audit tool, which will complement criMSon and is based on the NSF for Long Term Conditions.

The audit will be online and it is hoped to have a working version available at the MS Trust Conference in November.

Teva and Delivery companies

UKMSSNA representatives have had a very positive follow-up meeting with Tom Bendall, Brand Services Manager, and Glyn Wright, General Manager of Teva UK, to discuss problems you reported with the new delivery companies. There are three key things to remember:

Flag issues early – *always* report problems;

Be specific (i.e. not only details of problem, but enough detail to identify patient without compromising confidentiality if email used – initials, hospital number, first part of postcode, DOB, for example);

Keep Teva informed of any issues(as well as the delivery company) by copying to Tom Bendall (Tom.Bendall@tevapharma.co.uk).

Specific issues

Timed delivery: Evolution “will make deliveries at a time convenient to the patient”. This is the same for both companies and is part of the contract so Teva need to know if it isn't working. Evolution have a Patient Charter which outlines their service.

Collection of sharps and unused medication: This is an essential part of the service and should be routine. Confusion has arisen where a patient has been taken off a drug therapy or changed to another one. Where this happens patients are advised that sharps and unwanted medicines should be taken to either a local pharmacy or GP surgery by the patient, but if this is a problem or a request is made to collect the sharps and unused medication by either the prescribing centre or patient, then these will be collected.

NB: In some rural areas (e.g. remote areas of Scotland) couriers are used and they cannot pick up sharps. Work ongoing to identify solution to this.

Refusal to leave delivery where requested or delivery left with inappropriate person: Delivery companies will not deliver to unsafe places, e.g. garden sheds. Deliveries should not be left without driver collecting a signature from an approved signatory. If the driver has a problem then s/he should contact base and a judgement call made. Similarly, if there is no reply, then the driver should contact base to ask what to do. It is important to let both the delivery company and Teva know if there are any special conditions relating to a patient (e.g. restricted mobility).

New Scripts: Issues that arose were pushed back to the prescribing centre by Evolution. Work has been done on this to resolve issues and Evolution have changed working practices as a result. Any continuing problems should be reported to Teva.

Answerphone: This has been resolved and was due to a technical problem. If patients had received a message and were returning the call, then they were seeing or receiving the DDI or switchboard number as the number calling them rather than the 'Copaxone Number'. This led to patients calling back using the DDI number which would revert to the answerphone. Teva is not aware of any continuing problems with this.

Service Level Agreements with MS prescribing centres: Evolution should be working with centres to find out what kind of service they want. This needs regular, consistent and frequent meetings and follow-up between centres and Evolution.

Buffer stock: Ensure two weeks' supply where possible.

The quality of contact between the MS Nurse and their Evolution representative seems to vary; one committee member attending the meeting complained to Teva that their contact didn't return phone calls and was very poor, whereas another member at the meeting said that the relationship with her Evolution rep was excellent. If you have a poor service from your delivery company representative, then be sure and let Tom Bendall know the details. Equally, I'm sure Tom would welcome compliments on the service as well!

Teva meets Evolution every 6 weeks so any issues can be dealt with then. It is important to feed problems through to Tom Bendall at Teva (e-mail: Tom.Bendall@tevapharma.co.uk)

Remember:

Flag issues early – *always* report problems;

Be specific - i.e. not only details of problem, but enough detail to identify patient without compromising confidentiality if email used – initials, hospital number, first part of postcode, DOB, for example;

Keep Teva informed of any issues (as well as the delivery company) by copying to Tom Bendall (Tom.Bendall@tevapharma.co.uk).

Committee representation

Jane Rogers, from Hull, has been co-opted onto the Committee as the representative for Yorkshire and The Humber, nominated by Liz Hill in Scarborough.

There are still vacancies for representatives for Northern Ireland and the East Midlands.

MS Trust Conference - Have you booked your place yet?

We look forward to seeing you there!

The UKMSSNA is looking for three members who would like to make a presentation on an aspect of their work at the Conference, to last about 10 minutes each. Research, new initiatives, clinics, pathways, protocols, partnership working.... proposals welcome! If you're interested send brief details to Mary – admin@ukmssna.org.uk

A further three presentations will be made at the March meeting in York, so again, please get in touch with Mary if a March date would suit you better than November.

New in post? Done the MS Trust residential Development Module?

The UKMSSNA is planning a break-out session at the Conference for nurses who have been in post for a year or less. It will complement the Development Module run by the Trust and will cover more practical aspects of being a nurse. The session will be repeated at the Trust's meeting in March. The committee has set up a working group to plan the session and they would welcome suggestions, from new nurses in particular, about any aspect of their work on which they would welcome more information.

Send your suggestions to Mary.

CBT Masterclass

I gather that all places on the Masterclass being held in July at the University of Warwick are now taken. Depending on the feedback we get, we do hope to organise more CBT courses in the future, so if you didn't get on this one, there should be another one along next year.

If there are any other topics of interest which are missing from the usual round of study days, conferences, etc. let us know.

“Thank you very much” Members’ Queries

We invariably get an excellent response to queries posed by members – so on behalf of everyone who has posed a question to members – **THANK YOU** for your replies.

If you have posted a question and get a response, rude though it may seem, please **don't** reply to say thank you. It just comes back to me! If you want to contact the person who has replied to your question, remember to use **their** e-mail, not the ukmsna one. *Thanks! MF*



MS Society and the Risk Sharing Scheme

Multiple Sclerosis Society *The MS Society have provided the following statement regarding their position on the Risk Sharing Scheme for DMTs.*

“In late 2009, the MS Society withdrew its support for the Risk Sharing Scheme (RSS). This decision was not taken lightly but only after four years attempting to work with the Department of Health (DH) to resolve problems with the RSS.

In all of our communications we have been quite clear we do not believe there is a problem with the drugs themselves. And the introduction of the RSS has resulted in many people having access to DMDs and improved healthcare for people with MS, including a network of MS nurses and specialist care centres across the UK.

But eight years on, the RSS is hampered by methodological problems, is expensive to run and now urgently needs to be independently reviewed. The RSS is inherently inflexible and does not take into account changes to MS care guidelines, changes to evidence or the introduction of new drugs (like oral therapies). Faulty methodologies, delays in analysing observational data, and then the inordinate delays in publishing the (inclusive) outcomes have wasted valuable opportunities for people with MS.

We have received written assurances from the DH that people should not be denied access to DMDs if the RSS is stopped. We know there must be continuing access to these drugs for those who need them but it is increasingly important that, as newer drugs come on to the market, people have access to the right drug for them at the right time.

The MS Society, and so many people affected by MS, values the work of MS nurses and this is reflected in our support for nurse posts across the UK. Since the start of the scheme the Society has made significant financial investment in funding, or part funding, over 200 of the approx 300 MS specialist nurses in the UK. The MS Society is the only UK charity to have funded MS nurse posts.

I hope this goes some way in clarifying the MS Society's position on the Risk Sharing Scheme.
Simon Gillespie, CEO, MS Society

MS Nurse Funding from the MS Society

The MS Society has provided support for MS Nurses since 1999, funding 116 posts totalling £5,920,851 in grants. In addition there have been 13 Fast Track funded posts, into which the four drugs companies and MSS put equal shares, which adds approximately £1million collectively. With the pharma companies the Society is looking at what the successor to the FTS will be. Money is likely to be tight in NHS in next couple of years and posts and specialist nurses need to be protected. However, charity money should not be used to substitute for government money and the MSS will be fighting to protect posts.

The UKMSSNA is working closely with both the MS Society and the MS Trust to make the case for the value of MS Specialist Nurses within the NHS.

New – launch of discussion board for professionals!

In order to enable professionals to communicate easily with one another, exchanging ideas and information, sharing best practice etc, the MS Society has created a password-protected discussion board exclusively for members of the Professionals' Network. This discussion board is password-protected to ensure that it is secure and private. If you wish to use this facility, you will need to register.

How do I sign up?

This message board is part of the MS Society's main message board system so you will have to register with that first and then let us know your username so we can give you special access to the secure board.

You also need to be signed up with the Professionals Network so we can verify that you are a healthcare professional

Sign up to the Network here:

http://www.mssociety.org.uk/for_professionals/professional_network/index.html

Register with the message boards at:

<http://www.mssociety.org.uk/applications/discussion/register>

Contact the web team with your username: webteam@mssociety.org.uk

Security and confidentiality

The professional's board will be a closed group that is only visible to specific users. We will only grant access to people who are also signed up with our Professionals Network and no other users will be able to access the board or view messages on it.

What can I discuss?

That is entirely up to users – as long as any discussion doesn't break the terms and conditions for using the MS Society's discussion boards

(<http://www.mssociety.org.uk/applications/discussion/termsandconditions.rm>) . Additionally it is important to ensure confidentiality and anonymity of clients, colleagues and other contacts at all times.

If you have any queries contact Rhona MacLean, Strategic Lead Education, MS Society, 0208 438 0888, 07824 695325. rmaclean@mssociety.org.uk

UKMSSNA Members' Forum

Rhona has stolen a march on me – I've been wanting for ages to set up a Discussion Board and now the Society have got there before me!! Still, they are a slightly larger organisation than the UKMSSNA. Not downhearted, I have immediately commissioned my resident IT support to set a Forum up for the UKMSSNA and it will shortly go live!!



MS Trust Charity Cycle Ride



Nikki Embrey's husband Neil will be cycling from Land's End to John O'Groat's in July for the MS Trust. To support them please click onto the live web page link below or send sponsors to Nikki at the address below. Neil decided to take on this personal challenge following the publication of 'MS and Me - a guide to self-management in MS' - now available from the MS Trust.

"I am proud to say that my husband Neil Embrey is undertaking a Charity Cycle Ride from **Lands End to John O' Groat's** in aid of the MS Trust. He will set off from Land's End on July 18th and hopefully arrive in John O'Groat's on 30th July 2010. He will cover over 1,000 miles, cycling for over 90 hours!"

Neil says "I have seen how hard Nikki works to help people with MS in the area and I know how much support she has had from the MS Trust. I love cycling and even though I know this will be extreme cycling, I want to do it to show my support to Nikki and people with MS".

Please could you send your pledged donation to uk.virginmoneygiving.com/neilembrey or send to Nikki at work Ward 27 University Hospital North Staffs ST4 7LN. All cheques should be made payable to 'MS Trust.' A massive thank you for all your support

As well as Neil's cycle ride, **Nicki Ward-Abel** is also raising funds for the **MS Trust** by going on one of their Treks. More details about how you can support Nicki in due course.

In the meantime, **support Neil!!**

Respite care review

The MS Society has recently carried out a review of respite care which has resulted in a decision that the Society will no longer directly provide residential respite care and will instead move to a more personalised system of support, providing people with more choice, control and equitable respite options. For details of the review process and outcome – see http://www.mssociety.org.uk/support_and_services/respite_care/respite_review.html

Nature Reviews Neurology

The National MS Society (USA) and its drug development subsidiary, Fast Forward, are sponsoring free access to five milestone papers to encourage broad distribution and increased understanding of current trends and research opportunities in MS. Access to these papers is free for three months from Nature Reviews Neurology - <http://www.nature.com/nrneurol/focus/ms/index.html>

MS Linx website

MS Linx website, aimed at professionals working in primary care, is now live – see <http://www.mslinx.org.uk/home>

Competencies Framework and Training Guide

By Vicki Matthews, Nurse Advisor, MS Trust

The MS Trust has contacted all the specialist nurses in the UK to ensure they have a hard copy of the competency folder and the link to the training tool. We are looking at some interesting times ahead and I want to make sure I am doing everything I can to secure the most important thing for patients with MS - you!

I really need your help over the coming weeks and I know how busy you are but I will be sending out a number of key questions about your PDP in the near future. They will be simple and quick but will help to inform work the MS Trust is undertaking to ensure we get your needs met as much as we can.

The recent MS-NEED research project highlighted UK MS Specialist nurses as the gold standard in Europe and I know there are days when it certainly doesn't feel that way but we may have some good opportunities despite the economic climate. We need to make sure we are well prepared and I think one of the key things is that we have managers who understand better what we do and therefore support us more effectively.

If you have not received your letter or folder please contact us at the MS Trust. I know only too well the NHS postal service and my worry is that some folders/letters might go astray and at £50 per folder it is an expensive stray!

If you are about to leave a post, or know of someone who has left a post and may have left the folder behind, please let us know. We can recycle them.

There is also a CD version of the framework available and this is being sent to every CNO, Chief Nurse and Trust Clinical Services leads in the UK with an explanatory letter. We are also sending this to the ABN to get their acknowledgement of the complex role of the MSSN. Neurologists KNOW they could not function without the MSSN but their level of support remains variable.

Have a look at the training guide and have a play with the self assessment tool. You can download the tool and save it or delete it as many times as you want and it is a good start in self appraisal. If you are not sure or concerned about how to navigate through the guide, just contact me; as a computer novice myself I can reassure you it is easy to use. I would really

welcome some ideas on what should go into the guide and if you have any good things we can use that would be great too.

Working on the wards

Following several requests for some support when being pressured to work on the wards I have developed a quick and easy tool to carry out a risk assessment if you are asked to go back to the wards. You will find the tool on the Health Care Professional section of the website.

The MS Trust is also keen to give any additional support required to any MSSN who feels that they are being inappropriately pressurised to work in an unsafe way. You can also find additional information on the RCN website.

Key Steps

The Essential Standards of Quality and Safety 2010 states that people who use services “will have their medicines at the times they need them.....and personalised care through effective use of medicines” and “have their views and experiences taken into account in the way the service is provide and delivered” (1)

The NHS requires care to be “*QIPPable*” and that means delivering care with Quality, Innovation, Productivity, Prevention. (2)

The Key Steps resource is now available as a download on the MS Trust website. This invaluable resource provides you with all you need to deliver a cost effective, bespoke and person centred relapse service. It can be found in the Health Professional section in information and resources. It meets all the criteria of Essential Standards and QIPP.

1 Care Quality Commission: Guidance about compliance Essential standards of quality and safety. March 2010 London

2 DH: 2012- 2015 NHS – From Good to Great, preventative, people centred, productive. Dec 2009 London

RCN Neuroscience Forum

This is the first of regular updates from the RCN Neuroscience Forum. Any RCN member can go to the RCN website to view all the news. Some of my work for the forum is not MS related so I will report only MS specific topics.

The neuroscience forum no longer has the presence of Sue Thomas, who has left the RCN to pursue her role in Commissioning. This has made responsibilities for the committee more onerous but I am delighted that the RCN and Peter Carter consider MS Specialist Nursing as one of the flagship specialist nursing groups. Work that I was able to do for the RCN pre-election campaign raised the profile of MS nursing and RCN Congress featured MS Specialist nurse Carrie Day from Southampton, and the MS Trust, on a *very* large screen before each keynote speaker. They are also interested in the pan-European potential for the competency framework and will offer their support. The competency framework is also being used as a template by other specialities including neuro-oncology. The infrastructure that MS nurses currently have is considered the ideal model by many but there is work to do to ensure that the model can adapt, develop and deliver. One aspect of MS Specialist nursing we should consider is the future of the HCA role in MS care and what the role of the potential nurse

practitioner or assistant nurse might be. Is there a place for UKMSSNA membership for HCAs' who are interested in MS care?

The NICE pharmacological guide for neuropathic pain is now available and RCN Neuroscience forum was very involved in the development of these guidelines.

RIMS

The 2011 RIMS conference will focus on Ageing and MS. It is a special birthday for RIMS and we hope that the conference in Turku will be equally special. Membership in the UK is disappointingly low, and we are missing out on some great opportunities including two research grants for 5000 Euros. There is also a new special interest group (SIG) on evidenced-based patient information (EBPI); again UK nurses are seen as a gold standard but their presence is not seen at any of the activities! If you would like to participate in any of the studies, projects etc. on EBPI let me know.

Vicki Matthews

Slide Library

The Slide Library Working Group have been working hard and have sent through a number of updated presentations which I will put on the UKMSSNA website shortly.

Check out:

What is MS
Treatments
Altered Muscle tone
Fatigue
Newly diagnosed
Hot Topics

Do you visit the website?

I hope that our website is useful to you. I'm trying to rationalise some of the pages within the Members Section and make it easier to navigate, but there is always more to do than I have time for. In particular I'm attempting to get all the information about a given topic on the page it relates to (makes sense!), mostly within the **MS Information** section. Do let me know if you spot any errors or have any suggestions for inclusions, links, etc.

Audience Healthcare survey – a warning!

A company called Audience Healthcare is apparently sending faxes round to elicit specialists' views on the visits they receive from pharma companies (the usual 5). It seems unlikely that this has been jointly funded by all 5 companies, and if only one then they are surely in breach of ABPI guidelines by eliciting responses from service users as to the content and types of visits received from their market competitors and also our perceived effectiveness in fine detail about each of the company representatives. There is a carrot of £30 offered as incentive to this private information. I would urge all members NOT to complete this unless all companies can assure us that they are compliant with the survey.

Alan Izat